Discussion Paper
UNAIDS | December, 2013

Gender-Related Barriers to Services for Preventing New HIV Infections Among Children and Keeping Their Mothers Alive and Healthy in High-Burden Countries

Results from a Qualitative Rapid Assessment in the Democratic Republic of Congo, Ethiopia, India, Nigeria and Uganda

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Acknowledgements

UNAIDS wishes to thank the local assessment teams in the Democratic Republic of Congo, Ethiopia, India, Nigeria and Uganda for their excellent work in assessing the gender barriers to prevention of new HIV infections among children and keeping mothers alive and healthy. Their support was essential in reaching out to and engaging with communities.

The undertaking of the rapid assessment was supported by funding from the government of Israel.

Executive summary

Since the 2011 launch of the Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping Their Mothers Alive, much progress has been made in accelerating access to these services. Yet, an estimated 700 children acquire HIV every day and anecdotal reports from women living with HIV point towards challenges in utilizing and adhering to services. Therefore, UNAIDS decided to assess potential gender-related barriers to services engaging women living with HIV. The qualitative assessment was carried out in five high-burden countries, namely: i) the Democratic Republic of Congo; ii) Ethiopia; iii) India; iv) Nigeria; and v) Uganda; involving a total of 306 participants.

The rapid assessment elicited basic gender and cultural perceptions and beliefs related to HIV, to people living with HIV in general and to women, in particular that posed barriers to the uptake of and adherence to HIV services. The findings revealed—across all sites—substantive gaps in comprehensive HIV knowledge, with cultural perceptions and beliefs about HIV and gender roles often acting as effective deterrents to service access. Women were frequently blamed for spreading HIV, resulting in considerable stigma and discrimination against women living with HIV, as well as limiting utilization of and adherence to HIV services. Moreover, unequal gender relations and women's socio-economic dependency—and related fear or occurrence of violence and abandonment—were found to limit their decision-making power regarding accessing HIV and maternal health services. Also traditional customs and beliefs—related to conception, pregnancy and childbirth—served as barriers. For example, pregnancy and delivery were believed to be only a woman's issue, hindering timely seeking of supportservices and supportive male engagement. While belief in traditional methods and treatments, as well as a lack of trust in modern medical interventions discouraged visits to antenatal care facilities and the use of HIV services, attitudes of health workers towards women living with HIV further compromised use of such services.It is clear that despite the unprecedented medical and social response to the HIV epidemic, harmful gender norms and inequalities continue to pose serious challenges, to the achievement of effective HIV responses, including in terms of access and adherence to HIV services. Women living with HIV face specific challenges in terms of stigma, discrimination and violation of their sexual and reproductive rights, requiring dedicated attention and support in the roll-out of the Global Plan. As a minimum, services need to be provided in a gender sensitive, confidential and non-judgmental manner, aligned to the needs of women in all of their diversity and to respect their human rights. Other approaches would include rights and gender literacy training for health-care providers to deliver services that are grounded in human rights and that links sexual and reproductive health services and HIV care. This must be complemented with community discussions on issues such as harmful gender roles and norms, economic empowerment of women and violence against women. Efforts to prevent new HIV infections among children and keep mothers alive and healthy are unlikely to be successful without also addressing violence against women. Such efforts and working towards the empowerment of women, as these issues are at the core of the gender-related barriers to access and adherence to HIV services and treatment. At the same time, there is also a need to identify alternative service delivery approaches when facing constraints in availability and accessibility of health services. This should be done in consultation with communities and building on models led by women living with HIV themselves.

Introduction

Globally approximately 700 children are estimated to acquire HIV every day, mostly during pregnancy, birth or breastfeeding.[1] Prevention of new HIV infections among children has proven to be a fundamental strategy in reducing transmission of HIV. Today it is possible to reduce the transmission of new HIV infections among children to less than 5% if pregnant women living with HIV and their children have timely and continued access to antiretroviral drugs.[2] Furthermore, enrolment in services to prevent new HIV infections among children is increasingly being seen as an opportunity to enable women to access HIV treatment and care for their own health and well-being.[3]

While effective approaches to prevent new HIV infections among children and keep their mothers alive and healthy are available, in countries with a high burden of HIV, even when these services are available, access and adherence to these services remain weak. Thirty-seven per cent of pregnant women living with HIV in low- and middle-income countries in 2012 did not receive antiretroviral therapy to prevent new HIV infections among children [4]; of those that do access services, rates of non-adherence have been found to be high, up to 40 per cent in one study.[5] Furthermore, among pregnant women who needed antiretroviral therapy for their own health in 2012, 58 per cent received HIV treatment— lower than the 64 per cent (61–69 per cent) treatment coverage for adults overall.[6]

Anecdotal reports by women living with HIV strongly indicate that gender inequality related to cultural and economic issues poses major barriers to women in utilizing HIV treatment services.[7] Indeed, harmful gender norms are often an embedded part of people’s lives and deeply influence their daily activities as well as their health behavior. They also intertwine with economic, political, social and gender-related issues in specific contexts.[8] When women have not been able to access education, lack decision-making power, are economically dependent and are unable to move freely outside their homes, they tend to have lower rates of maternal health service utilization.[9] However, data on these phenomena from the perspectives of affected women and their communities remain limited.

Rationale. The Global Plan recommends that each country conduct a strategic assessment of key barriers to elimination of new HIV infections among children and keeping their mothers alive, and improve outcomes assessment, data quality, and impact assessment. Alerted by reports by women living with HIV of the challenges faced in utilizing and adhering to services to prevent new HIV infections among children, UNAIDS decided to undertake a qualitative rapid assessment of cultural and gender-related barriers to services to prevent new HIV infections among children and keep their mothers alive and healthy.

Purpose and scope. The rapid assessment aims to improve the understanding of and response to socio cultural and gender-related barriers that hinder women’s utilization and adherence to services that prevent new HIV infections among children and access treatment for their own health. It is anticipated that the qualitative findings obtained through the study may support country-level advocacy, as well as the adoption of gender-responsive approaches and actions to address these barriers, thus contributing to the likelihood that pregnant women living with HIV are able to make use of these HIV services for their own health and the health of their infant.

