

Review Article

Indian J Med Res 122, December 2005, pp 471-484

The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs

Nita Mawar, Seema Sahay, Apoorvaa Pandit* & Uma Mahajan*

*National AIDS Research Institute (NARI) (ICMR) & *Stigma Study, NARI, Pune, India*

Received November 16, 2004

An overview of social responses to AIDS, characterized by high levels of stigma, discrimination central to the global AIDS challenge, as related to human dignity is described. Stigma is conceptualized as a problem of 'they' and 'us', or interactions perspective. Causes and consequences to enable the varied perspectives in understanding this third epidemic of social impact of HIV/AIDS are described. In the absence of an effective medical intervention, the social factors like stigma and discrimination attached to HIV/AIDS are a major obstacle in the curtailment of the disease requiring urgent action. The different forms of stigma associated with other diseases are compared. Ignorance about the disease, fear of discrimination and consequent denial for testing and treatment, contribute to spread of the disease. The disease status adds to vulnerability especially in women. The disease is often identified with groups like intravenous drug users (IDUs), and homosexuals who face a double stigma as a result of HIV. Research scenario on stigma associated with HIV/AIDS is reviewed to understand the future needs. Initiatives of ongoing intervention to reduce stigma exist globally. Emerging issues in research priorities have been highlighted to counter consequences of pandemic from social perspective of human dignity and rights.

Key words AIDS - discrimination - social issues - stigma

The AIDS scenario

HIV/AIDS is increasingly being recognized as not merely a medical problem, but a social problem as well¹. The latter aspect requires an understanding of the determinants of risk behaviour and factors influencing behaviour changes related to the issues of treatment of opportunistic infections, anti-retroviral therapy (ART), and adherence and prevention of secondary transmission. In India,

prevention programme interventions initially focused on increasing awareness and knowledge of HIV/AIDS, and in nineties it became evident that increased knowledge was not enough to change behaviours, but in absence of a cost-effective therapy or a vaccine, the behavioural change for preventing HIV transmission remains a viable option. However, research focusing on intervention, behaviour research and human rights needed to be pursued intensively².

With nearly 87 per cent of infections contracted sexually and transfusion associated, intra-venous drug use and vertically transmitted infections accounting for the rest^{3,4}, focus on behaviour change and prevention intervention seems to be crucial. In India, HIV prevalence varies widely according to geographical areas and risk groups leading to stigma and discrimination. The consequences of this stigma indicate two different situations. Firstly, there is a lack of support and care for the HIV infected both at the level of community and in health care setting, secondly, the fear of stigma may dissuade many individuals to get themselves tested⁵⁻⁷.

Social issues related to HIV/AIDS

One of the major factors that plays a role in the dynamics of HIV infection, is the level of empowerment. The low level of education, especially in women and patriarchal system puts women in a subservient position. Consequently, women have lesser control over their own bodies and lack negotiating skills for their protection⁸⁻¹¹. Also, sex and sexual behaviour were hitherto tabooed subjects for discussion between parents and children and even in a formal set-up between teachers and college youth. Thus, children and youth are likely to have more misconceptions and be misinformed, and in the long run, pose risk for HIV/AIDS⁸⁻¹².

People living with HIV are stigmatized leading to severe social consequences related to their rights, health care services, freedom, self-identity and social interactions. It also severely hampers the treatment and diagnosis of HIV contributing to further spread of the disease^{1,13,14}. Infected people are blamed for causing the condition through their risky behaviour, observed as early as in late eighties in opinion polls in US among Americans^{15,16}. According to the polls, 'It's people's own fault if they get AIDS'. Such responses disrupt an individual's social interactions and thereby lead to a feeling of isolation¹⁶.

The eventual death with AIDS evokes anxiety and may lead people to believe that not enough time remains to weigh carefully the strengths and

weaknesses of various alternative solutions to an AIDS related problem. These beliefs are likely to foster a vigilant style that can isolate HIV infected still further. In such decision making the easiest or most readily available perceived solution is adopted without considering its consequences^{17,18}.

In India, public health officials until recently held that women in prostitution, homosexuals, or intravenous drug users (IDUs) only could contract AIDS largely ignoring a dramatic rise in new AIDS cases among monogamous, married women¹⁹. Even diseases like tuberculosis (TB) carry stigma as children with TB were not permitted to return to classes even after successful treatment due to misconceived notions, that they would still spread the disease to others¹⁹. The HIV/AIDS scenario appears to be even worse as this still remains an incurable disease. The persons suffering from stigmatized diseases are assumed to have violated certain social norms and taboos and thus responsible for it. Stigma and discrimination take different forms for varied diseases indicating a need for focused prevention and treatment strategy. Lessons learnt from the successful experiences of stigma associated with other diseases must be borne in mind when HIV/AIDS related programmes are developed as it amounts to denying the rights of the infected individuals²⁰⁻²³.

HIV and its consequences

The AIDS epidemic has often been associated with severe negative public reactions ranging from banning entry of HIV infected individuals to isolating an individual in the family, deserting a pregnant wife on knowing her HIV status in the hospital, or removing a person from his job, or even denying a child admission in school. These negative reactions have shaped the behaviour of infected individuals and have limited the effectiveness of prevention efforts. AIDS also evokes anxiety because of its association with death¹⁴. People in AIDS group reported lower levels of social support in response to bereavement²⁴, as compared to that in cancer group indicating the social stigma attached

