Prevention of mother-to-child transmission (PMTCT) of HIV

KEY POINTS:

- Prevention of mother-to-child transmission (PMTCT) programmes provide antiretroviral treatment (ART) to HIV-positive pregnant women to stop their infants from acquiring the virus.
- PMTCT services should also continue after an infant has been born - although this remains a major challenge to programmes - with early infant diagnosis at four to six weeks after birth and ART initiation within the first 12 weeks for HIV-exposed infants.
- PMTCT services, where implemented, are effective. Around 1.6 million new HIV infections among children have been prevented as a result of these programmes since 1995.

HIV can be transmitted from an HIV-positive woman to her child during pregnancy, childbirth and breastfeeding. Mother-to-child transmission (MTCT), which is also referred to as ‘vertical transmission’, accounts for the vast majority of new infections in children.

Prevention of mother-to-child transmission (PMTCT) programmes provide antiretroviral treatment (ART) to HIV-positive pregnant women to stop their infants from acquiring the virus.

Without treatment, the likelihood of HIV passing from mother-to-child is 15% to 45%. However, ART and other effective PMTCT interventions can reduce this risk to below 5%.1
Around 1.6 million new HIV infections among children have been prevented since 1995 due to the implementation of PMTCT services. Of these, 1.3 million are estimated to have been averted in the five years, between 2010 and 2015.2

Despite this significant progress, in 2015 23% of pregnant women living with HIV did not have access to ARVs and 150,000 children (400 children a day) became infected with HIV.3

A comprehensive approach to PMTCT

Effective PMTCT programmes require women and their infants to have access to - and to take up - a cascade of interventions including antenatal services and HIV testing during pregnancy; use of ART by pregnant women living with HIV; safe childbirth practices and appropriate infant feeding; uptake of infant HIV testing and other post-natal healthcare services.4

The World Health Organization (WHO) promotes a comprehensive approach to PMTCT programmes which includes:

- preventing new HIV infections among women of childbearing age
- preventing unintended pregnancies among women living with HIV
- preventing HIV transmission from a woman living with HIV to her baby
- providing appropriate treatment, care and support to mothers living with HIV and their children and families.5

World Health Organization PMTCT guidelines

Guidelines for pregnant and breastfeeding women living with HIV
WHO’s 2013 guidelines recommended that a woman living with HIV only continue on ART after breastfeeding if it would benefit her own health. However, in September 2015 the WHO released new guidelines recommending that all pregnant women living with HIV be immediately provided with lifelong treatment, regardless of CD4 count (which indicates the level of HIV in the body). This approach is called Option B+.7

By 2015, the implementation of Option B+ had resulted in 91% of the 1.1 million women receiving ARVs as part of PMTCT services being offered lifelong ART.8
In resource-poor settings, when formula feeding is not a viable option, the WHO advises women living with HIV to exclusively breastfeed (rather than mixed feeding), providing that they are on ART. This is because, while formula feeding offers the safest option for postnatal HIV prevention, in resource poor settings it is not always easy for families to afford formula or access things such as clean water which are needed for it use.

**Guidelines for HIV-exposed infants**

If an HIV-exposed infant is given ART within the first 12 weeks of life, they are 75% less likely to die from an AIDS related illness.

This is one of the reasons that WHO recommends that infants born to mothers living with HIV are tested between four and six weeks old. This is often referred to as ‘early infant diagnosis’.

The WHO further recommends that another HIV test is carried out at 18 months and/or when breastfeeding ends to provide the final infant diagnosis.

According to WHO guidelines, all infants who test positive for HIV should be immediately initiated on treatment. The treatment should be linked to the mother’s course of ARVs and would vary according to the infant feeding method as follows:

- breastfeeding - the infant should receive once-daily nevirapine from birth for six weeks
- replacement feeding - the infant should receive once-daily nevirapine (or twice-daily zidovudine) from birth for four to six weeks.

**Global PMTCT targets**

In 2011, a Global Plan was launched to reduce the number of new HIV infections via mother-to-child transmission by 90% by 2015.

The WHO identified 22 priority countries, with the top 10 (Angola, Botswana, Burundi, Cameroon, Chad, Côte d’Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana and India) accounting for 75% of the global PMTCT service need.