The report is based on qualitative research, undertaken in partnership with women living with HIV, at six sites in five high-burden countries: the Democratic Republic of the Congo, Ethiopia, India, Nigeria and Uganda. While the qualitative data points towards widespread perceptions and practices and thus may serve as a basis for improving services, the data obtained remains context-specific. However, raising awareness on the daily life-challenges faced by women, particularly women living with HIV, and their implications for service utilization and adherence, will assist other countries in achieving gender-responsive HIV approaches, by engaging women living with HIV in creating service demand, overcoming gender-related barriers to access and adherence, and improving quality of services.

This report is meant to inform and support partners in ensuring that the implementation of the Global Plan in their respective countries considers and takes action to overcome the gender-related barriers to preventing new HIV infections and keeping their mothers alive and healthy. It is particularly intended for programme designers and implementers, at national and decentralized level, as well as for networks of women living with HIV, NGOs and women’s rights groups.

The report presents a brief review of previous studies conducted on the relationship between gender-related barriers to use of services to prevent new HIV infections among children, and the methodology of the assessment. The report continues with an overview of the data available on each country that took part in this assessment. It then discusses the findings and provides recommendations for action, followed by a concluding section.

1. What do we know about gender-related barriers to HIV and maternal health services?

Previous studies indicate that cultural perceptions and practices surrounding pregnancy and childbirth, as well as distrust of health care services, can pose barriers to HIV prevention and treatment services[10]. In addition, studies found that women in particular faced difficulties related to unequal gender power relations and stigma[11].

Mistrust of health services, in particular due to lack of cultural sensitivity and confidentiality by health service providers, has been linked to non-utilization of services by women. In Liberia, a 2011 study found that secrecy surrounding pregnancy and childbirth, related to the perceived dangers of sharing this information, influenced the type of care sought. Women in the study distrusted the formal health care system and preferred to deliver at home with traditional birth attendants, who understood the community norms and practices[12]. Women in a 2003 Ugandan study worried that if they were found to be living with HIV-their diagnosis would be revealed, i.e. that health clinic staff would not adhere to confidentiality rules[13].

Stigma against women living with HIV is both widespread and severe[14]. Studies have found that fear of abuse and mistreatment related to stigma of being identified as living with HIV deterred women from accessing services. A 2011 study conducted in Addis Ababa and Adama, Ethiopia, documented that women frequently refused to enroll in programmes to prevent new HIV infections among children and discontinued antiretroviral therapy for fear of revealing their HIV status to their husbands, which could have negative consequences on their marriage, including divorce. These fears were related to unequal economic opportunities for women, making it difficult for a single mother to support herself and her children[15]. A 2007 study in Malawi, undertaken during the roll-out phase of the national programme to prevent new HIV infections among children, found that four in ten women living with HIV and utilizing services to prevent new HIV infections among children had been divorced by their husbands due to their HIV status[16] .

Lack of women's autonomy over their sexual and reproductive health has also been found to be associated with reduced uptake of maternal health services[17]. In India, a 2006 survey indicated that the majority of women who did not attend antenatal care were prevented from doing so by their husbands or family, while the proportion of women who decided not to go themselves was very low[18].

It is clear then that awareness of beliefs about HIV, gender sensitivity of service delivery and the existing gender norms may determine to a large extent the success or failure of HIV programmes. For example, approaches that empowered women and engaged male partners in antenatal care sessions seem to have contributed to increased rates of women's utilization of services to prevent new HIV infections among children. Also, support from peers and their extended families have been found to support increased access to HIV and antenatal services by women living with HIV[19] [20].

This suggests that understanding and adequately responding to gender-related and cultural barriers is critical to maximize access and adherence to services to prevent new HIV infections among children and keep their mothers alive and healthy. The rapid assessment sought to expand understanding on these issues by engaging communities in six sites in five countries, in order to pinpoint these issues via dialogue with the women themselves as well as community members and leaders and health providers.

2. Country situation overview

The five countries chosen for this rapid assessment are among the countries with the highest burden of unmet needs for prevention of new HIV infections among children. Collectively they account for 56% of the gap in provision of service to prevent new HIV infections among children in low and middle income countries[21]. Below is a brief overview of each country's most recent data on HIV prevalence, new HIV infections among children, testing and treatment of pregnant women, and national policies created to address these issues.

Table 1. Epidemiological overview

Country	**Population, millions** (a)	**Adult (15-49) HIV prevalence**	**Pregnant Women all ages HIV prevalence, 2009**(b)	**Estimated no. of new HIV Infections among children (0-14) 2012**
Congo, Dem. Rep. of	67	1.1% [1.0-1.2]	1.0% [0.9-1.2]	11,000 [9,300-12,000]
Ethiopia	83	1.3% [1.2-1.5]	1.3% [1.1-1.6]	9,500 [7,300-12,000]
India	1,225	0.3% [0.2-0.3]	n/a	n/a
Nigeria	158	3.1% [2.8-3.5]	2.7% [2.4-3.2]	59,000 [49,000-70,000]
Uganda	33	7.2% [6.4-8.4]	6.1% [5.3-7.2]	15,000 [10,000-22,000]

Unless indicated otherwise, all data from UNAIDS Report on Global AIDS Epidemic, Geneva, 2013
(a) United Nations, Department of Economic and Social Affairs, Population Division
(b) UNAIDS, unpublished estimates, 2012

As indicated in Table 1, the five countries in the study have rather varying HIV epidemics. A common trend though across all countries, except for India, is that HIV prevalence is significantly higher amongst women than men.

Table 2. Overview of coverage of services to prevent new HIV infections among children

Country	**HIV testing and counselling coverage among pregnant women**	**Pregnant women living with HIV receiving effective ART for prevention of new HIV infections among children**
Congo, Dem. Rep. of	9%	13% [11-15%]
Ethiopia	39%	41% [35-49]
India	31%	n/a
Nigeria	19%	17% [15-19]
Uganda	65%	72% [62-86%]

Data on estimated percentage of pregnant women living with HIV who received antiretroviral therapy (ART) for prevention of mother-to-child transmission (PMTCT) is from the UNAIDS 2013 Global Report

As indicated in table 2, selected countries show differing rates of service coverage to prevent new HIV infections among children. In all countries, there are substantial numbers of pregnant women living with HIV who do not receive the services they need to prevent new HIV infections among children and access treatment for their own health. This assessment attempts to shed some light on why that is happening and put forward recommendations on how to overcome these limitations.

