

## INHERITED INJUSTICE

### *Stigma and Gender Discrimination as Barriers to AIDS Prevention in India*

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OVER THE PAST DECADE, PROGRAMS THAT PREVENT THE VERTICAL TRANSMISSION OF HIV FROM PARENTS TO THEIR CHILDREN HAVE BECOME WIDELY ACCESSIBLE IN INDIA. DESPITE THIS OSTENSIBLE SUCCESS, MOST INDIAN WOMEN AND THEIR UNBORN BABIES DO NOT UTILIZE THESE PROGRAMS, AND THEREFORE REMAIN VULNERABLE TO VERTICAL TRANSMISSION. THIS ARTICLE EXPLORES THIS TROUBLING PHENOMENON BY HIGHLIGHTING THE PARTICULAR EFFECT OF HIV/AIDS-RELATED STIGMA ON WOMEN WHO LIVE IN HIGHLY PATRIARCHAL SOCIETIES. IN THESE CONTEXTS, THE EFFECTS OF STIGMA BECOME TANGIBLE RATHER THAN SIMPLY EMOTIONAL. WHEN STIGMA EXISTS ALONGSIDE GENDER INEQUALITY, THESE FORCES COLLUDE AND BECOME A STRUCTURAL BARRIER THAT KEEPS WOMEN FROM SAFELY OBTAINING THE TREATMENT TO PREVENT VERTICAL TRANSMISSION. THIS PROBLEM IS DOUBLE-PRONGED AS NEGATIVE ATTITUDES FROM HEALTH CARE STAFF CREATE PREJUDICE AND PROMPT PATIENTS TO KEEP THEIR HEALTH STATUS A SECRET OUT OF FEAR OF JUDGEMENT. ATTENDING TO ISSUES OF STIGMA AND GENDER INJUSTICE IS A NECESSARY STEP IN THE MISSION OF HOLISTICALLY ADDRESSING THE CRISIS OF HIV/AIDS IN INDIA AS WELL AS THE GLOBAL COMMUNITY.

## INTRODUCTION

Every year, 49,000 women living with HIV in India become pregnant and give birth.<sup>1</sup> These women are at a high risk of transmitting HIV to their babies while pregnant, during delivery, or through breastfeeding. Their difficulties are compounded by the intense social stigmatization that they experience throughout their pregnancies, especially if they openly seek treatment in hopes of preventing transmission to their children. Given how little agency women possess in the context of a patriarchal society, addressing the issues surrounding HIV-positive pregnancies is an urgent ethical and public health concern.

The situation of a pregnant woman who is HIV-positive presents a unique opportunity in which a potential transmission can be immediately foreseen and prevented. Despite this occasion, UNAIDS maintains “there are currently few interventions being implemented to help women to remain HIV-free during pregnancy, breastfeeding and beyond. More effort is needed to address this gap.”<sup>2</sup> As a result, HIV is still the leading cause of death among women of reproductive age.<sup>3</sup> Vertical transmission, the transmission of HIV from mother to child, is the largest source of HIV in children.<sup>4</sup> Socioeconomic disadvantages can fur-



BAIGA WOMAN AND CHILD IN INDIA (COURTESY OF WIKIMEDIA COMMONS)

ther increase transmission risks, as “Women in the poorest quintile are two to three times less likely than those in the richest households to have access to or to use these vital interventions.”<sup>5</sup>

As the Gap Report suggests, the quantitative lack of prevention of parent to child transmission (PPTCT) programs is one factor that limits access to care. However, the solution transcends simply creating more services. Powerful cultural factors often preclude women from utilizing the programs that already are in place, and India is a society in which these cultural barriers are in full force. The case above is the introduction to a thorough study of the experience of HIV-positive women and their interaction with and attitudes toward PPTCT programs in the South Indian state of Tamil Nadu. This case begins to illuminate the underlying cultural issues that prevent women from accessing PPTCT services. These social factors are symptomatic of an underlying problem that keeps women from utilizing PPTCT programs and predisposes them to HIV in the first place: the marginalization of women in patriarchal cultures.