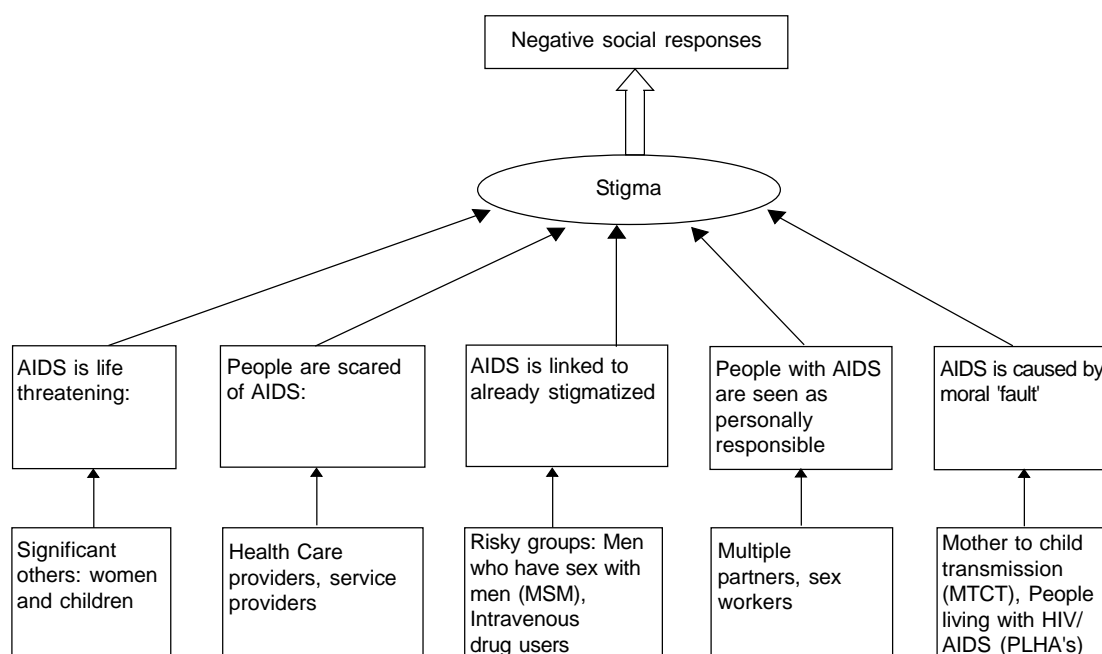


Fig. Conceptualizing stigma: Key determinants to AIDS - related stigma.

Source: Modified from ref. 27-29.

to HIV/AIDS that does not get erased even after death. Also, there is no control over stressors like communal and social ostracization, victimization, and deprivation in India²⁵.

Conceptualizing HIV/AIDS stigma

AIDS and HIV stigma can be better understood when the perspectives are realized from both the outsider's and the insider's viewpoints. According to Goffman²⁶, stigma in context of HIV/AIDS may be interpreted from the point of view of the outside observer as follows, "Psychological, interpersonal, sociological, economic and/or political effects on persons who possess certain characteristics. Alternatively, the focus of attention may shift to those who identify themselves as not possessing the specified traits" or "Stigma may be understood from an interaction's perspective based on the language of relationships, stigma viewed as a product of, and inherent in a relationship between 'normal' and the 'other'."

This approach attributes state of mind or describes socio-economic effects of the possessor,

the accuser, or the relationship of one or the other. Thus, the approach uses the viewpoints of persons who are themselves stigmatized and those who actually stigmatize. Stigma may be approached from a phenomenological perspective. Stigma incorporates an acknowledgement of cultural values; it is a depiction of life as an individual experiences it within the social cultural milieu. In the context of HIV/AIDS, stigma is associated with the medical progression of opportunistic infections, moral transgressions of both homosexual and heterosexual relationships and afflictions transmitted through the notion of risky group as opposed to risky behaviour. These descriptions have led to the notions of 'us' and 'they' where the latter are stigmatized through the values and attitudes based on moral judgments rather than the medical aspects of the infection²⁷⁻²⁹.

HIV/AIDS stigma has been described in varied ways starting from understanding it as a social construct existing in relation to a deviance. Stigma is a multi-dimensional concept, its essence centering on the issue of deviance³⁰. Further, stigma is a feature of HIV infection/disease and many people who are

HIV-positive report that their lives are affected by fear of discrimination and how the infection affects the life of these individuals. Stigma can be described as a felt and as an 'enacted stigma', that refers to sanctions individually or collectively applied upon those with HIV whereas the felt stigma relates to feelings of shame and an oppressive fear of enacted stigma. The social consequences of both felt and enacted stigma are experienced by the individuals in terms of their rights, freedom, self-identity and social interactions that often influence the decisions to seek HIV testing and to access prevention services³¹ (Fig.).

Individuals with HIV and AIDS are stigmatized because their illness is associated with behaviours that are not acceptable socially, both as a product and producer of such behaviour³². It is viewed as the responsibility of the individual³³, tainted by a religious belief as to its immorality^{30,34} and/or thought to be contracted via a morally sanctioned able behaviour³³, not well understood by the general community and viewed negatively by health care providers³⁵. All these factors influence the appropriate health care that an HIV infected individual is otherwise entitled to as a right^{1,2}.

Global response to HIV/AIDS stigma

The organized global sector responded to the HIV/AIDS epidemic in eighties and since then there has been a serious concern about how the epidemic would impact the community. As defined by Mann³⁶, HIV epidemic exists in three phases. In the first phase, the epidemic enters a community silently, unnoticed and often develops over many years without being widely perceived or understood. The second phase is the epidemic itself, the syndrome of infectious diseases that can occur because of HIV infection but typically after a delay of number of years. The third phase is a response to AIDS and that revolves around the social, cultural and political issues, this phase has been described as the most explosive phase resulting from the reactions that are characterized by exceptionally high levels of stigma, discrimination and at times collective denial. These social and behavioural issues are central to the global AIDS

challenge, as the disease itself requires concerted action from local to national and global level^{36,37}.

HIV is a biologically complex virus, but this complexity pales in comparison to the complexity of the social forces involved in the production and reproduction of stigma in relation to HIV/AIDS³⁸. However, factors related to stigma, discrimination and denial are poorly understood, and there have been few attempts made to understand this very complex problem. Each country has responded to the consequences of this epidemic in its own ways.

