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# Increasing the Uptake of HIV Testing in Maternal Health in Malawi

Monique van Lettow, Atupele Kapito-Tembo, Blessings Kaunda-Khangamwa, Emmanuel Kanike, Sonja Maosa, Medson Semba, Martias Joshua, Lughano Ndovi and Fabian Cataldo Copyright © 2012 by Monique van Lettow, Atupele Kapito-Tembo, Blessings Kaunda-Khangamwa, Emmanuel Kanike, Sonja Maosa, Medson Semba, Martias Joshua, Lughano Ndovi and Fabian Cataldo.





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# ACRONYMS

| ANC antenatal care clini | С |
|--------------------------|---|
|--------------------------|---|

- ART antiretroviral therapy
- HTC HIV testing and counselling
- IQR interguartile range
- MTCT mother-to-child transmission (of HIV)
- PMTCT prevention of mother-to-child transmission (of HIV)
- UNAIDS Joint United Nations Programme on HIV/AIDS
- UNICEF United Nations Children's Fund
- WHO World Health Organization

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# ABSTRACT

Despite the availability of HIV testing and counselling (HTC) in antenatal care clinic (ANC) settings, many HIV infected mothers in sub-Saharan Africa give birth in health facilities without knowledge of their own HIV status, thereby missing an opportunity to prevent the vertical transmission of HIV to their infants and to care for their own health. The study identifies systemrelated, social and behavioural reasons that pregnant women present themselves at labour wards with unknown HIV status and do not receive HTC, either during labour or following delivery. Using primarily qualitative methods, a descriptive study was conducted in two districts in southern Malawi. In-depth interviews were conducted with mothers identified in labour ward or postnatal ward registers as having an "unknown HIV status" and nurse-midwives working in these wards. Facility registers in the four study sites revealed that 6 to 18 percent of mothers had an unknown HIV status when presenting in labour. The primary barriers identified to getting tested during pregnancy included: a lack of available resources; women not being offered a test; power relations and peer pressure; and mothers' fear of being judged, stigmatized and blamed for being infected and infecting their children, combined with anxiety and stress associated with a potentially fatal diagnosis. Such barriers compelled women to refuse testing, hide results or develop strategies to keep their HIV status unknown or undisclosed. Understanding the dynamics and cultural boundaries that limit women's access to testing is essential to improving this gateway to prevention of mother-to-child transmission (PMTCT) care. The success of PMTCT Option B Plus, the new "universal test and treat" strategy in Malawi, will depend not only on an adequately organized health system, but also on effectively integrating into the program an awareness of cultural values, attitudes and beliefs.

# INTRODUCTION

Mother-to-child transmission (MTCT) of HIV is the major route of HIV infection in children. In 2010, the Joint United Nations Programme on HIV/ AIDS (UNAIDS) estimated that of the 1.36 million pregnant women living with HIV in sub-Saharan Africa, up to 61 percent had received HIV testing and counselling during their pregnancy and approximately 50 percent of those tested were receiving effective drug regimens to prevent MTCT of HIV. In the same region in 2010, an estimated 390,000 children were infected with HIV (World Health Organization [WHO], 2011). The majority of transmissions occur during pregnancy, labour and delivery, or through breastfeeding (Government of Malawi, 2008). In the absence of interventions, MTCT rates are estimated between 25 and 35 percent (Government of Malawi, 2008; United Nations Children's Fund [UNICEF], 2007). According to WHO recommendations, the biomedical prevention of MTCT interventions using antiretroviral therapy (ART) has reduced the rate of MTCT to less than 5 percent in breastfeeding populations in several study settings (WHO, 2009; Chasela et al., 2010; Shapiro et al., 2010). In program settings, however, less than 35 percent of all women completed the sequence of interventions involved in effective PMTCT (Mofenson, 2009). In late 2011, the Malawi Ministry of Health began to implement the 2010 WHO guidelines by rolling

out a "universal test and treat" strategy for pregnant women. This innovative strategy, called Option B Plus, uses immediate lifelong ART for all pregnant women who test positive. Option B Plus has the potential to virtually eliminate pediatric HIV, however, the strategy has never been operationalized in a country with a high HIV prevalence and will be effective only if a high proportion of pregnant mothers whose HIV status is unknown are tested and treated during pregnancy or prior to delivery.

