

## Factors Influencing the Uptake of HIV Testing During Antenatal Care in Rural Uganda

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### Abstract

Despite critics of the 'opt-out' policy surrounding HIV testing during antenatal care visits in Uganda suggesting that women may be deterred from seeking antenatal care at facilities with on-site testing, empirical evidence suggests the acceptability of HIV testing during antenatal care has been significantly increasing over the last decade. Furthermore, there is a disconnect between high rates of antenatal care and low rates of facility births implying that there are other reasons women use antenatal care besides to prepare for a facility delivery. The aim of this paper is to investigate the role HIV testing has in the high rates of antenatal care uptake in Uganda. A focused ethnographic study was undertaken in two areas of Kabarole district between the period of September 2009 and January 2010. Data collection consisted of in-depth interviews, focus groups and participant observation. Overall, 58 interviews were undertaken with new mothers and pregnant women, older women, and formal and informal health care providers. Four focus group discussions were undertaken with a total of 41 husbands. Data collection tools included semi-structured guidelines for both the interviews as well as the focus group discussions. Our findings revealed that HIV testing was an important motivator for women to seek antenatal care. There are three reasons for this: 1) knowledge of mother-to-child transmission and prevention has increased, 2) health care providers refuse to attend to women during childbirth who do not know their HIV status and who do not have proof of their HIV status in the form of an antenatal card, and 3) HIV testing during pregnancy is transforming into a societal expectation and is linked to notions of 'good motherhood'. It appears that the two decade old HIV campaigns in Uganda have resulted in increased knowledge and awareness leading to a change in expectations and practice. HIV testing and having proof of their HIV status as another key motivator for seeking antenatal care may also help to explain the disconnect between high antenatal care rates and low rates of facility births.

**Keywords:** Uganda; Antenatal care; HIV testing; Qualitative methods

**Abbreviations:** AIDS: Acquired Immunodeficiency Syndrome; ANC: Antenatal Care; FGD: Focus Group Discussion; HIV: Human Immunodeficiency Virus; TBA: Traditional Birth Attendant

### Introduction

Over one million people are estimated to be living with Human Immunodeficiency Virus (HIV) in Uganda. The first Acquired Immunodeficiency Syndrome (AIDS) control program in Uganda was initiated in 1987. In 2000, as part of the implementation of the Prevention of Mother-to-Child Transmission Strategy by the Ugandan Ministry of Health, HIV testing was incorporated as a component of antenatal care (ANC). The government initiated the current 'opt-out' policy in 2006 whereby all mothers attending ANC will be tested for HIV unless they specifically decline [1,2]. In cases of a positive diagnosis, women are treated, counseled, and educated regarding precautionary measures at the time of delivery as well as infant feeding practices [3]. Women are also asked to disclose their status to partners and bring them in for testing [4].

A large body of literature has explored the acceptability of and barriers to accepting HIV testing during ANC [2,5-7]. A study in 2003 found some of the barriers to accepting HIV testing during ANC were lack of HIV-testing facilities, unavailability of HIV counselling, and perceived lack of benefit for HIV infected women and their children [6]. Later, in 2008, Dahl et al. [7] found that most women refused testing because they first wanted to discuss being tested with their partners while a small proportion had confidentiality concerns and feared discrimination from the community or by the health care staff. Larsson et al [5] also investigated women's experience with HIV testing during ANC using qualitative research methods. They found that women felt they did not have a choice in the matter and that they were obliged

to be tested. This perceived lack of choice and the fact that men were free to choose, were identified as unfair. The authors concluded that perhaps these kinds of experiences may lead women to avoid seeking antenatal care, particularly from facilities that have on-site HIV testing.

However, empirical survey data suggests there has been a substantial increase in the practice of acceptance of HIV testing during antenatal care in Uganda. In 2003, only 10% of pregnant women were being HIV tested [6]. By 2011, according to the national Demographic Health Survey (DHS), this rate had increased to 60.4%. If women who were tested during childbirth are included, this number rises to 76% [8]. These increasing rates are supported by smaller studies. Between 2008-2010, Larsson et al. [2] found an HIV-testing rate of 64% in the Iganga and Mayuge districts in eastern Uganda. Dahl et al. [7], in 2005, found 85% of women attending an ANC visit in the Mbarara district tested for HIV. More optimistically, the Ministry of Health, in 2009-2010, estimated that 98% of all women who accessed antenatal care, post-natal care and delivered in a health facility had been HIV tested [9]. Clearly, the literature suggests HIV testing during pregnancy and childbirth has increased significantly in the past decade in Uganda.

