

Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda

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Accepted 6 December 2010

Two years after the introduction of provider-initiated, opt-out HIV counselling and testing during antenatal care (ANC) in Uganda, HIV testing uptake is still low. This study was carried out to explore pregnant women's experiences of, and views on, the policies for opt-out, and couple HIV testing, and to understand how the policy implementation could be improved in order to increase access to prevention of mother-to-child-transmission (PMTCT) services.

The study was conducted at three ANC health facilities at different levels of care in rural eastern Uganda. Data were collected through sit-in observations during ANC and 18 semi-structured interviews with pregnant women receiving ANC, and thereafter analysed using latent content analysis.

Pregnant women who received ANC from facilities that provided HIV testing on-site perceived HIV testing as compulsory without actually fully realizing the benefits of HIV testing and PMTCT. No referral for HIV testing or information about testing was given at ANC facilities that lacked HIV testing on-site. A major challenge of couple HIV testing was that pregnant women were made responsible for recruiting their spouses for testing, a precarious dilemma for many women who tried to fulfil health workers' requests without having the power to do so.

In order to increase uptake of PMTCT services, the pre-test counselling in groups that precedes the provider-initiated HIV testing should be adjusted to inform women about the benefits of PMTCT. Further, if testing is perceived as compulsory it could potentially deter some women from seeking ANC services. In order to increase HIV testing of male partners new strategies are needed, for example peer-sensitization and male clinics. Moreover, to achieve the desired outcomes of the PMTCT programme, monitoring and evaluation should be built into the programme.

Keywords Provider-initiated, HIV testing, gender, antenatal care, Uganda

KEY MESSAGES

- Counselling preceding provider-initiated HIV testing during antenatal care should be improved to inform women about the benefits of HIV testing and prevention of mother to child transmission services.
- In order to increase male partner HIV testing during antenatal care, recruitment strategies that are more gender-sensitive are needed.

Introduction

In 2003, only 10% of Ugandan women giving birth were tested for HIV, despite the fact that 94% attend antenatal care (ANC) and that Uganda has an overall HIV prevalence of 6.4% (Karamagi *et al.* 2006). Three years later, the proportion of pregnant Ugandan women receiving pre-test counselling (40%) and HIV testing (21%) had doubled but still remained unacceptably low (Ministry of Health [Uganda] and ORC Macro, 2006).

Consequently, the goal of 80% coverage of prevention-of-mother-to-child-transmission (PMTCT) services and a reduction of new paediatric infections by 50% by 2010 as stated in the universal access declaration, does not seem to be within reach (WHO *et al.* 2008). HIV testing during ANC is the entry point to PMTCT services, and in order to increase coverage of PMTCT, the Ugandan government launched new policy guidelines in 2006, moving from voluntary counselling and testing (VCT) to a provider-initiated opt-out HIV testing model (Ministry of Health 2006). The new policy states that all pregnant women and their male partners should routinely be offered counselling and testing for HIV during ANC, and that health facilities without testing services should refer couples for testing to a nearby facility with HIV testing.

In Uganda, HIV counselling and testing is organized similarly at most government health facilities: all women who come for ANC, receive pre-test counselling combined with general health information, together in a group. Thereafter, a venous blood sample for a rapid test for HIV antibodies is taken and analysed while the pregnant woman receives a physical check-up. Test results can be received the same day during individual post-test counselling (Ministry of Health 2006).

The Ugandan policy is in line with the policy for provider-initiated HIV testing recommended by the World Health Organization (WHO) for countries with a generalized HIV epidemic, aiming to integrate HIV testing in standard medical care at all health facilities (WHO and UNAIDS 2007). The rationale is that if more people get to know their HIV status, the number of people linked to treatment and prevention interventions would increase (De Cock *et al.* 2003; De Cock *et al.* 2006). Health facility-based studies from sub-Saharan Africa, including Uganda, show that opt-out HIV testing during pregnancy may increase the testing uptake by up to 80% (Perez *et al.* 2006; Chandisarewa *et al.* 2007; Creek *et al.* 2007; Homsy *et al.* 2007; Dahl *et al.* 2008; Mugore *et al.* 2008). However, the latest UNGASS progress report from Uganda shows that despite a substantial improvement in coverage doubling the number of ANC sites offering PMTCT, only 30% of all pregnant women estimated to be HIV infected received