In Malawi, ANCs use a routine opt-out HTC strategy for all pregnant women. About 12 percent of pregnant women who accepted HTC were HIV infected (Government of Malawi, 2010a) and offered PMTCT. According to the Ministry of Health guidelines, women who present in labour with unknown HIV status are supposed to be offered HTC and then ART prophylaxis at the maternity wards before delivery. Program studies demonstrate that even though HTC is offered in the ANC setting, many HIV infected mothers still give birth in health facilities without documented knowledge of their HIV status and thereby miss an opportunity to prevent vertical transmission to their children and also to care for their own health (WHO, 2010). Labourbased HIV testing and treatment provides an extra opportunity for women who were not tested through an ANC to access preventative interventions. In Malawi, records show that missed opportunities for HTC of unknown status women in maternity and labour wards are as high as 63 percent (Bettman et al., 2010). Although regional literature indicates a high acceptance rate of HTC during labour (Homsy et al., 2006), literature from Zimbabwe and Malawi suggests that barriers to HTC access for unknown status women in this setting may include the hesitation of staff to counsel patients because of confidentiality issues, understaffing and the absence of partner approval (Bettman et al., 2010; Perez et al., 2005; Homsy et al., 2007).

From a policy perspective, therefore, as the Malawi government and other high-prevalence HIV countries aim to adopt the new WHO recommendations, it is critical to understand both systemic and behavioural reasons that pregnant women do not, or are unable to, take advantage of the gateway step of HTC at the various times when they access the health system. Identifying barriers will help policy makers and those who implement the program to improve access to, and uptake of, PMTCT services.

## Study Design and Methodology

The overall aim of this study was to identify the system-related, social and behavioural reasons that pregnant women who present with unknown HIV status at labour wards do not receive HTC at an ANC, either during labour or after delivery. A descriptive study was conducted using a qualitative approach.

## POPULATION AND RESEARCH SITES

This study was conducted in two districts in the southern region of Malawi, where adult HIV prevalence is estimated at 14.5 percent (Government of Malawi, 2010a).

**G** BARRIERS COMPELLED WOMEN TO REFUSE TESTING, HIDE RESULTS OR DEVELOP STRATEGIES TO KEEP THEIR HIV STATUS UNKNOWN OR UNDISCLOSED **G** OF THE FACILITY-BASED DELIVERIES, 16 PERCENT OF THE WOMEN PRESENTED WITH UNKNOWN HIV STATUS; OF THOSE OF UNKNOWN STATUS, ONLY 20 PERCENT WERE TESTED DURING OR IMMEDIATELY AFTER DELIVERY Zomba District comprises over 670,000 inhabitants, 80 percent of whom live in rural areas. One primary care facility, Zomba Central Hospital, and 33 auxiliary health care facilities provide public health services in the district. At present, PMTCT services have been implemented in 31 of the district's health care facilities. In 2010, there were more than 32,000 new antenatal visits and 24,000 facility-based deliveries in the district. Of the facility-based deliveries, 16 percent of the women presented with unknown HIV status; of those of unknown status, only 20 percent were tested during or immediately after delivery (Dignitas International, 2010).

Blantyre District comprises a population of approximately 1.2 million inhabitants, 65 percent of whom live in urban areas. Thirty-six health care facilities, including one central hospital, Queen Elizabeth Central Hospital, provide antenatal health care. Twenty-eight health care facilities provide labour and delivery services and PMTCT services have been implemented in all of the 36 public health care facilities. In 2010, there were 42,450 new antenatal visits and 32,907 facility-based deliveries in Blantyre District. Of the facility-based deliveries, 13 percent of the women presented with unknown HIV status (Government of Malawi, 2010b).

One central hospital and one rural health facility from each district were chosen as study sites for this research project. In Zomba District, the sites selected were Zomba Central Hospital and Pirimiti Rural Hospital, and in Blantyre District, Queen Elizabeth Central Hospital and Limbe Health Centre were selected. These health facilities accounted for 30 to 50 percent of all pregnant women who were recorded as having unknown HIV status when they presented for labour in their respective districts (Dignitas International, 2010; Government of Malawi, 2010b).

# DATA COLLECTION AND ANALYSIS

Data collection took place over six weeks, during November and December 2011. Women identified as "HIV status unknown" in labour ward or postnatal ward registers were interviewed in the post-labour ward once their medical condition was considered stable. In addition, nurse-midwives who were also trained as HTC providers were invited to share their experiences and perceptions through in-depth interviews.

These in-depth interviews were conducted using an interview guide. Interviews with nurse-midwives were conducted in English, audio recorded and transcribed, while interviews with mothers were conducted in Chichewa, the local language, audio recorded, transcribed verbatim and then translated into English. Interviewers were native Malawian women who were fluent in both English and Chichewa.

