

# Women and HIV/AIDS: Experiences and Consequences of Stigma and Discrimination - Nepal



This study was commissioned by Family Health International (FHI)/Nepal Country Office to investigate and understand the causes, manifestations and consequences of HIV/AIDS related stigma and subsequent discriminatory acts.

The study was conducted to explore the attitudes and fears that non-HIV positive community members have regarding how HIV/AIDS is contracted, as well as their perception of HIV/AIDS as a moral transgression. In addition, the study also aimed to present the experiences and consequences of stigma and discrimination on people living with HIV/AIDS (PLWHA), as they confront the responses and attitudes of individuals regarding HIV/AIDS, and interact with them in families, communities and health care settings.

FHI/Nepal hopes to gain an understanding of factors that enforce stigma and how they create barriers to HIV prevention, care and support efforts. FHI/Nepal will use the research findings to develop pilot interventions to minimize the influence of HIV related stigma and discrimination in Nepal.

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## **The Situation**

The HIV/AIDS epidemic is taking a devastating toll on women in Nepal. Gender inequities, poverty and a growing prevalence of HIV in South Asia have increased the vulnerability of women to HIV risk behaviors and exposure. These circumstances have also made them susceptible to stigma and discrimination when they are identified as being HIV-positive. Many women are often stereotyped as having contracted HIV through immoral sexual behavior. They are, thus, blamed for being HIV-positive even though their husbands had infected them or when they return home after having been abducted and trafficked for sex work. Negative social responses in these situations may result in their being rejected from their family and denied access to resources from their marital and natal households. Women who are positive also carry the social and psychological burden of pregnancy and parenthood, and therefore, have to face the potential morbidity, mortality and eventual abandonment of their children.

In this socio-cultural and public health context, heterosexual contact is considered the most predominant source of HIV in Nepal. There has been much attention focused on female sex workers with rates of HIV among them greatly increasing from one percent in 1992 to 17 percent in Kathmandu in 2000, with FSWs showing rates of 73 percent if they had worked in Mumbai or 75 percent if they were injecting drug users. However, there has been an upsurge of HIV infection among returning

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migrant workers, so that an increasing number of women are becoming infected by their husbands when they return home from work abroad.

Fueling the female vulnerability to HIV infection and stigma and discrimination are women's lack of social and economic independence and their low status in their marital households. When married, women are expected to bear children and perform household work. If they fail to produce progeny, their husbands may reject and abandon them. These circumstances may hamper women from asserting condom use by their husbands. In addition, raising children and attending to household chores may limit their access to education and employment opportunities. In Nepal, only 14 percent of women are literate compared to 40 percent of men, so that many also have limited access to printed information (e.g., pamphlets, newspapers, billboards) on HIV risk behaviors and prevention.

## **The Project**

The study *Stigma and Discrimination for People Living with HIV/AIDS* examined the experiences and consequences of stigma and discrimination (S&D) from the viewpoint of those affected by HIV/AIDS. The study also explored how women who became HIV-positive were treated in their families and communities. These experiences often led to problems with survival, their level of suffering and their ability to care for children.

## **Methods and Sample**

In this study, 57 PLWHA were interviewed. They were recruited in urban Kathmandu and Patan (44 individuals) and in the terai towns of Makawanpur and Nawalparasi districts (13 individuals). Respondents were contacted largely through PLWHA support organizations, an infectious disease hospital and drug rehabilitation centers.

Following initial information on the history of their disorder, respondents were encouraged to discuss in an open-ended fashion the key forms and consequences of stigma and discrimination that they experienced in their lives.

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## Project Findings

Out of the 57 PLWHA who were interviewed, 24 (42%) were women. They were between the ages of 18-42 years old. They reported that the greatest source of infection was from husbands who had returned from work outside of the country. Thus, 13 or over a half of women reported this form of exposure. Eight or a third of women were infected through sex work, with six or 75 percent of these women trafficked and sold into sex work at a young age. The remaining individuals thought they might have been infected through injecting drug use, or both sex and injecting drug use. Most of the women in the latter group were introduced to drug use through their husbands.

