

The Gender and Reproductive Health Research Initiative  
Mapping a Decade of Reproductive Health Research in India

**HIV/AIDS in India**  
**A Critical Review of**  
**Selected Studies (1990-2000)**

*Anita Rego,*  
*Vimla Nadkarni,*  
*Deeksha Vasundhra*

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The Gender and Reproductive Health Research Initiative has been supported by The Ford Foundation. Support for printing, publishing and dissemination has been provided by The Rockefeller Foundation.

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**Suggested Citation:**

Rego, A., V. Nadkarni, D. Vasundhra. HIV/AIDS in India: A Critical Review of Selected Studies (1990-2000). The Gender and Reproductive Health Research Initiative. CREA. New Delhi.2002.

Thanks to Sundari Ravindran who reviewed a draft of this critical review and gave her comments and inputs.

**Published and disseminated by:**

Creating Resources for Empowerment in Action (CREA)  
2/14, Shantiniketan, Second Floor, New Delhi 110021  
Phone: 91-11-24107983, 91-11-26874733 Telefax: 91-11-26883209,  
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## I. CONTEXT

The number of people living with HIV/AIDS globally stood at 40 million at the end of 2001, with five million more being newly infected each year. According to estimates from the year 2001, HIV/AIDS is now the leading cause of death in Sub-Saharan Africa, and is the fourth largest killer worldwide<sup>1</sup>. In India, since the first case of HIV was identified in Chennai in 1986, the number of people infected by the virus has increased drastically. It was estimated that 3.97 million people were infected with HIV at the end of 2001, of which one fourth were women<sup>2</sup>. Although overall adult prevalence is only 0.8 percent, the number of people living with HIV in India is the second highest in the world. The epidemic in India is not a single unified epidemic but an amalgamation of regional epidemics, each with distinct vulnerabilities, impact and modes of transmission<sup>3</sup>. Of India's thirty-one states, ten states account for 96 percent of total reported AIDS cases: specifically, Maharashtra, Tamil Nadu, and Manipur account for more than seventy five percent of infection<sup>4</sup>.

The official body responsible for establishing AIDS policy in India is the National AIDS Control Organisation (NACO). It is supported by thirty- eight state level AIDS control societies (SACS). These bodies implement programmes at the state and district levels. Till recently, prevention and control strategies focused on targeted interventions aimed at groups that had been identified as having a high risk of being infected such as sex workers, truck drivers and injecting drug users. It is only in 1999 that the National AIDS Control Policy (1999-2004) recognized AIDS as not "merely a public health challenge," but also a political and social development issue<sup>5</sup>. By doing so, NACO has officially recognised that the epidemic has moved from vulnerable or 'high risk' groups to the general population.

In India, unprotected sexual activity accounts for close to 85 percent of HIV transmission<sup>6</sup>. The infection was initially identified amongst groups designated by NACO to engage in high-risk behavior. It then shifted through bridge populations such as truck drivers to the general population including married women in monogamous relationships, and most recently, adolescents<sup>7</sup>. In states with generalised epidemics, data indicate an increasing prevalence among married women in monogamous relationships. An increasing number of women attending antenatal clinics are testing positive for the virus.

Women are especially vulnerable to HIV infection because of a combination of physiological and biological factors as well as socio-economic reasons. A larger proportion of all new infections in India are in women and young people, with mother to child transmission sharing a large part of the epidemic. Some of the factors that facilitate the spread of infection and complicate prevention include exposure to the virus at a relatively early age of life due to early marriage, the long incubation period of the infection, delayed help seeking and treatment, poor health status of women and subsequent intrusive medical interventions. The gendered roles, the primarily disempowered status of women, poor decision making capacity and increasing migration, are other factors that aggravate risk of infection.

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1. AIDS Epidemic Update, UNAIDS, December 2001
  2. UNAIDS and WHO 2002
  3. Desai 2003
  4. UNAIDS and WHO 2002
  5. NACO 1999
  6. NACO 1999
  7. De Sarkar 2002

## II. VIEWING RESEARCH ON HIV/AIDS THROUGH A GENDER LENS

This paper attempts to examine documented social science research in HIV/AIDS and analyse the emerging trends in research using a gender lens. Gender in this article is not a euphemism for exploring only the women's point of view but focuses on both men and women.

Using a gender lens would mean understanding:

- the manner in which biological and gender factors combine to impact upon risk and vulnerability to HIV/AIDS.
- the gender dimensions of the social and economic consequences of HIV/ AIDS including responses to the epidemic at the household, community and national level, access to health care and violations of rights.

The analysis is based on 126 studies on HIV/AIDS conducted in India between 1990 and 2000. Abstracts of these studies have already been published as an Annotated Bibliography<sup>8</sup>. These include published and unpublished reports from various sources including books, journals, internet searches, educational institutions and both government and non-governmental organizations.