Missing in this literature is an analysis of why HIV testing rates

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have increased at this impressive rate; why are more women now accepting this test? Between 2003 and 2006, HIV testing during an antenatal visit had been voluntary. Women had to actively seek out the test. In 2006, when Uganda implemented the 'opt-out' policy, every woman seeking ANC was tested for HIV unless she actively refused. This may explain the increase in rates of HIV testing. At the same time, rates of ANC uptake increased from 92% in 2006 to 96% by 2011. As mentioned above, critics of the 'opt-out' policy have suggested that such a policy could lead women to select ANC from facilities without access to on-site HIV testing capabilities or that it could deter women from seeking ANC altogether [5]. Empirical evidence suggests that this is not happening.

A paradox in maternal health care use in Uganda is the disconnect between high rates of antenatal care and the low rates of facility delivery (98% versus 57%). A large body of literature has explored this discrepancy and identified numerous barriers to facility births. These include husband's lack of support and that most husbands (who are the main decision-makers [10]) perceive pregnancy and reproduction as a women's issue [11,12], no access to financial resources [13], and abusive health care staff behaviour [11].

The maternal health discourse has promoted ANC use as a step to increasing facility births. However, the Ugandan experience suggests that the high rates of ANC care are not translating into high rates of facility births. In fact 18% of women continue to deliver under attendance of a traditional birth attendant (TBA) despite the fact that TBA practice has been declared illegal. This suggests women are seeking ANC for reasons other than preparing for a facility birth. In light of the increasing rates of HIV testing during ANC and enduring high and sustained ANC rates, the specific objectives of this study are to explore: (1) what role HIV testing has in the high levels of ANC uptake, and (2) what factors underlie the high uptake of HIV testing during pregnancy.

## Methods

Data for this paper are part of a larger focused ethnographic study that aimed to investigate the gap between high rates of antenatal care and relatively lower rates of facility births. Data were collected in two areas of the Kabarole district – Fort Portal Town, the surrounding villages and Hakibale Sub County in Uganda during the period of September 2009 to January 2010. This particular field site was chosen because of the 15-year long research collaboration between the University of Alberta and Kabarole District Health Office.

Three main data collection methods were used: in-depth interviews, focus group discussions (FGD) and participant observation [14] (Table 1). Semi-structured interview guides were created prior to traveling to Uganda and were designed to help illicit local knowledge, attitudes, perceptions and beliefs related to pregnancy and childbirth [15, 16]. The initial interview guide was loosely based on the McGill Illness Narrative Interview (MINI) and Explanatory Model Interview Catalogue (EMIC) interview styles [17,18]. Upon arrival in Uganda, the interview guides were translated into Rutooro and assessed for clarity and cultural appropriateness. This guide was used for the first three interviews and after reviewing transcripts and discussing findings with research assistants, modifications were made to collect more specific information and ask additional questions. This process of reviewing transcripts and making modifications to the interview guide continued throughout the research process [16].

Overall 31 in-depth interviews were conducted with new mothers who had given birth in the previous 12 months, nine with formal health care workers, eight with informal health care workers and 10 with older women, for a total of 58 interviews. The majority of the interviews were conducted in Rutooro by trained Ugandan interviewers, in the presence of NM. Focus group discussions, which use group interaction to produce data and insights, were conducted with 41 husbands whose wives' had given birth in the previous two years to gain insight into men's understandings and practices with respect to pregnancy and childbirth [16,19]. A moderator facilitated the discussion and a note-taker took observation notes. A translator simultaneously translated the session so that the researcher (NM) could ask additional questions or clarify the discussion. All interviews and focus group discussions were digitally recorded, translated and transcribed by native Rutooro speakers (Table 2).

