



## ORIGINAL ARTICLE

# HIV/AIDS in women and children in India

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**Management of HIV in India has significantly improved with many international and local programmes supporting prevention and treatment. However, there are areas in India where women and children living with HIV endure a myriad of medical, psychological and social challenges. Women in rural poor areas in India have little control over important aspects of their life. Often, they have little decision-making powers within their families on matters that affect them personally. They find themselves unable to negotiate to protect themselves from harm or risk of infection. Those who are known to have contracted HIV are reluctant to access health care for fear of discrimination and marginalization, leading to a disproportionate death rate in HIV women. India is arguably home to the largest number of orphans of the HIV epidemic. These children face an impenetrable barrier in many Indian societies and endure stigmatization. This situation encourages concealment of the disease and discourages children and their guardians from accessing available essential services. This article provides an overview of the relevant literature and presents an insight into a complex mix of issues that arise directly out of the HIV diagnosis, including the role of social attitudes in the spread of HIV, and in creating barriers to accessing care. The review identifies international programmes and local initiatives that have ensured better access to antiretroviral therapy and have led to prolonged survival and reduction in the vertical transmission of HIV in India.**

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## Introduction

HIV/AIDS is an epidemic that continues to be a major public health challenge around the world, having claimed

more than 34 million lives since first recognized. Effective treatment, early diagnosis and public health campaigns have contributed to a 35% decrease in new HIV infections and 24% decrease in AIDS-related deaths between 2000 and 2015 (WHO HIV/AIDS Fact sheet, 2015).

India has a low prevalence of HIV/AIDS of 0.34% but as a heavily populated country, this ranks as the third largest number of people living with HIV in the world (UNICEF, India 2015). The complex culture and the social stratification in India increase the risk of acquiring HIV infection in vulnerable groups of women and children and create barriers for these groups to access health care. The aim of this article was to present a description of the circumstances of HIV-positive women and children in India.

## Women living with HIV in India

Globally, every minute one young woman is infected by HIV, and AIDS-related illness is the leading cause of death among women of reproductive age group (UNICEF UK, 2010). The Indian government estimates that around 40% of HIV-infected individuals are women, constituting around one million of the 2.5 million people living with HIV/AIDS in India (The World Bank speakers-bureau 2015).

The main route of HIV transmission in India is unprotected heterosexual intercourse, accounting for more than 87% of new infections in the country. This route of transmission is focused in female sex workers (FSW) and their clients (NACO Annual Report, 2014–2015). The prevalence of HIV infection in FSW in India is 2.61%. In a heavily populated country, this relatively low prevalence translates into a large number of women. Furthermore, a high proportion of FSW in India are mobile, contributing to the spread of HIV across the country.

Challenging economic circumstances in some parts of India lead to men migrating mainly to the cities for work, where the prevalence of HIV infection is higher than in rural areas. Men being away from their families facilitate the engagement in risky sexual behaviour (UNICEF, India 2015). Transmission of HIV from FSW to their clients has a ripple effect causing a significant proportion of women of child-bearing age who are monogamous, being infected by their regular partner who has acquired the virus from sex workers.

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Encouragingly, public health programmes have been implemented in some areas in India (Kumar *et al*, 1998; Jana *et al*, 1998) and recent figures have shown a decline in HIV infection as a result. In 2013–2014, 74% of pregnant women in India were tested for HIV. Although this ratio did not meet the set target, it still meant that 9.7 million pregnant women had access to HIV information and treatment if needed. Of the 12 000 pregnant women found to be living with HIV, 84% were provided antiretroviral drugs to prevent mother-to-child transmission (NACO Annual Report, 2013–2014). Despite this, HIV infection rates have been on the increase among women and their infants in some states of India, probably due to complex social and cultural issues that limit the effectiveness of prevention programmes. HIV-positive women in India continue to face health, social and economic ramifications. Gender inequalities and the low status of women limit their access to resources. Women feel powerless and unable to protect themselves as they are in no position to negotiate safe sex within or outside of marriage.