prophylactic antiretroviral drugs (ARVs) for PMTCT in 2007 (Ministry of Health 2008). The policy of couple HIV testing during pregnancy, i.e. offering joint HIV testing for pregnant women and their spouses, has shown to increase women's access to and completion of PMTCT services, but the uptake of couple HIV testing in Uganda and other sub-Saharan Africa countries remains low at 5–12% (Farquhar *et al.* 2004; Homsy *et al.* 2006; Elisabeth Glaser Pediatric AIDS Foundation 2008; Msuya *et al.* 2008).

Changing policies is a complex process and the effect of the opt-out HIV testing policy has mostly been evaluated quantitatively; for example, in Zimbabwe it was shown to contribute to high uptake of HIV testing (Walt 1994; Mugore *et al.* 2008). The aim of this study was to explore how the intended target group, i.e. pregnant women, experience the new HIV testing policy since, to the best of our knowledge, this has never been evaluated in-depth in sub-Saharan Africa (Gruskin *et al.* 2008; Thorsen *et al.* 2008). Further, the aim was to understand how the policy implementation could be improved in order to increase access to PMTCT services.

Methods

Study setting

This study was carried out in the rural districts Iganga and Mayuge, 120 km east of Uganda's capital city Kampala, between February and March 2008. In these rural districts all health facilities provide ANC, ranging from level II up to hospital level. Level II health facilities provide outpatient services; level III health facilities include a general ward, a laboratory and maternity services; and level IV health facilities also have operation theatres.

HIV testing and PMTCT services were introduced at Iganga district hospital in 2004 and soon thereafter expanded gradually to lower-level health facilities. The policy for opt-out HIV testing during ANC was introduced in the two districts in 2006, and implemented similarly regardless of level of care. Pre-test counselling is always provided in groups during the general health education sessions. The number of women per counselling session varies with the level of care, ranging from five at level II facilities to 40 at hospitals. The duration of a group counselling session is about 15 minutes regardless of facility level. Most of the health facilities in the two districts are government health facilities but a few are run by non-governmental organizations. The majority of the facilities are level II, and most of them cannot perform HIV testing. Instead, according to the guidelines, these lower level facilities should

provide HIV counselling to all pregnant women and their partners, and then refer them for testing at higher level of care.

Study design

This study included both semi-structured interviews and sit-in observations. The interviews aimed to investigate pregnant women's experiences of provider-initiated HIV testing, and included questions about how women experienced the pre-test counselling received; what information they had received about HIV; whether they had understood the purpose of HIV testing; and their view on couple HIV testing. In order to get views from women who received ANC from different levels of care, respondents were recruited from three purposely-selected health facilities: one district hospital ($n=10$), one health facility III ($n=6$) and one health facility II ($n=2$). The hospital and the health facility III provided HIV testing during ANC, while the health facility II was supposed to refer patients for HIV testing. All pregnant women visiting one of the three facilities were eligible to participate.

In total 18 women were interviewed. Purposive sampling was performed in order to obtain the views of both first-time pregnant women ($n=4$) and women who had been pregnant before ($n=14$), as well as women with unknown ($n=10$) vs confirmed HIV infection ($n=8$). Women were approached at registration for ANC in collaboration with a nurse working at the health facility. The aim of the study was described to eligible women, and they were invited to participate in an interview while waiting for their HIV test results or other ANC services. The interviews were conducted in a separate room at the health facilities in order to ensure confidentiality. Each interview was carried out in the local language Lusoga by one of two Ugandan female sociologists with previous experience of qualitative and HIV research, and the interviews lasted for about 40 minutes. Four women attending ANC at the hospital declined participation since they had to attend to their children. The interviews were audio-recorded, transcribed verbatim and translated into English by one person, and thereafter checked for errors by a second person.