This paper consists of three sections: the first section of which this commentary is a part, presents the context within which research on HIV/AIDS is taking place and also attempts to define the scope of the paper. The second section attempts to classify existing research into categories, analyse their findings and identify the existing gaps through a gender lens. The third and last section lists the gaps in existing research and the gender and social dimensions that need to be addressed within it.

Medical practitioners, social scientists, funding organizations, government organizations and individuals have researched the two decade long epidemic widely. The existing research on HIV/AIDS has been grouped under the following categories. The analysis for each of the categories has been given in section two of this paper.

1. Understanding and response to HIV/AIDS
2. Safer sexual practices and other modes of risk reduction
3. Biological and societal vulnerabilities to HIV/AIDS
4. Economic impact of HIV/AIDS
5. Disclosure, stigma and discrimination
6. Mental health issues including alcohol and substance abuse
7. The rights of positive people
8. Prevention programmes and interventions

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8. Rego, A., V. Nadkarni. HIV/AIDS in India: An Annotated Bibliography of Selected Studies (1990-2000). The Gender and Reproductive Health Research Initiative. TISS and CREA. New Delhi.2002

### III. WHAT DO WE KNOW?

#### 3.1 Understanding and response to the epidemic

##### Knowledge and perceptions of youth<sup>9</sup>

A large number of studies (16 studies) from the beginning of the epidemic have focussed on youth. Despite the fact that in the earlier days of the epidemic young people were considered a high risk group, most of the studies have restricted themselves only to young people's knowledge and perceptions about AIDS. Knowledge has been defined as knowing about the existence of HIV/AIDS and the modes of transmission. It does not include an understanding of other aspects of sexuality and knowledge about the body, sexual functions and sexual activity. Only two of the studies (93,111) attempt to examine these aspects. Both reported that young people had insufficient information about their bodies, sexual functioning and sexually transmitted diseases. Girls had even less knowledge about their bodies, putting them at greater risk for infection. Students who are sexually active and involved in penetrative sex are not necessarily aware of safer sex practices. Girls reported lesser sexual activity as compared to boys though there is a possibility of girls not reporting sexual activity due to social conditioning. While most studies acknowledge that girls are reluctant to talk about these issues as well as HIV/AIDS, only two of the studies (56, 85) have acknowledged the special vulnerability of women to AIDS because of the restrictions on their movements and other factors inhibiting access to information.

Findings on gender differences in knowledge and perception about HIV/AIDS have been inconclusive, although there seemed to be greater awareness amongst boys and urbanites. Knowledge gaps were noticeable through misconceptions on modes of transmission, information on availability of diagnostic tests, preventive strategies and condom protection. While most studies ask for the source of information, two of the studies were conducted following information, education, communication (IEC) interventions. The media, including the print media is the major source of information for youth on HIV/AIDS. Some of the other sources of information were films and magazines.

All the studies have been conducted amongst students at either the high school or university level. There have been no studies with out of school youth in both rural and urban areas. The majority of the studies have been conducted in urban areas. Only three studies have been conducted in rural areas (81,82,87), of which two attempt to measure the difference in urban and rural areas. A study conducted in Delhi (87), reported greater levels of knowledge amongst rural girls which was explained as a result of early marriage and exposure to sexual activity amongst rural girls. Early marriage and sexual activity also make young girls more vulnerable to HIV/AIDS. Their husbands are often much older to them and may have had sex before marriage. However, none of the studies have taken this into consideration.

Only three of the studies (5,78,81) examine the attitude of young people towards persons with AIDS. Two of these (78,81) are very basic, measuring attitude by ascertaining whether patients with AIDS should be isolated or not. One study, conducted amongst university students in Hyderabad (5) tries to define the predictors of attitude of young people towards persons with AIDS. While the study itself examines knowledge of AIDS, attitudes towards AIDS and safe sex behaviour, perception or risks and socio-economic variables as determinants of attitudes towards PLWHA, it does not examine the factors that enable young people to access the information that will determine their attitudes.

Sexual minorities such as gay men and other males who have sex with males, lesbians and

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9. The following studies fall under this section: Reference numbers: 5,13,37,56,78,79,81,82,84,85,87,90,93,94,105,111

transgendered people also encounter sexual coercion and are therefore at risk. A study conducted with adolescent truck cleaners in Indore (37) has identified anal sex with senior drivers as a cause for infection. In a study from Pune (111) 15% of boys and 5% girls reported same sex encounters. However, there are no detailed studies on youth who identify as lesbian, gay or bisexual.