In India, to alleviate the epidemic's devastating social and economic impact, the National AIDS Control Organization (NACO) vision envisages to catalyze an expanded response to the HIV/AIDS epidemic in order to contain the spread of infection; reduce people's vulnerability to HIV; and promote community and family based care to HIV/AIDS cases in an enabling environment without any stigmatization and discrimination³⁹. However, mechanisms to cope up with these consequences are not specified making prevention efforts far more challenging. This is especially so, when it involves vulnerabilities of populations that include the women, the youth, the specific groups with sexually transmitted infections, the men who have sex with men and the intravenous drug users.

HIV/AIDS and the groups with risky behaviours

People living with HIV/AIDS (PLHAs): PLHAs and the social groups to which they belong to, have been stigmatized worldwide since the beginning of epidemic⁴⁰⁻⁴³. Perhaps, the epidemiological need to conceptualize risky groups has alienated the marginalized groups. This is especially so, when research has shown that poverty and associated high risk behaviours may be far more predictive of acquiring the disease. PLHAs have been distanced by strangers and family members, discriminated against in employment and health care, driven from their homes, and subjected to physical abuse. Such fears of stigma has deterred individuals from being tested for HIV and from disclosing their seropositivity status to sexual partners, family, and friends⁴⁴⁻⁴⁸ (Fig.).

Men who have sex with men (MSM): The recent surveillance report indicates an HIV prevalence of 24 per cent in Mumbai and 4 per cent in Tamil Nadu among the MSMs⁴⁹. Among the MSMs in a rural area, stigma was predictive of modified high sexual risk when compared to low and no risk categories⁴⁷.

Women: The traditional patriarchal societies put women at low risk of HIV infection but men's behaviour is tolerated even if it puts them to certain risky behaviours, their greatest risk being husband's behaviour ranging from 1 per cent in general population of antenatal cases to 14 per cent in monogamous women attending STD clinics^{11,26,50}. The social hierarchy and the differential power relations that exist, blame women for bringing the infection in the family, especially seen when the woman has been tested for HIV before the husband, as happens in several antenatal clinics⁵¹. Coping with her HIV status and looking after her child is a double burden that she has to manage along with her own health and social vulnerabilities. Social norms, subservience in marriage, often reinforced by violence, can compromise women's ability to protect themselves, while a husband although asymptotically HIV positive gets opportunity to leave his wife with AIDS and his children to find another wife^{52,53}. Further, women are often blamed for spreading both STDs and HIV⁵⁴⁻⁵⁶. However, the early cases reported in women were attributed to their being "prostitutes" or drug abusers and the source of HIV/AIDS⁵⁷.

When women are diagnosed with HIV/AIDS, the psychosocial implications, rather than the physiological impact, become the focus. Though research indicates that method of transmission affects the level of stigma, this was not true in women⁵⁸. Those infected by their husbands or blood transfusions suffered as much stigma as those who contracted the virus from a sexual encounter with an unknown individual. Though women are more likely to disclose their HIV/AIDS status to employers than men, they are still hesitant to tell and often do not, unless it is necessary to adjust work demands to accommodate their health status⁵⁹.

Women with HIV/AIDS are hesitant to access health care for fear of breach of confidentiality, perceive stigma from provider, and are reluctant to take medications that identify them as being ill⁶⁰. Women are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism, or their property being seized after their partner died⁶¹⁻⁶³. The denial of these rights increases women and girls' vulnerability to sexual exploitation, abuse and HIV. The impact of epidemic on women and girls is especially marked as they face heavy economic, legal, cultural and social disadvantages⁶⁴. According to the Centers for Disease Control and Prevention (CDC), the number of women with HIV/AIDS continues to increase. Women with HIV/AIDS are not rare but hidden⁶⁵.

India is a signatory to numerous international agreements on the rights of the women and has a constitution that prohibits discrimination and exploitation by gender, however, it has failed to protect the human rights of women satisfactorily particularly those of sex workers. This discrimination is manifested in high levels of violence in the sex industry, child sex workers, lack of access to health care and high levels of HIV infection⁶⁶. Rising levels of HIV among sex workers can provide early warning of increasing probability that the epidemic will expand into the general population⁶⁴. In India, commercial sex workers have been documented as sources of HIV/AIDS, STDs and other communicable diseases⁶⁷⁻⁶⁹.

Intravenous drug users (IDUs): The IDUs carry the double burden of stigma of addiction and HIV infection. The HIV prevalence among IDUs in Manipur was 54 per cent, in Kohima and Dimapur it was more than 50 per cent⁷⁰. These increasing numbers are adding to the social problem. It is seen that stigma associated with HIV/AIDS is known to have a negative impact. The people with HIV/AIDS, were often quarantined, subjected to universal mandatory testing, and tattooed for identification^{60,71}.

Stigma at health setting: Influence of stigma upon health decisions has been studied extensively. It has been suggested that a high degree of stigma among

individuals living with HIV infection could have the potential to impact an individual's decision to enter medical care regimens⁷². Stigma shares a relation with care, drop out and inconsistency in adhering to medical regimens^{73,74}.

HIV testing and counselling support: HIV/AIDS stigma affects issues related to HIV testing including delays in testing, the effect of delay on secondary transmission, and individuals' responses to testing positive⁷³. Voluntary counselling and testing is an important strategy for HIV prevention entailing pre-test to post-test counselling for optimal impact. Failure to return for report and post-test counselling has been reported to be associated with lower levels of social support, knowledge about HIV/AIDS testing and perceived risk for HIV infection and more common among those with higher perceived risk of HIV stigma⁷⁵⁻⁷⁷. A study in Pune⁷⁸ showed ongoing confidential counselling and testing were positively associated with risk reduction behaviours among men. On the other hand, lack of privacy in stores, the social stigma associated with using condom were the most significant barriers for its use⁷⁹.

