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# The Prevention of Parent-to-child Transmission Programme: Is it fair to women?

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In February 2014, the Government of India launched a multi-antiretroviral drug regimen to treat infected women and infants in efforts to reduce parent-to-child transmission (PTCT) of the human immunodeficiency virus (HIV) (1). The announcement has been long awaited because the multidrug regimen can reduce the risk of transmission during childbirth from 30%–35% to less than 2% with replacement feeding (2). Multidrug regimens to prevent PTCT have been used in high-income countries since the 1990s and in many low- and middle-income countries (LMICs) since 2010, when the World Health Organisation (WHO) removed the single-dose nevirapine (SdNVP) regimen from its list of recommended treatments. However, until now, India has been one of the few countries where infected pregnant women and their infants received the SdNVP, which reduces the risk of transmission to 16% in combination with breastfeeding, and to 11% in combination with replacement feeding. Meanwhile, new recommendations from the WHO suggest that for maximum efficiency, antiretroviral therapy (ART) should be given to all HIV-positive pregnant women irrespective of their CD4 counts (3). However, India will initiate the multidrug regimen among women with CD4 count  $\leq 350$  cells/mm<sup>3</sup> as per the recommendations of 2010 (4).

This delay in switching to a multidrug regimen has been ascribed to the need to strengthen infrastructural and human capacity to handle the clinical and monitoring requirements of CD4 counts and treatment adherence involved in this regimen for women and infants (5). Unlike the SdNVP regimen, the multidrug regimen is initiated in HIV-positive women 14 weeks after conception and is continued until after the woman has stopped breastfeeding. Infants are recommended the one daily dose of NVP for about six weeks after birth.

As effective as the multi-drug regimen is in preventing transmission from infected women to infants, the switch does not address the important aspect of preventing infection in women in the first place. This should be an integral component of the programme's design and is the most effective way to ensure zero risk to infants, while protecting the mothers as well. We examine the impact of the Prevention of Parent to Child Transmission programme on women in India, especially because it is the only initiative in the country that targets women outside sex work for HIV prevention and care. We locate our discussion in the wider context of the subjugation of women's autonomy and well-being in national health policies and practices related to population and reproductive health.

Women account for 39% of all infected people in India but the overwhelming majority – over 90% – have been infected after

marriage by husbands with a history of unsafe pre-marital or extra-marital sex and/or injecting drug use (7). Most often, the infection occurs early in the marriage but is usually identified only when the woman seeks antenatal care during pregnancy. In many cases, husbands too become aware of their HIV status only after the wife has tested positive (8). Thus, for most women marriage is the only risk factor (9). However, in stark contrast to the attention paid to preventing mother-to-child transmission, the issue of preventing husband-to-wife transmission still remains unaddressed, and women continue to be at risk. We draw attention to the ways in which women's bodies are used to meet national and international goals to prevent mother-to-child transmission while their rights to autonomy and HIV prevention are overlooked, and the role of men in preventing transmission to women is ignored.

### **The PPTCT programme in India**

The PPTCT programme was initiated in India in December 2001 following the commitment by member states of the United Nations to halve the proportion of infants acquiring HIV from infected mothers by 2010 (10). A feasibility study in six high-prevalence states in India – Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu – had shown that a combination of interventions, including counselling and HIV testing for pregnant women and treatment for infected women and exposed infants with the SdNVP regimen, could substantially reduce the risk of transmission to infants during childbirth (11). In 2009, UN agencies committed to further reduction of transmission to infants to less than 5% by 2015. Since that time India has rapidly scaled up the programme. Between 2009 and 2012, the numbers of public and private healthcare facilities implementing the programme almost doubled – from 6480 to 12,897 – while the numbers of pregnant women covered by the programme rose steadily to 8.5 million in 2011–2012 against a target of 9.0 million (12). The programme has been supported by the Global Fund since 2004, but it also draws heavily upon the existing healthcare delivery system for space, staff, and other resources (13).

Except for replacing the term “mother” with “parent,” acknowledging the role of the father in infecting the child (14), the design of the PPTCT programme is similar to the global programme to prevent mother-to-child transmission (PMTCT). There are four components to address HIV prevention and care needs for women and children: (i) preventing infection among young women, (ii) preventing unintended pregnancies among uninfected women, (iii) preventing transmission from an infected woman to her infant during labour, delivery, and breastfeeding, and (iv) ongoing treatment and support for infected women, children, and families.