The studies tend to reflect prevailing attitudes about sexuality and sexual behaviour. More information is needed about the sexual knowledge of young women and the vulnerabilities they face including incest, date rape and paedophilia. Nor are there any studies on body perceptions and attitudes towards oneself amongst girls- both factors that determine the ability to negotiate safer sex as well as health seeking behaviour. While both urban and rural youth have been covered, there are no studies on out of school youth including street children who are susceptible to violence as well as substance abuse.

#### Knowledge and perception of 'high risk groups' and the general community<sup>10</sup>

As in the studies on youth, studies with 'high risk' groups also define knowledge as information about the existence of AIDS and the modes of transmission. The levels of knowledge among people in the studies conducted was poor. Knowledge gaps were observed on all components including general information, modes of transmission, signs and symptoms, preventive strategies and diagnostic and testing services. Education, income and occupation are all factors that influence knowledge levels positively (74,104,92). The highest levels of awareness were reported in the north-eastern parts of the country but this did not translate into increased condom usage.

Studies have been conducted both amongst the general population as well as amongst 'high risk groups'. These include studies in STD clinics, sex workers, truck drivers, blood donors, men who have sex with men and barbers. Two of the studies deal with sexual minorities and sexual practices. While one only acknowledges the existence of homosexual practices and same sex partners in a slum community in Delhi (97), the other discusses in detail the knowledge and attitude of men who have sex with men in Mumbai (110). This article draws a distinction between men who have sex with men without leading a gay lifestyle and those who identify as gay. It also examines sexual behaviour and practices amongst both groups including the risk to women partners of men who have sex with men.

Sex workers have always been considered a high risk group as well as a major cause of transmission. Studies have been conducted to study their behaviour as well as the prevalence of the infection amongst them. Surprisingly, only one study from Vellore (91) assesses knowledge amongst sex workers. This study has been conducted with sex-workers who are attending an STD clinic. This study found 96% of sex workers attending the clinic to be unaware of AIDS. Given the fact that the movement and access to information of most sex-workers is controlled by the madams and pimps in the brothels, only those women who would have some degree of freedom as well as knowledge about their bodies and infections would have been able to access an STD clinic.

A number of the studies have included both men and women in their samples. However, the ratio is often skewed in favour of men. A community based study conducted in Ahmednagar (104) goes to the extent of explaining that it has a smaller number of women as they are shy and therefore difficult to interview. Only one of the studies (2) has concentrated specifically on women in the general population. Conducted in Mumbai to assess knowledge about AIDS amongst married women, the study found that nearly 67% of the 350 women surveyed had heard of AIDS. Three fourths of these women had heard of AIDS through the media and only 6% through the newspaper. This paper also acknowledges the issues in negotiation with partners by differentiating between a general discussion about HIV/AIDS with a

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10. The following studies fall under this section: Reference numbers: 6,7,66,7,69,74,76,91,92,96,97,102,104,107, 110



partner as compared to negotiating for safer sex with a partner. None of the studies looked at married men. There are no studies conducted to look at the knowledge and perceptions of single adult women, pointing to a moralistic and stereotypical attitude amongst researchers. Not only does this point to a silence around the activities of these groups, it also means that it would be equally difficult for them to access information and services.

The majority of the studies conducted amongst the general population have been conducted in urban areas. There are very few studies in rural areas. Only one of the studies look at vulnerabilities of indigenous groups (7). Conducted in Manipur, this study mentions that civil unrest and other socio-economic problems are leading to an increased vulnerability to HIV/AIDS. Women are often the greatest sufferers in situations of civic unrest, vulnerable to violence and therefore infection both by insurgents and by security agencies. There are no studies looking at the impact of these issues on women. No studies have been conducted in dalit communities. In most parts of the country, dalit women are vulnerable to violence by members of higher castes, thereby increasing their vulnerability to infection.

#### Understanding and response by health care providers<sup>11</sup>

Most of the studies were inspired by the fact that HIV/AIDS was an occupational hazard in medical care. They have concentrated on learning about the level of knowledge on HIV/AIDS. While most of them did attempt to measure the attitude of health care professionals towards people living with HIV/AIDS, it has been done through questions such as opinions on isolation and whether denial of first aid to positive people was valid. Only one study (99) had questions relating to the socio-biological vulnerability of women. Sixty three percent of the respondents did not know about the factors that made women more vulnerable and thirty percent did not even attempt the question.

The information sources for medical practitioners studied are no different from the general populace. Most medical practitioners have also learnt about HIV/AIDS through the media. There does not seem to be a very strong trend of gaining knowledge from scientific and medical journals. They also share the same knowledge gaps and misconceptions. In a study conducted amongst final year medical students and doctors in Bangalore (80) some modes of HIV transmission were identified as casual contact (11%), through mosquito bites (20%), through coughing (12.5%), and through hair cutting (23%). The same study reported that 41% of medical personnel suggested isolation of positive people and 20% suggested denial of first aid. This becomes significant as most often than not, they are the ones educating the public and those testing positive for HIV.

