‘What mother wouldn’t want to save her baby?’ HIV testing and counselling practices in a rural Ugandan antenatal clinic

Eva Vernooij a & Anita Hardon a

a Amsterdam Institute for Social Science Research, Centre for Social Science and Global Health, University of Amsterdam, Amsterdam, The Netherlands


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‘What mother wouldn’t want to save her baby?’ HIV testing and counselling practices in a rural Ugandan antenatal clinic

Eva Vernooij* and Anita Hardon

Amsterdam Institute for Social Science Research, Centre for Social Science and Global Health, University of Amsterdam, Amsterdam, The Netherlands

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Drawing on an exploratory qualitative case study investigating everyday practices within an antenatal clinic in rural Uganda, this paper investigates the dynamics of consent and counselling within a prevention of mother-to-child HIV transmission (PMTCT) programme, from the perspectives of various health professionals involved at different stages of the PMTCT trajectory. The paper contributes to the existing literature by focusing not on clients’ views but, rather, by elucidating how different cadres of health workers view and practice the human rights principles of informed consent and opting out, that are reflected in Uganda’s HIV testing policies. By investigating the roles and responsibilities of community counsellors, post-test counsellors, and midwives, we illustrate how the practice of counselling in PMTCT is influenced by two hegemonic discourses: the health of a child should be protected, and the health worker knows best. As a result, a directive form of counselling in PMTCT settings, with its focus on the health of the baby, silences women’s right to opt out of HIV tests.

Keywords: PMTCT; Uganda; HIV testing; counselling; consent

Introduction

Recent paradigms for health and development have increasingly advocated for the incorporation of the notion of human rights and responsibilities into HIV-prevention and-treatment programmes. People are viewed as citizens with rights and obligations – and not merely as beneficiaries – who make claims and participate in decisions affecting their lives (Whyte 2009). Those who fear enacted stigma can choose to be tested for HIV. If they opt for a test and are found to be HIV-positive, they have the right to good care (Hardon et al. 2011). Moreover, the concept of sexual and reproductive health and rights has, since the 1994 International Conference on Population and Development (ICPD), granted several reproductive rights: the right to decide whether or not to have children, the right to choose any method of contraception, and the right to receive family planning education (ICPD Programme of Action, Paragraph 7.2, United Nations 1994).

Although human rights have been an important part of the struggle to overcome social injustice and achieve basic standards of living and care in many places, the underlying principle of individuality within the rights discourse has been critiqued. Opponents, for example, have pointed to the influence of a particular liberal Western ‘ego-centric’ understanding of personhood (Schlyter 2009). Instead of perceiving human beings as separate individuals striving for autonomy, scholars have argued that in many cultures...
people are conceived of as relational beings. In such contexts, it is the social network to which one belongs, rather than the individual body, that constitutes the fabric of personhood (Munalula 2009). For example, in many African countries motherhood is highly valued and reproduction is seen as essential for a woman’s social identity (Hollos and Larsen 2008). Describing a case study on the relationship between motherhood, social responsibility, and women’s autonomy in Zambia, Munalula (2009) posits that in the ‘African’ context, women’s autonomy is always subject to corresponding responsibility to the community. The notion of reproductive autonomy (and individual rights) is therefore contested because women’s childbearing is influenced and sometimes controlled by male partners, families and the wider community (Munalula 2009). With consideration for the challenges to the human (and reproductive) rights discourse, this paper focuses on the contested sphere of reproductive autonomy in the context of prevention of mother-to-child HIV transmission (PMTCT) interventions in Uganda.

In the 1990s, reflecting the human rights discourse, healthcare providers made HIV testing available through voluntary counselling and testing (VCT) services. With VCT, individuals must purposely seek out and voluntarily request an HIV test (Bayer and Edington 2009). Low testing rates throughout sub-Saharan Africa have been attributed to this client-initiated VCT approach, and in the mid-2000s public health officials called for a routine opt-out approach to HIV testing, whereby tests would be routinely performed on all patients accessing healthcare services, unless the patient ‘expressly declines’. This had been termed provider-initiated testing and counselling (PITC), also sometimes referred to as routine testing (De Cock, Bunnell, and Mermin 2006). In countries with generalised HIV epidemics, PITC means that healthcare providers recommend HIV testing to all individuals attending healthcare facilities as a standard component of care (WHO 2007). Such provider-initiated approaches to HIV testing have only been considered ‘ethically sound’ under the condition of a rights-based approach, as outlined in the World Health Organisation’s (2003) publication The Right to Know.