Sit-in observations during ANC were also performed at all three health facilities. The aim of the sit-in observations was to explore the organization of PMTCT services and the content of the pre-test counselling. The interviewer together with the first author observed pre-test counselling sessions during the same 6 days as when the interviews were performed. Through interviews and sit-in observations at the level II health facility it was found that no information about HIV testing was given, nor were women referred for testing. Since the aim of this study was to explore women's experiences of routine HIV testing during ANC, no more respondents were included from that facility for this reason.

Data analysis

We analysed the data using latent content analysis which aims to analyse the underlying meaning of the respondents' statements (Graneheim and Lundman 2004). Analysis started during data collection. Transcripts were read and discussed

within the research team after finishing an interview to identify probes or follow-up questions to be included in the next interview. These reviews also helped to decide when saturation for the main research question had been reached. After data collection, the transcripts were read several times to get a feeling for the data. Thereafter so-called meaning units were identified and labelled with codes (Graneheim and Lundman 2004). The codes were compared for similarities and differences, and grouped into categories on a manifest level. The categories were subsequently interpreted for the latent meaning and organized into themes on an abstract level. The first author initially coded the data. Analyst triangulation was applied during the process: co-authors read selected transcripts, discussed codes, categorization of codes and development of themes at several points, until consensus was achieved (Patton 2002). An additional source of triangulation regarding the content of the pre-test counselling came from comparing the findings with findings from another study in the same setting exploring the quality of ANC (Patton 1990). This is described in a forthcoming article from the same research consortium (www.arvmac.eu) (Conrad, undated).

Ethics

Ethical approval was obtained from the Makerere University School of Public Health Institutional Review Board and the Uganda National Council of Science and Technology. All participants received detailed information about the study, and were informed that their participation was voluntary. It was emphasized that they could decline participation without any negative consequences for their ANC, that information obtained would be kept confidential and that data would be analysed after de-identification. All respondents gave written informed consent before participation.

Results

Two main themes were identified during the analysis: 'To test or not is not a woman's choice' and 'Absent partners: the responsibility of women?'. Themes and categories are summarized in Table 1. The themes are described and illustrated with quotes below.

To test or not is not a woman's choice

Respondents from the ANC clinics that provided HIV testing generally thought that they could not receive any ANC services unless they accepted being tested for HIV.

"I am told that when you come for ANC, they have to take your blood sample for testing: if you refuse they will not give you any treatment (ANC) ... No one (health worker) will care about you when you're pregnant, if you don't accept to be tested for HIV."
(unknown HIV status, multi-gravida, health facility III)

On the other hand, sit-in observations and interviews in the health facility that did not provide HIV testing on-site revealed

Table 1 Summary of themes and categories

Themes	To test or not is not a woman's choice	Absent partners: the responsibility of women?
Categories	<ul style="list-style-type: none"> • HIV testing is mandatory • Poor knowledge of HIV • Health workers decide for me • Not possible to ask questions • Health workers know what is best for me 	<ul style="list-style-type: none"> • Health workers request that we bring our partners • Male partners refuse to come to antenatal care clinics • Bringing the message causes anxiety • Risk of discordance—a challenge • Partner would not disclose • Health workers should teach partners

that women there were neither informed about, nor referred for HIV testing as the PMTCT guidelines prescribe.

Few of the women who received ANC from clinics that provided HIV testing on-site had fully understood the reasons for testing and the majority had little knowledge about PMTCT.

"I also do not understand why they examine us and even go ahead to take off blood..." (unknown HIV status, primi-gravida, hospital)

Women further commented that they felt inferior in relation to the health workers and that they would never question anything a health worker said, or ask questions for clarification.

"What the health worker would decide upon is what I would go with, because me I am just a patient..." (HIV infected, multi-gravida, health facility III)

Another example of the power imbalance described by the pregnant women was the fact that staff often took blood samples for testing without informing the women about why they did so. The women themselves did not dare to question the rationale behind it, but suspected that health workers did it in order to test women who otherwise would not accept being tested.