The studies on health care professionals are of two categories- on medical practitioners and students and studies on other health care professionals such as nurses, anganwadi workers and PHC staff. Amongst medical staff, there are some categories such as nurses, cleaners and obstetricians that are more exposed to infection. There are no studies on the attitude of obstetricians and midwives, a necessary point of contact with the health system for most women. These are also groups that have to deal with blood and blood products as an integral part of their daily work. Only one study (100) examined the knowledge and attitude amongst indigenous health care providers. There are also no studies conducted on the knowledge and perceptions of unregistered medical practitioners or quacks. Both these groups often form the first point of contact for medical care in large parts of the country. This is especially so in the case of sexually transmitted diseases (STD).

None of the studies attempted to examine the attitude of medical care professionals from the point of view of the patient. While a number of health care professionals claimed to be counselling their patients about condom usage, it is not known whether they actually do so. It would be interesting to note how

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11. The following studies fall under this section: Reference numbers: 8,60,71,75,77,80,86,89,95,99,100

many health care professionals actually counsel patients. It was apparent from most of the studies that there exists a fear of being at risk due to the nature of the profession. Health professionals display a lack of openness towards PLWHA, history taking was poor and physical examination for sexually transmitted infections nearly absent.

### **3.2 Safer sexual practices, and other modes of risk reduction<sup>12</sup>**

Of the eighteen studies that studied safer practices for risk reduction, the majority have concentrated on 'high risk' groups. Ten of the studies deal only with 'high risk' groups, the prevalence of infection amongst them and practices for prevention. Of the remaining eight, six deal with both the general population and with 'high risk' groups. Only two study only the general population. A study based in Gujarat (24) attempts to study the usage of condoms by married men while another study (45) examines positive women's knowledge about AIDS and their ability to control the sexual behaviour of their spouses. This study acknowledges the difficulty in women being able to use condoms or abstain from sex when they know their partners have been practising risky behaviour.

The studies on 'high risk' groups include studies on sex workers, men who have sex with men, intravenous drug users (IDU), eunuchs, truck drivers and even one study with mentally ill persons (47). Condom use has been equated to safer sex methods and therefore a number of studies have attempted to explore its usage (33,37,24,16,70,108,25). According to a study in Indore, 96% of adolescent truck cleaners had engaged in sexual activity without using a condom. A study with sex workers in Tamil Nadu reported that 78% of the respondents had never used condoms. There are no studies examining people's knowledge and practice of other safe sex techniques.

While exploring the use of the condom, nearly all the studies have restricted themselves to gathering information about whether people used them or not. The only study (24) that examines whether condoms are being used correctly found that only 1.8% of men who had not adopted any permanent method of family planning used condoms. It also found that people were re-using condoms as well as using oil based lubricants which tear the condom. However, this study restricts itself to men on the basis that only men will be using condoms and that it is very difficult to gather information from women.

The understanding of modes of transmission is very narrow with the most attention is being paid to safer sex. Sex has been equated with penetrative intercourse There are a few studies on barbers, tattoo artists and blood donors (39,69,74,76). While a number of studies on the knowledge and attitude of health care professionals do check their knowledge about transmission, very few actually ask them about the preventive measures that they are practising. None of the studies explore the health and economic issues around anti retroviral therapy (ART) and caesarean sections in order to reduce the risk of mother to child transmission.

The studies conducted amongst sex workers tended to concentrate on gaining information about their knowledge about AIDS, prevalence of AIDS and condom usage. Within high risk groups such as sex workers, poor negotiation skills in the context of the relationship further complicate condom use, despite knowledge. Only one study from Sonagachi (44) discusses the rights of sex workers, their attitudes, social organising amongst them as well as condom negotiation with clients and the economics of the sex trade that keeps women so vulnerable to the HIV/AIDS epidemic. It explores in detail the role of peer support, improvement in the status of sex workers and social mobilisation towards enabling women to practice safer sex. However, the same issues have not been explored amongst married women and single women.

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12. The following studies fall under this section: Reference numbers: 1,3,16,24,45,33,36,37,54,25,47,39,69,76,40,44,108

Only two of the studies look at sexual behaviour in infected people. One study (45) found a change in sexual behaviour post interventions. Fifty percent of the couples who were regularly counselled continued to practice safe sex. The other (34) has stated that some people have sex less frequently once they found out that they were positive. This was based either on medical advice or the fear of being further weakened by sex. Others continued to have sex, with or without using condoms. By the time they found out that they could have sex using safer sex methods, their partners were very sick and so they abstained.