Provider-initiated testing and counselling has had a significant impact on healthcare dynamics and service delivery in antenatal clinics in Uganda (MoH 2006). Due to the incorporation of routine PITC into everyday practice, health personnel have had to cope with an increased workload and shifting responsibilities. The increased number of facilities providing routine HIV counselling and testing for pregnant women has raised the uptake of HIV testing from 70% of all clients attending antenatal care at health facilities providing PMTCT in 2006 to 93.6% in 2011 (UAC 2010, 2012). While research in Uganda has shown high levels of patient acceptance of routine HIV testing in PMTCT programmes (Wanyenze et al. 2008), few have studied the experiences and notions of health providers (Whyte, Whyte, and Kyaddondo 2010; Rujumba et al. 2012) and the HIV counselling and testing practices under routine conditions in PMTCT (Angotti 2012).

In this paper, we describe the processes at stake and the interactions between counsellors, midwives and pregnant women in a PMTCT programme in one rural district in Uganda, with the aim of uncovering the underlying power dynamics. Our aim is not to assess whether human rights are respected but, rather, by describing the dominant discourses and the micro dynamics of power that are reflected in situated counselling practices (Hardon et al. 2011), to contribute to ongoing policy debates. This paper contributes to existing literature by focusing not on clients’ views (Angotti, Dionne, and Gaydosh 2011) but, rather, by elucidating how different health providers involved in PMTCT counselling view the human rights principles of informed consent and opting out that are reflected in Uganda’s PMTCT policies, and by pointing out the challenges that health providers face in implementing PMTCT programmes. Specifically, we investigate
three different forms of counselling offered in the field site: that offered by community counsellors, that given by midwives, and that implemented by post-test counsellors at healthcare facilities.

As part of HIV- and AIDS-related care, Lie and Biswalo (1994) offer the following definition of counselling:

[A] process of helping someone accept and use information, and advice for solving or coping with a problem (the ‘counsellor-centred/directive’ tradition), or as a process of helping someone make a decisions [sic.] and plan how to solve or cope with a problem (the ‘client-centred/non-directive’ tradition). (139)

To explain the forms that counselling takes in the study site, we make use of the Foucauldian concept of governmentality, which seeks to understand how power is exercised by analysing the discourse underpinning it (Foucault 1979). Inspired by Rose, Malley and Valverde (2006), our methodology for studying how PMTCT works as a governmental technique is to provide in-depth descriptions of how it is practiced. We have done this by analysing the different health worker actors involved in the programme, and argue that multiple governmentalities occur simultaneously in PMTCT. We illustrate how the practice of counselling in PMTCT is influenced by two hegemonic discourses articulated by health workers: that the health of a child should be protected and that the health worker knows best. As a result, a ‘directive’ form of counselling in which counsellors are seen as ‘advice-givers’ (Lie and Biswalo 1994), silences women’s rights to opt out of HIV tests as well as the expression of their sexual and reproductive needs.

Methods
The study design
Fieldwork was carried out over a period of three months from April until July 2008. A combination of qualitative research methods was employed: participant and non-participant observations, semi-structured interviews, and a review of international PMTCT and PITC policy documents.

The study setting
Healthcare delivery in Uganda is highly decentralised. National governmental hospitals occupy the highest level of the healthcare system, followed by regional and district hospitals and then four types of health centre (HC). Each HC is graded according to the administrative zone that it serves and the services offered, ranging from HC I, which serves a village, to HC IV, which serves a sub-district. By June 2009, 77% of all healthcare facilities in Uganda (from national hospitals down to HC IIIs) were offering PMTCT services (UAC 2010).

Data collection focused on an HC IV in a rural district in Uganda’s Central Region. Here, the regional HIV prevalence increased from 8.5% in 2005 to 8.7% in 2011 (for 2011, this was higher than the national average of 6.7%) (UHSBS 2004/2005; UAIS 2011, as cited in UAC 2012). The study district’s population primarily consists of the Baganda, the largest ethnic group in Uganda, who speak Luganda. The majority of households engage in subsistence farming. This district was selected because of previous research conducted by the research team on HIV testing and counselling services in the area (Hardon et al. 2012). The particular HC was selected because it was the only one in the district offering comprehensive PMTCT services at the time: post-test services (including non-ART care: mosquito nets, safe water facilities and treatment of opportunistic infections),
antiretroviral therapy (ART) for mother and child, tuberculosis screening and treatment, and a ‘post-test club’ with peer support groups and income-generating activities. The HC started offering PMTCT services in 2007 and functioned as a ‘model site’ for PMTCT in Uganda, and hence received additional international funding. Additional staff were hired to conduct PMTCT counselling in the community as well as the HC, medicine stock-outs for PMTCT were rare, and most staff received PMTCT training. In addition, at the time of the study the antenatal clinic had recently been renovated to accommodate the increased flow of patients because of PITC – to this end, a group counselling room, that could hold approximately 80 people had been constructed.