3. Methodology

In order to enhance the understanding of gender-related barriers to the utilization of services to prevent new HIV infections among children—and keep their mothers alive and healthy -both from the users' and community perspectives—a qualitative methodology was adopted for this study. Such an approach aims to bring out the subjective reality that is experienced by each individual.

The rapid-assessment process used is an intensive, team-based, participatory and qualitative inquiry[22]. The sites in all five countries were selected in consultation with national and local authorities, including the Ministries of Health and AIDS Commissions. Three sites were in urban settings and three in predominantly rural areas. The rapid-assessment country teams were composed of a researcher, a research assistant, people living with HIV (especially women living with HIV), as well as health care workers and community members.

The rapid assessment included 306 participants in five countries: Democratic Republic of the Congo (50 participants), Ethiopia (49 participants), India (85 participants), Nigeria (53 participants) and Uganda (69 participants). The first participants were selected with the assistance of community members, women's organizations and networks of people living with HIV, and the health facilities in the selected sites. The selection then continued using the snowball technique. Among the participants were pregnant women (including women living with HIV), women with small children and male partners and other men from the community, as well as key informants (leaders of women's organizations, traditional birth attendants, community leaders and medical staff). Written interviewguides were culturally adapted and translated into the local languages by the country rapid-assessment teams as part of the team-building and training process carried out in preparation for the assessment in the selected country sites.

Participants were engaged home communities using a participatory approach, with active community involvement throughout the process. This approach allowed participants to tell their stories in a non-judgmental atmosphere. Participants were interviewed either individually in-depth or through focus group discussions. Informed consent was obtained prior to the interviews and discussions, with the assurance that all names would be kept confidential.

It should be noted that neither the sample nor the data obtained are representative of entire country populations. Nevertheless, such qualitative data often reflect widespread perceptions and practices and thus may serve as a basis for improving services as well as for more comprehensive studies in the future.

4. Key findings

The rapid assessment elicited basic gender-related cultural perceptions and beliefs related to HIV, to people living with HIV in general and to women living with HIV in particular, and explored issues posing barriers to the uptake of and adherence to testing, treatment and services to prevent new HIV infections among children. and keep their mothers alive and healthy. The quotations included herein enable the reader to hear the voices of pregnant women, women living with HIV, community members and health workers in the field.

4.1 *Cultural perceptions and beliefs regarding HIV and people living with HIV*

The assessment revealed a lack of comprehensive knowledge about HIV. Although many participants knew that transmission could be through sexual contact, many also believed that HIV could be transmitted by eating together, sharing toilets or hand-shaking. Their understanding of the epidemic was often based on cultural perceptions related to its origins, effects, modes of transmission and treatment—which often reinforced fear and stigma about HIV and people living with HIV, thus posing barriers to testing and treatment.

Communities had also undertaken efforts to explain the existence of HIV, stating for example that:

> “Some people believe that one can be infected through spiritual means (witchcraft). Such people rather than go to the hospital for medical attention they go to churches and witch doctors for help.” (Female Nurse/Midwife, 42, Nigerian site)

> “There are also people who believe in witchcraft [and those] who consider HIV as [the] rage of the spiritual powers including ancestors.” (Woman living with HIV, Ethiopian site)

The concept that HIV was something that could only happen to individuals engaging in certain stigmatized, high risk behaviors, such as sex workers, presented a barrier to testing and treatment, in that some study participants believed that their lifestyle protected them from HIV.

> “I have no need to be tested … we are all right. They didn’t say that I should be tested. Why to do [a test]? We have no risk behaviors.” (Pregnant woman, rural Indian site)

> “You don’t take a fine car to the mechanic … So only those who are sick will visit the hospital to be treated; that is only when they are tested.” (Community leader, Nigerian site)

Perceptions of people living with HIV as deliberately infecting others, and a threat to the well-being of the community, led some participants to believe that they should not be treated or should be isolated. These perceptions led to fear of and actual stigma and discrimination, posing barriers to testing and treatment.

> “The community may view them [persons living with HIV] as people who are set to kill other people’s daughters and sons.” (Participant, Ugandan site)

> “People think that HIV-positive people intentionally infect others … my grandmother used to say when somebody talks about a woman who is suspected of HIV-positive in the neighborhood: ‘please, all of you take care, do not go to her house because you will contract the disease and bring to our home.’ So, if she knew my status, she will not let me go to her house.” (Woman living with HIV, 24, Ethiopian site)

4.2 *Stigma against women living with HIV*

Some participants expressed a belief that women were primarily responsible for spreading HIV. Such a perception sometimes led to blaming the woman who tested HIV-positive for bringing it into the family, even when her partner also tested HIV-positive.

> “Men have never been accused of killing women [through infection]. Only women are [accused], as people believe that whoever gets HIV may have got it from a woman, who are said to kill Luambo [a male singer who died from the disease] today. A woman is thought to be the vector for the virus, being accused of being killers of men.” (Participant, the Democratic Republic of the Congo site)

> “HIV is from the girls who travel to Italy and other European countries that came back with it.” (Community leader, Nigerian site)

Thus, HIV was found to be associated with perceptions of the women engaging with multiple partners, which further stigmatized women, given the taboos and social control related to female sexuality. Many respondents indicated that women living with HIV were perceived as having been immoral, and as a result face more negative attitudes than men.

> “For a man, the community says ‘let it be, because he is a man;’ if it is a

> woman, they say, ‘she is a woman, how come [she got the disease]? She must have caught it fooling around’.” (Woman living with HIV, Ethiopian site)

> “I felt shameful in my own eyes. … The problem with this disease is because of this sexual nature of HIV, no one gives you respect, they don’t give sympathy and also don’t talk to you anymore.” (Woman living with HIV, 32, urban Indian site)

At all rapid assessment sites, participants held the view that women living with HIV should not get pregnant, as they believed that the mothers will soon die and the babies will be born with HIV. It was considered irresponsible since they were less capable of fending for their children. This key finding discouraged pregnant women from testing or following up with antiretroviral drugs.

> “It is irresponsible or ignorant of an HIV-positive woman to bring a child into this world.” (Participant, Ethiopian site)

> “The children to such a woman will eventually die. They will eventually be contaminated by the mother. They will not have a long life.” (Community leader, Democratic Republic of the Congo site)

This stigmatizing belief was internalized by some pregnant women living with HIV. They reported going through periods of depression upon learning of their HIV-positive status, and did not seek treatment because they believed there was no hope for them.