Women diagnosed with HIV infection face widespread stigma propagated by the misconception that HIV only affects men who have sex with men, sex workers and drug abusers (UNAIDS report, 2012). Often women are held responsible for infecting the rest of the family. With their children, they are ostracized from families, communities, workplaces and schools. Stigma and discrimination are also very common within the healthcare sector. Negative attitudes among healthcare staff prevent people from disclosing their status or seek treatment (Solomon *et al*, 2016).

A study comprising 757 women living with HIV who had been pregnant within the past 18 months in six Asian countries (Bangladesh, Cambodia, India, Indonesia, Nepal and Vietnam) reported that significant number of pregnant women living with HIV in these regions are denied their right to health care and are subjected to discrimination from health professionals, including refusal of care provision and antenatal care, coerced abortion and sterilization (Women of the Asia Pacific Network of People Living with HIV, 2012; Head *et al*, 2014).

Programmes to reduce the rate of infection provide equality in provision of health care and promote women's well-being, which have been established for some time in India. A joint directive from the National AIDS Control Programme and the National Rural Health Mission has stated explicitly that universal HIV screening should be included as an integral component of routine antenatal care, with an objective of ensuring that pregnant women diagnosed with HIV get linked to HIV services for their own health as well as to ensure prevention of HIV transmission to their babies. The WHO recommends providing lifelong ART for all HIV-positive pregnant and breastfeeding women, which will not only help reduce mother-to-child transmission but will also significantly improve women's health and prevent the spread of infection to their partners. Reaching this at risk group remains a challenge. As many as half of all pregnant women in India do not give birth in institutional settings, particularly if they live in poor rural areas, and thus will probably never get access to HIV testing even if it was available in hospitals.

There are also concerns of inadequate training of health-care workers, which results in misinformation and high level of stigmatization against HIV/AIDS individuals, discouraging women from disclosing their status and from attempting to seek treatment. The National AIDS Control Programme currently in phase IV, is aiming to utilize mass media campaigns and existing interventions to eliminate of stigma and discrimination by 2017 (NACO Annual Report, 2013–2014).

There has been support for women in India in challenging human rights violations through powerful stories and essays. Calls for urgent action to end the AIDS epidemic and violence against women focused on addressing women's rights and encouraging their empowerment and increase capacity of healthcare service provision (UNAIDS, 2014).

The ambitious goal of 'zero new HIV infections, zero discrimination and zero AIDS-related deaths' made on Worlds AIDS day in 2010 (Sidibé, 2010) will be made more realistic if the barriers to prevention, treatment and care for HIV women and children are tackled.