Although the predominant modes of exposure of women in this study were through ways in which they had little control, they still suffered greatly from stigma and discrimination. The difficulties faced by women were:

- (a) Receiving less support than their husbands when both were HIV-positive;
- (b) Being morally condemned and blamed for their HIV status;
- (c) Facing serious loss of social and economic support; and
- (d) Confronting the psychological burden of having been trafficked and having children.

### **A. There are differences in support for men and women who are HIV-positive**

A number of women described a greater lack of acceptance and support by their family compared to their husbands who were also HIV-positive. This occurred even though in many of these cases they had been infected by their husbands. As one woman stated:

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*My family members were not very supportive towards me right from the beginning. It was clear that it was my husband who infected me. The same family members were good to my husband who was also HIV-positive. When they came to know I was also positive at the time I gave birth to my son, they made sure I did not use the same toilet used by others in the family. By then my husband was dead. When I returned from my maiti<sup>1</sup>, they kept telling me to go back... (Female 21 yrs, Nawalparasi).*

This woman was convinced that her in-laws wanted her to move to her maiti so that they would not have to transfer property to her name since they thought that she would die soon and the property would be theirs. It is not uncommon for in-laws to attempt to sever relations with a widow, especially if she has a son because having a son gives her additional claim to her husband's property. This case shows how married females may be in a fragile position after their husbands die and they become financially insecure. Being HIV-positive, thus, greatly exacerbates the tenuous position of women in their marital households.

## **B. Women are often morally condemned and blamed for their HIV status**

A number of women were automatically blamed for their husbands becoming HIV-positive. These responses contrast with the high number of women having been infected by their husbands in this study. Attitudes towards women as being morally guilty for their own and others positive status often created an unforgiving and serious loss of support for them. The following case shows how women are both blamed for their HIV infection and for their husbands' positive status, and subsequently lose the support of their families.

*I am no more considered a person in my family. My father-in-law blames me for his son becoming HIV positive. I do take total responsibility for my son being positive... My father-in-law came and took his son and grandson away from me and left me in a house where I have no source of support...I have nowhere to go (Female, 32 yrs old, Kathmandu)*

The combination of morally blaming women for becoming infected with HIV and abandoning them leads to lose much needed support from their families. Aspects of stigma and discrimination accumulate to result in

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<sup>1</sup> Natal family (in Nepali)

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devastating circumstances for many women. Household members also expressed fears that their HIV-positive family member might infect others. Further, they also were often anxious about losing their social standing in their communities.

### **C. Many women are faced with serious loss of social and economic support**

Families, especially with a female who was HIV-positive, expressed fear that their *ijjat*<sup>2</sup> or honor may be lost in their communities. Family members' anxieties over the transfer of stigma and discrimination to them often led to female PLWHA being ostracized and losing much needed household social support. These situations occurred even for people who were innocently led into risky behavior and helplessly infected with HIV. The following individual had been trafficked to Mumbai at the age of 11 and returned home HIV-positive after a number of years. Yet, as she narrated:

*The biggest problem I faced was from my family. They are scared to let me enter their house. Once I was very ill with continuous fever and severe diarrhea, I asked my mother to loan me 100-200 rupees for medicine. She refused to give any money and said it was better I did not come home as they were humiliated and had no *ijjat*<sup>2</sup> in the society (Woman 31 yrs, terai).*

In addition, many women lack education and economic skills for living on their own. A critical safety net for many respondents in the study were AIDS support organizations where they found much needed housing and support. The following is a remark by one of the women on the extent of her vulnerability and lack of economic independence:

*I do not know what I would have done if I was not in this organization. I have no education, no skill, no power... (Female, 42 yrs, Rautahat).*

This woman had also been innocently lured into the sex trade and sent to Mumbai at a young age. Yet, the stigma and discrimination she experienced for having been involved in sex work and returning as an HIV-positive left her bereft of family support. Her lack of education and occupational skills intensified the difficulties of her situation.