### **3.3 Biological and societal vulnerabilities to HIV/AIDS<sup>13</sup>**

Women are more susceptible to HIV infection at each sexual encounter, where male to female transmission of HIV is 2-4 times more efficient than female to male<sup>14</sup>. Since immunity is suppressed during pregnancy, there is concern that this may also accelerate the progression of the infection in HIV positive women. Added to this are a series of socio-cultural factors that make women even more vulnerable to infection. Women do not have access to information that may make it possible for them to protect themselves. They are often married early, to partners who are much older and more experienced than them. Societal norms accepting extra-marital sexual relationships amongst men as normal, when combined with women's inability to negotiate safer sex with their partners makes even women in monogamous relationships even more vulnerable to infection. Violence against women also plays a large role in making women more vulnerable to infection.

While experiential data shows that women come to know about their own and the partner's positive status at antenatal check-ups, it was not possible to find any article on this issue. Similarly, a lot of concern has been generated about mother to child transmission. However only one study dealing with the coping strategies of positive mothers was reviewed (115). Literature on women as a person undergoing these experiences, care of women during labour, concerns and anxieties during different stages of pregnancy and development of her child could not be located.

The presence of sexually transmitted diseases creates a fertile ground for transmission. At the same time, HIV makes it easier to acquire STD's. Seven of the studies deal with STD and HIV/AIDS transmission. Only one study (8) attempts to link HIV/AIDS to other STD's and examined the possibility of linking HIV/AIDS treatment with STI/STD interventions. No studies examining the links of HIV/AIDS with other opportunistic infections were reviewed. All available studies were bio-medical in nature and outside the purview of this review. One of the studies (33), is predominantly a bio-medical study which examines the prevalence of STD's amongst infected patients. A number of the studies try to draw a relationship between the presence of STD's and HIV (36,37,43,68,) by examining the high risk behaviour amongst groups such as truck drivers and intravenous drug users. Multiple sexual contacts were found to be the most common route of transmission and 65% of positive people had a history of sexually transmitted diseases (43). Having an STD is not a condition that leads to immediate help seeking because of the embarrassment faced in exposing oneself. Younger women who had STD's tend to go untreated for long periods of time. Only one of the studies (45) explores women's responses to STD's. Despite knowing that they and their husbands were infected they were unable to raise the issue and negotiate for abstinence or safer sex.

A few of the studies make the links between education, economics and marginalisation and identified the factors that make marginalised groups more vulnerable to HIV/AIDS. A household study used severe

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13. The following studies fall under this section: Reference numbers: 33,68,37,36,43,45,115,23,54,25,40,2,45,56,85

14. Women of South East Asia: A Health Profile. WHO 2002

mental illness as a proxy for AIDS to find the impact of AIDS in all parts of Delhi ranging from slums to upper income neighbourhoods (23). It found that economic status was directly related to AIDS awareness. Higher income groups were also aware of and able to invest in protective measures such as disposable syringes. Some studies (54, 25) examine the economic factors that make people more vulnerable to infection. Poverty has been cited as a reason for women entering sex work in one of the studies (54). It has also been cited as a factor that reduces the negotiating power of women in professions such as sex work (25). Only one of the studies looked at sex tourism and the high vulnerability of young children in tourist areas such as Goa.

The study in Goa mentioned above mentions youth involvement in tourism as an area of vulnerability. The practices and lifestyles of a number of groups such as migrant labourers (40) and truck cleaners (37) have been studied in order to assess their vulnerability to infection. Male vulnerability has also been looked at beyond the classical approach of sexual behaviour, examining the context of realities of risky behaviour. However, none of the studies examines the gender norms that prevent men from seeking information or indulging in unsafe and unprotected sex in order to prove their machismo. Not only do such stereotypes put the men themselves at risk, they also indirectly affect the women partners of these men.

Very few studies examine women's vulnerability to infection because of socio-cultural factors. Some of the studies make references to the lower status of women but do not examine the contributions of culturally proscribed gender roles, their associated traits and behaviours that impact detrimentally on women, vulnerability and progression on illness. None of the studies examine women's increased vulnerability due to violence, including forced sex and marital rape. However, in the case of sex workers, rape and sexual abuse by pimps and clients has been mentioned as a factor that increases vulnerability to HIV/AIDS (54). A number of the studies (2,45,56,85) also acknowledged the need to pay special attention to information dissemination amongst women as socio-cultural factors make it difficult for them to access information.