Participants were recruited through a snowball sampling method, which falls under the broader category of purposeful sampling. Purposeful sampling selects participants based on characteristics that are deemed appropriate for the research question and objectives. Snowball sampling involves identifying a person or "case of interest" and then asking that person to recommend other potential participants who would also be appropriate and asking subsequent participants to recommend more potential participants to be included [20].

Participant observation was undertaken by NM who lived within the community for four months and maintained a journal with notes on observations made at health centers, observations from interviews,

Data collection strategy	Tools Used	Quality Control
In-depth interviews	Semi-structured interview guide based on the McGill Illness Narrative Interview (MINI) and Explanatory Model Interview Catalogue (EMIC) interview styles because the aim of both is to attain local explanatory models regarding illness [17,18]	Upon arrival in Uganda, the interview guides were translated into Rutooro and assessed for clarity and cultural appropriateness and test interviews were undertaken [32].
Focus-group discussions	Same as above	Same as above.
Participant observation	Maintained a journal with notes on observations made at health centers, observations from interviews, focus group discussions, and accumulative probing questions that arose [25].	Lived in the village for four months and through continuous conversations with colleagues and verification with participants [21,22,25].

**Table 1:** Three data collection strategies used in the study.

	Number of interviews conducted in total	Fort Portal and surrounding area	Hakibale Sub-county
Mothers	31	14	17
Formal health care workers	9	5	4
Informal health care workers	8	1	7
Older women	10	4	6
	<b>Number of focus groups conducted</b>	Fort Portal and surrounding area	Hakibale Sub-county
Focus groups with husbands	4 (41 participants in total)	2	2

**Table 2:** Total number of participants, interviews and focus group discussions.

focus group discussions, and any cumulative probing questions that arose. Observations were made of the facilities available, transport methods and living conditions.

Data collection, coding, and latent content analysis were concurrent to ensure credibility and reliability [21]. The data were analyzed in five steps: reading, coding, developing domains, developing themes, and interpretation [22]. The process of coding involves reading and re-reading the transcripts to identify key words and phrases that are important or relevant. These codes were categorized into domains based on the key ideas arising from interviews, focus groups and observations. The domains were then sorted, re-read and developed into themes based on identified connections in the data [19,22,23]. During the entire process of analyses, notes containing insights, thoughts, questions and ideas were maintained. These memos were used to help understand the findings and develop themes and conclusions [24]. The findings and data were continuously discussed and verified through conversations with colleagues, supervisors and other research team members to ascertain that appropriate meanings had been identified [19,21,25]. Rigour is an important aspect of qualitative research as it ensures that findings are generated from the data and interpreted appropriately. It is important to maintain an accurate representation of participants (internal validity/credibility), appropriately apply the findings to other settings (external validity/transferability) and ensure that findings are verified through review and audit trails (reliability/dependability) [25].

Informed consent was garnered from participants only after explaining the study to them. No participant declined the invitation to be interviewed. As all participants were over the age of 18, they provided their own informed consent. Due to differing levels of literacy, some participants were unable to sign their names on the consent form and in these cases a thumbprint was accepted. Ethical approval for this research was obtained from the Health Research Ethics Board Panel B at the University of Alberta as well as the Uganda National Council for Science and Technology in Kampala.

## Results

### Seeking ANC for HIV testing

The majority of our respondents had sought biomedical antenatal care at least once during their pregnancy. While this was not unexpected, a surprise finding was that the key reason given for seeking this care was to get tested for HIV and have a physical exam to assess the position of the baby.

Our respondent narratives revealed a high degree of sensitization towards the importance of HIV testing during pregnancy. The majority of women who had sought ANC in a biomedical facility consistently identified HIV testing as a key process of the care they received: "The first thing they do – they instruct you to first go for HIV testing" (mother, M2). Specifically, women deemed it important and, in some cases, essential, to be tested in order to have a healthy baby. They were aware that without testing, they were "increasing the risk of giving birth to a child who is infected with the HIV virus ... if [they had] gone to the hospital for testing, [they would] give birth to a healthy child" (mother, M29). Partners of women who had recently given birth (identified as husbands) also encouraged their wives to be tested for HIV because "if the woman is found positive, she's recognized and at the time of giving birth, she delivers a HIV free baby" (husband, P4, FGD 4).