The need to address infrastructural shortcomings such as understaffing and medicine stock-outs in order to strengthen the quality of PMTCT programmes has been noted by another research study conducted in Uganda (Rujumba et al. 2012). Prevention of mother-to-child HIV transmission delivery at the research site for this study thus might not reflect what occurs at other sites in Uganda. However, because the centre was lauded as an example of ‘best practice’ and had established linkages with international agencies, it was particularly suitable for studying the interaction between ethical notions of HIV testing, as formulated in policy guidelines, and the moral realities of health providers and women in the clinic.

**Participants and data collection**

The study population consisted of three groups of healthcare providers involved in PMTCT: midwives, community counselling aides (CCAs) and post-test counsellors. Semi-structured interviews were conducted with 12 healthcare providers involved in PITC. These healthcare providers were selected through purposive sampling, whereby at least two respondents from each cadre of health providers were interviewed to provide a comprehensive picture of all personnel. Both post-test counsellors were interviewed, two out of four midwives, both clinical officers, both laboratory technicians and the two PMTCT managers. Because the CCAs were larger in number (25) we selected two participants based on their degree of work experience in the PMTCT programme. Even though 12 participants is a small sample size, it was adequate for achieving data saturation at the study site.

Interviews were conducted by the first author in English. They were focused on interpretations of the PMTCT policy regarding notions of informed consent and opting out, the operationalisation of these notions in practice, the practical changes that have occurred since the shift towards routine testing and broader societal issues, such as male involvement and stigmatisation. All interviews were audio recorded. Interviews varied in length from 45 minutes to 2 hours.

During the first four weeks of data collection at the antenatal clinic, non-participant observations were conducted to gain an understanding of the way in which PITC was carried out and to build rapport with staff. Observations took place during group and pre-test counselling sessions, HIV testing, pregnancy check-ups, laboratory tests, in the maternity ward and at the post-test club. No observations were made during post-test counselling because of the sensitivity of the discussions. Away from the HC, observations were made during community mobilisation and sensitisation outreach sessions, an antenatal follow-up visit by midwives and a community counsellor’s follow-up visit to pregnant women. Participant observation was carried out on several occasions at the antenatal clinic when it doubled as an ART clinic. In these instances the researcher, who also conducted the interviews, assisted a midwife, counsellor and administrative assistant with the preparation of medications.
Data analysis

All interviews were audio recorded and transcribed verbatim. During transcription the data were grouped into thematic categories. Data were then coded manually using ‘framework analysis’ to compare recurring themes in the interviews with different respondent types (midwives, community counsellors, post-test counsellors) and to compare them with field notes made during observations. Framework analysis provides an appropriate approach in studies where the research questions are predetermined and the aim is to generate policy and practice-oriented findings (Green and Thorogood 2004). After initial categorisation, open coding (where categories are derived inductively) was conducted to allow for the emergence of new themes (Pope, Ziebland, and Mays 2000). Data coding and analysis were done by the first author.

Ethical considerations

Permission to undertake this case study was granted by the Amsterdam Institute for Social Science Research at the University of Amsterdam, the Ugandan District Government, and the studied HC’s management. All participants provided verbal informed consent and were asked for their approval for the conversation to be recorded, which was always granted. All study participants were assured that participation was voluntary and that their anonymity would be maintained. All participants’ names in this article are pseudonyms.

Findings

The Ugandan PMTCT counselling policy

At the time of study, the shift towards routine PITC had led Uganda to revise its national HIV testing and counselling policy to embrace other forms of testing, including counselling and testing of pregnant women (MoH 2005). Uganda’s 2005 national HIV counselling and testing (HCT) policy states that all HIV testing (except for mandatory and diagnostic testing) should be carried out with the patient’s consent: if possible, the patient’s signature or thumb print should be recorded, otherwise consent should be expressed verbally (MoH 2005). The policy emphasises that ‘in RCT [routine counselling and testing], patients always have the right to accept, reject or to defer testing. Routine testing is not mandatory’ (12). The HCT policy states that the routine testing of pregnant women requires a modified routine testing approach, which stipulates that pregnant women receive more detailed pre-test counselling than patients seeking general medical care, because of the potential to prevent congenital HIV infection.

According to the 2006 PMTCT policy, the main goal of the PMTCT programme is to achieve a new generation free of HIV and AIDS by following the WHO/UNAIDS’ four-pronged approach: (1) primary prevention of HIV (preventing HIV among women and men of reproductive age), (2) prevention of unintended pregnancies among women living with HIV, (3) prevention of HIV transmission from pregnant women living with HIV to their babies and (4) provision of care, treatment and support to women living with HIV and their families (MoH 2006). The 2006 PMTCT policy, however, omits the issue of informed consent and opting out and provides no details on how and when testing should be offered (MoH 2006).

