

POLICY BRIEF NO. 3 > JULY 2012

INCREASING THE UPTAKE OF HIV TESTING IN MATERNAL HEALTH IN MALAWI

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KEY POINTS

- The key to reducing the rate of mother-to-child HIV transmission is improving the uptake of HIV testing among women who have an unknown HIV status.
- Pregnant women present themselves at labour wards with unknown HIV statuses and do not receive HIV testing as a result of one or more of the following factors: peer pressure, stigma surrounding testing positively, household power relations, lack of knowledge about HIV and other system-related barriers to access to care.
- Findings from this study have operational and policy-level implications for the improvement of ongoing prevention of mother-to-child transmission (PMTCT) programming in Malawi.
- The success of Option B Plus, the new PMTCT program in Malawi, depends on adequately organized health services and PMTCT service delivery. There is the potential to improve both by integrating cultural values and addressing current attitudes towards testing and perceptions associated with the consequences of test results.

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INTRODUCTION

Mother-to-child transmission (MTCT) of HIV is the primary means of HIV infection in children. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that 20 percent of all children born in sub-Saharan Africa are exposed to HIV; among those children, 130,000 new HIV infections occurred in 2010 (UNAIDS, 2010).

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ACRONYMS

ANC antenatal care clinic
ART antiretroviral therapy
HTC HIV testing and counselling

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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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 to be 25 to 35 percent (Government of Malawi, 2008; United Nations Children's Fund [UNICEF], 2007).

According to the most recent recommendations of the World Health Organization (WHO), biomedical prevention of MTCT using antiretroviral therapy (ART) interventions can reduce the rate of MTCT to less than 5 percent in breastfeeding populations (WHO, 2009; Chasela et al., 2010; Shapiro et al., 2010). In program settings, however, less than 35 percent of all women complete the sequence of interventions involved in effective PMTCT (Mofenson, 2009; Government of Malawi, 2010).

In 2011, Malawi's 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. It has the potential to make serious advances towards eliminating pediatric HIV.

Option B Plus has never been put into operation nationwide in a country with a high prevalence of HIV, and will be effective only if a high proportion of pregnant mothers whose HIV status is unknown are tested during pregnancy or prior to delivery.

Despite the offer of HIV testing and counselling (HTC) in the antenatal care clinic (ANC) setting, many HIV-infected women give birth in health facilities without knowledge of their HIV status, thereby missing an opportunity to prevent vertical transmission to their infants and care for their own health (WHO, 2010).

medical **Dignitas** International, a humanitarian organization focused on HIV/AIDS-related treatment, conducted a qualitative study in collaboration with the Malawi College of Medicine to identify the system-related, social and behavioural reasons that pregnant women present themselves at labour wards without knowing their HIV status and without receiving HTC at an ANC, during labour or following delivery. A total of 129 in-depth interviews were conducted; those interviewed included 106 mothers identified in labour wards or postnatal ward registers as "unknown HIV status" and 23 nursemidwives. The study was conducted in two health centres and two central hospitals located in the districts of Zomba and Blantyre in Malawi.

REASONS FOR UNKNOWN HIV STATUS

Key reasons that pregnant women present themselves at labour wards with unknown HIV status and do not receive HTC at an ANC, either before labour or after delivery, include: system-related barriers; power relations; peer pressure stigma and discrimination; and misconceptions about HIV and the sometimes negative attitudes towards people living with HIV. It is important to examine and understand these reasons in order to improve the chances of success for the Option B Plus plan.

SYSTEM-RELATED BARRIERS

Although most women accept being tested at an ANC and, if not tested previously, during or after labour, some health system-related issues keep mothers from accessing such services.

A lack of available HTC providers and lack of test kits were reported as recurring barriers to women being tested. In other cases, where providers and test kits are available, mothers are tested but their results are not documented. Women may have been tested previously, but either no supporting documentation is available or results have not been properly recorded in their health passports (books). In other cases, health providers may, because of heavy workloads, neglect conducting HIV testing; as a result, mothers are simply not offered the test.

These findings were substantiated by the argument from mothers that the best timing for testing is during or before pregnancy, while some health providers argued that testing should not take place at the labour ward.

POWER RELATIONS

Power relations between women and their partners were reported as an important barrier to women accessing testing. In typical Malawian households, women need consent and approval from their partners in order to accept HIV testing. The women interviewed referred to mistrust about sexual faithfulness and fear of discordant test results between partners as some of the factors that cause men to oppose HIV testing for their female partners. Women often fear the repercussions of a positive test, which may include domestic conflict, rejection by their partners or separation.

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

PEER PRESSURE, STIGMA AND DISCRIMINATION

Pressure from peers related to the fear of potentially receiving a positive test result was another reason that discouraged women from testing. In many cases, health providers' attitudes also played a role in discouraging women from testing. Some women stated that health providers did not demonstrate a supportive attitude towards those who missed an earlier opportunity to be tested.