"When a woman visits a health unit, she is tested for HIV/AIDS and the fetus inside gets that chance of being treated also... when the

baby is delivered... it comes out in a healthy state because it was given medication. It is good advice to always get health services from hospitals because there is enough treatment..." (Husband, P12, FGD 1).

Given that ANC consists of a number of services such as measurement of blood-pressure, urine testing, testing for anaemia, and malaria, these were rarely mentioned by our respondents. Their emphasis was on HIV testing, which itself is revealing of the pervasiveness of the practice of HIV testing and its importance to our respondents.

Our data show that all pregnant women in our field site prepared for delivery with a card acquired by attending at least one antenatal care visit. This card documented whether she had or had not been tested for HIV and her HIV status. Women obtained this card even if they planned on delivering at home with a TBA. It was the documentation of their HIV status that emerged as a key reason for women making at least one ANC visit. An ANC card was also essential to receive any biomedical care from a biomedical health care facility in the event of a childbirth complication.

"When you go for antenatal care they first remove your blood and they test you for HIV. I went there and they tested my blood for HIV and thereafter gave me a small paper to take to the midwife". (mother, M6).

Our data identified three reasons that appeared to be pushing this increased acceptability of HIV testing during ANC: 1) Increased knowledge of maternal-to-child transmission and how it can be avoided, 2) Health care providers' fear of contracting disease and 3) Societal policing of HIV testing of pregnant women (Figure 1).

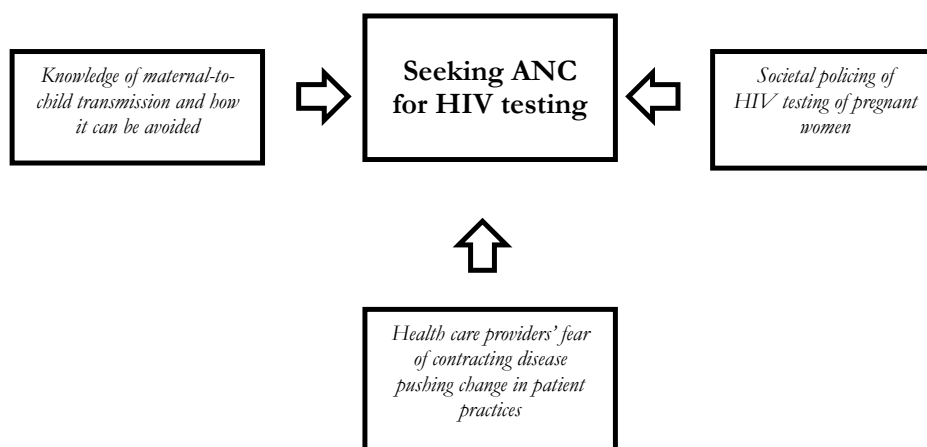
### Knowledge of maternal-to-child transmission and how it can be avoided

Our data suggest a crucial factor that led pregnant women to seek HIV testing was their knowledge of the possibility of the transmission of the HIV virus to the baby during birth. They also knew that this transmission could be effectively prevented through treatment with specific medicines at the time of birth and throughout their pregnancy. It was protection of the newborn that emerged as the primary reason women were willing to undergo the apprehension that goes along with finding out one's HIV status. Moreover, when women were identified as HIV positive, they were aware of the need to seek additional ANC services as well as skilled attendance at the time of delivery so that the risk of transmission was reduced.

"They also gave me an injection for HIV/AIDS so that the baby is not born with it. When you deliver in the hospital and you are HIV positive, they give the newborn baby a tablet and they also give you a tablet. They even stop you from breastfeeding the baby ... So that the baby is not infected" (mother, M15).

"They [nurses] said that it is not good for a woman to deliver in the villages and they explained to us that the TBAs are unhygienic and if a woman has HIV and she delivers in the village, the baby can easily be infected with the virus. The TBAs in the village don't have enough knowledge" (mother, M30).