It was estimated that the effective scaling up of interventions in these countries would prevent over 250,000 new infections annually.

**Progress in the prevention of mother-to-child transmission**

**Progress among pregnant and breastfeeding women**

The proportion of pregnant women living with HIV receiving ART more than doubled in 21 of the 22 Global Plan priority countries, from 36% in 2009 to 80% in 2015. Perhaps more importantly, 93% of pregnant women receiving treatment, were receiving lifelong treatment, up significantly from 73% in 2014. India does not feature in the latest data.

In 2015, six priority countries (Botswana, Mozambique, Namibia, South Africa, Swaziland and Uganda) met the Global Plan target of reducing mother-to-child transmission by 90%.

Outside of the priority countries, in mid-2015, Cuba became the first country to eliminate the mother-to-child transmission of HIV. In 2016, Belarus and Armenia achieved the same feat while
Thailand became the first country in the Asia and Pacific region to eliminate MTCT. As PMTCT is not 100% effective, elimination is defined as a reduction of transmission to such low levels (below 5%) that it no longer constitutes a public health problem.

CASE STUDY: The Community Health Alliance Uganda

For two months in 2016, a promising pilot programme, led by the grass-roots alliance at a government facility, supported pregnant and breastfeeding women living with HIV by funding transport to clinics and recruiting and training volunteers. The recruits came from the local association of people living with HIV, who were trained to provide counselling, create awareness campaigns and encourage action.

Some of the women had to walk miles when they were able to attend their nearest ART clinic, often leading to late administration of their drugs. The initiative saw a surge in the number of clinic visits and ART enrollments by pregnant and breastfeeding women, as well as helping to address stigma and increase trust between sexual partners, family planning, female condom use and male circumcision.

Many point to the implementation of Option B+ as a major reason behind coverage progress. By the end of 2015, all priority countries except Nigeria had rolled out Option B+. Consequently, AIDS-related deaths among women of reproductive age in the Global Plan countries declined by 43% between 2009 and 2015.

Another target of the Global Plan was to reduce the MTCT rate to 5% or less among breastfeeding women, and to 2% or less among non-breastfeeding women. Together, the 21 Global Plan countries reduced the MTCT rate among breastfeeding women from 22.4% to 8.9% between 2009 and 2015. Four countries (South Africa, Uganda, Swaziland and Namibia), achieved the 5% milestone. Botswana, the only non-breastfeeding Global Plan priority country, has a transmission rate of 2.6% - just above the threshold of 2%.

However, the number of pregnant women testing for HIV is still relatively low. In 2013, an estimated 54% of pregnant women were not tested for HIV. There has also been little change in the rate of new HIV infections among women.

The Global Plan aimed to reduce the number of new infections among women of reproductive age by 50%, but they declined by just 5% between 2009 and 2015. As a result, an additional 5.2 million women of reproductive age were newly infected with HIV between 2010 and 2015.

There has been some progress in preventing unintended pregnancies in countries with high HIV prevalence. Unintended pregnancies declined by more than 10% in Ethiopia, Kenya, Lesotho, Malawi and Rwanda between 2000–2004 and 2010–2014.

Progress among children

Between 2009 and the end of 2015, there was a 60% decline in new HIV infections among children in the Global Plan priority countries, from 270,000 to 110,000. This compares to a fall of just 24% between 2000 and 2008, meaning that the rate of the decline in new infections since the launch of the Global Plan nearly tripled. Without Nigeria, the remaining countries reduced new HIV infections by 69%.

While this progress is encouraging, it is significantly below the 90% target. However, some countries got close to this target including Uganda (86%), South Africa and Burundi (both 84%). Botswana, Burundi, Namibia and Swaziland had fewer than 1,000 new infections in 2015. These are
small enough numbers that, with determined efforts, could be reduced dramatically.30

At the other end of the scale, Angola and Cote d’Ivoire have experienced less than a 40% decline in new HIV infections among children since 2009.31

**East and Southern Africa** is the region to have made the most significant progress on mother to child transmission (MTCT). In 2015, 6% of infants born to mothers living with HIV acquired HIV, compared to 18% in 2010, this is a threefold decline.32

Although West and Central Africa has seen a 31% reduction in new child HIV infections between 2010 and 2015 it has made less progress than East and Southern Africa.33 In Nigeria, new child HIV infections have declined by just 21% between 2009 and 2015. In 2015, an estimated 41,000 children became infected with HIV in the country, the same number as the next eight countries combined.34

In 2015, nearly one third of pregnant women living with HIV in the Middle East and North Africa passed the virus on to their infant, meaning it is the region that has made the least amount of progress.35

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### Barriers to the uptake of PMTCT programmes

As well as the scale-up of PMTCT, a number of barriers need to be overcome in order to increase access to these services.