"That is why they take the blood before telling you, because if they tell you before, you can dodge and tell them that I will come back and fail to come, because not everybody is willing to test." (unknown HIV status, multi-gravida, hospital)

The power asymmetry between the pregnant women and health workers was further made clear by the fact that some women had to pay informal payments to staff. Although women knew that they should not have to pay for ANC services, they felt unable to demand the services they were entitled to free of charge.

In contrast to the negative view of opt-out testing among most respondents, there were women who viewed the new testing policy during ANC as something positive that could benefit both them and their children.

"...it was compulsory to test...It is good because I got to know my status, and yet before I used to produce children without knowing that I was positive. But now health workers counsel me well, they carry my baby whenever I come and they give me Seprin." (HIV infected, multi-gravida, hospital)

Absent partners: the responsibility of women?

The PMTCT policy in Uganda states that all pregnant women and their male partners should be offered HIV testing routinely

during ANC. However, since very few men spontaneously accompanied their wives for ANC, health workers tried to recruit men for testing through the pregnant women. This was also confirmed by the sit-in observations.

"...health workers asked if I could convince my husband to also come for testing." (HIV infected, multi-gravida, hospital)

Women felt obliged to accept the request to try and persuade their partners to come for HIV testing. However, the majority described it as a complicated mission and a major dilemma to try to recruit their spouses while having very limited power to influence their partner's actions.

"You can tell him but he will refuse to come. He will just tell you that he is not coming. He does not give any reason why he won't come." (unknown HIV status, multi-gravida, health facility II)

Since the women rarely felt they could just ask their partners directly, they talked about using alternative strategies, including lies, to get their spouses to come to the health facilities, hoping that once there, the health workers would help to convince the men to be tested.

"Maybe we can get somebody to go and deceive him that his wife is stuck in the clinic, then I think he can come." (unknown HIV status, primi-gravida, hospital)

Some health workers offered HIV-infected women assisted disclosure and recommended that the women should delay partner disclosure until the man had joined them at the ANC clinic.

"She (health worker) also told me that when I go back home I shouldn't tell my husband directly. That I should tell him to come along with me to the health centre such that they can test both of us." (HIV infected, multi-gravida, hospital)

Some women with a confirmed HIV infection revealed that they felt forced by the ANC staff to unwillingly disclose their HIV status. Their fear of abandonment made some refuse to bring their partner for testing.

"He told me that he tested and was negative though it was some time back and he is faithful, he does not cheat on me. If we test positive it will be me who infected him. That's why I cannot come along with him to let him know that we are positive...He will chase me away..." (HIV infected, multi-gravida, hospital)

There were a few women who felt ready for couple testing and realized that the assisted disclosure would release them from the burden of being the messenger.

“When we come here together, it would be easy for the health worker to explain to him all the details of my sickness unlike me who would not tell him everything that I was told at the health centre.” (unknown HIV status, multi-gravida, health facility III)

In general, couple testing was not appreciated, and for the women, bringing home the message of HIV testing to the spouse was associated with great anxiety due to fear of negative reactions, and severe consequences.

“Because there is a time I jokingly told him that if the test results show that we are infected, what do you do? And he said that he can kill himself.” (unknown HIV status, primi-gravida, hospital)

The fear of HIV sero-discordance within the couple, especially if the woman would be infected and the man not, was a common concern and a major barrier to couple testing. Many feared being accused of infecting their partners, something that could lead to relationship problems and separation.

“When you test as a couple, you may turn out to be discordant; when one of us is positive and the other is negative this may lead to separation and misunderstanding, and the man will claim that it’s the woman who brought the infection. Men will never accept their mistakes. They are normally rude.” (unknown HIV status, multi-gravida, hospital)

When the male partner was known to have concurrent sexual relationships, the value of couple testing was described as limited, and the women asked the health workers for advice on how to protect themselves against being infected during pregnancy.