Consequences of disclosure of HIV status: Disclosure of HIV infection can lead to important social support to mitigate the negative effects of stress. Such stress may arise due to the perceived discrimination, disgrace, disharmony, concern about insurance and employment, a desire to protect oneself and others emotionally and from violence^{45,80-83}. Hiding one's serostatus may not only preclude HIV related social support and benefits but may also have direct negative effects on disease progression for HIV-positive individuals⁸⁴. The choice of disclosure is a complex decision and varies in different cultures from revealing HIV status to friends and sharing this with family members^{80,82,85,86}. Studies indicate that disclosure rate of HIV infected individuals to family members is higher than to friends for illness management and treatment for HIV in India and Thailand^{86,87}. It has been shown that perceived stigma and discrimination are at times more powerful than enacted stigma and discrimination in discouraging people from being open about their own serostatus and in accessing treatment and support especially for reducing the development of psychological morbidity

and its cost^{50,88,89}. Consequence of disclosure with respect to mental health was also found to be favourable among asymptomatic males⁹⁰.

Research on HIV/AIDS related stigma

As a result of the social impact of HIV epidemic, studies on HIV/AIDS related stigma have been initiated globally, especially in Europe, US, Australia, Africa and Asia including India to document the forms of the stigma and the resulting discrimination in varied settings, particularly in health care settings. These studies^{6,31,90-92} attempted to understand the complexity of stigma using both qualitative and quantitative research approaches (Table).

A National AIDS Research Institute-Yale University (USA) study being conducted in a high prevalent city in Maharashtra, India, used qualitative and quantitative methods to document stigma in health settings^{5,6}. The study has shown that (i) a wide range of feelings exhibited by clinicians about HIV-positives who often made moral and non clinical attributions about individuals' past "misbehaviour," and "misconduct"; (ii) few providers reported fear of touching HIV/AIDS patients, while others considered it a special duty. Initial testing and disclosure often occur without the patient's knowledge, consent, or counselling; (iii) hospital practices, such as a separate AIDS ward, HIV diagnoses on open charts, and the conspicuous use of biohazard labels serve to discriminate HIV/AIDS patients; and (iv) hospital policy is often unclear to clinicians and the hospital practices often have discriminatory consequences.

It is recommended that inconsistent knowledge, beliefs and standards of care for HIV positive patients by hospital staff should urgently be addressed through comprehensive training to focus on HIV/AIDS care standards, universal safety precautions, patients sensitivity, and modified standards.

Quantifying scales that measure stigma

As a result of collaborative efforts of Yale University, USA and NARI, Pune, India, for the first time an Implicit Association Test (IAT) has been

Table. Research studies on HIV/AIDS related stigma

Author/year/study title	Study site/population/methodology	Importance of the study/lessons learnt for future action
GIPA ⁹⁸ , 2004	Paris PLHA Participatory methodology approach	A high level of satisfaction amongst study participants who felt that their rights were respected and for the first time their consent was truly valued.
G. Gill ³¹ , 1995	U.K. Men and women Street survey questionnaire	The public's avowed attitudes towards HIV are not a punitive or stigmatizing as the infected believe them to be. Need to alleviate the felt stigma with HIV diagnosis through counselling.
Bharat <i>et al</i> ⁹² , 2001	India PLHA, Health care providers, NGO staff, Industry personnel, Social welfare officers, Lawyers/Activists, Patient rights activists, Insurance expert, Gay activists Qualitative: KII, IDI, FGD	Identified forms of stigma in health care and community setting. It is recommended that there should be more proactive responses that address the root cause of discrimination an stigmatization namely AIDS related misconceptions, ignorance, prejudices and biases. Need to understand the extent of stigma issues influencing policy changes in HIV/AIDS.
Cobb & Chabert ⁹¹ , 2002	U.S. Social Service providers (men and women) Questionnaire	The service providers working with HIV/AIDS affected, attributed more anger and were less likely to help male targets than female targets. More studies to validate the findings in other settings.
Kalichman & Simbayi ⁹⁰ , 2004	South Africa Men and women IDI, FGD, Questionnaire	Misinformation about AIDS among the community is the cause of stigmatizing beliefs. Need to explore factors affecting HIV/AIDS stigma in depth.
Bird <i>et al</i> ⁹⁴ , 2004	U.S PLHA Questionnaire	Discrimination based on race and socio-economic status was perceived by the HIV infected in their interactions with providers while seeking treatment for HIV/AIDS. Need to explore perceptions of discrimination based on other factors among HIV-positive individuals.
Mawar N ⁶⁻⁷	India Doctors, nurses, ward boys, counsellors, PLHA and their family care givers IDI, FGD, Implicit association test (IAT) & explicit questionnaire. IAT is developed first time in India to measure HIV/AIDS stigma	Understanding of stigma processes in health care settings. Identified the forms of stigma at structural, attitudinal levels, behavioural level in health care providers Self stigma at individual level. Quantifying stigma through IAT and explicit questionnaire. Need for urgent intervention in health care setting. Also, to measure changes in stigma with ART intervention.
SHARAN ⁹³ (Horizons/ Population Council), 2001	India PLHA Self assessment questionnaire	Assessing factors that affect the quality and type of care received by PLHA. An additional objective is to assess and address factors that affect staff safety with respect to infectious diseases.

GIPA, Greater involvement of people with HIV/AIDS.

PLHA, People living with HIV and AIDS; NGO, non government organization; KII, Key informant's interview; IDI, In depth interview; FGD, focus group discussion; ART, anti retroviral therapy

developed and used to measure stigma associated with HIV/AIDS as a fatal disease or as a sexually transmitted disease or as an infectious disease^{5,6,14}. This test has been developed specifically to suit Indian culture. It is a self-administered test, designed to examine thoughts and unconscious feelings of health care providers that exist while treating patients with HIV⁶. The IAT was introduced by Greenwald *et al*⁹⁵ to assess attitudes related to race and gender issues in the West, and reveal the existence of discrepancy between our implicit and explicit attitudes. Once this method is standardized, it would serve as a useful tool to measure HIV/AIDS stigma in other settings.