Data was analyzed on an ongoing basis using directed content analysis, and was collected until saturation was reached and no new category of information was provided through the interviews. Investigators read transcripts independently, initially looking for emerging themes and subthemes. Based on this initial review, an analysis framework and corresponding coding table were developed and used to organize data by themes and subthemes. Three reviewers individually coded data by hand and then compared their results.

## ETHICAL CONSIDERATIONS

This study was approved by the hospital and district health management teams in each district and by the Malawi National Health Science Research Committee. It was ensured that every woman participated on a voluntary basis. Written, informed consent in Chichewa or English was obtained from all participants.

## Results

Review of the patient registers in the labour and postnatal wards in the selected study sites revealed that, during the period from October to December 2011, the average number and proportion of women presenting in labour with unknown HIV status per month were 54 of 561 women (10 percent) at Zomba Central Hospital and 22 of 381 women (6 percent) at Queen Elizabeth Central Hospital, and 61 of 348 women (18 percent) and 27 of 186 women (15 percent) in the peripheral health facilities in Blantyre and Zomba, respectively.

## CHARACTERISTICS OF PARTICIPANTS

A total of 129 in-depth interviews were conducted; of these, 106 were with mothers who were identified as "unknown HIV status" when presenting in labour and 23 were with nurse-midwives. Table 1 shows the number of study participants at each study site.

## Table 1: Number of Study Participants per Study Site

|  | Queen<br>Elizabeth<br>Central<br>Hospital,<br>Blantyre | Limbe<br>Health<br>Centre,<br>Blantyre | Zomba<br>Central<br>Hospital,<br>Zomba | Pirimiti<br>Rural<br>Hospital,<br>Zomba | Total |
|--|--|--|--|---|-------|
| Mothers with<br>unknown HIV status<br>when presenting in<br>labour | 27   | 21                                     | 27                                     | 31                                      | 106   |
| Nurse-midwives   | 10   | 5                                      | 4                                      | 4                                       | 23    |

The median age of the mothers was 24 years (interquartile range [IQR], 21–28) and the mothers had, at the time of interview, just given birth to their median third (IQR 1st to 4th) child. The median age of the nurse-midwives (21 were female and two were male) was 35 years (IQR 27–48), and they had worked at the labour and/or postnatal ward for a median of two years (IQR 1–4). In the central hospitals, five nurse-midwives worked in the labour ward and nine in postnatal wards. In the rural health centres, nine nurse-midwives worked in both labour and postnatal wards.

The data collected shows that system-related barriers, fear of being stigmatized, power relationships, a lack of knowledge about HIV and

WOMEN IDENTIFIED AS 'HIV STATUS UNKNOWN' IN LABOUR WARD OR POSTNATAL WARD REGISTERS WERE INTERVIEWED IN THE POST-LABOUR WARD ONCE THEIR MEDICAL CONDITION WAS CONSIDERED STABLE

sometimes negative attitudes towards people living with HIV are key reasons that pregnant women present at labour wards with unknown HIV status and do not receive HTC, either before labour or following delivery. We elaborate on each of these key factors below.

## SYSTEM-RELATED BARRIERS

Health care providers and mothers noted that most women, when offered an HIV test, accepted being tested at the ANC and, if not tested previously, accepted being tested either during or after labour. Issues with the health system, however, such as a lack of available HTC providers or test kits, were reported as a primary barrier keeping women from being tested.

We were told that they have run out of test kits...I checked here every time I came for ANC I got tired and gave up. I visited the ANC three times. The private clinics are expensive so I did not even check how much they charge.

- mother, age 19, first child, rural health centre

Another frequently reported reason for having a presumed unknown status was undocumented HIV test results. Women may have been tested previously, but either did not bring supporting documentation, or their results were not properly recorded in their health passport. Some study participants reported using more than one health passport.<sup>1</sup> One mother reported using two health passports, one of which did not show that she had previously been tested.

It's not that I did not test, I did test, but I am using two health books and since I was referred here, I think, that is why they did not record my status, but I did test.

- mother, age 33, third child, rural health centre

Not being offered an HIV test was also mentioned frequently by mothers. Data collected show that, at the time of interview in the postnatal ward, few women of unknown HIV status were offered a test during their hospital visit to give birth.

They did not ask me to get tested...They asked me if I had been tested and I told them that for this pregnancy I did not get tested and she just said "okay." I was waiting for them to ask me to get tested...