> “[I considered myself] a dead person, a walking corpse … I believe that God doesn’t like me. How come that me, his faithful servant, I can suffer this much?” (Woman living with HIV, 38, Democratic Republic of the Congo site)

> “[I didn’t share my status with others because] I was afraid of the consequence—stigma, exclusion around my workplace and neighbourhood. I was always weeping, [being] truant from my job; but my colleagues attributed changes in my behaviour to pregnancy.” (Pregnant woman living with HIV, 24, Ethiopian site)

In addition to feeling ashamed, some pregnant women felt guilt due to the felt risk for their children of acquiring HIV.

> “My morale went low until it got to zero. I tried to commit suicide many times. One day, I wanted to take poisoned water. Should not my firstborn daughter be there, I would have killed myself already.” (Woman living with HIV, Democratic Republic of the Congo site)

4.3 *Gender power relations, fear of violence and abandonment*

Unequal gender relations and women’s socio-economic dependency were found to limit their decision-making power regarding accessing HIV and maternal health services. Male partners, or other family members, sometimes refused to allow their pregnant women to visit antenatal clinics because they did not trust in the efficacy of the services, did not want to pay a fee (for transport or the services) or were afraid of the stigma that might be directed at them if their own HIV-positive status was somehow discovered through their wives' treatment.

> "I cannot do anything because he is the owner of the pregnancy and he is the one who can give me money to go to the hospital." (Pregnant woman, Nigerian site)

> "My husband does not want me to seek medical care [for] fear of being known by people who might suspect of his HIV-positive status. He warned that if people know his status because of me, he will walk away from our marriage." (Woman living with HIV, Ethiopian site)

> "My mother-in-law and husband make this decision whether I need to go to a hospital or to a *dai* [traditional birth attendant]. I do whatever my mother-in-law says. If I don't obey her, there will be fights in the house … If my husband forbids me to go anywhere, then I don't go. Because I don't like fights." (Pregnant woman, 24, rural India site)

Fear of abandonment was related to a woman's lack of economic opportunities to support herself and her children should her husband leave her, or her family to abandon her, due to her HIV positive status.

> "At times it is harder for the woman because she depends on the man for survival. If the man has money and many members of the family depend on him for survival they will care for him and pamper him so that he does not die. So money is actually important here." (Male participant, 29, Nigerian site)

Fear of being blamed for HIV and thus being physically or emotionally abused or abandoned sometimes led pregnant women not to disclose their status and therefore to avoid treatment services.

> "The reason I refused to disclose to him is that the man had earlier on threatened that if he finds out that I am positive … he would kill me." (Woman living with HIV, 24, Nigerian site)

> "Just think if this disease would have happened to me first instead of my husband, what my husband and in-laws would have thought about me. They would have thrown me out of the house; my mother in-law would be talking about my husband's second marriage. But now things are different as my husband was the first one to get this." (Woman living with HIV, Indian site)

> "The HIV-positive pregnant women do not share their HIV-positive status with their fathers and in-laws because of stigma and fear of violence as they could accuse them of being harlots. They can also be abused and told that they infected their sons. Sometimes they don't share because they want to keep it a secret to avoid fights." (Key informant, Ugandan site)

4.4 *Traditional gender roles concerning pregnancy and childbirth*

Traditional customs or beliefs related to conception, pregnancy and childbirth sometimes acted as barriers to accessing services to prevent new HIV infections among children as well as treatment for their own health.

The message shared by most participants in all sites is that pregnancy and delivery are women's issues. Thus, in some cases, women did not seek care from family or others.

> "It is [a] common superstition that if a wife told her husband about labour pains, the labour would be prolonged and the baby would take long[er] to be born." (Key informant, Ugandan site)

> "Most women are able to bear the pain but they don't trouble their family for their pain. She want that no one in the family should face any trouble because of her. … When the water breaks, then she tells them, but it is very late by then and taking her to the hospital is not possible, and naturally delivery takes place at home." (Traditional birth attendant, rural Indian site)

Beliefs that childbirth is a normal occurrence that does not require medical care were factors in low utilization of antenatal care services, which then affected access to HIV services.

> "There is no problem in delivery at home ... Childbirth is not a disease… All my children were born at home, all were delivered by *dai* [traditional birth attendant], it was all normal. I had no problems at all. When we come to know that the labour pains have started, we call for the *dai*." (Pregnant woman, rural Indian site)

Male involvement in women's visits to antenatal clinics and in services to prevent new HIV infections among children and keep women alive and healthy was generally limited. This was sometimes a barrier to testing and to accessing treatment, as pregnant women living with HIV needed help with transport to clinics, to receive and take antiretroviral drugs, as well as emotional support, particularly in the face of stigma from family members or the community at large. Men reported that their lack of involvement was due to fear of social embarrassment, stigma or simply disinterest in what was considered a "woman's affair", or exclusion at health clinics.

> "A man is not a man when he moves around with his women, as others say 'omuhasi yamutuuka', meaning that his wife has authority over him." (Participant, Ugandan site)

> "There is no reason why people should go with her because she is the one who carries the pregnancy." (Man in focus group discussion, the Democratic Republic of the Congo site)

> "One of the reasons men do not go to the clinic with their wives is that the men are not allowed into the hall. The nurses say they should go and sit under the

> tree and wait for their wives during antenatal care." (Male participant, focus group discussion, Nigerian site)

Women's fear of revealing their status, as by not breastfeeding, was also mentioned as a barrier in two sites. Fear of lack of confidentiality regarding their HIV status and related stigma, discrimination and gender-based violence was also mentioned as a barrier to adherence to treatment programmes.

> "After delivery, if [the mother] doesn't breastfeed, then she is asked, 'Why aren't you breastfeeding? What's your problem?' They of course don't openly say what their problem is … then it's very difficult for them to answer these questions. Also, the first 40 days or a month, the woman has to live with her mother in law or sister-in-law, then it becomes problematic. 'Why are you taking so much care?'" (Counsellor, rural Indian site)

4.5 *Community perceptions of health services and health service providers.*

A wide range of gender-related barriers were identified concerning the community perceptions of the effectiveness and safety of health services and the trustworthiness of service providers.