When we interviewed the clinical officer in charge of management of the HC about how the ‘right to refuse’ HIV testing was dealt with in practice, she explained that testing
was not compulsory for pregnant women, but that health staff would attempt to convince a client:

Someone who refuses to take the test is not forced. ... [But] you keep talking to her. Especially those midwives, they want to protect the baby. We don’t have a policy as a health centre per se, but the government policy says you are not supposed to force someone. They are not supposed to refuse, but they are not forced at the same time. (Clinical officer, Mary)

Counselling in practice at the field site: a six-stage approach

In the HC IV where we conducted our study, the PMTCT programme consisted of six stages: community mobilisation and sensitisation, group counselling, pre-test counselling, HIV testing, post-test counselling and referral and follow-up care. Counselling was compartmentalised at this HC, with different cadres of health workers doing pre-test, post-test and follow-up counselling.

The CCAs played a key role in the programme and were involved in the first three stages – mobilisation, group and pre-test counselling – as well as the last stage, when they followed up women in their homes after testing in the antenatal clinic. HIV testing and post-test counselling were done by a different cadre of workers, – post-test counsellors – who, unlike the CCAs, received a regular salary and training in post-test counselling. The CCAs and post-test counsellors were incorporated into the PMTCT programme with overseas funding, granted to the centre to increase the percentage of health facility births and ensure that women understand how to take the antiretroviral drug nevirapine (NVP) to prevent HIV transmission to their baby. The PMTCT manager described the importance of the CCAs:

So, first and foremost the mother should realise that this drug is saving her baby and what mother would not want to save her baby? Because every mother loves the baby. So what we realised is that when we give the mother the [NVP] tablet, the ideal logic is the moment you go into labour you swallow. ... So you realise when you ask how many [of the NVP tablets] are given you can say 100%, when you ask how many swallowed nobody knows. Because we don’t have the capacity to follow up each and every woman. ... So that’s why we brought on board the CCA[s] and that’s why we want to go and visit them at their homes. (PMTCT manager, Eric)

Around 25 volunteer CCAs had been trained. The CCAs were selected through the involvement of the Local Council system of civic administration: parish chiefs and local leaders of the sub-county met and decided (together with the NGO recruiting the CCAs) which villagers would be suitable volunteers to strengthen the PMTCT programme. Often these CCAs had already worked as volunteers in other types of preventive health-related activities, such as immunisation campaigns, and saw PMTCT as another preventive action. Unlike the HIV-positive peer educators and ‘expert clients’ who work as volunteers in AIDS-care programmes (Kyakuwa and Hardon 2012), the CCAs and post-test counsellors at the study site did not assert their HIV status.

Before the extra counsellors (CCAs and post-test counsellors) were brought in, the midwives had been responsible for all counselling and testing activities within PMTCT. Below, we discuss how the CCAs, midwives and post-test counsellors engaged in the PMTCT programme and how they understood their ambiguous aims of protecting the unborn child while upholding pregnant women’s right to refuse an HIV test.

The role of the CCAs

The involvement of CCAs within PMTCT at the study site was twofold: first, they educated the community about PMTCT services at the village level and, second, they
provided (group) pre-test, adherence and post-test (club) counselling at the antenatal clinic and conducted post-test follow-up visits to offer support and advice.

During community mobilisation activities, CCAs either visited women door-to-door or organised group sessions, during which they educated the community about the benefits of seeking antenatal care. During community mobilisation outreach sessions, CCAs often combined their different functions: encouraging pregnant women to come to the clinic for an HIV test, while performing hygiene check-ups to monitor the house, kitchen and pit latrines for health ‘violations’. The pregnant women were given forms that stated their name and reason for visiting the clinic, to present during their antenatal visit. According to Frances, a CCA who had been working as a community health worker for over 10 years, the CCAs try to convince pregnant women by explaining that they can prevent their child from becoming infected with HIV. Frances’ discourse was reflected in all the interviews we held with CCAs. Over time, however, this approach seems to have been replaced by a more directive strategy, as Frances explained:

At first the mothers feared, what we call stigma: they did not want to go for testing. So we went on sensitizing on PMTCT, so more women came . . . but still many women feared: ‘Will I die when I am positive, how will I tell my husband?’ So we made it compulsory, when the women is pregnant she has to be tested . . . (CCA, Frances)

Hamidu, a young male CCA, reported that during community mobilisations a commonly asked question was, ‘Can they check me [antenatal check-up] without [HIV] testing?’ He reported that his usual response was, ‘It is compulsory. You test when you are pregnant’. Our discussions with the CCAs suggested that they emphasised the compulsory nature of PMTCT for pragmatic reasons: to convince their clients to go to the clinic, which they considered to be their objective. As a consequence of this community mobilisation, many women who visited the clinic were already aware that they would be tested for HIV before receiving the antenatal check-up.