### **3.4 Economic impact of HIV/AIDS<sup>15</sup>**

The connection between poverty and AIDS and poverty is not, at first sight as obvious as that between poverty and poor health in general. However, the connection of poverty with AIDS is much more disastrous when we look at the impact of AIDS versus the determinants of infection. The psycho-social impact of HIV/AIDS have been documented by researchers. However, only three studies examined the economic impact of the syndrome. While these studies acknowledge the cost that the nation will bear as more and more young people fall ill and stop contributing to the economy, they do not examine this in detail. All three of the studies (23,28,58) examine the economic impact of HIV/AIDS on the individual and the family.

Illness has a faster impact upon the poorer than the rich, as those in manual and unskilled jobs cannot afford to take even a day off from work without loss of income. Younger individuals, men, individuals with lower incomes, those with at least one child and with a minimum of one illness were the most vulnerable to the impact (58). AIDS related female mortality was found to have an even higher impact than male mortality as families found themselves unable to handle household finances. When working women were infected, the family was greatly impacted as her income formed an essential part of the family income (58).

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15. The following studies fall under this section: Reference numbers: 23,28,58

Though these studies concentrate on male samples they are sensitive to the impact of the epidemic on women. They acknowledge that families have more than one person who is infected. The spouse and one or more children may also be infected with the virus. They examine social welfare services and the lack of insurance and medical facilities. Medical care incurs the highest expenditure, the costs increasing with the period of infection. Very few people in the country have access to any kind of formal insurance (28). These studies also acknowledge the socio-cultural factors preventing women from earning a living and contributing to the household income as the primary wage earner begins to fall ill.

### **3.5 Disclosure, stigma and discrimination<sup>16</sup>**

Responses from the community as experienced by infected people and in general have been judgemental with a great deal of attention to the source of infection. This means that marginalised groups such as IDU's, sex workers and women are doubly disadvantaged. The greatest stigma has been from the health workers and this has impeded accessing information, service delivery and care seeking. Fear of discrimination by health care professionals, fear in breach of confidentiality and guilt did not make care acceptable (20). Nearly all the studies give attention to women's health seeking behaviour, especially when both partners are infected and resources scarce.

A number of the studies have looked at the knowledge and attitude of people towards HIV/AIDS. However, these studies have tended to study attitude from the perspective of the 'other'. Six of the studies reviewed have actually looked at the perspective of PLWHA. In general, these studies have been able to document the PLWHA fears and experiences with regards to the family and the community. Findings on family responses have been mixed. While some studies have shown that while family responses have been fairly positive with a component of historical contribution based on the relationship between caretaker and caregiver, others (34) have documented negative experiences including blame, ignoring and desertion. Persons whose families were HIV/AIDS literate have reported a more positive response.

One of the studies, conducted by a network of positive people (34) has successfully documented the range of discriminatory practices faced by infected people. It also explores the discrimination faced by children and partners of positive people. They have also documented PLWHA health seeking behaviour and experiences with the medical community. Respondents said they faced considerable discrimination from medical personnel- their status was clearly pinned on hospital beds and case sheets, hospital staff physically distanced themselves and they found themselves isolated in separate wards. Their records were available to all staff in the hospital. Hospital procedures like wrapping a positive person's corpse in a polythene packet labelled HIV positive often subjected the family to discrimination.

This study also took care to ensure that the number of male and female respondents was equal. However, the differences in male and female experiences have not been documented in this study, nor the additional burden faced by positive women who are care givers themselves. The same study discusses the role of support groups and NGO's. However, this study does not detail the participation of women in these groups. Hence there is no information on women's involvement, satisfaction, and contribution, especially when their attendance is likely to be governed by personal, societal and family demands and needs.

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16. The following studies fall under this section: Reference numbers: 4,10,19,20,27,34,

### 3.6 Mental health issues including chemical dependency<sup>17</sup>

The studies on mental health are of three types: those studying psychiatric issues before and after infection, those studying the coping strategies of PLWHA and those studying chemical dependency. A study conducted amongst psychiatric inpatients in Bangalore (47) found that 59% with schizophrenia, 48% with affective disorder and 5% with personality disorders had a history of HIV related high risk behaviour. Depression among positive patients was linked to concerns associated with a decrease in social activities and fears of infecting others. Homosexual and unprotected coerced sex did not feature significantly as a risk behaviour (47). All of these studies are based in institutional settings and do not explore the differences in impact due to gender. Women who are mentally ill are often abandoned, leaving them more susceptible to rape and other forms of abuse.

While a number of the studies looking at disclosure and stigma deal with coping strategies, four of the studies pay special attention to the coping strategies used by PLWHA. One of the studies (115) examines the coping strategies used by young mothers with HIV/AIDS including dealing how they deal with queries about caesarean sections and breast feeding. The other three studies (3,27,109) examine the psychological responses to disclosure. A suicidal tendency was reported though suicidal attempts were rare (3). Others reported 'fear' and 'anxiety' (40%), depression (17%), shock (7%) and numbness (20%) (27). These studies explore the different coping strategies used by women. Women reported anger at having been infected by their husbands (27).