4.5.1 Perceptions of antenatal clinics and HIV testing

A belief in traditional methods and treatments as well as a lack of trust in modern medical interventions can discourage visits to antenatal care facilities and the use of HIV prevention and treatment services. Women in rural sites in the Democratic Republic of the Congo, Nigeria, Uganda and India frequently turned to traditional birth attendants over official health providers. They were considered more familiar, friendlier and are perceived as more culturally aware. For example, in accordance with some Ugandan tradition, birth attendants bury the placenta cord facing upwards to retain fertility as opposed to hospital attendants, who throw away the placenta, which is taboo and believed to cause female infertility. They are also considered less of a financial burden, for example in Uganda payment of a traditional birth attendant for her assistance could be 3,000 shillings (just over USD$1) or material items such as a bar of soap.

Of those women who did access antenatal care services, they started accessing them at varying stages of pregnancy. Many women only tended to go to an antenatal care clinic when already in labour, which health workers attributed to poverty, domestic chores and distance to the heath facility. Some women indicated that their access to services was limited by a lack of autonomy.

> "My in-laws decide about [going to a health care facility]… If I step out of home without permission, I will be scolded at home. People in the village will raise finger at me saying that what kind of a woman is she who does everything on her own". (Pregnant woman, HIV status unknown, Haryana, India site)

4.5.2 Discrimination against women living with HIV by health service providers

Fear and actual occurrence of discrimination by health care workers was reported as a major deterrent for pregnant women to be tested for HIV, take medication to prevent HIV transmission to their child and access treatment for their own health. Participants described the following situations of discriminatory treatment based on a person's HIV-positive status:

> "When my wife was pregnant, they were initially good at giving services. They asked for routine tests and they asked to do HIV tests. The whole problem arose when the results turned out to be positive. Then after that they started misbehaving and treating [us] very badly. They told us that we are dirty people and will spread the germs; they said that even after repeated denial. Why do we need to come?" (Man living with HIV, 35, urban Indian site)

> "When I was pregnant with my second child, I started a follow up at a private clinic. When the nurse knew and informed me my HIV-positive status, she advised me, 'You don't need to give birth with this situation, never. You are positive and you need to terminate the pregnancy'. But my husband and I said, 'God always has His ways' and we decided to have the baby … We delivered a healthy baby whom after some years we took and showed to the nurse." (Woman living with HIV, Ethiopian site)

According to some participants, by just being seen at health facilities where HIV treatment is provided, people assume that a person has HIV and begin to gossip. To avoid their status being revealed, people living with HIV travel far to access treatment. Some women even avoid antenatal clinics where HIV testing is carried out altogether, preferring ignorance to possible stigma and related stress.

Some participants noted that a perceived and sometimes actual lack of confidentiality by health care workers and subsequent stigma and discrimination in their community deterred women living with HIV from accessing services to prevent new HIV infections among children or led to discontinue the treatment:

> "Fear of [being] seen by others is a factor for mothers not to go [to] the health centres to take the baby's medicine. … There are some mothers who quit giving medicine to their babies." (Woman living with HIV, 24, Ethiopian site)

Thus, the fear of disclosure—which is so often present in communities where people know each other—extends to local health services.

At the same time, there were also positive developments. At the Nigerian and Ugandan rapid assessment sites, some pregnant women affirmed that in general nurses and midwives are kind to patients, but this also was found correlated to the providers personality. Others said that overburdened health service providers sometimes treat patients badly:

> "Yes, they treat us well, but when the hospital is crowded with patients they run out of patience and can be angry sometimes" (Woman living with HIV, 32,

> Nigeria site)

At the Ethiopia site some participants perceived that health personnel’s attitudes are changing for the better—especially among those offering services to prevent new HIV infections among children.

4.5.3 Perceptions of HIV treatment

Some differences were noted from site to site regarding attitudes towards HIV treatment. Participants at the Democratic Republic of the Congo and Nigerian sites expressed some ambivalence about antiretroviral medications based on the fact that the therapy does not cure the disease. Several Congolese participants expressed the belief that antiretroviral drugs were considered to be types of sedatives or vitamins that make people “feel good for the time being but the people are thought to die anyway.” At the Nigerian site, several participants opined that antiretroviral treatment was dangerous, as it made people living with HIV-look healthier, which meant that they could no longer identify them on sight. Two community leaders feared that the drugs would allow persons living with HIV greater opportunity to infect others:

> “The government should stop giving drugs to those who are HIV-positive as they come back healthy to infect others. Let them die.” (Male community leader, 60, Nigerian site)

> “People just take those vitamins to get fat and look good to deceive partners and community members.” (Female participant, 24, Democratic Republic of the Congo site)

Such perceptions suggest that antiretroviral treatment and the possibility for healthy living it offers were not fully understood, while also pointing to the pervasive stigma and discrimination which persists.

The belief in the efficacy of traditional medicine sometimes led to its use and to the exclusion of antiretroviral therapy.

> “We also believe in traditional medicines that have proven efficacious as well. One of these is called ‘kamasongo,’ which cures AIDS. It is made from roots by a man called Landu in the Lower Congo Province.” (Male participant, 48, Democratic Republic of the Congo site)

At the Haryana sites, participants also expressed strong trust in traditional healers, who are often accessed for different kinds of diseases and problems. Therefore, some turned to traditional medicine and even discontinued antiretroviral treatment. Nevertheless, sometimes these treatments were not successful:

> “On the advice of his friend, my husband took me to a traditional healer. He gave us some medicines to have, which we ate but gave us no relief. My husband became more sick and he died after three months.” (Woman living with HIV, urban Indian site)

Similarly, in Ethiopia, there was some ambivalence regarding efficacy of antiretroviral treatment. Some persons living with HIV also combined antiretroviral therapy with traditional medicine and treatments. In some cases, they were concerned with the medications' side effects, which caused them to discontinue the treatment. Other persons living with HIV did not begin or continue antiretroviral treatment due to their cultural or religious beliefs. They either believed that they are cured through their faith or that the disease is God's will or punishment.

A number of participants at the Uganda and Nigerian sites reported that preachers at church were telling people living with HIV or AIDS to stop antiretroviral treatments, claiming they had already been healed through faith. In contrast, a few religious leaders in Ethiopia have recently come out supporting combining religious and antiretroviral treatment.