#### Knowledge about HIV, MTCT and PMTCT

A number of studies have identified the link between knowledge of HIV, MTCT and PMTCT and uptake of PMTCT services.

For example, research from Togo reported a 92% HIV testing uptake among participants where:

- 77% of pregnant women agreed that unprotected sex increased the risk of HIV transmission
61% recognised that the risk of HIV transmission to their child was higher for mixed breastfeeding than for exclusive breastfeeding.\textsuperscript{36}

A study of more than 10,000 women in Tanzania found that only 46% of respondents had an adequate knowledge on MTCT and PMTCT. Factors associated with having adequate knowledge were experiencing at least one pregnancy, higher education levels, higher household wealth, living in an urban area, being exposed to HIV education, having taken an HIV test or knowing where to get tested for HIV. Women living with HIV were more likely to have adequate knowledge of MTCT than women who were HIV negative (56% compared to 46%).\textsuperscript{37}

Conversely, other studies have associated high levels of HIV, MTCT and PMTCT knowledge with lower acceptability of PMTCT.

One study from south west Nigeria recorded that, while 99.8% of pregnant women were aware of HIV and had very high knowledge of MTCT (92%) and PMTCT (91%), 71% had negative views towards PMTCT. This was due to factors such as stigma and discrimination.\textsuperscript{38}

**Knowledge of HIV status**

Knowledge of HIV status is vital in order for pregnant women to access the appropriate treatment and care for themselves and their infants.\textsuperscript{39}

The traditional model for HIV testing is Voluntary Counselling and Testing (VCT) also known as the 'opt in' method, in which people take initiative in asking for an HIV test. Whereas, increasingly, PMTCT services are adopting an 'opt out' strategy, also known as Physician or Provider Initiated Testing and Counselling (PITC), which means that women have to actively opt out or decline an HIV test after being given information and counselling about it.\textsuperscript{40}

A study was carried out to determine the perception about 'opt out' HIV testing among 500 pregnant women attending the antenatal clinic at Adeoyo Maternity Hospital, Ibadan in Nigeria. Almost all (97%) respondents had done an HIV test and received the results due to the 'opt out' approach.\textsuperscript{41}

Slightly less than half (48%) mentioned the hospital as the first source of information about HIV. However, knowledge of HIV and PMTCT was high among the vast majority of women (95%), which the study partly attributes to the information and counselling session that all respondents had attended before testing.\textsuperscript{42}

Some women in the study reported testing because they feared they would be suspected of being HIV positive should they decline. Others thought they might be denied antenatal care (ANC) if they refused testing. This brings to question the voluntariness of the 'opt out' strategy as about a fifth of the study participants felt that they were forced to have an HIV test.\textsuperscript{43}

Not knowing one's HIV status acts as a barrier to PMTCT services. The point at which women are tested for HIV can also impact on their journey through PMTCT, should they test positive. For example, a study of pregnant women living with HIV from Cameroon, Cote d'Ivoire, South Africa, and Zambia found women who were diagnosed with HIV before their pregnancy were more likely to adhere to PMTCT treatment than women who tested positive during pregnancy.\textsuperscript{44}

**Confusion over exclusive breastfeeding**

The fact that formula feeding can be difficult to achieve in resource poor settings, coupled with breastfeeding’s recorded benefits for preventing malnutrition and serious infectious diseases\textsuperscript{45},
has resulted in exclusive breastfeeding being recommended by WHO for women living with HIV in resource poor settings provided they have access to ART. Formula feeding is recommended for women living with HIV in countries in high resource settings.46