Pre-existing stigma and the burden of dual stigma of HIV/AIDS

At the initial stage, the HIV/AIDS epidemic in the west was socially defined as a disease of the marginalized groups, often identifying the disease with the four H's: the homosexuals, the heroin addicts (through iv drug use), Haitians, and the haemophiliacs. This identification of an illness with group of individuals, defined as "risk group" gave an opportunity to others to see themselves "as removed from the epidemic and protected from it"⁹⁴. Thereby, the stigma attached to AIDS as an illness is layered upon pre-layered stigma. The definition of the HIV/AIDS syndrome results in a dual stigma, first from identification of AIDS as a serious incurable illness, second from the identification of AIDS with persons and groups already stigmatized due to their behaviour prior to the epidemic^{13,96,97}. This discrimination was in a way the starting point of differentiating the infected from the uninfected individuals. According to the CDC report⁷², AIDS had been a disease of already the stigmatized group of homosexuals (63%); IDUs (19%) and about 7 per cent cases fitting in both groups, and Blacks and Hispanics were disproportionately represented in all transmission categories. The only exception was the group of haemophiliacs who did not represent any of the stigmatized group. In United States, AIDS became a symbol and reactions to AIDS are reactions to gay men, drug users, racial minorities and outsiders in general¹⁴.

AIDS related stigma interacts with pre-existing stigma in various ways. According to Goffman's terminology²⁶ identification of a person with AIDS transforms a man from "discreditable" (secretly gay) to "discredited" (publicly gay). This also leads to bifurcating individuals with a disease as outsiders that further leads to increasing community's solidarity by clearly identifying its boundaries⁴⁴. The frequent use of the "general public" as counterpart to the "risk group" conveys a clear distinction between in-group and out-group; with the gay men, IDUs and their sexual partners not considered part of "the general public"^{14,27,44}. HIV related stigma refers to the prejudice, discounting, discrediting and discrimination that are directed at people living with HIV or AIDS (PLHAs) and at the individuals, groups and communities associated with the PLHAs⁹⁸.

Innocent victims to most blame able victims

The persons who did not contract AIDS through homosexual behaviour or drug use have been categorized as innocent victims and included the haemophiliacs, spouses of HIV positives, children of the HIV infected mothers *etc*⁹⁹. The social fall out thereby, has been seen as a wide spectrum of the haemophiliacs, monogamous women and infants with HIV infection as the most "blameless victims" to the "most blame able victims" who were infected due to an already stigmatized behaviour like being a gay, an IDU, or being a promiscuous person.

In developing countries, particularly in African and Asian countries like South Africa and India, the heterosexual route is the most common route of transmission where the high and low risk behaviour groups were identified on the basis of the sexual behaviour and in restricted pockets through the intravenous drug use. Moral connotations were used to describe the behaviours as those with 'promiscuous behaviour' while the haemophiliacs and the infants with HIV infection were considered as the innocent victims. In India, more than three fourths of the HIV infections are due to the heterosexual route, thereby the groups with risky behaviours like the commercial sex workers, truck drivers and the mobile populations were labeled as the groups with 'promiscuous' behaviour and the 'others' as the innocent victims

who were the partners of these persons particularly the spouses⁴. The ‘other’ group of concern was children of infected mothers. This concern eventually paved way for a short-term zidovudine (AZT) intervention programme to prevent mother-to-child transmission on an urgent basis at eleven sites with successful results^{3,51}. This has now been translated into a major intervention programme at government hospitals with the replacement nevirapine given to HIV infected mothers just before delivery to avoid the transmission to the newborn.

Stigma associated while participating in HIV/AIDS research studies

While intervention research is on its way to look for solutions, identifying participants for such HIV/AIDS research during trials is not easy, as it involves the HIV/AIDS associated stigma as seen in the following studies:

(i) Short-term AZT intervention feasibility study to prevent mother-to-child transmission (PMTCT): Pregnant women volunteering to be enrolled for AZT intervention to reduce the HIV transmission to their newborn evinced interest in participating in this study. However, these women were not clear about the long-term implications of participating in this short-term AZT intervention feasibility study during pregnancy to reduce the HIV transmission. This included the fear of being stigmatized by the family members on revealing her HIV status, especially by participating in the study entailing several visits to the clinic. Thus, monitoring women’s comprehension during follow up visits with provision of psychosocial support is essential. This should be incorporated through understanding women’s comprehension of the trial as an ongoing strategy and support provided accordingly⁵¹.

(ii) Vaccine trials: A study conducted with STD clinic attendees¹⁰⁰ to assess their willingness to participate in HIV vaccine trials in India also raised the issue of fear of stigma of being labeled as high risk individual. Of those who thought that HIV is discriminating disease, 56 per cent individuals feared discrimination due to vaccine induced HIV-positive report. Therefore, a reduction in stigma is required to

actually conduct vaccine trials that would contribute to curb HIV infection.

Strategies to eradicate stigma and discrimination related to HIV/AIDS

HIV/AIDS stigma exists at both individual and societal levels, and all attempts to eradicate this stigma need to target at these two levels. It is imperative to design intervention and education programme to impart information for individuals at varied levels to reduce the stigma attached to HIV/AIDS. There is an urgent need that the public policies address issues of treatment and prevention to establish social norms based on acceptance and respect for HIV infected persons. Initiatives in this direction have been made across all continents, keeping in mind the foremost issue of human rights that includes by its very definition social acceptance, respect, compassion and support without blame. A change in attitudes of service providers through greater knowledge and political will is considered as the most significant approach to challenge the existing stigma in health care settings and in the community as well.

Eliminating AIDS related stigma would require action in the following areas: (i) An individual’s HIV status must remain confidential and unauthorized disclosure of this information should be condemned. (ii) Discrimination on the basis of HIV status should be prohibited. (iii) Public education efforts must directly confront HIV/AIDS related stigma and these efforts enable norms that increase acceptance, respect and compassion for the infected, starting from home and the family to the place a person works, seeks health and other services. (iv) The responsibilities of researchers on rights of research participants through the involvement of PLWA are utilized.