Some participants at the Uganda site showed determination to access their medication and daily dose of antiretroviral treatment, after noticing a positive impact of treatment on their health. This suggests that once the importance of treatment is understood, its uptake may increase. As shared by a pregnant participant living with HIV at a hospital:

> "Antiretroviral therapy has helped to keep me alive so that I can live long enough to look after my children and educate them. I also hope that my child on antiretroviral therapy will be healthy and grow and play with his friends."

In Ethiopia, participants reported that after sensitization, some priests were counselling followers living with HIV to continue using holy water as a treatment for AIDS, but at the same time to adhere to their medicines, because these were also created by God's will. Such approaches should be leveraged to make people aware of the dilemmas and challenges facing persons living with HIV and the possibility of living healthily and having children born without HIV.

4.5.4 Awareness and perception of services to prevent new HIV infections among children

At all sites, most people living with HIV and some women who had visited antenatal clinics had heard of services to prevent new HIV infections among children. Some participants indicated that they had never heard of them or were unaware that HIV could be transmitted from mother to child.

> "No, I don't know about [vertical transmission of HIV]. This is a rare disease and people don't talk much about it. People only know that this can spread through illicit relation with other women." (Community leader, rural Indian site)

> "We have never heard of that type of protection of [a] baby." (Man in focus group discussion, 45, Democratic Republic of the Congo site)

Others expressed disbelief that prevention of new HIV infections among children was possible. Even women who had successfully used those services and had given birth to children without HIV indicated previously having these beliefs:

> "The community finds it hard to believe that an HIV-positive mother would deliver a negative child. Even I found it difficult to believe except for the fact that I have a negative child. That is what made me believe." (Woman living with HIV, 24, Nigerian site)

> "My daughter was tested HIV negative three times, but my neighbor never hugs her while doing so to my niece. Do you think that she does not know that my baby is negative? No, it is because she doesn't believe that an HIV-positive mother can deliver a healthy child." (Woman living with HIV, Ethiopian site)

4.6 *Availability and accessibility of comprehensive health services*

At all rapid assessment sites, participants were aware of the health centres near them. At the urban sites in Ethiopia (Addis Ababa) and in India (New Delhi), they were accessed by community members more than at the other sites.

Participants highlighted resource problems as barriers to health services in general, and in relation to prevention of new HIV infections among children in particular. These ranged from a lack of service availability in certain areas—leading to increased difficulty in travel and expense on the part of patients living with HIV—to undersized, underequipped and understaffed health facilities. Many health facilities offered antenatal care, but not HIV testing and services to prevent new HIV infections among children or vice versa. Some women were referred to clinics that were inconvenient for them to get to. Others, knowing the difficulty in accessing services, did not bother to get tested at all.

> "The public health centre is ill equipped. Sometimes you do not even meet anybody there. The child I tried to have there, I had it before the nurse came. If you go to a place and you do not meet anybody there, will you go there again?" (Pregnant woman, 33, Nigerian site)

> "Our centre does not have any facility for HIV. Neither is there HIV testing nor any medicine. Only HB [haemoglobin] and blood sugar tests are done here. People get ultrasounds done from outside. There is no other facility." (Health care worker, rural Indian site)

The remoteness of a village combined with lack of roads and transport and inadequate human resources can have negative consequences on health system coverage. Lack of resources can lead to a shuffling of patients from one health centre to another, a problem that is exacerbated if transportation is not easy. Nigerian participants reported that people were at risk of road accidents on the way to Makurdi town (the state capital with the main hospital), thus further discouraging pregnant women to travel and access treatment.

> "What is the use of testing when you know you cannot access medicine from your nearest health centre and you can't travel to reach where the medicine is given? This can worsen your health with stress and probably kill you, so it is better when you don't confirm your HIV status." (Pregnant woman living with

> HIV, Ugandan site)

The correlation between the quality of the services provided and out-of-pocket payment came up strongly as described by a participant in the Democratic Republic of the Congo:

> "There is a welcoming atmosphere, nice sensitization during antenatal care, very kind personnel, talking politely to women. Doctors know how to deal with us. But for special examinations like scanning, that is where we find that we are not well treated if we don't have money".

Even when services were free, the costs and opportunity costs associated with taking time to access services to prevent new HIV infections among children and protect their own health were cited as a barrier. Many women reported that they lacked the time to visit health centres, or have no one to take care of their responsibilities in their absence.

Health care workers at all sites reiterated the opinion of community members that the quality of services was severely impacted by lack of resources, including a shortage of well-trained staff.

5. Discussion

After more than 30 years of the HIV epidemic—and an unprecedented medical and social response to the epidemic—harmful gender norms and related stigma, discrimination and violence continue to pose challenges to an effective HIV response This assessment clearly shows that culture- and gender-related issues also influence the prevention of new HIV infections among children and efforts to keep mothers alive and healthy. Although the sites where the assessment was conducted were very diverse, findings tended to be similar in most of the rapid-assessment process sites, thus strengthening their relevance to global policy.

5.1 *Awareness and cultural understandings of HIV remain major challenges*

The findings of the rapid assessment point towards gaps both in terms of knowledge and understanding of HIV, with cultural perceptions contributing to misunderstandings, as well as HIV-related stigma. This suggests that the response to HIV as a whole, including programmes to scale up access to services to prevent new HIV infections among children and keep their mothers alive and healthy, should not assume that HIV is understood the same way in all communities and should include components to address broader issues of incorrect knowledge and related stigma and discrimination. For example, in the Democratic Republic of the Congo, where people living with HIV were given a name equating to death, participants in the assessment recommended to begin by focusing on the basic fact that an HIV diagnosis is not a death sentence.

5.2 *Stigma and discrimination against women living with HIV is hindering access and adherence to services to prevent new HIV infections among children and protect their own health*

In all sites, women living with HIV reported experiencing particularly high levels of stigma and discrimination. Indeed some participants indicated that just the fact of being seen at a health centre and being suspected of having HIV caused some mothers living with HIV not to go to the services or to take medication after giving birth. The stigma was often related to the attitudes of community members and at times health providers. This is in line with the findings revealed through the Stigma Index which found widespread stigma against women living with HIV.[23] Sometimes women living with HIV appeared to have internalized the stigma and blamed themselves, especially in the context of pregnancy, when they were also blamed for transmitting the virus to their child.