The entry point to the programme is counselling and testing for pregnant women with their informed consent. Although this excludes women who may not become pregnant or older women who have completed their desired fertility, these women are meant to be covered by the prevention and care programmes for the general population. The emphasis on informed consent is to promote women's reproductive autonomy and to protect them from the risk of stigma and discrimination associated with a positive result (14). Before the test, women must receive basic information about HIV, the benefits of testing including reducing chances of transmission to infants, risks such as discrimination associated with a positive result, and their right to refuse the test without loss of access to services not dependent upon knowledge of HIV status. Women must explicitly agree to the test before it can be administered (12). Post-test, uninfected women must be counselled to remain HIV-negative. Women testing positive must receive ongoing counselling and support to cope with the infection, register for ART for their own healthcare needs, and for institutional delivery.

A review of official reports and other empirical evidence of the programme shows that, despite its comprehensive design and policy commitments to women's autonomy, most of the evidence is on testing and NVP treatment for women and infants. There is very little evidence on aspects related to HIV prevention for women, informed consent of women in antenatal testing, and ongoing care for infected women. For example, the annual reports of the National AIDS Control Organisation (NACO) list programme related data under only three heads: numbers of pregnant women undergoing the HIV test, numbers of women testing positive, and numbers of infected mother-baby pairs receiving NVP prophylaxis (13). Ongoing care for infected children is reported separately. The focus on counseling and testing is also reflected in empirical research on the provision and utilisation of services on the programme. Similarly, a systematic review of research related to the PPTCT program in India showed that only about 15% of the empirical literature was related to provision and utilisation of services, with the majority (60%) discussing the issue of counseling and testing for women (15). Not a single study included in the review evaluated services related to primary prevention, prevention of unintended pregnancies, or ongoing treatment and care for women (15).

### **Informed consent in antenatal HIV testing**

Most studies on counseling and testing report high acceptability of antenatal testing among women. However there is less evidence that test acceptance is accompanied by the informed consent of the women. Only 3.2% of the women in one study in Tamil Nadu reported receiving information about their right to refuse the test, while 15% reported receiving information about the risks of not testing such as loss of access to care (8). Providers also threatened to stop welfare benefits to which the woman was entitled if she did not accept the test. Women who left the healthcare facility without testing were followed up in their homes

to “persuade” them to complete the test (8).

The paucity of evidence about informed consent of women coupled with very high test acceptance rates, especially in some states, such as Tamil Nadu where rates have consistently exceeded 95%, leads to the suspicion that (unofficial) targets have been set for test acceptance by women. Reports by providers about threats of transfer and/or loss of increments in case of failure to meet targets substantiate this suspicion (16).

Paradoxically, the programme’s focus on testing and treatment did not stop children from becoming infected thanks to the suboptimal ARV prophylaxis used and the relative lack of exclusive replacement feeding practices. Indian studies have estimated the risk of transmission with the SdNVP regimen to be between 19.8% and 5.55% with and without breastfeeding (17–18). With more infected women choosing to continue breastfeeding though not exclusively (19), the risk of transmission to infants is not completely eliminated.

### **Preventing HIV infection among young women**

The first component of the PPTCT programme is to prevent HIV infection among women because it is the most effective way of ensuring that infants have zero risk of becoming infected. Antenatal HIV prevalence is very low and the overwhelming majority of women will test negative for HIV. Because the entry point to the programme is counselling and testing, post-test counselling becomes the most important opportunity to discuss ways in which women who test negative can continue to remain uninfected. But other than giving women information about their negative test result, there is no evidence of interventions with them and their husbands to discuss continued protection from HIV. Once women have completed the test, the programme focuses all resources on the relatively small number of women who test positive to help prevent transmission to the infant, thus losing a golden opportunity to promote primary prevention for women testing negative.

For example in 2011–2012, of the 7.8 million women tested in the programme 13,213 tested positive, and most received counselling and ARV prophylaxis (20). But the 7.78 million women who tested negative are unlikely to have received any intervention to help them remain negative; and will continue to be at risk of acquiring HIV even after being covered by the PPTCT programme. One study in Tamil Nadu showed that 14% of women who tested negative had sero-converted by the next pregnancy (21). Another study from south India showed that a substantial amount of unprotected sexual activity took place within married couples even with knowledge of HIV infection of one partner, usually the man, who was more likely to transmit it to the wife (22).

The fundamental problem with HIV prevention programmes for the general population is that they are designed for men, not women. For example, all prevention messages advocate monogamy as the safest option to protect against sexual transmission of HIV and (male) condom use where monogamy is not practised. Both these messages are inapplicable for most young women in India because they are in monogamous relationships with their husbands and yet at risk for HIV (9). Moreover, women themselves cannot use condoms and are unlikely to be able to negotiate condom use with husbands for at least two reasons. The condom has been promoted largely as a prevention resource in casual/multi-partner sexual encounters, ie sex outside marriage. This is reflected by the evidence from Tamil Nadu showing a condom use rate of 92.6% in commercial sex as compared to 2.3% within marriage (23–24). The association of the condom with illicit sex inhibits women from discussing its use with husbands for fear that they will be suspected of infidelity or of accusing the man of infidelity, both of which can lead to violence and/or desertion by the husband.