- mother, age 27, third child, central hospital

Several women stated that they would have accepted HIV testing had it been offered. Others had been offered a test but refused it. One teenage mother told us:

ISSUES WITH THE HEALTH SYSTEM... WERE REPORTED AS A PRIMARY BARRIER KEEPING WOMEN FROM BEING TESTED

<sup>1</sup> A client health booklet (health passport) contains records of the medical history of the individual, assessment of current problems and types of care given.

I was not happy to be tested here at the hospital. I think they wasted my time; I have just come here to deliver and not bother with testing.

#### - mother, age 16, first child, central hospital

Many participants argued that the best time for testing should be during or before pregnancy, and not during labour. Few women stated that mothers should be tested before getting pregnant and for each pregnancy. One mother said:

The best time to test is when she is single, it helps to plan for the future and cater for one's lifestyle. Women do understand that for each pregnancy they have to test.

# - mother, age 23, first child, rural health centre

Some mothers reported that they did not, or could not, accept HIV testing when it was offered while they were in labour. These mothers explained that during labour, women are experiencing pain and cannot engage in meaningful communications with the HTC providers, making it difficult to understand the HTC information and to give a true informed consent to the test:

It's not good to test during labour. I did not hear what the doctors said most of times as I was in pain.

#### - mother, age 20, first child, central hospital

Similarly, most providers reported that they had not offered testing to the mothers during labour because it was not an appropriate time; some providers argued that it is difficult to provide testing during labour, citing the lack of time as a constraint for offering the test. Others argued that testing should take place elsewhere and not in the labour ward. One nurse-midwife said:

We are not a testing centre, how can one test a woman on the labour bed; that is wrong. HIV testing should be done during antenatal care at the health centre.

- female, age 57, nurse-midwife, labour ward, central hospital

Most providers stated that testing is offered and women are encouraged to be tested at postnatal wards if their status is unknown when they present for labour.

#### FEAR OF STIGMA AND DISCRIMINATION

The fear of being stigmatized and discriminated against for living with HIV appears to be strongly linked to decisions not to accept a test when it is offered. Mothers and health care providers reported that reasons for not accepting a test were related to the fear of being judged and given a "death

AT THE TIME OF INTERVIEW IN THE POSTNATAL WARD, FEW WOMEN OF UNKNOWN HIV STATUS WERE OFFERED A TEST DURING THEIR HOSPITAL VISIT TO GIVE BIRTH

sentence." A woman expressed her fear of testing positive because of the common negative perception of what it means to be living with HIV:

Because of stigma and discrimination some people are afraid of testing...they are afraid others may know and how their life will turn out; because of that many are afraid to test.

- female, age 29, nurse-midwife, labour ward, central hospital

Some preferred not to test, rather than suffer the stress and anxiety of disclosing their status to others:

Better not to test and not know one's HIV status for a peace of mind and good life. Being diagnosed with HIV is a death sentence and that causes discomfort in one's heart, [because of] the stress most women do not want to go through that.

- mother, age 28, fourth child, central hospital

A number of mothers and health providers indicated that some women did not want to get tested for fear of disclosing their HIV status to their partner, relatives and friends, or they worried that someone else may disclose their status.

Some people are afraid...some are afraid that other people will disclose their status.

- mother, age 27, fourth child, rural health centre

Another interviewee stated:

It is very difficult for most Malawian women to cater for themselves when they are found positive, they fear to disclose their status. However it is impossible not to disclose because when a woman gives birth, they are surrounded by extended family and face challenges when they are told to take ART or exclusively breastfeed.

- female, age 25, nurse-midwife, labour ward, central hospital

Several health care providers and mothers indicated that women often prefer not to deal with the test results. During this study, the denial of test results meant that several women appeared to not know their HIV status, although they may have been tested previously. A nurse-midwife reported that:

Some women refuse to be tested, not because they do not want to know their status; they know it already, but they want to pretend they do not know they are HIV positive.

- female, age 57, nurse-midwife, labour ward, central hospital

SOME PREFERRED NOT TO TEST, RATHER THAN SUFFER THE STRESS AND ANXIETY OF DISCLOSING THEIR STATUS TO OTHERS

Another nurse-midwife told us that:

The worst problem is denial; when you inform the women about their status they do not accept, most of them are shaken up when it is positive. What will lead us to our deaths as Malawians is stigma, and denial, refusing to accept the results and they do refuse to inform their families — they also refuse to take medication, in the end they do not understand the need for medication and to test.