While women are often not able to claim their rights and access legal services, against a broader context of non-enforcement of laws and regulations to protect women, the findings of the rapid assessment also point to specific challenges related to accessing services to prevent new HIV infections among children and protect their own health. Women living with HIV are likely to be the first in a couple or family to learn their HIV status, as testing is increasingly offered through ante-natal clinics, contributing to such high levels of stigma. Another challenge is the assumed link between contracting HIV and multiple sexual partnerships, a matter largely accepted for men, but not for women, thus adding to the stigma and discrimination faced by women living with HIV and further exposing them to the risk of abuse, violence or abandonment.

These specific challenges faced by women living with HIV suggest that they require focused attention and support in the implementation of the Global Plan. A critical element of this should include literacy training, including on rights and gender, for health-care providers to deliver services that are grounded in human rights and that focus on quality, non-discriminatory care that links sexual and reproductive health services and HIV care, as well as community discussions on issues such as harmful gender roles and norms, economic empowerment of women, and violence against women. Such sensitization would not only focus on HIV in general and services to prevent new HIV infections among children and keep mothers alive and healthy in particular, but also include discussions on gender and rights issues such as harmful gender roles and norms, economic empowerment of women, and violence against women.

5.3 *Violence and abuse is stopping women accessing services to prevent new HIV infections among children and protect their own health*

Threats or actual occurrence of violence and abandonment was cited many times as a barrier to service access and adherence by women and to disclose their status. This is in line with reports from women living with HIV around the world revealing that fear or actual occurrence of violence, abandonment and divorce, are strong forces that hinder women living with HIV to utilize and adhere to HIV services.[24] [25]

The findings of the assessment also point towards socio-economic factors undermining women’s decision-making power, as further compromising factors, placing the issues of violence, abandonment and divorce within a broader context of gender inequality and the disempowerment of women and girls, including violence against women.

As such, efforts to prevent new HIV infections among children and keep mothers alive and healthy are unlikely to be successful without also taking actions to eliminate violence against women. Services to prevent new HIV infections among children would need to include services to both prevent and address violence against women, while building health workers understanding of the risk of violence faced by women and the importance of respecting confidentiality and the rights of clients at all stages of service delivery. Services to prevent new HIV infections among children could also serve as an entry point for dealing with violence, and routine screening for any sign of violence or abuse and, if needed, be accompanied by referral to appropriate medical and/or legal, counselling and social services for survivors of violence.

Transforming harmful gender norms, in particular those that legitimize violence against women and men’s control over women—often quoted by women participating in the rapid assessment—is equally important for increasing the effectiveness of efforts to prevent new HIV infections among children and keeping their mothers alive and healthy, in ways which truly meet the needs of women and uphold their rights. There is a body of promising and established community engagement approaches, for example Stepping Stones[26], developed by women living with HIV, to address their vulnerabilities and reduce violence. These can be adapted to the local context and utilized to increase utilization of and adherence to HIV services.

5.4 *Traditional gender roles related to maternal health were found to be barriers to access and adherence to services to prevent new HIV infections among children and keep mothers alive and healthy*

One specific issue impacting on uptake of services to prevent new HIV infections among children and keep mothers alive and healthy, frequently noted during the rapid assessment, was the existence of harmful gender roles in relation to maternal health. In all sites, respondents indicated that culture had a significant influence on service access for maternal and child health in general, and prevention of new HIV infections among children, in particular.

Participants in all rapid assessment sites expressed that pregnancy and childbirth are women’s business, with men often feeling ashamed to participate in maternal health services. In other cases, men were discouraged from attending antenatal clinics by the staff, even though supportive male partner involvement tends to be associated with increased uptake of prevention of vertical transmission services. This suggests that potential users may not be able to benefit from services to prevent new HIV infections among children unless the related-gender norms are addressed and policies, programmes and services include actions to transform harmful gender norms towards the achievement of gender equality.

Conversely, when provided in a gender sensitive manner, health services would be able to contribute to transformation of those gender norms and the achievement of gender equality within HIV responses, by encouraging the supportive attendance of male partners at antenatal care, securing the informed consent of the woman, while still upholding women’s right to confidentiality. Such services would provide an opportunity to discuss perceptions and misunderstandings related to HIV and pregnancy, as well as to offer and provide couple counsellingvoluntary and informed couples counseling and testing, thus reducing anxiety over disclosure to male partners and potential risk of violence. Peer sharing of experience would then likely result in increased acceptance of services for prevention of new HIV infections among children and treatment to keep mothers alive and healthy.

Given the strong reporting on the influence of the extended family, there is also need to strengthen and scale-up approaches which engage the family, including through community dialogues and education to reduce HIV and gender-related stigma and discrimination and the acceptance of violence against women. The mother-in-law, mother or other family member may have a gatekeeper role in allowing the pregnant woman access to services, and their involvement in such initiatives may reduce stigma and facilitate access as well as adherence. Women suggested that peer-support visits from other women, e.g. mothers living with HIV in their homes, to talk with the women of their extended family would be helpful. Indeed, community support and family engagement are documented to support HIV service uptake.[27] [28]

5.5 *Lack of awareness and mistrust of services to prevent new HIV infections among children and keep mothers alive and healthy*

The rapid assessment revealed lack of awareness and distrust of modern medical interventions. Awareness and perception of the quality of formal health and HIV services in general, and services to prevent new HIV infections among children and keep mothers alive and healthy in particular, was identified as a key barrier to services utilization. While knowledge about the benefits of antiretroviral treatment also in relation to prevention of new HIV infections among children was limited, fear of discrimination by health care workers served as a major barrier to services. Some women living with HIV reported suffering from discriminatory, humiliating treatment by health professionals. Such behaviours will not only reduce adherence for the women who experience them but also deter future clients of the services.

Strong belief in traditional treatments further discouraged pregnant women to register at antenatal care facilities and to utilize HIV prevention and treatment services. Many participants expressed a preference for traditional birth attendants and treatments as they were perceived as more supportive, with their services aligned to shared cultural norms and beliefs.

This suggests that sustained efforts to better spread the message regarding the safety and effectiveness of HIV treatment and prevention of new HIV infections among children, as well as improved understanding of traditional approaches to medicine is important. Positive experiences reported through the assessment underline the critical role that networks of women living with HIV have to play in increasing awareness and understanding.