Future needs and other research priorities

Research that elucidates the ways in which public health decisions are taken in view of the epidemic would be useful. Research is needed to explain differential standards for men and women, the meanings of sexual “promiscuity”, “prostitution”, interactions of different power relationships and the

nature and extent of stigmatization experienced by persons with AIDS.

While earlier studies have given useful insights through the systematic use of qualitative methods and contributed to the recommendations for prevention programme, generalization based on these data may not be adequate to influence policy. Research focusing on stigma in health care settings and related services would increase the scope of such studies to become realistic advocacy tools to influence policy changes. Few studies in India are underway and it is hoped that these would contribute in developing prevention strategies that focus on minimizing the social harm resulting from stigma and discrimination^{5,6,99}.

Research priorities on HIV/AIDS related stigma

Research is required to enable a better understanding of the varied forms of stigma taking place in the community and at the level of service providers. It is imperative that the lack of adequate documentation be fulfilled. This would interface with developing models to influence the much desired policy changes for meaningful interventions to take place. More studies are needed to focus on the following: (i) Measuring stigma in health care and related service providers through development of implicit and explicit scales appropriate for Indian conditions in different health care, service delivery settings and community settings. (ii) Develop models to reduce HIV/AIDS stigma for strengthening the role of voluntary counselling and testing centres. (iii) Improving patient care approaches through measuring changes in treatment seeking behaviour of HIV infected individuals for opportunistic infections through improved patient care approaches. (iv) Develop strategies for greater involvement of PLHA (GIPA)⁹⁸, especially to create an ambience for women to access antenatal care services and avail prevention of mother-to-child transmission (PMTCT) intervention. (v) Understand the role of the GIPA in reducing the process of stigma and discrimination in the community. (vi) ART and treatment related issues in the context of HIV stigma. (vii) Stigma related to participation in research trials for HIV vaccine, microbicides, ART and other research trials. (viii)

Utilize research initiatives to influence policy level decision- making for reducing stigma in health care settings, workplace and other service providers. (ix) Assessing the prevalence of varied forms of stigma and focus on the dual stigma and discrimination that impacts on services in public and private health care settings, workplace and community especially among vulnerable population like women, drug users, MSMs to develop models for meaningful preventive interventions. (x) Develop and demonstrate the impact of intervention strategies at vertical and horizontal levels to reduce the stigma and discrimination practices and influence policy changes.

Conclusions

AIDS related stigma poses a problem for all in the society thereby, imposing severe hardships on the people who are its targets and it ultimately interferes with treatment and prevention of HIV infection. Emphasis on the eradication of AIDS related stigma would enable in creating a social climate conducive to a rational, effective and compassionate response to this epidemic^{93,97,98}. Public health managers and the government need to address the following types of AIDS stigmatization¹⁰¹: (i) Theologically/morally based blame on those who are infected, (ii) The concern for the health of those not afflicted by disease, (iii) Eliminating risk group categories as it gives false security to its marginalized group, and (iv) The civil rights problems, human rights centered approaches are enforced.

A major challenge that requires frequent debates, the human rights approach would prove to be a long term investment for HIV/AIDS treatment and prevention. There is a need to bring an understanding between the rights of the individual, who is at risk of exposure and condemnation because of stigma, and the rights of the rest of the society for the effective development of large scale effective public health programme. A human rights approach lies at the heart of any HIV/AIDS programme that seeks to prevent HIV transmission and supports those already infected^{102,103}. In the long run of the third phase of HIV pandemic centering on the human rights would

emphasize on minimizing the erosion of the social, economic, cultural and political impact this pandemic has caused. The human rights approach would also reduce the stigma.