- female, age 49, nurse-midwife, postnatal ward, central hospital

Fear of being marked with the stigma of HIV by peers and health care providers led women to devise strategies that allowed them to receive care without disclosing their status. According to one nurse-midwife:

Some travel with two health books and if they are found positive, they bring the one without the HIV test indicated in it.

- female, age 60, nurse-midwife, postnatal ward, central hospital

In some instances, a mother's fear of rejection after disclosing a positive HIV status was an impediment to receiving care. Health care providers reported that mothers were actively covering up their HIV status, which meant that they refused medication and did not adhere to PMTCT recommendations.

It is not good for the woman to get tested at postnatal ward and then be put on treatment right there and then...It is hard for most women to accept and when you introduce the idea for the woman to start on drugs [ART] straight away...Some women are leaving paper bags full of medication [ART they received for themselves and their infant] in the toilets when they leave the hospital.

- female, age 49, nurse-midwife, postnatal ward, central hospital

# POWER RELATIONS AND PEER PRESSURE

Power relations between women and their partners were reported as significant barriers to women accessing testing. A common trend in the interviews was that women needed consent and approval from their partner in order to accept HIV testing. They referred to mistrust about sexual faithfulness and fear of discordant test results between partners (where one partner tests positive and the other negative) as factors that cause men to oppose HIV testing for their female partners. A woman may fear the repercussions of a positive test, such as domestic conflict, rejection by her partner or separation. One mother stated:

FEAR OF BEING MARKED WITH THE STIGMA OF HIV BY PEERS AND HEALTH CARE PROVIDERS LED WOMEN TO DEVISE STRATEGIES THAT ALLOWED THEM TO RECEIVE CARE WITHOUT DISCLOSING THEIR STATUS

Some of us do not want to be tested in fear of our husband... If you are found positive and tell him, he divorces you, saying, "Why did you go for testing before telling me?" But even if you tell him he stops you from being tested.

- mother, 23, first child, rural health centre

Another mother, who had just given birth to her fifth child, said,

We women are afraid to test because if we are found positive and we tell our husband, the marriage will break and that is why most women are afraid to test.

- mother, age 33, fifth child, central hospital

Several women added that men repeatedly discouraged their partners from testing because they may have worried about their own HIV status or were unwilling to disclose it to their partner and family. A mother gave an account of her friend whose husband did not want her to be tested, claiming that "It brings worries to a pregnant woman to know her status before giving birth because she may miscarry." She was not convinced that this was his actual reason for not testing and expressed the thought that:

[My] husband knows something about his past and he doesn't want his wife to be tested because people say that his former wife died of AIDS.

- mother, age 19, third child, rural health centre

Other women argued that they did not need permission from their partner to get tested. A teenager who gave birth to her first child shared her opinion with us:

I could not walk properly and that hindered me to go for testing during my pregnancy and again as a woman we sometimes do not need to wait for our husband to give permission to test; we need to test for our own health and the health of our baby.

- mother, age 16, first child, central hospital

Pressure from peers related to a fear of potentially receiving a positive test result was another reason that discouraged women to test. One mother explained:

We discuss with other women...We say we are afraid [to test] and can we kill ourselves because we do not want to know the truth about our HIV status. Life will become hard if they [others in the community] know you are positive.

- mother, age 28, fourth child, central hospital

Some women and providers attested that health providers' attitudes played a role in discouraging women from testing. Some stated that health providers

SOME WOMEN AND PROVIDERS ATTESTED THAT HEALTH PROVIDERS' ATTITUDES PLAYED A ROLE IN DISCOURAGING WOMEN FROM TESTING

did not demonstrate a supportive attitude towards those who had missed an earlier opportunity to be tested. One of them told us:

When I was starting antenatal care they did not ask me to get tested but in my previous pregnancy I got tested. When I came in October they told me to come again in November but I got sick on the date I was supposed to come to the hospital. I did not come again because I heard that if you do not come on your appointed date they do not attend to you until they finish attending to all the women, so with this heat I got discouraged.

## - mother, age 24, second child, central hospital

# KNOWLEDGE AND ATTITUDE TOWARDS HIV TESTING AND LIVING WITH HIV

Although stigma and fear of discrimination are key barriers to testing, a majority of mothers interviewed had a positive attitude towards HIV testing. Most understood that they needed to know their status in order to receive appropriate medication and to care for their infant, their partner and themselves if found HIV positive. One of the mothers shared that:

It's important to know your status to maintain good health. The clinic helps you to get medication early and that helps to preserve one's life and if one is not infected, it helps you to make decisions on how one has been living and prevent you from getting infected.