## PPTCT PROGRAMS AND THEIR LIMITS

In response to the problem of parent to child transmission, the most common solution has been the implementation of PPTCT programs. Though these programs have proven to reduce transmission rates when utilized, societal stigma often limits their efficacy.

Around the world, wherever PPTCT programs exist and are utilized, they have been instrumental in reducing the rate of HIV transmission from mother to child (vertical transmission). In fact, effective PPTCT interventions reduce the risk of vertical transmission from 33% to 3%.<sup>6</sup> These programs have had a positive global effect. According to the UNAIDS Gap Report, “The rate of mother-to-child transmission [has fallen]—16% of children born to women living with HIV became infected compared to 25.8% in 2009.”<sup>7</sup>

Consistent with this global trend, the PPTCT program implemented by the government of India has met many of its goals.<sup>8</sup> By 2008, “4.61 million pregnant women were counseled and tested for HIV during their prenatal care in government maternity hospitals; 21,483 pregnant women were found to be HIV-positive; and 10,494 mother-baby pairs were given a single dose of nevirapine.”<sup>9</sup> However, these promising figures hide the difficulties inherent in

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ensuring access to PPTCT programs. As Cecilia Van Hollen notes, “While the government of India has made progress increasing the availability of prevention of mother-to-child transmission of HIV services, only about one quarter of pregnant women received an HIV test in 2010, and about one-in-five that were found positive for HIV received interventions to prevent vertical transmission of HIV”.<sup>10</sup> Despite the successes of PPTCT, the majority of HIV-positive pregnant women in India remain vulnerable to vertical transmission.

In her case study, Van Hollen indicates that this gap could be caused by underlying cultural factors that stigmatize women with HIV/AIDS and therefore deter pregnant women from seeking treatment. When women publicly disclose their HIV status by participating in PPTCT, they face discrimination throughout their pregnancy and birth by the community, family members, and healthcare workers. This experience of stigmatization can be extremely isolating, and detracts from what little agency these women had to begin with. For this reason, pregnant women in India who fear discrimination might be less likely to seek out PPTCT programs and undergo HIV testing, therefore risking their own health, the health of their unborn child, and the health of the community. In light of these high stakes, it is necessary to examine the societal factors that facilitate such a decision.

Firstly, participation in PPTCT programs implies a risk of revealing one’s HIV-positive status to the community, and therefore a resulting risk of societal stigmatization and isolation. In many communities, those with HIV are labeled as “harijan or dalit (“untouchable” in the context of the historical Indian caste system).”<sup>11</sup> In the words of a nineteen-year-old Indian mother, “I do not think it is advisable for the people infected with HIV/AIDS to tell others about their [HIV] status because if they do so they will be treated as untouchables. They will not be allowed to mingle with other people . . . They will not be allowed to speak to others. The food they prepare will not be touched by anybody; nor will they [community] give them food. They will not be allowed to touch others, sit with others, etc.”<sup>12</sup> This moth-

er’s advice stems from a concern for social flourishing and material wellbeing. A mother considering how she and her future child will fit into and thrive within the community will likely be deterred by the emotional and material detriment that could ensue if her HIV status becomes public. Therefore, fears of community stigmatization become a legitimate factor that hinders women from pursuing the PPTCT services they need.

PPTCT participation can also risk disclosure of women’s HIV status to her relatives, from whom HIV-positive women often experience blame and rejection. Due to the intensely patriarchal kinship models common in India, females are already alienated within the context of the family. Van Hollen notes that an unintended effect of India’s PPTCT programs leads women to be diagnosed as HIV-positive before their husbands, which “can have negative repercussions on the status of women within the extended patrilineal, patrilineal family structure, because women are accused of being promiscuous and are blamed for bringing HIV/AIDS into the family, thereby exacerbating pre-existing gender inequalities.”<sup>13</sup> As a result, the husband’s family may throw the wife out of the house and refuse to care for either her or her children.<sup>14</sup> For an HIV-positive woman responsible for HIV-positive children in the context of a highly patriarchal society, this could be a death sentence. The potential consequences of a mother’s relatives discovering her HIV status are often enough to deter her from risking participation in a PPTCT program, even in light of the potential long-term benefits it could bring.