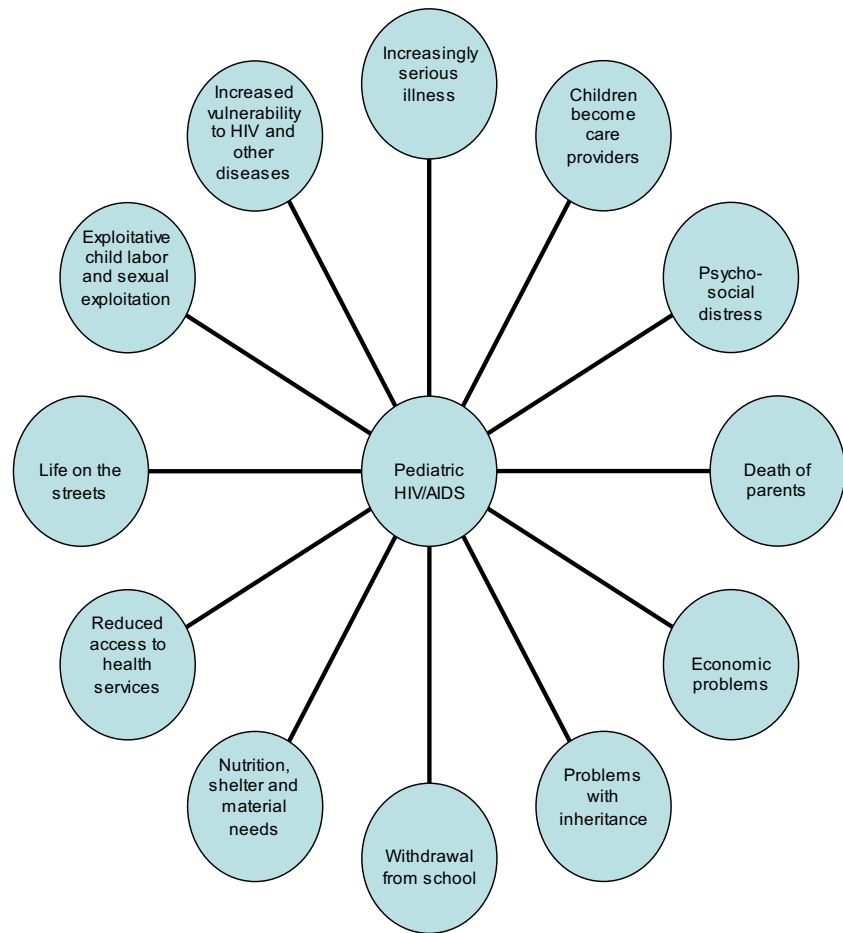
### Children living with HIV in India

Globally, every minute a baby is born with HIV, passed on by their mother during pregnancy, or delivery (UNICEF UK, 2010). There are 3.2 million children younger than 15 years living with HIV worldwide. The Indian Government have estimated that 3.5% of the 2.5 million HIV-positive individuals are children <15 years of age (The World Bank speakers-bureau, 2015).

In India, the rate of perinatal transmission of HIV is 5.7%, with approximately 23 000 newly born HIV-infected children annually (NACO Annual Report, 2013–2014) A small proportion are infected by contaminated needles and unsafe blood transfusion, but mother-to-child transmission of HIV is by far the most significant route of transmission in children <15 years. Therefore, successful management of the disease in pregnant women is essential for the prevention of HIV transmission to children.

During 2013, around 54% of pregnant women globally were not tested for HIV and were therefore unaware of their HIV status; of those who got tested and were diagnosed to be infected, 70% received the necessary treatment needed to prevent mother-to-child transmission, thereby averting approximately 900 000 new HIV infections in children (The Gap Report UNAIDS, 2014). The overall rate of mother-to-child transmission declined to approximately 17% in 2013, but this was still well below the goal set by the Joint United Nations Program on HIV/AIDS in its 'Countdown to Zero' Global Plan, of eliminating new HIV infections among children and keeping their Mothers alive by 2015 (UNAIDS, 2011, 2013).

Older children in India can also be vulnerable to acquiring the disease especially if they suffer from extreme poverty and are living on the streets. Social problems that inflict this group of children are multifaceted (Figure 1) and include child trafficking, and exploitation for sex and cheap labour (Mothi *et al*, 2012). Adolescents with longstanding HIV infection often face considerable physical challenges including delayed growth and development and



**Figure 1** Challenges of Children with HIV/AIDS Source: Mothi SN. Orphans of the AIDS Epidemic. Mamatha M. Lala, Rashid H. Merchant. 'Principles of Perinatal & Pediatric HIV/AIDS', India, Jaypee Brothers Medical Publishers (P) Ltd, 2012.

late puberty. Psychological and social factors deeply impact the ability to deal with the illness as these children are faced with the dilemmas of disclosing their status, transition from paediatric to adult care, and the choice of appropriate treatment regimens and adherence. Their caretakers often fear the impact of disclosure on the child's psychological status and emotional health and tend to rationalize that concealing the HIV status is in the child's interest.