- mother, age 18, first child, central hospital

However, a few mothers believed that their own HIV test would affect their child's health, and felt that it was not necessary to get tested.

There is nothing to worry about...He [the child] will get tested before he grows up.

- mother, age 19, second child, rural health centre

Data collected illustrates that most women were aware of the need for HIV testing during pregnancy. They were exposed to information through health education and media messages. Several misconceptions were reported, however. Women thought, for example, that testing was not needed if they had a negative test result in the past, or when they have had a single sexual partner. Some used their partner's or child's negative test result as a proxy for their own HIV status. One mother said:

The last time I got tested was in 2003 and I have not tested since, I sleep with the same husband and all my children are not sickly, what is the purpose to get tested?

- mother, age 28, fourth child, central hospital

# SOME STATED THAT HEALTH PROVIDERS DID NOT DEMONSTRATE A SUPPORTIVE ATTITUDE TOWARDS THOSE WHO HAD MISSED AN EARLIER OPPORTUNITY TO BE TESTED

**FARTICIPANTS BELIEVED THAT HEALTH CARE SYSTEMS WERE NOT SUFFICIENTLY ORGANIZED TO RESPOND TO THE NEED FOR TESTING DURING PREGNANCY AND IN LABOUR** 

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Health providers reported that some women did not accept HIV testing when it was offered during pregnancy, labour or after delivery because of their level of education or age. A nurse-midwife said:

Those with better education, it's not a challenge, but to those with little education or not at all, it is difficult to know, if indeed they have understood what is HTC.

- female, age 25, nurse-midwife, labour ward, central hospital

## Discussion

This study shows that a relatively large proportion of mothers (6 to 18 percent) have an unknown HIV status when they present in labour at hospitals or health care centres in Malawi. Most mothers involved in the study had multiple pregnancies and had been tested during previous pregnancies. Others may have experienced several pregnancies without being tested at all. Some mothers were of the opinion that they should be tested for each pregnancy, while others argued that they would not need to be tested again because they had been tested for an earlier pregnancy.

Study participants believed that health care systems were not sufficiently organized to respond to the need for testing during pregnancy and in labour and, as a result, missed opportunities to potentially prevent MTCT. Some participants cited concerns about the confidentiality of test results. A study originating from Kisumu, Kenya, similarly showed that health care providers may not be adequately prepared to handle issues related to consent, confidentiality and disclosure of HTC in labour wards (Turan et al., 2008). According to the study we conducted, the primary health service-related barriers that kept women from getting tested during pregnancy included a lack of available resources, such as HTC providers and test kits, and not being offered a test. Limits on providers' time and a lack of compliance by providers with standard operational procedure for testing all women of unknown HIV status may have also resulted in women not being tested during labour. A study from Burkina Faso noted that a lack of training, the disruption of services and heavy workload were barriers preventing health care workers from testing women as a gateway to PMTCT (Sarker et al., 2009). Already-limited resources are further strained when previous test results are not documented and, as a result, women need to be retested.

Interviews revealed that power relations also play an important role in either encouraging women to, or discouraging them from, testing for HIV. It is important to understand the cultural boundaries and dynamics within households that may limit women's access to testing as a gateway to PMTCT care. Women's partners were found to inhibit and hinder health care efforts to expand the universal testing of women. The fear of rejection among women by their peers and partners, as well as the fear of undisclosed HIV infection among men and women, create further barriers to testing and access to PMTCT services.

A recent study in rural Uganda (Larsson et al., 2012) explains that, because pregnant women are responsible for recruiting their spouses for testing as part of PMTCT services, they were afraid to discuss HIV testing with their partners; such fear may potentially deter some women from seeking care. A study by Njunga and Blystad (2010) suggests that the Malawian matrilineal system ostracizes men, who fear rejection and feel powerless when blamed by their partners' families when a positive HIV test is revealed. Women who disclose their HIV positive status to their mothers or brothers often provoke feelings of animosity towards their husbands (Njunga and Blystad, 2010). Data collected in these studies shows that power relations are key to understanding women's barriers to testing. Both studies illustrate how the fear of rejection and blaming may influence a woman's decision to either accept or reject testing and access to PMTCT care, and highlight that understanding power relations and cultural customs is essential to providing an environment that enables and supports HIV testing for women.