“For my husband, I don’t know whether he would take my advice. So I don’t know how I would protect myself, maybe I can consult a health worker. For instance if the husband has got other sexual partners, it is easy to infect me, yet I might not have the virus [now].” (unknown HIV status, multi-gravida, health facility III)

Men’s freedom of choice, having the possibility to decline an HIV test was often mentioned. It was seen as unfair that men, as opposite to women, could choose to opt-out of testing during ANC, to test alone without informing their partners, or even receive antiretroviral treatment without disclosing this to their partners.

“...for example there was a couple that was infected but the husband used to take care of himself alone, even treatment, without taking care of the wife. The wife passed away last year...” (unknown HIV status, multi-gravida, hospital)

Discussion

This study found that women who received ANC from health facilities that provided HIV testing on-site generally perceived

testing as mandatory, and rarely fully understood the benefits of HIV testing or PMTCT. Women who received ANC from health facilities that lacked on-site testing were neither informed about nor referred for testing. Couple-testing was generally not appreciated and put women in a precarious dilemma where they felt forced to comply with health workers’ requests to recruit their husbands for HIV testing while fearing negative consequences at home. Below, these findings are discussed in relation to how implementation of provider-initiated HIV testing during ANC in Uganda could be improved.

The fact that HIV testing was viewed as compulsory is in line with recent concerns that the global policy change from VCT to provider-initiated HIV testing could make patients feel obliged to test (Maman and King 2008). Despite the fact that we interviewed women who had just attended a group pre-test counselling session, many did not fully understand the benefits of HIV testing and PMTCT, and since they felt submissive in relation to the ANC staff, they avoided asking questions. In order to improve the outcome of counselling, it is crucial that women feel comfortable to ask questions, and that the power-imbalance between health workers and pregnant women is taken into account during ANC. Requests for informal payment during ANC were reported, and further emphasized the power hierarchy between health staff and pregnant women.

HIV testing of pregnant women is the first step in the PMTCT programme and the entry point for HIV-infected women to receive other PMTCT services. The new opt-out HIV testing policy aims to achieve higher coverage of PMTCT and to reduce HIV transmission, but since women did not fully understand why HIV testing was carried out, the current pre-test counselling seems to be insufficient for reaching these goals (WHO and UNAIDS 2007; WHO *et al.* 2008). Similarly, since existing data on provider-initiated HIV testing show that this testing model results in an increased workload and less time for counselling, new strategies for counselling need to be considered. One option is sensitization campaigns about PMTCT at the community level to raise awareness among both women and men before they come to the health facilities (Evans and Ndirangu 2009).

The reported lack of counselling and referral from health facilities without HIV testing capacity on-site has confirmed our observations from the same district, that referral systems for PMTCT need further review (Larsson *et al.* 2009). Since the majority of health facilities that provide ANC belong to this category, the failure to counsel and refer pregnant women for HIV testing means that these women miss the opportunity to receive other PMTCT services as well. One strategy to improve both quality and access to pre-test counselling would be to monitor and evaluate pre-test counselling at all health facilities, including level II, as well as monitoring the referral system on a regular basis. Further, a more robust referral system should be introduced to follow up those who have been referred for testing. For example, women who receive ANC where testing is not available could be given a referral note to present at the testing facility that should then be fed back to the first ANC facility. Another option could be to introduce HIV testing at lower level health facilities, perhaps through outreach activities from a higher level of care or by diverting more resources for

testing equipment and staff training to lower level health facilities. Independently of where pregnant women receive ANC, they should be empowered with information about the importance of HIV testing during pregnancy.