If the condition is managed successfully, the transition of HIV from an acute terminal illness to a chronic manageable illness will have major consequences for children. There is a need in this group of patients for ongoing psychosocial support to help cope with not just the illness but the transitioning from childhood to adulthood and associated issues of education, employment, social security, sexuality and relationships. There is a pronounced need for a strong advocacy to implement legislations on basic rights of these adolescents (Cherie-Ann *et al*, 2011).

### HIV antiretroviral treatment in India

Fifty-one per cent of AIDS-related deaths in Asia happen in India, which maybe a reflection on the low treatment coverage in the country of 36% (UNAIDS The Gap Report, 2014). Substantial progress has been achieved in

India with respect to treating HIV as there has been a move to the more effective drug regimens following the current WHO recommendations (NACO National Guidelines, 2013).

Pregnancy in women found to be infected by HIV should be classified as high-risk pregnancy and managed by a multidisciplinary team (Kaizad *et al*, 2010). The immediate concerns of a woman informed of HIV infection in pregnancy are perhaps support and counselling especially regarding her own health, probability of foetal infection and how to prevent it, and disclosure to her partner and family members. Therefore, the support offered for HIV-positive women should include social and psychological support as well as medical management.

Although more children are receiving ART globally, access remains unacceptably low with only 3 of 10 eligible children are receiving HIV treatment worldwide. The situation for children in India is similar where they are under-represented among those receiving ART (World Health Organization, 2013).

The WHO reinforces the need to reach out to children as early as possible, recommending initiation of ART for all HIV-positive children younger than 5 years. Currently, 2.6 million children worldwide are eligible for treatment (UNAIDS The Global Plan, 2013). In India, there are approximately 145 000 children below the age of 15 years living with HIV, and as of March 2014, the number of

children registered in ART centres was 1 06 824 children, 42 015 of whom are receiving free ART.

Early diagnosis and treatment initiation are crucial to improve management of HIV-infected children. Although there is an increase in early diagnosis among infants, early initiation of treatment is not implemented, and hence, there is a lag of ART provision in children as compared with adults (Lala and Merchant, 2014).

Emphasis has been laid on aligning the treatment recommendations for children with those of adult such as the use of potent first-line regimens with non-thymidine analogs, viral load based monitoring and protease inhibitor based as a first-line regimens in children <3 years irrespective of their mother's status (World Health Organization, 2013).

As for the infected children, the critical preliminary steps for better management are prioritizing early diagnosis and treatment initiation. Although current regimens have substantially and dramatically decreased AIDS-related opportunistic infections and deaths, retention in care with lifelong adherence is imperative to achieve and maintain viral suppression as well as prevent drug resistance. Availability of fixed-dose-combinations has led to regimens with lower toxicity, lower pill burden and lower frequency of medication administration, which are factors associated with better adherence and clinical outcomes. However, these children face daunting challenges of life-long adherence and exposure to potentially toxic drugs requiring continued vigilance in the context of being orphaned or having parents who are themselves battling the consequences of HIV. Treating the HIV infection has to be supplemented by managing other equally crucial aspects being the successful ongoing management of concurrent nutritional deficiencies and co morbidities, which are ever so common accompaniments, as well as sensitively addressing the growing psychosocial, financial and developmental needs of these children as they grow.

It is alarming to note that patients are experiencing first- and second-line treatment failures in resource-limited settings and currently have no or limited access to third-line regimens. Strengthening awareness about prevention and care for HIV, making diagnostic tests and child friendly formulations including third-line and salvage regimens readily available in resource-limited settings are urgently needed.

The targeted interventions and treatment are becoming more widespread in India. These programmes have to be sustained and expanded rapidly in high-risk areas and reach those population groups that are most at risk (The World Bank speakers-bureau, 2015).

### **Prevention of HIV in women and reducing transmission to children**

Preventing HIV infection in women and treating those who are already infected are key to reducing the HIV infection rate in children. A UNICEF report stated four strategic elements of preventing HIV infection: preventing vertical transmission of HIV, preventing HIV infection in couples of child-bearing age, avoiding unplanned pregnancies in HIV-positive women and protecting HIV children and their families (UNICEF, India, 2015).