References

1. UNAIDS World AIDS Day message: Dr Peter Piot (1 December 2002) Available at http://www.unaids.org/whatsnew/speeches/eng/2002/WAD02PPmessage_en.html.
2. Technical Resource Group on Research and Development on HIV AIDS: AIDS Research Priorities for India - Phase II National AIDS Control Programme - Consultative Document. National AIDS Research Institute, Pune (undated mimeo).
3. NACO-UNAIDS: India Responds to AIDS: A strategic response to the HIV epidemic by the Government of India, the UN and its development partners in India; 2000.
4. National AIDS Control Organisation 1997-98: Country Scenario. NACO, Ministry of Health and Family Welfare, NACO, Govt. of India, New Delhi.
5. National AIDS Research Institute: Annual Report 2002-2003: NARI, Pune.
6. National AIDS Research Institute: Annual Report 2003-2004: NARI, Pune.
7. Salunke SR, Shaukat M, Hira SK, Jagtap MR. HIV/AIDS in India: A country responds to a challenge. *AIDS* 1998; 12 (Suppl B) : S27-31.
8. Moore AR, Williamson DA. Problems with HIV/AIDS prevention, care and treatment in Togo, West Africa: professional caregivers' perspectives. *AIDS Care* 2003; 15 : 615-27.
9. Norr K, Tlou S, Norr J. The threat of AIDS for women in developing countries. In: Cohen F, Durham JD, editors. *Women children and HIV*. New York: Springer Publishing Co; 1993 p. 263.
10. Mawar N. Women, AIDS and shared rights, shared responsibilities. *CARC Calling* 1995; 8 : 11-3.
11. Gangakhedkar RR, Bentley ME, Divekar AD, Gadkari D, Mehendale SM, Shepherd ME, *et al*. Rapid spread of HIV infection in married monogamous women in India. *JAMA* 1997; 278 : 2090-2.
12. Mawar N, Kohli R, Joglekar N, Bagul R. Children and young people in context of HIV/AIDS: Listen, learn and live! World AIDS Day campaign with children and young people. *ICMR Bull* 1999; 29 : 125-35.
13. Bharat S. HIV/AIDS related discrimination, stigmatization and denial in India - A study based in Mumbai and Bangalore (sponsored by UNAIDS, Geneva, TISS Mumbai) 1999. UNAIDS, Geneva.
14. Mawar N, Paranjape RS. Live and Let Live: Acceptance of people living with HIV/AIDS in an era where stigma and discrimination persist. *ICMR Bull* 2002; 32 : 105-14.
15. Gallup G. Survey results indicate difficulties gays face in a heterosexual society. *The Gallup Opinion Index* 1977; 147 : 17.
16. Gallup G. Backlash against gays appears to be leveling off. *The Gallop Report* 1987; 258 : 12.
17. Slovic P. Perception of risk. *Science* 1987; 236 : 280-5.
18. Janis IL, Mann L. Decision making: a psychological conflict of choice and commitment. In: Weber EV, Baron J, Loomes G, Lopes L, Arkes HR, editors. *Conflict and trade of decision making*. New York Free Press 1997 p. 154.
19. Das V. Stigma, contagion, defect: Issues in the anthropology of public health. Stigma and Global Health: Developing a Research Agenda, An International Conference. September 5-7; Bethesda, Maryland; 2001. Available at <http://www.stigmaconference.nih.gov/DasPaper.html>.
20. Lazare A. Impact of Biotechnology on Cancer Diagnostic & Prognostic Indicators; 2000 October 28-31; Geneva, in the section on G Haidak memorial lecture. Available at <http://www.cancerprev.org/Journal/Issues/24/101/121/3823>.
21. Arole S, Premkumar R, Arole R, Maury M, Saunderson P, Principal P. Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy. NSP-CENIDS 2002-2003. Available at <http://bvs.insp.mx/componen/svirtual/ppriori/nbibliodet.asp?idb=7781>).
22. Weiss, MG, Ramakrishna J. Interventions: Research on reducing stigma. Stigma and Global Health: Developing a Research Agenda. International Conference. September 5-7; Bethesda, Marylandd. 2001. Available at <http://www.stigmaconference.nih.gov/WeissPaper.html>.
23. Jaramillo E. Tuberculosis and stigma: Predictors of prejudice against people with tuberculosis stigma, tuberculosis. *J Health Psychol* 1999; 4 : 71-9.
24. Kelly B, Raphael B, Statham D, Ross M, Eastwood H, Mclean SO, *et al*. A comparison of psychosocial aspects of AIDS and cancer related bereavement. *Int J Psychiatr Med* 1996; 26 : 35-49.
25. AVERT. HIV and AIDS stigma and discrimination web page edited by J Fredriksson and A Kanabus 2005 available at http://avert.org/aids_stigma.html. Updated Nov. 2005.

26. Goffman E. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice-Hall; 1963.
27. Parker R, Aggleton P. HIV and AIDS related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med* 2003; 57 : 13-24.
28. De Bruyn T. Women and AIDS in developing countries. *Soc Sci Med* 1992; 34 : 249-62.
29. De Bruyn T. HIV/AIDS and 1. discrimination, 2. Stigma and Discrimination: Definitions and Concepts. Ottawa, Canadian HIV/AIDS Legal Network and the Canadian AIDS Society; 1999.
30. Alonzo AA, Reynolds NR. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Soc Sci Med* 1995; 41 : 303-15.
31. Green G. Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be? *Soc Sci Med* 1995; 41 : 557-68.
32. Conrad P. The social meaning of AIDS. *Soc Pol* 1989; 17 : 1-51.
33. Sontag S. AIDS and its Metaphors. Farrar, Straus, and Giroux, New York 1988 p. 47-54.
34. Strommen EF. Hidden branches and growing pains: homosexuality and the family tree. *Marriage Family Rev* 1989; 14 : 9-34.
35. Kelly JA, St. Lawrence JS, Smith S, Hood HV, Cook DJ. Stigmatization of AIDS patients by physicians. *Am J Public Health* 1987; 77 : 789.
36. Mann J. AIDS - a global perspective. *West J Med* 1987; 47-673.
37. Piot P. Stigma, bias present barrier in fight against AIDS pandemic. *AIDS Policy Law* 2001; 16 : 5.
38. WHO, UNICEF, UNAIDS, World Bank, UNESCO and UNFPA. Report on response to infectious diseases. *Public Health Rep* 2002 ; 117 : 84-5.
39. USAIDS/INDIA. HIV/AIDS Programme. Available at <http://www.usaid.gov>.
40. Singhal A, Rogers EM. Combating AIDS: Communication strategies in action. Sage Publication, New Delhi; 2003.
41. Herek GM, Glunt EK. An epidemic of stigma: Public reactions to AIDS. *Am Psychol* 1988; 43 : 886-91.
42. Farmer P. AIDS and Accusation: Haiti and the geography of blame. Berkeley CA: University of California Press; 1992.
43. Herek GM, Capitanio JP. Public reactions to AIDS in the United States: A second decade of stigma. *Am J Public Health* 1993; 83 : 574-7.
44. Durkheim E. The rules of sociological method. Lukes S, editor. W.D. Halls, (Translated version). New York: Free Press; 1982 (Original work published 1895).
45. Hays, RB, Mcukusick L, Pollack L, Hillard R, Hoff C, Coates, TJ. Disclosing HIV seropositivity to significant others. *AIDS* 1993; 7 : 425-31.
46. Gielen AC, O'Campo P, Faden RR, Eke A. Women's disclosure of HIV status: Experiences of mistreatment and violence in an urban setting. *Women Health* 1997; 25 : 19-31.
47. Derlega VJ, Lovejoy D, Winstead BA. Personal accounts on disclosing and concealing HIV-positive test results: Weighing the benefits and risks. In: Derlega VJ, Barbee AP, editors. *HIV and social interaction*. Thousand Oaks, CA: Sage; 1998 p. 147-64.
48. Lester P, Partridge JC, Chesney MA, Cooke M. The consequences of a positive prenatal HIV antibody test for women. *J Acquir Immune Defic Syndr Hum Retrovirol* 1995; 10 : 341-9.
49. Blackstone Market Facts. Mapping of commercial sex access points and relevant service outlets in Maharashtra: Study conducted by SERD with technical assistance from FHI, USAID, 2001.
50. Zanello D, Gala C, Pergami A, Catalan J, Burgess A, Durbano F, et al. Heterosexual and HIV disease: controlled study of psychosocial factors associated with psychiatric distress. *Int Conf AIDS* 1992; 8 : 148 (abstract no.7595).
51. Mawar N, Joshi PL, Sahay S, Bagul RD, Prasad Rao JVR, Paranjape RS. Concerns of women in mother-to-child transmission: Lessons learnt from a trial of AZT feasibility in pregnant women. *Int AIDS Conf, Barcelona; 2002*. (Abst No. TuPeD4987).
52. UNAIDS. Report on the global HIV/AIDS epidemic. June 2000. UNAIDS/00.13E.
53. Danziger R. Social impact of HIV/AIDS in developing countries. *Soc Sci Med* 1994; 39 : 905-17.
54. Schoepf BG. Culture, sex research and AIDS prevention in Africa. In: Brummelhuis H, Herdt G, editors. *Culture and sexual risk. Anthropological perspectives on AIDS*. Amsterdam: Gordon and Breach Publishers; 1995.
55. Laver S. AIDS education is more than telling people what not to do. *Trop Doct* 1993; 23 : 156-60.