The fear of being stigmatized and discriminated against for living with HIV appears to be strongly linked to decisions made not to accept a test when it is offered. One of the reasons for not accepting a test was related to the fear of being judged and given a "death sentence." Some women prefer not to test rather than suffer the stress and anxiety of disclosing their status to others.

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

The fear of being marked with the stigma of HIV by peers and health care providers leads women to devise strategies that allow them to receive care without disclosing their status.

Some [women] travel with two health books [passports] 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

Some health care providers reported that mothers were actively covering up their HIV status, which also meant that they decided to refuse medication and did not adhere to PMTCT recommendations.

KNOWLEDGE AND ATTITUDES TOWARDS HIV TESTING AND LIVING WITH HIV

Although most women are aware of the importance of HIV testing during pregnancy, some mothers reported misconceptions. Some thought that testing was not needed if they had a negative test result in the past, or when they had a single sexual partner; some used their partner's or child's negative test result as a proxy for their own HIV status.

Some mothers thought that they did not need a test because they believed that they were healthy.

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

PROGRAM AND POLICY IMPLICATIONS

Findings from this study have shown what areas need targeted policy action to improve ongoing PMTCT programming in Malawi.

IMPROVING HEALTH SERVICES

Health services in Malawi are understaffed and lack sufficient organization to respond to the needs surrounding testing during pregnancy and in labour and, as a result, potentially prevent MTCT. This study shows that systemrelated barriers to women being tested during pregnancy are, in most cases, attributable to a lack of available resources, such as HTC providers and test kits, and patients not being offered a test.

ADDRESSING POWER RELATIONS

Power relations play an important role in encouraging or discouraging women to test. It is important to understand the cultural boundaries and dynamics within households that limit women's access to testing as a gateway to PMTCT care. Women's fear of rejection, as well as the fear of undisclosed HIV infection among men and women, creates further barriers to testing and access to PMTCT services. Such fears may potentially deter some women from seeking care. An understanding of power relations and cultural customs is essential to providing an environment that enables and supports HIV testing for women.

ELIMINATING STIGMA AND FEAR OF REJECTION

The 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 pregnant women to refuse testing, hide test results or develop strategies to keep their HIV status unknown or undisclosed. In addition, the fear of accessing services can compromise a mother's own health and that of her child if preventative treatment to reduce the risk of MTCT is not received.

IMPROVING KNOWLEDGE ABOUT HIV TRANSMISSION

A lack of knowledge about MTCT has been a contributing factor to women opting out of HTC (Chivonivoni, Ehlers and Roos, 2008: 1618–1624). Misconceptions, such as a perceived low exposure or risk of infection, can often prevent women from understanding how testing would

benefit their own and their infant's health. There is a need to more purposefully challenge such misconceptions during pre-test counselling and educational campaigns on HIV transmission and MTCT.

RECOMMENDATIONS

- Additional test kits and adequately trained PMTCT and HTC providers are required to fill the increased need for HIV testing as a gateway to the PMTCT Option B Plus strategy. These resources should be provided to local PMTCT services to ensure that testing is readily available at different times during pregnancy, labour and postpartum.
- HTC training must be included in the training curriculum for PMTCT providers. Specific training modules must focus on confidentiality, disclosure, power relations, local and cultural understanding of life with HIV, and on dealing with stigma, discrimination and blaming.
- Novel interventions must address power relations that prevent women from accessing HIV testing and, as a result, negatively affect their own and their child's health.
 Culturally appropriate interventions are currently being researched by the authors.
- PMTCT prevention campaigns should more actively address current misconceptions — such as perceived good health as a reason for not testing — that prevent women from accessing HIV testing and PMTCT services.
- Education and counselling programs should actively tackle the stigma of HIV and discrimination against people living with HIV. They should also address prevailing fears of testing, including issues regarding the receiving and sharing of test results.

CONCLUSION

Improving the uptake of HIV testing among women who have an unknown HIV status is essential to reducing the rates of MTCT.

This study highlights a number of key issues that can be addressed through targeted programs and policies. The lack of available resources, ongoing power relations, mothers' fears of being judged and blamed for being infected and infecting their children, and their anxiety and stress associated with the disclosure of test results and the diagnosis itself — are all factors that limit women's access to testing as a gateway to PMTCT care.

The success of the new "universal test and treat" strategy in Malawi, the PMTCT Option B Plus, will depend not only on adequately organized health services but also on effectively integrating into the program an awareness of cultural values, attitudes towards testing and perceptions associated with the consequences of a positive test result.

ACKNOWLEDGEMENTS

This policy brief was written by Fabian Cataldo, Felix Limbani and Monique van Lettow. The full study (2012) will be available at: www.cigionline.org/series/africa-initiative-discussion-paper-series.

The following institutions have contributed to this study: Dignitas International, Zomba, Malawi; College of Medicine-Malaria Alert Centre, Malawi; District Health Office, Zomba, Malawi; Zomba Central Hospital, Malawi; and Queen Elizabeth Central Hospital, Malawi.

This study was funded through a research grant from the Africa Initiative, a program that works in partnership with and is headquartered at CIGI in Waterloo, Canada.

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