More importantly, a large part of a woman’s value in Indian society is associated with her fertility and most family and community norms dictate that women should bear a child within a year or two of marriage (25). Those who fail to become pregnant within this time risk being stigmatised as “barren” and being set aside for another woman by their husbands. This contributes to the lack of contraceptive use among couples, at least until the first pregnancy (8).

There are several women-specific prevention options that can be considered to protect women as well as children. The female condom has been found to be more than 99% effective and is something that women can control. However, this has only been tested among sex workers in India and is not being considered for other women. A more effective intervention is pre-marital testing for men and provision of ongoing ART for infected men. Early ART for infected men reduces the efficiency of transmission (26). The logic for this intervention would be very similar to the testing and treatment of women to prevent transmission to infants. However, this is not currently under consideration.

### **Preventing unintended pregnancies among infected women**

Preventing unintended pregnancies among infected women appears to receive even less attention than HIV prevention for women. Unintended pregnancies include those that are unwanted as well as those that are mistimed (27). In India, the total unmet need for family planning in the general population is estimated at 12.8% (20). The figure may be higher for infected women because of fears for their own health and lack of family support. Services to prevent unintended pregnancies include

contraception to prevent conception as well as medical termination of pregnancies (MTP). However, the only contraceptive method promoted for pregnant women is the male condom, which is difficult for women to use as discussed earlier. We have not been able to find any mention of improved access to MTP services for HIV-positive pregnant women either in the counselling guidelines or on the document on women's empowerment, where one may expect to find this evidence (28,29). On the contrary, studies in Tamil Nadu show that women who become pregnant after knowing they have HIV and want to terminate the pregnancy are usually discouraged by providers, usually due to fear of infection (8,30).

### **Ongoing treatment, care and support for infected women**

A major justification for the programme is that it helps infected women and children to access ongoing treatment, and helps with psychological support. However, this support can be patchy and depends on availability of drugs and equipment. For example, between January 2010 and September 2010, only 60.3% of women identified with HIV nationally and 72.5% identified in Tamil Nadu underwent CD4 testing, necessary to initiate ART (31). Although the number of people receiving ongoing treatment has risen, there is no disaggregated data to show the proportion of infected women who receive treatment for their own health.

The lack of confidentiality within the programme also harms women in several ways. For example, providers follow a system of line-listing whereby the names and addresses of infected women in a particular district are available to all service providers on the programme in the district. This is meant to help outreach workers to track women for institutional delivery and provide ongoing treatment if they do not keep scheduled appointments. In addition to the possibility of breach of confidentiality by providers, the visits by outreach workers can lead to speculation about the woman's HIV status and expose her to stigma and discrimination within the community.

Although infected women in India receive more support in the community because they are acknowledged to be the victims of their husbands' improper behaviours (30), they report disproportionate levels of abuse and discrimination within families and healthcare facilities as compared to infected men, probably because HIV is closely associated with moral impropriety and women's bodies are viewed as its source. In Tamil Nadu, for instance, the vernacular term for any sexually transmitted infection is *pombalai vyaathi* (women's disease). They may be blamed for bringing the infection home, face violence and/or desertion by husbands and rejection by family members who often force them to return to their natal home after the death of the husband. Many widows are also unaware of their right to their husband's property, and often have little knowledge and resources to claim them (32). Stigma and discrimination against women at healthcare facilities take the form of verbal and physical abuse, reluctance to touch, treatment delays, and denial of care. In Tamil Nadu, 97% of infected women in one study reported stigmatisation by physicians and other healthcare workers, and 50% said they would not return to the facility for ongoing care (33).

### **Conclusion**

The PPTCT programme continues the legacy of target-based approaches in the country's reproductive health programmes of the past. Women continue to be used instrumentally to prevent transmission of HIV infection to the child. The programme seems to systematically overlook options that might facilitate women's autonomy in terms of overseeing the obtaining informed consent for testing women or providing options for MTP to them when confronted with unwanted pregnancies. Violations of women's rights to autonomy and self-protection are uncritically accepted, while approaches that could target men for testing and treatment in order to protect women and their unborn children are not even considered. The PPTCT programme's treatment of women primarily as a reproducing body is unfair and needs to be challenged.

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