This study shows that a mother's access to testing is highly influenced by her fear of the stigma of living with HIV, which may prevent her from accessing treatment and care, in turn compromising her own health and that of her child if she does not receive preventative treatment to reduce the risk of MTCT. A mother's fear of being judged and blamed for being infected and infecting her child, combined with the anxiety and stress associated with a potentially fatal diagnosis, compels some to refuse testing, to hide their test results or to develop strategies to keep their HIV status unknown or undisclosed. Similarly, in a recent study conducted in Burkina Faso, Kenya, Malawi and Uganda, 79 percent of HIV positive pregnant women reported that they generally keep their status secret, and only 37 percent had disclosed their status to their partner (Hardon et al., 2012).

A recent study among pregnant women in Ethiopia shows a positive association between acceptance of HIV testing and having comprehensive knowledge of HIV (Malaju and Alene, 2012). Data collected for the study we conducted shows good levels of understanding of the importance of HIV testing. This does not, however, always translate into an accurate perception of what is entailed in a test and the consequences of the results. A lack of knowledge about MTCT has been a contributing factor to women opting out of HTC (Malaju and Alene, 2012; Chivonivoni et al., 2008). Misconceptions, such as a perceived low exposure or risk of infection, prevent women from understanding how testing would benefit their own health and their infants' health. Our study highlights the need to more purposefully challenge such misconceptions during pre-test counselling and educational campaigns on HIV transmission and MTCT. While some program and policy implications may be relatively easily to address, such as improved resource allocation or reiterating the message that a mother's testing protects her child and that all mothers should test for the health of their children, addressing other societal and cultural factors is likely to be more challenging.

# CONCLUSIONS

This study has explored why some women presenting in labour wards with unknown HIV status do not receive HTC at an ANC or do not accept HTC

" FEAR OF **REJECTION AND BLAMING MAY** INFLUENCE **A WOMAN'S DECISION TO** EITHER ACCEPT **OR REJECT TESTING AND ACCESS TO PMTCT CARE, AND HIGHLIGHT THAT** UNDERSTANDING **POWER RELATIONS** AND CULTURAL **CUSTOMS IS ESSENTIAL** 

OPTION B PLUS... OFFERS ALL HIV INFECTED PREGNANT AND BREASTFEEDING WOMEN LIFELONG ART, REGARDLESS OF CD4 BLOOD COUNTS OR THE CLINICAL STAGE OF THEIR ILLNESS either during or after labour. Several contributing factors were found. The main system-related barriers to getting tested during pregnancy are a lack of available resources and not being offered a test. Power relationships and peer pressure are also important factors in encouraging women or discouraging them from testing. Mothers' fears of being judged and blamed for being infected and infecting their children, combined with the anxiety and stress associated with a potentially fatal diagnosis, compelled many to refuse testing, hide test results or develop strategies to keep their HIV status unknown or undisclosed. Mothers' denial or fear of stigma may prevent them from accessing treatment and care and, as a result, compromise their own health and their children's when they do not receive preventative treatment to reduce the risk of MTCT. It is essential to understand the dynamics and cultural boundaries that limit women's access to testing as a gateway to PMTCT care.

Option B Plus, the new PMTCT "universal test and treat" strategy, has been progressively employed in Malawi since July 2011. It offers all HIV infected pregnant and breastfeeding women lifelong ART, regardless of CD4<sup>2</sup> blood counts or the clinical stage of their illness. The success of Option B Plus will depend not only on adequately organized health care services, but also on effectively integrating an awareness of cultural values, attitudes towards testing and perceptions of the consequences of a positive test result into the program. Further studies are planned to investigate culturally appropriate models of support to improve HIV testing that will consequently increase uptake and retention of mothers and their family in PMTCT services in Malawi.

# **WORKS CITED**

- Bettman, J. J. et al. (2010). "Accelerated HIV Testing for PMTCT in Maternity and Labour Wards is Vital to Capture Mothers at a Critical Point in the Programme at District Level in Malawi." *AIDS Care 22*, no. 11: 1367–1372.
- Chasela, Charles S. et al. (2010). "Maternal or Infant Antiretroviral Drugs to Reduce HIV-1 Transmission." *The New England Journal of Medicine* 362, no. 24: 2271–2281.
- Chivonivoni, C., V. J. Ehlers and J. H. Roos (2008). "Mothers' Attitudes towards using Services Preventing Mother-to-Child HIV/AIDS Transmission in Zimbabwe: An Interview Survey." *International Journal of Nursing Studies* 45, no. 11: 1618–1624.
- Dignitas International (2010). Quarterly Program Statistics 2010. Internal Monitoring and Evaluation Data.
- Government of Malawi (2008). *Prevention of Mother to Child Transmission of HIV Care Guidelines*, 2nd ed. July. Lilongwe: Ministry of Health. Available at: www. aidstar-one.com/sites/default/files/PMTCT%20Guidelines%20Malawi%20 2008.pdf.
  - (2010a). "2010 Malawi Demographic and Health Survey HIV Prevalence." Zomba: National Statistical Office. Available at: www.measuredhs.com/pubs/ pdf/HF34/HF34.pdf.