Lastly, women fear discrimination and maltreatment from healthcare workers when they opt for obstetric care through a PPTCT program as openly HIV-positive. Medical employees that perform PPTCT services are often influenced by the same cultural stigmas about HIV that inform Indian society as a whole. These prejudices are manifested in the report that “HIV-positive mothers had experienced refusal for treatment, abusive behavior, moral judgment and lack confidentiality by health staff.”<sup>15</sup> One woman reports, “During the delivery, there were two nurses and they did not even touch me during delivery even

when I was suffering from pain . . . Even when I was bleeding they did not come to my help. They scolded my grandmother to wipe the blood, and they even did not touch my child.”<sup>16</sup> In addition to being emotionally traumatizing and physically painful, this lack of intervention drastically increases the likelihood of poor quality of obstetric care and complications during childbirth. Additionally, discrimination by health workers increases the chances of vertical HIV transmission, the very event PPTCT care is supposed to prevent. If this is the quality of care women risk when opting into PPTCT programs, it should come as no surprise when they decide to avoid the effects of discrimination and avoid HIV-specific services.

These potentially deadly consequences associated with disclosing one’s HIV status deter pregnant women from seeking the resources they need to prevent vertical transmission. These examples indicate that the significance of stigma transcends the emotional realm. Rather, the effects of societal stigma have concrete effects upon women known to be HIV-positive: they are rejected by their communities, cast out from their families, and discriminated against by health workers. These consequences disproportionately affect females in patriarchal communities, where women are already disenfranchised. In the words of an HIV-positive mother in Tamil Nadu, “Society is more unkind to HIV-positive women.”<sup>17</sup>

Understandably, women fear HIV-related stigma and try to avoid the risk PPTCTs pose to the confidentiality of their HIV status. Given the patriarchal society in which women are already relegated to the margins, women rationally choose to avoid jeopardizing what little agency they have to begin with. However, public health consequences of this phenomenon are too dire to ignore. Therefore, the barriers women face in accessing PPTCT programs must be examined and addressed at the cultural level.

### STRUCTURAL BARRIERS TO PPTCT ACCESS

The barriers women face in accessing PPTCT programs illuminate the underlying cultural dynamics that prevent them from experiencing safe pregnancies, delivering healthy babies, and ultimately thriving as individuals. The realities of female life in India persist, regardless of what services are currently available to pregnant women. Therefore, in order to truly prevent the transmission of HIV from mother to child, we must recognize the manifestations of structural violence in India that devalue and diminish the female experience.

In order to effectively decrease the vertical transmission of HIV, we must first reconsider what factors put women at risk for contracting the virus in the first place. Though married women are not typically considered a high-risk group by those working to combat AIDS in India, “a substantial proportion of new HIV infections are occurring among stable heterosexual couples.”<sup>18</sup> This observation should serve as a red flag. It indicates that risk is correlated with a standard, “stable” element of the female experience in India, rather than deviation from social norms. Furthermore, a study of pregnant women in western India suggests the following:

“[A woman’s] HIV risk perception seems more influenced by her socio-demographic status and her couple relationship than by her level of HIV-related knowledge... the significant factors identified in this study point out to the fact that risk perception and hence risk reduction among pregnant women, and probably overall women within stable heterosexual couples, must go far beyond imparting knowledge about HIV and must address the more deep-rooted issues such as partner communication, domestic violence, alcoholism, and lack of education among women.”<sup>19</sup>

Therefore, the factors that predispose women to HIV vulnerability are the same ones that decrease their quality of life, social status, and perceived value in society. Unsurprisingly, these are also the effects of second-class citizen-



A WOMAN WELCOMING A FEMALE PATIENT AT A HEALTH CLINIC IN INDIA. SMALLER ILLUSTRATIONS DEMONSTRATE THE WAYS IN WHICH AIDS CAN BE TRANSMITTED. (COURTESY OF WIKIMEDIA COMMONS)

ship in a patriarchal society. Therefore, working towards the general empowerment of women within Indian communities will simultaneously work to prevent the spread of HIV/AIDS.