Twice a week the CCAs held PMTCT group counselling in the waiting area of the antenatal clinic. At these sessions, the CCAs explained about HIV and AIDS and PMTCT and how to take medications in case of a positive test result. Apart from condom use, sex and sexuality were hardly discussed. After group counselling, the women were registered. First they were weighed, then the CCAs recorded their personal information (name, age, occupation, marital status, tribe, number of children) in the notebooks that the women must buy themselves and then they completed the information in the clinic’s register. The notebooks function as a personal patient file and have to be kept by the women and brought during every visit to the clinic. After this, the CCAs copied the information onto what was considered the consent form (provided by one of the programme’s donors). This form included the question: ‘Do you agree to be tested?’ However, during observations at the group and pre-test counselling sessions, none of the counsellors ever asked this question. David, one of the two contracted post-test counsellors who had been working for over three years in the antenatal clinic, explained:

At first, we used to ask them, to consent, do you want to be tested, they say yes I want to be tested or no I don’t. That was when there was only VCT. . . . Now we don’t ask them that consent question, because it is compulsory, we don’t want to ask that question because she can say no I don’t want. Since we know that [HIV testing of pregnant women] is our policy here, there is no need to ask that question. (Post-test counsellor, David)

David’s statement demonstrates the friction generated over obtaining informed consent when a testing policy is interpreted as compulsory. The other contracted counsellor, Beatriz, argued that she does ask women for consent: ‘Yes, you have to ask her, do you
want to be tested for HIV so you get a normal baby?’ In posing her question for consent, however, Beatriz alludes to the common morality discourse that pregnant women should test to protect their unborn child, suggesting that women who do not accept the offer of an HIV test do not want a ‘normal’ baby. While (early) HIV testing in pregnancy is promoted both for the sake of the baby and for the mother’s well-being in the 2006 PMTCT policy, in practice there is a clear absence in the discourse of health workers regarding the benefits of HIV testing and treatment for the mother’s health. The moral imperative seems to be that the baby’s health comes first.

In our attempt to monitor the process of consent, we observed the administrative course that the consent form followed. This form included specific questions: whether a person has been tested before, consents to be tested, wants to receive the test results and where she or he is to be referred for HIV care. We found that the form was filled in at different junctures in the process of testing: after group counselling, after pre-test counselling or during testing. This was related to the fluctuating arrival times of pregnant women and staff workload. On some days, there was only one counsellor and one CCA to hold group and pre-test counselling with an average of 40 women. On such days, women only received group counselling and were directed straight to the testing room, the forms were left uncompleted and consent was not requested or given. Sometimes, the forms were completed without the women being present or without explicitly obtaining their consent. A probable explanation for why the consent form was sometimes completed, irrespective of whether consent had been sought, was the need to provide evidence to the programme donors about the number of people reached and tested as part of PMTCT. The following statement from Beatriz makes clear that this practice excluded those who refused or opted out of a test:

When she agrees you fill the consent form, when she doesn’t agree you don’t fill the form. You fill it when she has agreed to be tested. We don’t waste the form . . . (Post-test counsellor, Beatriz)

But, as she added later, she had never experienced somebody refusing to test:

They know every woman must pass though HIV screening because it is announced on all the radios. (Post-test counsellor, Beatriz)

In pre-test counselling, women were counselled by the CCAs in smaller groups of three to six. The length of six observed pre-test counselling sessions varied between 10 and 30 minutes and the topics covered differed somewhat between the male and female CCAs. The male CCAs devoted much time to the imperative of disclosing test results and rushed over or even omitted how to take the antiretroviral drug nevirapine for PMTCT if the test proved positive. The female CCAs spent more time on the issue of breastfeeding and went into detail about how to tackle disclosing a positive status to one’s husband. They stressed that disclosure is an important part of achieving PMTCT, arguing that without the financial support of husbands, most women would not be able to afford travel to the clinic for safe delivery, or the nevirapine syrup or bottle-feeding for the baby, all of which decrease the baby’s chances of infection.

After pre-test counselling, all women were directed to the testing room. In theory, when a woman refuses to be tested she can simply leave. Another way of refusing is to tell the counsellor before he or she draws blood and, in this scenario, she will not be obliged to test but should still be able to obtain antenatal check-up services. However, because there was no specific moment when consent was asked for, and because the CCAs, who were seen as the women’s superiors, directly referred the women to the testing room, in practice there was scarcely an opportunity to opt out. Women’s common responses to the CCAs’
standard question about what she would do if she tested HIV-positive illustrated these power relations: ‘You have to do whatever the counsellor tells you to do’. Women looked up to the CCAs and perceived them as very knowledgeable, and they addressed them using the same title as used for other health providers: omusawo (meaning ‘health worker’ in Luganda).

Although in theory a woman could walk straight into the check-up room without being tested, this was unlikely to occur because midwives’ first procedure during the antenatal check-up was to note whether the woman had been tested for HIV. If a midwife did not find the code in the notebook, the woman would be redirected to the testing room.