Being asked to recruit male partners for HIV testing was associated with anxiety due to perceived risk of intimate partner violence among our respondents. These findings appear to be supported by studies in similar settings in Botswana, Kenya and Tanzania (Taegtmeyer *et al.* 2006; Weiser *et al.* 2006; Msuya *et al.* 2008). The Ugandan PMTCT policy is based on evidence that male partner involvement is associated with women's completion of PMTCT in sub-Saharan Africa (Farquhar *et al.* 2004; Ministry of Health 2006; Homsy *et al.* 2007; Sarker *et al.* 2007; Kasenga *et al.* 2010; Msuya *et al.* 2008). However, our findings raise the question of whether using women to recruit their unwilling male partners for HIV testing is the best way to get men involved. WHO emphasizes that gender patterns need to be considered in order to successfully implement policy, but gender aspects in terms of decision-making power and women's financial dependency on their male partners is rarely integrated in policy development and implementation, and few countries have followed the call from the United Nations to integrate gender dimensions into HIV plans (Vlassoff and Garcia Moreno 2002; WHO 2002; WHO 2003; Greig *et al.* 2008; WHO 2009). Though the Ministry of Health in Uganda has incorporated gender into the Health Sector Strategic Plan, our findings suggest that a more gender-sensitive implementation of the PMTCT policy could improve community effectiveness of couple testing during ANC (Theobald *et al.* 2005). Instead of targeting men through their pregnant wives, more men could be reached by using gender-sensitive interventions at community level, i.e. community health workers or male peers informing men about the potential benefits of HIV testing and PMTCT. Another solution might be to have male clinics in connection with ANC, where men could receive counselling and HIV testing and meet other men.

The current study focused on the pregnant women's experiences; no self-reported experiences of health workers and men are included, nor have we interviewed women visiting private ANC providers. However, our respondents were selected to represent various levels of care, different HIV statuses and different previous pregnancy experience, and we found consistency in the findings among these different groups, and concordance between interviews and sit-in observations. Since the ANC offered at different health facilities in the districts is rather similar, we believe that our findings are applicable also to other ANC facilities in Uganda. We used analyst triangulation within the research team, and in addition triangulated our findings with data from another study on the quality of ANC in the same setting. The two women interviewed at a health facility that did not provide testing were included in the analysis since quantitative studies from the same district confirm that despite PMTCT guidelines, few women are referred for, or carry through, any referral for HIV testing (Larsson *et al.* 2009; Larsson *et al.* 2010). The fact that interviews were conducted at the health facilities could have hampered some potential criticism about health workers or care received, but the interviews were always

conducted in a private space separate from the health workers. To create trustworthiness, both the first and the fourth author had prolonged engagements in the field at the health facilities.

Four women, all from the hospital, declined participation for the reason that their children needed their attention and as we observed them taking care of their children, we have no reason to doubt their reasons for declining.

In conclusion, provider-initiated HIV testing during ANC is crucial to increase the coverage of testing and PMTCT. Moreover, the preceding counselling needs to be improved so that women are properly informed about the benefits of HIV testing and PMTCT. However, this cannot be achieved unless pregnant women are empowered with information to make informed choices, and if testing is perceived as compulsory this could potentially deter some women from seeking ANC services. As health workers often are overburdened, one possible solution might be to use community health workers or peers to counsel women about HIV testing in the community before the women come for ANC. Moreover, alternative ways to recruit male partners for HIV testing during ANC are needed, for example through peer-sensitization and male-friendly clinics. Lastly, improved monitoring and evaluation should be built into the PMTCT programme to improve pre-test counselling as well as the referral system, in order to improve on the desired outcomes of the PMTCT programme.

Acknowledgements

We are very grateful to the study participants. This research is part of the project Effects of Antiretrovirals for HIV on African health systems, Maternal and Child Health (ARVMAC), in part supported by the European Community's FP6 funding. This publication reflects only the author's views. The European Community is not liable for any use that may be made of the information herein. The ARVMAC consortium includes the following seven partner institutions: Karolinska Institutet (Co-ordinating Institute), Stockholm, Sweden; Centre de Recherche en Sante de Nouna, Kossi, Burkina Faso; Ifakara Health Institute, Dar es Salaam, Tanzania; Institute of Tropical Medicine, Antwerp, Belgium; Makerere University School of Public Health, Kampala, Uganda; Swiss Tropical Institute, Basel, Switzerland; University of Heidelberg, Hygiene Institute, Department of Tropical Hygiene and Public Health, Heidelberg, Germany (<http://www.arvmac.eu>).

Funding

This research is part of the project Effects of Antiretrovirals for HIV on African health systems, Maternal and Child Health (ARVMAC), in part supported by the European Community's FP6 funding.

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