Discussions with participants revealed that if a woman tested negative for HIV, she could safely deliver with a TBA in attendance. All the respondents were adamant that if a woman tested HIV positive, she should deliver in a health facility. It was assumed she would receive the appropriate treatment to prevent the possibility of mother to child transmission. The fact that some HIV negative women preferred



**Figure 1:** The three forces influencing women's decision to seek at least one ANC visit for HIV testing.

delivering under the attendance of a TBA at home indicates that TBAs remain a provider of choice for uncomplicated deliveries. This practice persists despite the laws banning TBAs attending childbirth. There a number of reasons for this, the key being the reported abusive behaviour and attitudes of biomedical health care providers.

### Health care providers' fear of contracting disease pushing change in patient practices

Another factor pushing HIV testing during pregnancy is health workers' refusal to treat or even touch a woman during childbirth without first having proof of the HIV status of the woman. This is true of both biomedical and traditional health care providers. The only proof health care providers are willing to accept is an ANC card on which the woman's HIV status is documented (Figure 2).

Interviewer: But if the woman comes when she has not tested for HIV and she doesn't have any book, what do you do?

TBA (T1): That one... I don't touch at all—if she doesn't have any medical form I just send her to the hospital.

Interviewer: What if she comes at night? What do you do for her?

TBA (T1): Aaaah (no), I do not attend to her at all—if she is new and not in the register you saw there, and I have never treated her, I do not even touch her.. I just refer her to the hospital.

'Routinely for every pregnant mother that comes ... we screen them for HIV. So before we touch, before we examine, you must have passed through the lab' (Health care worker, P5).

'And during childbirth I first have to ask the woman if at all she went and tested her blood in the hospital and if she says yes, then I ask for her medical form. If she checked and was found HIV positive, then I send her to deliver in the hospitals. If the woman is HIV negative, then I can assist in conducting the delivery...' (TBA, T5).

A key reason underlying the health care providers' behaviour is a fear of contracting HIV from the pregnant women. Both traditional and biomedical providers expressed this fear. Some providers, mostly the traditional birth attendants, claimed they were confused about the risks of HIV infection. They felt they did not have the resources to protect themselves from accidentally becoming infected or to prevent the transmission from the mother to the baby during childbirth.

'But the most important thing I am seeing here is that nowadays we

as TBAs... we are also confused because we fear to be infected with the disease (HIV/AIDS) ... I know if I get infected while assisting women to deliver ...then I will bring the disease to my husband and our whole family will perish and that will be the end of it. It would be good for our services to be continued but now ... not many women come to us ... You can find in a month only one woman comes and sometimes we refuse to assist them because of that fear' (TBA, T4).

Traditional healer (TH2): These days we are scared a lot. We cannot conduct deliveries in the villages.

Interviewer: What are you scared of?

Traditional healer (TH2): There are diseases—this disease which came... we always advise women to deliver in the hospitals because there are so many things we require in the villages which we do not have.