The largest section of the studies on mental health issues look at chemical dependency. A total of eleven studies dealing with chemical dependency were reviewed. The links between high-risk behaviour and substance abuse have been strong, not as a direct source of infection, but as a factor that facilitates risky behaviour. Except for one study (49) which examines substance abuse as a coping mechanism after the disclosure of HIV/AIDS status, the rest examine the risks and behaviours associated with substance abuse. A study of positive people in a psychiatric hospital reported that 70% of respondents were dependent on alcohol, 44% of the total were admitted for substance abuse and 26% had a psychiatric disorder along with substance abuse.

A number of the studies (6,20,29,107) on intravenous drug use have been carried out in north-eastern India. The primary mode of transmission in the north-eastern state of Manipur has been needle sharing amongst IDUs. Only one of the studies (6) talks about the vulnerability of indigenous groups to both, substance abuse and the concurrent vulnerability to HIV/AIDS. The studies on substance abuse do not make any reference to the vulnerability of the partners of the substance abusers. They also do not refer to the issues faced by women who are chemically dependent. Women who are chemically dependent are more vulnerable to violence and abuse. They may also be forced to engage in unwanted sex by touts. A large proportion of sex workers are also chemically dependent, thereby decreasing their ability to negotiate as well as use condoms.

### 3.7 Rights of positive people<sup>18</sup>

Only one study, conducted by a network of positive people (34) makes any reference to the rights of positive people. It reported that positive people had little awareness about their rights. With regard to reproductive rights, the study noted that persons with HIV were not expected to marry and have children by society. It also mentioned that there was a fear of confidentiality being violated in medical institutions.

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17. The following studies fall under this section: Reference numbers: 3,6, 20,27,29,31,36,37,42, 43,49,107,108

18. The following studies fall under this section: Reference numbers:34

Other studies have made fleeting references to controlling sexual decisions, condom usage, and negotiation of safer sex with partners, especially when it is the man who is infected.

### **3.8 Prevention programmes and interventions<sup>19</sup>**

Interventions have been carried out to increase knowledge about HIV/AIDS and bring about behaviour change in order to decrease high risk behaviour. Strategies such as IEC interventions, counselling sessions, modular programmes and behaviour change interventions have been carried out. Different categories of risk groups such as adolescents, community groups, sex workers, IDU and chemically dependent people have been the target groups for interventions. Studies on interventions are of basically two types- those studying the impact of IEC materials and educational programmes and those studying the impact of counselling on high risk behaviour.

A number of the studies (13,51,56,64,94,101,112) on the impact of IEC programmes have used only pre intervention and post intervention questionnaires to measure the difference in KAP. Though the details about of the IEC programme are rarely given, all the studies report that knowledge levels increased perceptibly after the intervention. They also reported that respondents were clearer about causation than the modes of transmission, signs and symptoms, prevention modalities and referrals. Except for two studies (56, 112), which describe large district level programmes on AIDS prevention education, the rest have been conducted with small groups such as ICDS functionaries (51), voluntary organizations (101) and educational institutions (13,94).

The studies on impact of counselling have been conducted both in institutions and the community. Four of the studies (25, 29, 31, 38) have been conducted in institutional settings, two of which (29, 31) have been conducted in de-addiction centres and two (25, 38) in STD clinics. A study in a de-addiction centre (29) in Manipur found that counselling would have no impact unless supported by an increase in availability of safer injection material. Others (38) reported only a moderate change in behaviour after counselling.

Of the two studies looking at the impact of counselling upon the community, one was conducted solely with men (12) and the other only with women (45). Only one of the studies (45) looks at the difference in impact of interventions with women. It acknowledges the socio-cultural factors that prevent women from negotiating condom usage even though they are aware of their partners high risk behaviour or the presence of a STD. Even a study with sex workers (25) does not acknowledge the factors that prevent them from enforcing safer sex practices with their clients. The study states that women do not seem to be too keen to use condoms and that the condoms provided by the government are substandard and unacceptable to the client.

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19. The following studies fall under this section: Reference numbers: 12,13,25,29,31,38,45,51,56,64,70,94, 101,104,110

## V. OUTSTANDING RESEARCH NEEDS

Research on HIV/AIDS reinforces the earlier notions of the virus affecting only those who engage in risky behaviour- 'high risk' groups such as sex workers and intravenous drug users. As the epidemic moved from its original entry points such as sex workers to bridge populations like drivers and then to the mainstream community, the research has failed to keep pace. Almost till the very end of the last decade, studies adopted a moralistic tone about the behaviour of 'high risk' groups and most studies tried to examine their understanding and knowledge about HIV/AIDS.