The role of the midwives

The two midwives interviewed were outspoken about the PMTCT policy and their role and responsibilities within the PMTCT programme. According to Ann, a midwife who had been working at the clinic since 2004, testing was compulsory:

It is a routine, RCT: we make sure that we test each and every mother. .... We are sorry, but the programmes have been [announced] on the radio. All mothers should test. (Midwife, Ann)

Sara, a midwife who had worked at the clinic since early-2006, offered a different reason for why testing was compulsory for pregnant women: inadequate counselling leads to refusal to test. Midwives are trained to convince the women to test and if a woman refuses this, it is seen as a failure on the part of the midwife.

Midwives played a crucial role throughout the PMTCT counselling trajectory. Although they were no longer involved in pre-test counselling, the midwives continued to counsel HIV-positive women on feeding options, nutrition, and partner disclosure during prenatal, antenatal and postnatal counselling sessions, either when women came to the clinic for a check-up or when midwives occasionally visited them in their homes after work. The midwives argued that in order for them to be able to carry out their duties of convincing women to take the nevirapine tablet and to choose a feeding option, it was a prerequisite that women be tested and accept their results. The following quotation from Sara illustrates this:

I am supposed to counsel that lady, until she accepts to test. Then it is upon her to refuse the results. But again for me as a midwife it is my obligation to convince that mother to accept the results. She is supposed to choose a feeding option. She is supposed to accept nevirapine. How will I do this unless I re-counsel her to convince her to accept the results? Because my target is to have a live baby. To try and prevent transmission. (Midwife, Sara)

The other interviewed midwife concurred:

It is important to know the HIV status. .... This is important for our own protection and to follow the protocol of PMTCT; to save the baby. (Midwife, Ann)

For the midwives, protecting the child from HIV was their main goal – to protect unborn babies, all pregnant mothers should be tested. Hence the moral imperative dictated primacy of the child’s health. Additionally, the midwives wanted to be able to protect themselves when assisting at an HIV-positive mother’s delivery, for example by wearing two pairs of gloves. In order for them to provide good care, midwives thus saw testing as essential.

The role of the post-test counsellors

After HIV testing was carried out at the antenatal clinic, the post-test counsellors brought the results to the lab. It usually took around 30 minutes before the test results were ready. At the time of study, the serial rapid testing algorithm with Determine, STAT-PAK and
Uni-Gold were used to identify HIV antibodies. Health workers trained as post-test counsellors then called in the women one by one: first, women with negative results, for whom the counselling took between 5 to 10 minutes; second, women with positive results, because the counselling took longer (20 to 30 minutes).

Regarding the possibility of women refusing to receive their test results, David, a post-test counsellor, questioned, ‘Why do we test them if they are not supposed to take the results?’ His question reveals a different view of the ethics and purpose of testing than those presented by the midwives. The job of the post-test counsellors was to give the results and counsel people on behaviour change following the ABC model (Abstinence, Be faithful or use Condoms) and ‘living positively’ (disclosing their HIV status to their sexual partner(s) and family, refraining from unhealthy habits such as drinking and smoking and eating a healthy diet). However, both interviewed post-test counsellors acknowledged that there was still a lot of stigma in the community. Women feared taking the medication or delivering at the clinic because people might start rumours about them, and they avoided disclosure to their husbands for fear of abandonment and loss of financial support.

Because their duty was to offer ‘ongoing counselling’, post-test counsellors visited the homes of HIV-positive women to educate and counsel them and their partners. While midwives concentrated mainly on the unborn child and the mother, the post-test counsellors focused on the bigger and more holistic picture, taking into account women’s family, social and emotional life. For the post-test counsellors, to tackle issues of stigma and male involvement, the first step was for pregnant women to accept their test results. Hence testing without receiving the results has no purpose.

**Challenges confronted by the post-test counsellors and the midwives**

The midwives and post-test counsellors at the antenatal clinic expressed frustrations about their inability to convince women to disclose their status to their husbands and of the necessity to come back to deliver in the clinic and take nevirapine. They argued that because of high workload and understaffing, there was little time to provide sufficient personal post-test counselling in the clinic. Counsellors and midwives were exasperated because they were not reaching men through PMTCT and women were unable to convince their partners to come for testing.

During ongoing counselling for HIV-positive women, health workers’ prevention messages focused on condom use, abstinence and partner testing, with the aim of preventing future pregnancies:

> We tell them, you go and disclose and tell the husband to use a condom. We are not there to follow condom use. When they come back to the ART clinic, we are always asking them: do you have protected use? Most of them tell us they use a condom. Then eventually we discover some of them are pregnant, after condom, condom, condom! After abstinence abstinence abstinence. We give information. And it is upon them to deceive us every time they are coming. (Midwife, Ann)

According to Ann, the purpose of counselling is to give information, resembling a ‘directive’ approach to counselling as described by Lie and Biswalo (1994). This directive form of counselling leaves no space for discussions on the reproductive desires of people living with HIV.