### Societal policing of HIV testing of pregnant women: a gendered phenomenon

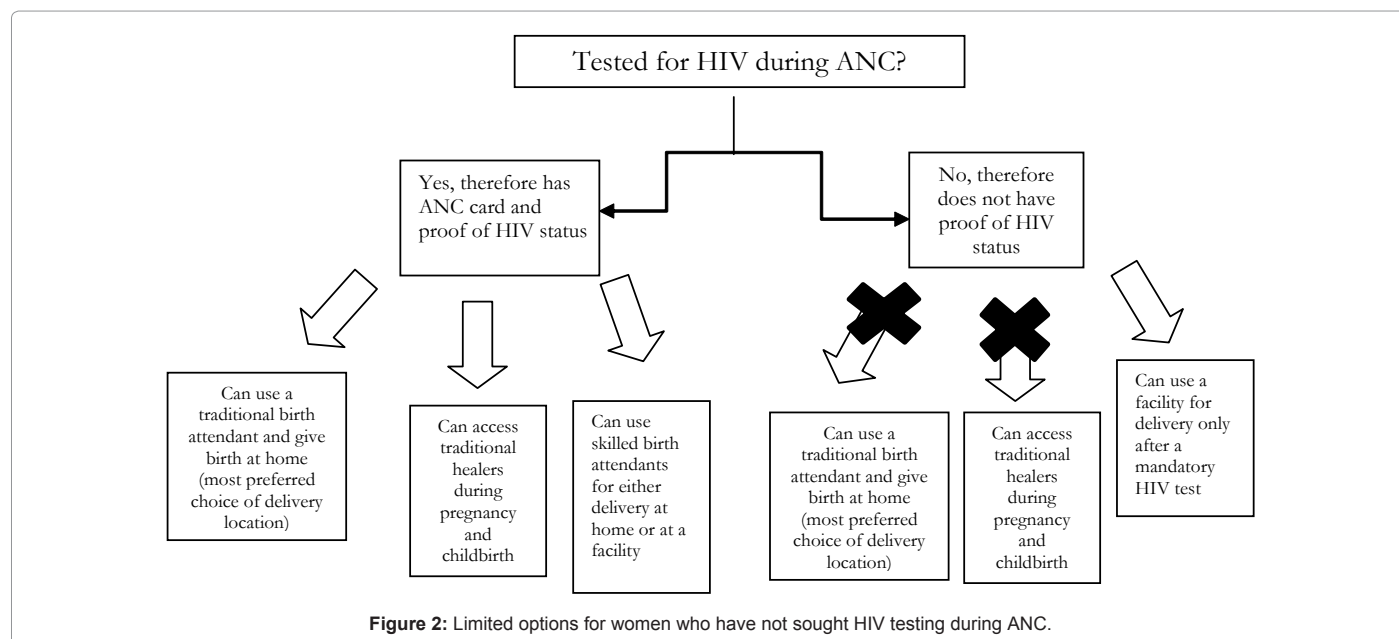
The third factor pushing uptake of HIV testing during an antenatal visit is a societal level expectation that pregnant women be tested for HIV. This expectation was imposed on women in a manner that is best described as a social policing of pregnant women. This policing was centered on the notion that getting tested for HIV while pregnant indicated that the woman was a responsible mother who took steps to ensure the birth of a healthy baby or, in other words, that she was a 'good mother'. A 'good mother' gave birth to a healthy baby. Women who have not been tested are perceived as lacking knowledge, being cowardly and negligent towards the health and wellbeing of their child. The knowledge that HIV could be transmitted from the mother to the baby during childbirth, coupled with the knowledge that this transmission could be prevented with modern biomedical technology, had translated into a discourse that responsible, good mothers used this technology to ensure healthy, disease-free babies. Very importantly, this ideal was only associated with women and not men, although men did say they supported women in getting tested.

Interviewer: You have said you have never tested for AIDS?

Mother (M3): No I have never tested

Interviewer: But why? There is a lot of sensitization going on, why haven't you come to be tested...?





Mother (M3): I will come and be tested ... I don't fear to be tested ... I am ... planning to come and be tested.

Interviewer: Do you know the benefits of being tested? ... What benefits do you know of?

Mother (M3): To prevent yourself from dying early...

The interviewer in the above example was an educated woman from a well-off family and the respondent a young, single woman whose appearance indicated a lower financial status. The mother in this conversation was the only mother who openly discussed the fact that she had not been tested for HIV. The research assistant adopted an air of condescension and judgment because this mother had not ensured that she was screened for HIV. The mother became defensive and wanted to prove that she was not fearful and she would be tested soon.

## Discussion

The objective of this paper was to explore the role of HIV testing in the uptake of antenatal care and document the various factors that might underlie the increasing uptake of HIV testing during pregnancy. Our research shows that HIV testing has become an additional motivator for seeking ANC. This practice was driven by increased knowledge of the possibility of maternal-to-child transmission and that this could be prevented by modern biomedical treatment. Furthermore, health care providers are refusing to attend to any woman who does not have proof of her HIV status, best documented by an ANC card. Overall, social values have changed to include HIV testing itself as one more indicator of being a good mother.