The fact that advice for women is different in low and high resource settings has led to a certain amount of confusion about the best approach to breastfeeding for women living with HIV.47

One study from Malawi reported that while the majority of mothers chose to exclusively breastfeed because "that’s the advice they give to HIV-positive women", most mothers reported mixed feeding in the first six months. A number of reasons were given for this including traditional feeding practices, a poor understanding of what exclusive breastfeeding involves, as well as poor communication about why women should exclusively breastfeed.48

Research from Tanzania compared two hospitals that offered different infant feeding options. Hospital A promoted exclusive breastfeeding as the only infant feeding option, while hospital B followed Tanzanian PMTCT infant feeding guidelines which promote patient choice. Women in hospital A trusted the advice given and were confident in their ability to exclusively breastfeed, whereas women in hospital B expressed confusion and uncertainty about how to best feed their infants.49

We were given the drugs to protect the baby from HIV infection but it can also happen that the baby may have already been born with HIV and then you breastfeed him. Again if he is not found with HIV, he may have it in future. So I start to think that I should just stop breastfeeding and start formula feeding.

- new mother who is living with HIV from Lusaka, Zambia50

Crucially, greater adherence during the breastfeeding period is needed to reduce the risk of MTCT of HIV. For example, in 2013 around half (49%) of women living with HIV continued to take ARVs while breastfeeding, compared to 62% of women who took ARVs during pregnancy and delivery.51

**HIV stigma, discrimination and PMTCT**

A body of research has highlighted how HIV-related stigma and discrimination affect a pregnant woman's decision to enrol on PMTCT programmes and interrupt adherence to treatment and retention in care.52

It has been estimated that over 50% of vertical HIV transmissions from mother-to-child globally can be attributed to the cumulative effect of stigma.53

A systematic review of studies on PMTCT in Cameroon, Côte d’Ivoire, Ethiopia, Kenya, Lesotho, Malawi, Rwanda, South Africa, Tanzania, Uganda, Zambia, Zimbabwe found HIV-related stigma impeded access to ARVs for mothers living with HIV.54

At the individual level, psychological difficulties following an HIV diagnosis were common among mothers and hindered ARV uptake. These included shock, denial of disease, depression, or fear of handling side effects and a lifelong commitment to treatment.55

Family and community-level barriers most frequently identified in the review were HIV-related
stigma and fear of disclosing status to partners and family members. These factors deterred women from attending HIV/PMTCT clinics to receive ARV drugs for themselves and their infants, or from starting or continuing to take treatment. Lack of partner support was also a major hindrance, and women anticipated or experienced negative reactions from partners, including violence and separation, after sharing their HIV test results.56

A study in England partnered six ‘Mentor Mothers’ with six mothers, all of whom were living with HIV. Some said they had been sneered at and called “dirty”, found themselves at the centre of gossip or felt that their condition had been “swept under the carpet”, leaving them fearful of even looking at information on HIV. They strove to hide their HIV status in order to avoid the stigma they sensed within diaspora African communities.

My immediate family...I don’t want [them] to go, ‘Oh, she’s got this thing, she’s going to die.

- Participant, Mentor Mother project, 2016.57

Trained peer support from their fellow mothers proved a powerful way of addressing many of their challenges, including fears and feelings of isolation, gaps in maternity care and emotional wellbeing.

CASE STUDY: Karnataka, India

In Karnataka – one of six high HIV prevalence states in India – stigma from multiple sources has provided a notable barrier to HIV-infected pregnant women accessing parent-to-child HIV transmission services.

Self-stigma was a significant issue for the women questioned in one study:58 they were observed to have judged themselves for “not fulfilling traditional gender roles of wife and mother.” They spoke of their fears about transmitting HIV during delivery and through contact with their children, balancing their desire to breastfeed, according to their beliefs and those of their community and family, against their fears of transmission.

Many of the women judged themselves for being widowed or separated from their husbands in a traditional Indian society where “being a wife and mother is of paramount importance.”59

Stigma in healthcare settings

I know of a woman living with HIV who went to [an] antenatal [clinic and] at the point of delivery, [the doctor] went through the files and when he saw her file he said ‘This one, [I] am not touching her.’ She was on the stretcher already and [was] in labour. He said, ‘It’s a positive case... I didn’t leave my house to
come and do a positive case today. I am not prepared.’ The woman was left on the stretcher.