**Discussion**

The international counselling ethos that focuses on consent and patient rights is challenged by the local practice of PMTCT in the antenatal clinic of the studied HC in rural Uganda.
Prevention of mother-to-child HIV transmission in local practice, with its main focus to prevent HIV transmission to the unborn child and reach targets around reducing incidence, reflects an underlying morality that health professionals are expected to know what is best for their patients. Health providers’ counselling practices are thus influenced by their perceived moral responsibilities as professionals, as well as the need to promote and adhere to public health goals of preventing further infections.

The findings show that although the clinical officer, who was also the manager of the HC, acknowledged the right of pregnant women to opt out, over time local level CCAs had adopted a clear message: testing is compulsory. Unlike peer counsellors in AIDS-care programmes, the CCAs did not discuss their own HIV status. In their counselling practice, they did not emphasise patient rights, but rather the moral responsibility to protect the unborn child. Midwives, who conducted antenatal care in the clinic, reinforced this message. They also considered HIV testing an essential step in providing good care. Similar findings have been articulated by Angotti (2010) and Agnotti, Dionne, and Gaydosh (2011) in two studies on provider-initiated testing in rural Malawi. Angotti, Dionne, and Gaydosh (2011) illustrate how in antenatal clinics the majority of the women interviewed perceived testing as compulsory and felt it was an ‘offer they can’t refuse’. In another study, Angotti (2010) looked at rural Malawian HIV counsellors working in health facilities offering HIV counselling and testing services (not specifically in antenatal care). The study showed how these health workers adapted testing guidelines, whereby overruling principles of strict voluntariness and confidentiality, so that they became congruent to what they perceived to be the programme’s main aim: to reduce further HIV transmission. Our study builds on this argument by showing how different cadres of health workers in a rural setting in Uganda interpreted the PMTCT policy differently from one another (and to the officially stated policy guidelines) and justified their actions based on their professional logic and role within the programme. Rather than conceptualising governmentality (Foucault 1979) as if it were a homogenous entity, we have shown how different types of governmentality occur simultaneously in one PMTCT programme by analysing the actors at play in practice.

Although not the focus of our study, previous studies have addressed clients’ perspectives on the relatively coercive HIV testing practices in Uganda. In another study in Uganda, we found that when people were asked who should be mandatorily tested for HIV, pregnant women were most commonly mentioned (also by pregnant women themselves) (Hardon et al. 2012). Furthermore, such studies suggest that women value not being offered a choice. Overall, the inherently medical context of PMTCT services provides, it seems, an attractive moral space for pregnant women to undergo HIV tests. In contrast, for many women presenting oneself at a VCT clinic is equated to an admission of sexual promiscuity and carries with it the related risk of social death. In PMTCT, HIV is not associated with sexual promiscuity, but rather with good medical care and being a responsible mother to the unborn child. Although the testing of pregnant women is considered positive because the woman is seen to take responsibility for her child (even when she does not have a choice), men do not seem to be subjected to the same kind of moral discourse, that being a good father or husband necessitates testing for HIV.

When pregnant women in the study site were found to be HIV-positive, the post-test counsellors and midwives demonstrated a commitment to providing ongoing family-centred care when they visited women in their homes after work hours. They tried to help HIV-positive mothers to convince their partners to be tested and made sure that they were adhering to the chosen feeding option. But they were frustrated that the women did not use condoms to prevent transmission and continued to become pregnant. The counselling messages they used focusing on condom use – the same as those for the general (HIV-
negative) public – have been critiqued for not taking seriously the sexual and reproductive rights of people living with HIV who are on ART (Seeley et al. 2009). When the approach to preventive counselling solely involves advising women to use condoms, with no discussion of sexual and/or reproductive desires, it is unsurprising that women ‘deceive’ midwives and do not inform them about their pregnancy desires. The withholding of pregnancy intentions has also been noted in another qualitative study in Uganda (and Tanzania) among young people living with HIV (Moyer, Namukassa, and Kyakuwa 2011, as cited in Moyer 2012). In this study, Moyer and colleagues reported that young people were faced with continuing stigma from healthcare providers about their desires to have children, which resulted in them routinely lying to healthcare providers.