The key finding of this research was that the desire to be tested for HIV is another rationale for seeking at least one biomedical antenatal care visit. Four primary reasons for seeking ANC in Uganda have been identified in the literature: assessment of the position of the baby, treatment when ill, tetanus vaccination and to receive an antenatal card [10,13,26–28]. No study has yet to indicate the desire to be tested for HIV is a reason for seeking ANC. That HIV testing may be another motivator for seeking at least one ANC visit is a new finding that, to the best of our knowledge, has not been reported before.

Our data also showed that it was their knowledge of the possibility of maternal-to-child-transmission of HIV and that this transmission can be prevented that led women to accept HIV testing. This finding is supported by the literature. A study from Zimbabwe found a positive correlation between HIV knowledge and willingness to be tested [29]. Another study from Tanzania showed that knowledge surrounding the prevention of mother-to-child transmission had increased, and they postulated that this knowledge may underlie the practically universal acceptance of HIV testing during ANC in this context [30]. The importance of knowledge having led to increased uptake of HIV testing is underscored by research that showed that, in the early part of the 2000s, women had identified the lack of available information regarding HIV testing and the prevention of mother-to-child transmission program as a major barrier to being tested for HIV [6]. Dahl et al. [7] shows that acceptance rate of HIV testing during an antenatal visit is proportional to the amount of time testing and counselling services had been available. The longer a program has been in existence, the higher is the uptake of HIV testing, pointing to the importance of knowledge assuming programs that have been around longer have disseminated knowledge to a larger proportion of people.

The finding that health care providers, both biomedical and traditional, are pushing the practice of seeking HIV testing by refusing to attend to women with an unknown HIV status is, to the best of our knowledge, a new finding. The fact that health care providers may refuse to see a patient has been alluded to in the literature surrounding the importance of having an antenatal card. Amooti-Kaguna and Nuwaha [10] showed that, in 1997, women sought at least one antenatal visit to receive their antenatal card. This card was sought as a birth-complication-readiness measure since it was known that women seeking care during childbirth at a health facility would encounter many barriers to receiving care if they did not have an ANC card. Another body of literature documents how women who refuse HIV testing are marked out by health workers clearly noting their refusal on their ANC card [27]. This literature does not explicitly state that health care providers refused to see patients with unknown HIV status during childbirth. Our findings, however, do suggest that such women are denied care until they have taken an HIV test. More research is

needed to explore the ways in which the stigma of HIV, fuelled by fear of contracting the disease, operationalizes at the health provider-patient interface in the Ugandan and in other sub-Saharan contexts.

The most interesting finding is the change in social climate around HIV testing during pregnancy and its linkage with notions of 'good mothers'. Stigma of AIDS has been documented as a key barrier to the uptake of HIV testing. But apparently, safety of the newborn seems to have trumped the stigma of AIDS. This is a new finding, although the literature does talk about notions of good motherhood and how these notions are linked with seeking ANC care, where being a 'good mother' can be proven by having an ANC card [10,28]. While there appears to be a lack of research on how this biomedical procedure of being HIV tested has been adapted into the local constructions of what it means to be a mother, there is evidence from other sub-Saharan countries that ensuring the birth of a healthy baby is more important than enduring stigmatisation [31]. All this suggests that capitalizing on women's inherent desire to have a healthy baby, together with societal support, may be the way to eradicate mother-to-child transmission.

In conclusion, it appears that the two decade-old HIV education campaigns in Uganda have resulted in increased awareness of the disease and modes of transmission, including mother-to-child transmission, of the virus. Together with the knowledge that mother-to-child transmission can be prevented therapeutically, the fact that health care providers decline to provide care to women with unknown HIV status and a societal-level expectation that pregnant women be tested for HIV may have led to this increased acceptance of HIV testing [32]. This may also help to explain the gap between high ANC use rates and relatively lower facility births. Apparently, a significant proportion of women continue to prefer home deliveries attended by a TBA or family member. An antenatal visit and a negative HIV test give women the confidence to proceed with a home-delivery.

## Study Limitations

Because the majority of the interviews were undertaken in the local language, the researchers had to rely on transcripts and cultural explanations provided by the research assistants. The researchers were aware of this limitation and made attempts to minimize it through ensuring accurate transcriptions and discussions of understandings and findings with the research team.

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