5.6 *Availability and accessibility of services*

An additional issue raised by participants, particularly in rural areas, was related to services that were not available or were considered to be so limited that there was no purpose in even trying to access them. Key problems identified were the distance to health centers that provided services to prevent new HIV infections among children—and for taking care of their own health, the costs involved in traveling and the time foregone. This must be considered in the context of the communities that participated in the assessment, where women's primary role is in the home and often under control of husbands or in-laws, their mobility being thus further limited.

While this system's issue requires a more comprehensive response at the national level, health workers and district leaders may want to interact with community-based women, particularly women living with HIV, and traditional leaders to be updated on challenges faced and to jointly identify potential solutions. Task-shifting, as recommended by the World Health Organization (WHO), can enhance services by helping to reinforce overburdened staff. The engagement of traditional birth attendants in service delivery, as reported through the gender assessment in Uganda, could contribute to increased availability of services to prevent new HIV infections among children and keep mothers alive and healthy, as well as improve its use.

In conclusion, overall the findings indicate that gender- -related barriers pose significant obstacles to the uptake of services to prevent new HIV infections among children and keep mothers alive and healthy and require urgent attention. Without such dedicated attention, current efforts will meet with limited success and the needs and rights of both women and children will remain compromised.

6. Recommendations

The findings of the rapid assessment reveal that a range of gender-related barriers currently hinder the effectiveness and reach of efforts to prevent new HIV infections among children and keep mothers alive and healthy. Overcoming these barriers requires targeted and sustained investment, but offers significant return in investment as through actions to address these barriers it is possible to end new HIV infections among children, while also protecting the rights and health of women living with HIV. Based on the findings and discussions held in the selected sites in Ethiopia, Democratic Republic of Congo, India, Nigeria and Uganda, the following recommendations are proposed to overcome gender-related and cultural barriers to services. The recommendations are closely aligned with best-practice guidelines of the concerned agencies of the UN system, in particular the World Health Organization 2013 *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*. The recommendations are intended to support the scaling up of comprehensive services to prevent new HIV infections among children and keep mothers alive and healthy as part of the continued implementation of the Global Plan at community and country level.

6.1. *Provide correct information on HIV using culturally-appropriate, gender-sensitive and rights-based approaches*

Correct and comprehensive information on HIV provided to communities to overcome the barrier posed by misperceptions of HIV and inaccurate knowledge must be culturally and gender sensitive, while also being rights-based and address prevailing misperceptions in order to be effective. This can be done through conversations and dialogues that explore the culture, gender norms and value systems through which they are constructed and understood, and adjust accordingly the approaches while also ensuring that approaches are evidence-informed. Grass-roots organizations, communities and the civil society at large should be encouraged and supported to lead some of the activities.

6.2. *Address stigma and discrimination against women living with HIV to increase utilization of and adherence to services*

Given the frequency and severity of reported stigma and discrimination against women living with HIV[29] and its consequences in terms of services, addressing stigma and discrimination remains a key strategy to increase utilization of and adherence to services. There is a need for continued awareness creation and sensitization of communities to address stigma and discrimination against women living with HIV. In addition, women living with HIV must be supported to claim their rights, including through literacy training and resourcing networks of women living with HIV. Engaging religious leaders may be a suitable entry point to informed dialogue on HIV-related stigma and discrimination in order to catalyse change.

6.3 *Address violence against women as part of programmes to prevent new HIV infections among children and keep mothers alive and healthy*

Violence against women has been shown to be both a cause and a consequence of HIV and, as the findings of this rapid assessment reveal, can significantly hinder women's access and adherence to services and treatment. Health services can be used as an entry point to identify and counter violence, dealing with the complexities around violence against women and underlying gender inequalities in a non-judgmental manner, while securing confidentiality and respecting the rights of women living with HIV. Referral to appropriate medical, and/or legal counselling and social services should be provided to survivors of violence.

Transforming harmful gender norms is equally important to increase utilization of and adherence to HIV services. This requires community engagement to challenge prevailing gender norms, while leveraging the experiences of and approaches developed by women living with HIV.

6.4 *Support transformation of traditional gender roles related to maternal health*

Gendered roles of men and women related to fertility and childbearing tend to hinder uptake of services. There is need to better understand and challenge those norms to ensure increased utilization of and adherence to services to prevent new HIV infections among children and keep mothers alive and healthy.

Awareness-raising and sensitization of the extended family in reducing stigma, discrimination and violence, as well as in promoting uptake of these services is likely to contribute to transforming such norms. Health services need to be delivered in a culturally and gender sensitive manner, while upholding the rights of women and welcoming supportive male participation. More specifically, opportunities need to be created for voluntary couple attendance, counselling and testing.

6.5 *Address lack of awareness and mistrust of services to prevent new HIV infections among children and keep mothers alive and healthy*

The identified lack of awareness and distrust of modern medical interventions are basic yet essential barriers to services to prevent new HIV infections among children and keep mothers alive and healthy. Service provision must be rights based, non-judgemental and confidential, with health care providers sensitized on the linkage between cultural practices and gender inequality and the rights of women. Dissemination of evidence-based information about services and treatment must go beyond the individual client-health care provider contact and reach out to communities, as part of decentralized approaches and awareness campaigns. Both women living with HIV and traditional birth attendants must be engaged in community mobilization efforts, for consistency in messaging and utilization of expertise.

7. Conclusion

The findings of this rapid assessment indicate that the gender-related barriers to prevention of new HIV infections among children and keeping mothers alive and healthy are complex and include cultural perceptions of HIV and gender norms that increase stigma and women's vulnerability. It is clear that effective investments in prevention of new HIV infections among children need to be accompanied by investment in gender- and culture-transformative approaches in order to overcome barriers to uptake of services. Systematically assessing and addressing gender and cultural issues, as detailed in the recommendations above can significantly contribute to the goal of eliminating new HIV infections among children by 2015 and keeping their mothers alive.

Policy makers responsible for guiding resource allocation in HIV responses at the global and national level should take note and ensure that adequate resources are invested in identifying and overcoming gender barriers. The development of concept notes and investment cases for Global Fund financing provide an excellent opportunity to enable that.

The rapid assessment provides a clear example of the importance and the power of engaging women living with and affected by HIV. The rapid assessment teams—which all included activists of women living with HIV—clearly demonstrated the capacities of these empowered women to talk to their peers, to counsel and bring out their stories in a very sensitive and supportive way. This principle should be reinforced at every opportunity.

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