-A woman living with HIV from Nigeria

For women living with HIV, experiences of stigma, discrimination, and abuse often occur when they seek maternal healthcare. This can take many forms including physical abuse, non-consented clinical care, non-confidential care, non-dignified care, abandonment or denial of care, and detention in facilities.

For example, the International Community of Women Living With HIV reports how pregnant women living with HIV have experienced service providers using extra gloves or bleach when dealing with them and asking women to not come close to them, touch things, and cover their mouths while talking. This discrimination and fear leads many women to avoid going to hospitals and thereby accessing PMTCT services.

"Many health workers don’t have the necessary skill and equipment to confidently handle delivery for an HIV positive woman and given the risk of accidental exposure, most nurses shy away from dealing with such patients."  

In more serious cases, women report direct abuse from healthcare workers. An HIV-positive woman from Mexico reported an interaction with her doctor:

How can you even think about getting pregnant knowing that you will kill your child because you’re positive?!!!’ He threatened not to see me again if I got pregnant. He told me that I was ‘irresponsible’, a bad mother, and that I was certainly running around infecting other people.

In various countries, women living with HIV report being sterilised during delivery via caesarean section with health providers giving PMTCT as the reason. They routinely report being asked to sign papers or verbally consent to sterilisation while in labour, or health care workers obtaining consent for the procedure from their husbands or fathers at this stage. Many women report being unaware they have been sterilised until they try to have another child.

During the caesarean and under the effects of the anaesthesia they forced her into sterilization so that she couldn’t have more children. She didn’t sign a consent. When she was recovering
from the anaesthesia, she saw that her finger was stained with ink.

-A woman living with HIV from Mexico, describing another woman’s experiences.

Country and clinic resources

In resource-poor settings, shortages of PMTCT staff, interruptions in treatment and supplies of medical equipment, as well as a shortfall in counselling services, all act as barriers to PMTCT services.

These factors often mean long waiting times for post-test counselling and many leave without getting their HIV test results.

Poor monitoring of PMTCT services by healthcare workers also leads to poor retention in care. Research from Ethiopia reported poor follow-up rates in the PMTCT programme because healthcare facilities did not have registered information on HIV-positive mothers.

A study on the provision of reproductive health services including PMTCT services in a primary healthcare setting in Tshwane, South Africa found patient overcrowding and long waiting times all hampered people’s access to services. The factors leading to long waiting times were staff shortages and an increase in clients as people moved to the area.

Early infant diagnosis

Early infant diagnosis (diagnosing and treating HIV-exposed and -positive babies) remains a major hurdle for PMTCT programmes. One barrier to successful early infant diagnosis is the waiting time for test results. Normally a sample would be taken at a healthcare facility and sent to a lab. It may take weeks or even months for results to come back, particularly in resource-poor settings.

Whatever the result, the mother must be contacted for follow-up – to start treatment if the result is positive and, if the result is negative, to ensure continued support with her own HIV treatment, especially during breastfeeding, and a follow-up test for the child at a later date.

This complex and prolonged treatment cascade creates many opportunities for loss to follow-up. To prevent this, the importance of early infant diagnosis must be understood by both healthcare providers and mothers or caregivers. Moreover, healthcare workers must know the protocols for providing the service, and have the drugs and supplies in place to do so.

The fact that in many places HIV treatment for mothers and babies is followed up separately, rather than as a pair, presents another barrier to successful early infant diagnosis.

Point-of-care testing has the potential of helping to overcome the problems associated with the time gap between test and result. Point-of-care technology makes it possible to test infants on-site and receive the results within hours. This means that HIV-positive infants can begin ART immediately which reduces the risk of loss to follow-up.

CASE STUDY: Point of care testing in Mozambique

A large, randomised study in Mozambique found infant HIV point-of-care tests significantly improved retention in care and ART initiation.

The study found that, whereas all of the results gained through point-of-care testing were
made available at the health facility, 19% of the results from tests gained through standard lab testing failed to be returned to the facility. Similarly, 99.5% of point-of-care results were provided to the infant’s caregiver, compared to 65% of the standard test results. In addition, only 7.2% of the results of standard care tests reached the caregiver within two months of testing, and only 47.2% within six months of testing.