In India, the transmission of the virus from via the mother-to-child route during pregnancy, labour and delivery or breastfeeding is called parent-to-child transmission to emphasize the role of the father in both the transmission of the virus and management of the infected mother and child (UNICEF, India, 2015).

Women empowered with awareness and knowledge will have the self-confidence to confront the social, sexual and gender norms that make them vulnerable to HIV. Availability of HIV prevention tools to women, be it barrier contraception or treatment as prevention, is essential to enable women to be in control. The study on 'Gender Impact of HIV and AIDS in India' clearly shows that there is need to design programmes to empower women to negotiate safe sex with their husbands, access to information on HIV. Addressing the issue of human rights and equality, disseminating knowledge and encouraging positive behaviour are thus extremely important in the campaign against AIDS (The World Bank speakers-bureau, 2015).

There is significant improvement in awareness due to efforts by the Indian government. Nevertheless, the stigma and discrimination against risk groups and people living with HIV and AIDS remain part of the culture, undermining efforts to reach out with effective preventative and therapeutic interventions to vulnerable groups (The World Bank speakers-bureau, 2015).

HIV transmission from mother to child has been essentially eliminated in the developed world, proving that HIV infection via this route is largely preventable. Recent advances in ART, the implementation of antenatal screening and the employment of early treatment, lead to a dramatic reduction to a negligible rate in perinatal transmission in most high-income countries, with many low- and middle-income countries already moving closer towards achieving this. Nevertheless, this route of transmission has not been prevented totally and children worldwide continue to be born with HIV. Parent-to-child transmission of HIV in India can be controlled with universal screening and therapy coverage. Appropriate antenatal, perinatal and postnatal management across all geographic boundaries are essential in reducing transmission via the mother-to-child route. In this respect, progress has been made in India as the country as a whole successfully transitions to the more efficacious treatment regimen in a phased manner, in line with the current WHO recommendations (National AIDS Control Organization, 2013).

In addition, there have been local initiatives in India as well as global programmes to raise awareness of the problem of the high rate of HIV infection in women and children. The Joint United Nations Programme on HIV/AIDS in its 'Countdown to Zero' Global Plan declared a commitment towards the elimination of new HIV infections among children and keeping their mothers alive (UNAIDS, 2011, 2013). UNICEF report (2013) recommends the good practice of outreach approach of following up women who have tested positive, through their pregnancy and delivery and the continuum of care for these women and their families (UNICEF report, 2013).

Correcting preconceived ideas and modifying attitudes and behaviour have a significant role in tackling the social

barriers to prevention and care that women and children in India are exposed to. In this respect, there have been several programmes empowering women and promoting their well-being. Marking the International Day for the Elimination of Violence against Women on 25 November, the UNAIDS emphasized that achieving zero tolerance for violence against women and girls and realizing total gender equality are essential for achieving the goal of seeing the end of the AIDS epidemic (UNAIDS, 2014).

There are international efforts to support the Indian government to stop and reverse the HIV/AIDS epidemic in India, and lessen its effect on affected women and children. UNICEF is assisting the government to improve the programmes of preventing the vertical transmission of HIV and to increase access to treatment. There is support for the reduction of stigma and discrimination against people living with HIV to ensure that they get equal access to healthcare provision and social services (NACO, 2013).

International workshops such as the World Workshop for HIV/AIDS held in Hyderabad, India, in 2015 bring together experts from around the world to identify and prioritize research, clinical and social HIV-related issues (Tappuni and Shiboski, 2016) and increase awareness of the specific challenges that HIV is presenting in India (Paranjape and Challacombe, 2016).

## Author contributions

SN Mothi, MM Lala and AR Tappuni contributed to the review of the the subject and to the witting of the manuscript.

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