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A measure of the progression of HIV. CD4 cell counts decrease as the disease progresses.

— (2010b). Ministry of Health Malawi HIV Unit Homepage. Lilongwe: Ministry of Health. Available at: www.hivunitmohmw.org.

- Hardon, A. et al. (2012). "Women's Views on Consent, Counseling and Confidentiality in PMTCT: A Mixed-methods Study in Four African Countries. *BMC Public Health* 12, no. 26.
- Homsy, J. et al. (2006). "Routine Intrapartum HIV Counselling and Testing for Prevention of Mother-to-Child Transmission of HIV in a Rural Ugandan Hospital." *Journal of Acquired Immune Deficiency Syndrome* 42: 149–154.

— (2007). "The Need for Partner Consent Is a Main Reason for Opting Out of Routine HIV Testing for Prevention of Mother-to-Child Transmission in a Rural Ugandan Hospital." *Journal of Acquired Immune Deficiency Syndrome* 44: 366–369.

- Larsson, E. C. et al. (2012). "Opt-out HIV Testing during Antenatal Care: Experiences of Pregnant Women in Rural Uganda." *Health Policy and Planning* 27, no. 1: 69–75.
- Malaju, M. T. and G. D. Alene (2012). "Assessment of Utilization of Provider-Initiated HIV Testing and Counseling as an Intervention for Prevention of Mother to Child Transmission of HIV and Associated Factors among Pregnant Women in Gondar Town, North West Ethiopia." *BMC Public Health* 12, no. 226.
- Mofenson, Lynne (2009). "Update on the Science of Prevention of Mother to Child HIV Transmission." PowerPoint presentation prepared for National Institutes of Health, UCSF Center for HIV Information, January 9. Available at: www. womenchildrenhiv.org/ppt/21034\_Mofenson\_2009.ppt.
- Njunga, J. and A. Blystad (2010). "The Divorce Program': Gendered Experiences of HIV Positive Mothers Enrolled in PMTCT programs — The Case of Rural Malawi." *International Breastfeeding Journal* 5, no. 14.
- Perez, F. et al. (2005). "Acceptability of Routine HIV Testing ("Opt-Out") in Antenatal Services in Two Rural Districts of Zimbabwe." *Journal of Acquired Immune Deficiency Syndrome* 41, no. 14: 514–520.
- Sarker, M. et al. (2009). "Insights on HIV Pre-Test Counseling following Scaling-up of PMTCT Program in Rural Health Posts, Burkina Faso." *East Africa Journal of Public Health* 6, no. 3.
- Shapiro, R. L. et al. (2010). "Antiretroviral Regimens in Pregnancy and Breast-Feeding in Botswana." *New England Journal of Medicine* 362, no. 24: 2282– 2294.
- Turan, J. M. et al. (2008). "HIV/AIDS and Maternity Care in Kenya: How Fears of Stigma and Discrimination Affect Uptake and Provision of Labor and Delivery Services." AIDS Care 20, no. 8: 938–945.
- UNICEF (2007). A Report Card on Prevention of Mother-to-Child Transmission of HIV and Paediatric HIV Care and Treatment in Low- and Middle-Income Countries: Scaling up Progress from 2004 to 2005. Available at: www.unicef. org/chinese/aids/files/PMTCT\_Report\_Card\_2006\_final.pdf.
- WHO (2009). Rapid Advice: Use of Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants. Geneva. Available at: www. who.int/hiv/pub/mtct/rapid\_advice\_mtct.pdf.

- (2010). *Priority Interventions: HIV/AIDS Prevention, Treatment, and Care in the Health Sector*. Geneva. Available at: www.who.int/hiv/pub/guidelines/9789241500234\_eng.pdf.
- —— (2011). Progress Report 2011: Global HIV/AIDS Response: Epidemic Update and Health Sector Progress towards Universal Access. Geneva.

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