As the study was conducted at a single exceptional health facility, the findings cannot be generalised outside the study context. In most Ugandan PMTCT programmes, nurses and midwives are the main cadres providing counselling. But because our study site received extra funding – as one of the country’s model sites for PMTCT – CCAs and post-test counsellors were responsible for the pre- and post-test counselling sessions, respectively, which reduced some of the midwives’ workload. Other studies from Uganda have shown that in settings where counsellors for PMTCT are women who are themselves HIV-positive (‘expert clients’), counselling focuses more on women’s rights and feelings (see for example Kyakuwa 2011). However, at this site, pre-test, post-test and follow-up counselling were compartmentalised and carried out by different cadres, which affected the relationship and level of rapport between the providers and clients.

Since data collection was carried out, significant changes have taken place at the global and national levels regarding ARV prophylaxis options for pregnant women: policies have moved away from the single dose nevirapine intervention, which only focuses on the baby’s health, to a more effective combination ART, which also benefits the mother’s health (ITPC 2011). Although, in terms of recommended medication, this shift in ART provision places greater emphasis on expectant mothers’ health, a recent evaluation study by the International Treatment Preparedness Coalition reported that Uganda’s PMTCT and reproductive health programmes are in practice structurally and operationally parallel to one another (ITPC 2011, 68).

Recently, east African treatment activists have been actively involved in ‘say no to single-dose nevirapine’ campaigns, demanding more comprehensive PMTCT services (www.four4women.org). These newly formed biosocialities, rooted in PMTCT-related activism, could contribute to a re-evaluation of a comprehensive and non-directive approach to counselling, which includes discussion of sexual and reproductive health needs. To achieve this, it is necessary to address health providers’ governmental rationalities, which seem to disregard pregnant women’s ability to make their own health choices.

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**Notes**

1. The terminology of PMTCT has been subject to ongoing debate. Some have argued in favour of the term ‘parent-to-child transmission’ (PTCT) in order to pay attention to the role of the father in preventing HIV transmission to the unborn child. Recently, the more neutral medical term ‘vertical transmission’ seems to be given preference. In this article we will speak of PMTCT because at the time of this study (2008) this was the generally used term.
2. The district and name of the health centre will not be mentioned to safeguard the privacy of the site and people involved.

3. Uganda is currently revising its PMTCT policy, which will replace the 2006 guidelines.

4. At the time of data collection, the regimen used for PMTCT was a single dose of NVP to be taken by the mother at the onset of labour and a single dose of NVP in the form of a syrup to be given to the baby within 72 hours of birth. Because of its limited effectiveness, the use of NVP in PMTCT is being phased out, though in many resource-poor settings it is still the only option available.

References


Résumé
En s’appuyant sur une étude de cas qualitative qui a enquêté sur les pratiques quotidiennes dans un centre de soins prénatal située dans des zones rurales de l’Uganda, cet article examine la dynamique du consentement et du conseil dans un programme de prévention de la transmission de la mère à l’enfant (PTME) à partir des points de vue des divers acteurs de santé s’impliquant aux différentes étapes de la PTME. L’article contribue à la littérature existante en se concentrant non pas sur les points de vue des patients mais plutôt en déterminant comment différents professionnels de santé perçoivent et appliquent les principes de droits humains que sont le consentement informé et l’option de refus du dépistage, reflétés par les politiques de dépistage du VIH en Ouganda. En explorant les rôles et les responsabilités des conseillers communautaires, des conseillers post-dépistage et des sages-femmes, nous montrons comment la pratique du conseil dans le cadre de la PTME subit l’influence de deux discours hégémoniques : la santé d’un enfant doit être protégée, et le professionnel de santé est celui qui sait le mieux. Il en résulte qu’une approche directive du conseil, utilisée dans les unités de PTME et centrée sur la santé du bébé, a un effet réducteur sur le droit des femmes à l’option de refus du dépistage du VIH.

Resumen
A partir de un estudio exploratorio y cualitativo de casos en el que se analizan las prácticas diarias de una clínica prenatal en una zona rural de Uganda, en este artículo se investigan las dinámicas de consentimiento y asesoramiento en el marco de un programa de prevención de la transmisión de madre a hijo (PTMH), teniendo en cuenta los puntos de vista de varios profesionales de la salud que participaron en las diferentes fases de la trayectoria de la PTMH. Este artículo contribuye a la bibliografía existente al prestar atención no a las opiniones de las clientes sino más bien al explicar el modo en que entienden y practican los trabajadores sanitarios los principios de derechos humanos del consentimiento informado y la exclusión voluntaria, que se ven reflejados en las reglas para la prueba del sida en Uganda. Al investigar los cargos y las responsabilidades de los asesores de la comunidad, los asesores tras la prueba y las comadronas, ilustramos cómo la práctica de asesoramiento en la PTMH está influenciada por dos discursos hegemónicos: se debe proteger la salud del niño y el trabajador sanitario lo sabe mejor. Por consiguiente, una forma autoritaria de asesoramiento en los entornos de la PTMH, cuyo tema central es la salud del bebé, silencia el derecho de las mujeres a la posibilidad de no hacerse la prueba del sida.