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<sup>2</sup> Honor, respect (in Nepali)

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## **D. Women who are positive may be confronted with the psychological burdens of having been trafficked and sold into sex work as well as having dependent children.**

Female PLWHA may be confronted with the psychological complications of having to deal with their HIV status, as well as with such problems as the trauma of having been forced into sex work. The social and psychological complexity of these circumstances may be heightened and drawn out by their self or other imposed isolation, and lack of supportive counseling. One woman who was trafficked at a young age described the overlapping impact of these experiences:

*I have not faced the problem (regarding disclosure of HIV status) directly because I have not told anyone... The fact that I am not able to talk about it to my family makes me in a way deprived of their support... that makes me sad and depressed... if they knew about it I think I would have to hang myself. They will talk about me being trafficked. I am not able to get over that terrible scar. At times I find myself screaming and running out of bed in the night when I dream that I have been sold again (Female, 21 yrs, Lalitpur).*

As suggested by this woman's experience among others mentioned above, women often lacked foreseeable means of resolution of their complex social and emotional situations. Accounts of NGOs' assistance with their everyday living and psychosocial support indicate one of the few means for PLWHA to process and adapt to these circumstances.

The shock of realizing that one is positive may be exacerbated by the possibility that one's child may also be positive. This experience can create much emotional distress for individuals,, as indicated in the following example:

*When I first heard that my husband was positive I ran around the hospital screaming like a mad woman... First, I knew that the disease is transferred to the wife and second, I was pregnant... I was sure I was positive and had the fear that my child would be positive as well (Female 21 yrs, Nawalparasi)*

HIV-positive women, especially those who are widowed or abandoned, faced concerns over the support of their children and the stigma that

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may be transferred to them. In the following case, a woman became distraught when she found out that she was positive and considered her daughters' future with the legacy of having had an HIV-positive mother and father. As she observed:

*I feel terrible about my daughters. I satisfy myself saying I will die soon but what about my children. ...I feel worried about them, they will have to face this society and gain ijat which their father and I have thrown down the drain (Female 32 yrs, Kathmandu, IDU).*

Other women described deteriorating economic conditions that they and their children were facing once their husbands died. They also worried about who would take care of their children once they passed away.

These cases demonstrate that becoming infected with HIV has a great impact on women in Nepal. Many women suffer severe and unforgiving stigma and discrimination in their households and often have few resources to draw on when they lose their families' social and material support. They also often face serious concerns for their children's future.

## **Recommendations**

These findings suggest a number of programs that need to be developed to reduce stigma and discrimination towards women, and provide the care and support that they need. Some of the programs that are needed are:

1. There needs to be women-oriented programs to raise awareness and understanding of the plight of women. These programs should provide information on:
  - How HIV is transmitted, i.e., it is not only spread by particular risky groups and through immoral behavior (e.g., through improper sexual relations), nor is it transmitted by casual contact, (e.g., shaking hands, wearing the same clothes or eating together.

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- Awareness campaigns and informational programs are needed to include information on the meaning of HIV, the difference between HIV and AIDS, that positive diagnosis does not mean “death,” how HIV progresses, opportunistic infections, and the care for a person with HIV/AIDS.
  - These programs should target households and communities throughout the country, but especially in high seroprevalence areas.
2. There needs to be support services especially for female PLWHA and their children.
    - These services should include: economic and income-generation skill development, educational programs, transitional economic and housing support, counseling and referral services, and consideration of support for women with children and for orphaned children.
    - Training in income-generating skills and initiatives may usefully coincide with HIV/AIDS-specific activities (e.g. providing awareness campaigns).
  3. There needs to be psychological support services available for female PLWHA.
    - Services need to include conventional and specialized counseling and support services, case management, family counseling, emergency response care, and care for those with dual diagnoses.
  4. There needs to be enforcement of the property rights of women upon divorce and widowhood, and advocacy for support for them.

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