The objective of a large percentage of studies is to assess the level of knowledge about HIV/AIDS. They have done so by using questionnaires with very basic questions about awareness and attitudes. No conclusive relationships have been drawn between knowledge and attitudes and practices. These studies are not able to make any concrete recommendations. With a few exceptions most of the studies have very small sample sizes and it is therefore very difficult to generalise their findings.

The foregoing review has suggested, that with a few exceptions, a gender perspective is largely lacking in research on HIV/AIDS in the last decade. Research has failed to explore the aspects that make women and other marginalised communities more vulnerable to infection, to lack of care and to the violation of their rights. Social science research on HIV/AIDS in India has also tended to restrict itself to the prevention of transmission stage and not moved onto issues around living with AIDS, care, treatment and the impact of the epidemic.

There exist substantial gaps in our knowledge about HIV/AIDS and its impact. The following is a summary, by no means comprehensive, of key areas of research warranting further attention. In most studies, there is little discussion on the ethical issues related to researching an issue such as HIV/AIDS. While most of the studies have stated that anonymity was maintained, there is a need for more discussion around these issues.

1. Very few studies examine women's vulnerability to infection because of socio-cultural factors. For example, restrictions on movement and education hinder young girls from accessing information. Early marriage and sexual activity exposes girls to an increased risk of STD's, especially if their husbands are older and have been sexually active. How do culturally proscribed gender roles, their associated traits and behaviours impact women's vulnerability and progression of illness? Research on these issues as well as the gender differences in risk perception and behaviour across different age groups and settings would help design more relevant IEC material and prevention programmes.
2. There is not enough information on single women in both rural and urban areas. Existing research seems to display a moralistic stance by being silent about the sexual behaviour and practices of this group.
3. The threat or experience of physical violence may be an outcome for women attempting to negotiate safer sex through the use of condoms. Violence in the form of coerced sex may also result in the acquisition of HIV, as coerced sex increases the risk of micro-lesions. More information is needed on women's increased vulnerability due to violence, including sexual abuse, forced sex and marital rape.
4. It is very difficult to reach men engaged with male-male sex with information and services. Knowing about their lifestyles, their sexual behaviour and practices is important in order to protect both them and their female partners from HIV/AIDS.



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5. What are the factors that inhibit condom use, as well as the issues involved in negotiating condom use? Safer sex has also been equated to condom use and there is no information documenting the knowledge and practice of other methods of protection.
7. Though mother to child transmission has been a topic of great concern, not enough information exists on the issue. Anti retroviral therapy is provided free of cost only to pregnant women in India. Sudden withdrawal of the drugs post delivery can cause the mother's immunity to drop drastically. More information is needed about the impact of pregnancy and the experience of delivery. Men have also been completely left out of the picture in ante-natal care and studies.
8. Not enough studies exist on the impact of the epidemic across economic groups and by gender. Are people being discriminated against in their place of work? Are they able to retain employment? If not, how does this impact their physical and mental well-being? How are they sustaining themselves as well as covering their medical expenses?
9. How has the epidemic impacted both rural and urban areas? What is the effect of migration by both men and women?
10. There is no information about the prevalence of infection among adolescents. The studies with adolescents have restricted themselves to assessing knowledge and perceptions. NACO figures are also presented only for women and children and for adults.
11. Studies in other countries have reported a devastating impact amongst indigenous groups. The differentials in impact and response across different social groups in India need to be documented.
12. The rights of positive people need to be further documented and studied. Positive people have been at the centre of legal debates around their right to marry. They are facing discrimination in medical settings around issues such as confidentiality and mandatory testing. They are often turned away or referred to bigger hospitals as soon as their positive status is revealed.
13. There are no studies looking at the availability, access and quality of care for PLWHA. Health care facilities and treatment including anti retroviral therapy and drugs for opportunistic infections need to be studied. Understanding the differentials in access to health care and medication based on gender from the perspective of positive people will help develop better care facilities.
14. Not enough is known about the care seeking behaviour of men and women from different socio-economic groups. Both the government and the state provide counselling services and health facilities for PLWHA. What are the facilities available and how many people access them? What are the factors that influence people accessing these services? And most importantly, if people are not accessing these services, then where are they going?

In order to slow down the progress of the HIV/AIDS epidemic and reduce its impact, it is first necessary to understand completely the factors that have made it so easy for the epidemic to have taken root and then spread so rapidly in India. It is also essential that the factors that affect and increase its impact are also recognised. This means that it is necessary to have meaningful research that is informed by a gender and social perspective. We hope that this review has contributed to this first step by identifying some of the unexplored issues, thereby initiating research into them. This would, in turn help bring about social, policy and programmatic changes.

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