Progress in women's empowerment will increase female agency in all areas of life, including the ability to pursue PPTCT services without fear of stigma and its effects. As demonstrated above, a substantial barrier to women's PPTCT access is their fear of the devastating consequences that follow from beings labeled as HIV-positive. The devastation of these consequences is not inherent, but results from the relative lack of agency females in Indian society have to cope with them. As Gillian Paterson reminds us, "It is the way we relate to each other that creates the conditions for transmission. We are actively welcoming AIDS when a person's identity is defined in terms of how successful an adjunct she or he is to wishes of family and culture."<sup>20</sup> In light of this wisdom, it becomes clear that in order to decrease HIV transmission rates and increase access to PPTCT programs, we must adjust our definition of female identity and work to empower women in all aspects of life.

#### MOVING FORWARD: CATHOLIC DUTIES

The obstacles faced by pregnant women with HIV in India reveal the extent to which women struggle with discrimination, marginalization, and a lack of agency in their everyday lives. Unfortunately, the availability of PPTCT programs cannot serve as a comprehensive solution for the issue at its root, no matter how effective they may be. As long as gender inequality exists, women will be systemically vulnerable insofar as acquiring HIV and transmitting the virus to their children. To ameliorate the issue in the long term, it is necessary to diminish the stigmatization of HIV and to promote gender justice.

Stigma and the status quo are powerful forces, but we are called as a global church to overcome them in hopes of bringing about justice. The first step is radical inclusion. Gillian Paterson reminds us that "the focus on stigma calls us to take a new look at the theological meaning of community ... An HIV-friendly church is not just one where people with HIV are welcome: it is one where those who are most vulnerable to transmission (often rejected by 'the world') are also welcome."<sup>21</sup> Christopher Vogt notes how the Gospels' "insistence that there be no limit upon who is to be considered a "neighbor" and [Jesus's] example of repeatedly attempting to build bridges

between marginalized persons and the rest of the community"<sup>22</sup> challenge the Church to stand up to stigma and social injustice. Jesus healed the leper not for the sake of public health, but to relocate him from social isolation back into the community.

We must accept the challenge of the Gospel by working to eliminate oppressive and isolating conditions on earth, including HIV/AIDS. We must also accept the challenge by making an option for those who are most condemned by society, including pregnant, HIV-positive women in India. As the hands and feet of God on earth, we must take seriously the dignity of each human person by actively and radically relocating all isolated individuals into our communities. The more we accomplish this task, the closer the world will come to eliminating the risk of HIV/AIDS for all its people.

## ENDNOTES

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2. Joint United Nations Programme on HIV/AIDS (UNAIDS), *The Gap Report*, (2014), 234.
3. *Ibid.*, 232.
4. Joshi, Urvish, et al. "Studying PPTCT Services, Interventions, Coverage and Utilization in India." *Journal of Global Infectious Diseases* 3.4 (2011): 371-7.
5. *Gap Report*, 235.
6. Joshi, 371.
7. *Gap Report*, 233.
8. The success of India's PPTCT program is detailed on Van Hollen 53 (see note 9).
9. Van Hollen Cecilia. *Birth in the Age of AIDS Women, Reproduction and HIV/AIDS in India*. Palo Alto: Stanford UP, 2013, 54.
10. Madhivanan, Purnima, et al. "HIV Testing among Pregnant Women Living with HIV in India: Are Private Healthcare Providers Routinely Violating Women's Human Rights?" *BMC international health and human rights* 14 (2014): 7.
11. Rahangdale, 839.
12. *Ibid.*
13. Van Hollen, 11.
14. Rahangdale, 839.
15. Subramaniyan, 2203.
16. Rahangdale, 839.
17. Van Hollen, 104.
18. Darak, Shrinivas, et al. "HIV Risk Perception among Pregnant Women in Western India: Need for Reducing Vulnerabilities rather than Improving Knowledge!" *AIDS Care* 26.6 (2014): 709.
19. Darak, 712.
20. Paterson, Gillian, *Escaping the Gender Trap: Unraveling the Patriarchy in a Time of AIDS*, 106.
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22. Vogt, Christopher, *Recognizing the Addict as Neighbour: Christian Hospitality and the Establishment of Safe Injection Facilities in Canada*, Theoforum 35 (2004), 322-23.

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