The study found that infants receiving point-of-care tests were seven times more likely to start ART within two months than those receiving standard tests. While 89.7% of infants who tested positive on a point-of-care test had started treatment within two months of diagnosis, only 12.8% of those tested by the standard method had started treatment. Six months after testing, infants in the point-of-care arm of the study were still around two-and-a-half times more likely to be on treatment than those tested using standard testing methods.

**Option B+ challenges**

Though the implementation of Option B+ has been attributed to progress in PMTCT coverage, for some, the immediacy of treatment initiation is a challenge.

A study from Lilongwe, Malawi, noted that some participants needed time, whether it was for discussing their status with their partner or personally accepting their HIV status:

I couldn’t accept them [ART] for the reason of my partner...The child’s father, I can say we could have problems...I was scared that he would be mad and also our marriage could be jeopardized.

I wanted my relatives to know about my status, I can’t just receive the drugs and take them home while I came here for antenatal services, they would be surprised....

Side effects were the most commonly reported barrier to adherence and were found to be more significant barriers compared to previous studies on barriers in non-B+ contexts. Another study from the same country revealed that women who started treatment in the context of B+ were five times more likely to be lost to follow-up compared to those who started treatment for their own health.

Evaluations of the roll out of option B+ and the challenges faced when implementing this strategy could hold valuable lessons to inform the ‘test and treat’ strategy, where people are offered immediate initiation onto ART if they test positive for HIV, now being rolled out globally.

**Cultural beliefs and gender dynamics**

In many settings, traditional gender roles and cultural beliefs mean that men often make decisions determining women’s participation in HIV testing. For example, according to recent Demographic and Health Surveys in Senegal, Niger, Burkina Faso, Côte d'Ivoire and Cameroon,
80% of married 15-19 year-old women do not have the final say on their own healthcare.79

In many communities in sub-Saharan Africa, pregnancy is viewed as a 'woman's affair', with a man's role primarily to provide financial support. Even where men view accompanying their partner to antenatal clinics or PMTCT services as good practice, many still feel their main role is to provide financing for registration and delivery fees.80

Men also report negative attitudes from community members when escorting their spouses to antenatal clinics. One report from Uganda stated:

Because of cultural beliefs, most men do not like to accompany their wives to the antenatal clinics. Men who accompany their wives to ANC are perceived to be weaklings by their peers. 81

Male involvement

Generally, research has highlighted the beneficial impact of male involvement in programmes to prevent the mother-to-child transmission of HIV to tackle new infections among infants.82

A 2015 study of couples in Midlands province, Zimbabwe looked at the factors associated with male involvement in PMTCT.

It found men from couples who had previously experienced HIV testing and counselling (HTC) were more likely to be involved in PMTCT. This implies that promoting HTC in all other HTC entry points might enhance male involvement in PMTCT. Having time to visit the clinic with his partner also meant a man was more likely to be involved in PMTCT.83

Health workers’ friendliness towards male partners was significantly associated with male involvement in PMTCT. The study found that those men who were made to feel needed and an important part of the pregnancy by health workers when they accompanied their wives for ANC were more likely to become involved in PMTCT.84

Being afraid of knowing one’s HIV status was associated with male partners being less likely to be involved in PMTCT. About 45 % of the male partners interviewed in the study reported that they engaged in extra marital affairs. The majority of these men refused to accompany their wives for PMTCT due to the fear of knowing their HIV status, which might result in stigma, discrimination, domestic violence or abandonment by their wife if positive. Three quarters of respondents also highlighted how fear of HIV test results was the main barrier to male involvement in PMTCT. Men who perceived themselves at risk of HIV were therefore more likely to refuse to go for couple HTC. This implies the need for more HIV educational and behaviour change communication programmes for male partners in order to address issues to do with the benefits of knowing one’s HIV status.85

Inviting men to use voluntary HTC services, offering PMTCT services at sites other than ANC ones (such as bars, churches and workplaces), as well as prior knowledge of HIV and HIV testing facilities have all been identified as ways of increasing male involvement.86

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