56. Mogensen HO. AIDS is a kind of Kahungu that kills. The challenge of using local narratives when exploring AIDS among the Tonga of Southern Zambia. Copenhagen: Scandinavian University Press; 1995.
57. Shilts, R. And the band played on: Politics, people, and the AIDS epidemic. New York: Penguin; 1988.
58. Herek GM, Capitanio J.P. AIDS stigma and sexual prejudice. *Am Behav Sci* 1999; 42 : 1130-45.
59. Fesko SL. Disclosure of HIV status in the workplace: Considerations and strategies. *Health Soc Work* 2001; 26 : 235-44.
60. Fife BL, Wright ER. The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav* 2000; 41 : 50-67.
61. Human Rights Watch. Ravaging the Vulnerable: Abuses against persons at high risk of HIV infection in Bangladesh. Human Rights Watch Report; August 2003. Available from www.hrw.org.
62. Maman S, Mbwambo JK, Hogan NM, Kilozi JP, Campbell JC, Weiss E, *et al*. HIV-positive women report more lifetime partner violence: findings from a voluntary counseling and testing clinic in Dar-es-Salaam, Tanzania. *Am J Public Health* 2002; 92 : 1331-7.
63. UNICEF. Africa's orphaned generations. 2003, UNICEF report available on http://www.unicef.org/publications/files/africas_orphans.pdf accessed on 16 Dec 2005.
64. UNAIDS Report on the global HIV/AIDS Epidemic July: 2004. Available on <http://www.unaids.org/bangkok2004/GAR2004html>.
65. Centers for Disease Control and Prevention. Update: The AIDS epidemic in the United States, 2001. *Morb Mortal Wkly Rep* 2002; 51 : 592-5.
66. Misra G, Mahal A, Shah R. Protecting the rights of sex workers: the Indian experience. *Health Hum Rights* 2000; 5 : 88-115.
67. Babu DS, Marwah SM, Singh G. Social and behavioural aspects of venereal disease among resident male university students. *Int J Epidemiol* 1976; 5 : 121-4.
68. Urmil AC, Dutta PK, Basappa K, Ganguly SS. A study of morbidity pattern among prostitutes attending a municipal clinic in Pune. *J Indian Med Assoc* 1989; 87 : 29-31.
69. Singh YN, Malaviya AN, Tripathy SP, Chaudhari K, Bhargava NC, Kahre SD. HIV serosurveillance among prostitutes and patients from a sexually transmitted diseases clinic in Delhi, India. *J Acquir Immune Defic Syndr* 1990; 3 : 287-9.
70. Sarkar S, Das N, Panda S, Naik TN, Sarkar K, *et al*. Rapid Spread of HIV among injecting drug users in North-Eastern state of India. *Bull Narc* 1993; 45 : 91.
71. Herek GM. AIDS and stigma. *Am Behav Sci* 1999; 42 : 1106-16.
72. Centers for Disease Control AIDS Weekly Surveillance Report. <http://www.cdc.gov/Atlanta>: 1988; June 6.
73. Herek GM, Mitnick L, Burris S, Chesney M, Devine P, Fullilove MT, *et al*. AIDS and stigma: a conceptual framework and research agenda, a Workshop report. *AIDS Public Policy J* 1998; 13 : 36-47.
74. Chesney MA, Smith AW. Critical delays in HIV testing and care: the potential role of stigma. *Am Behav Sci* 1999; 42 : 1162-74.
75. Reece M. HIV related mental health care: factors influencing dropout among low-income, HIV-positive individuals. *AIDS Care* 2003; 15 : 207-15.
76. Stein JA, Nyamathi A. Gender differences in behavioural and psychological predictors of HIV testing and return for test results in a high-risk population. *AIDS Care* 2000; 12 : 343-56.
77. Catania JA, Kegeles SM, Coates TJ. Psychological predictors of people who fail to return for their HIV test results. *AIDS* 1990; 4 : 261-2.
78. Sullivan PS, Lansky A, Drake A. Failure to return for HIV test results among persons at high risk for HIV-infection: results from a Multistate Interview Project. *J Acquire Immune Defic Syndr* 2004; 35 : 511-7.
79. Bentley ME, Spratt K, Shepherd ME, Gangakhedkar RR, Thilikavati S, Bollinger RC, *et al*. HIV testing and counseling among men attending sexually transmitted disease clinics in Pune, India: Changes in condom use and sexual behaviour over time. *AIDS* 1998; 12 : 1869-77.
80. Levy A, Laska F, Abelhauser A, Delfraissy JE, Goujard C, Bowe F, *et al*. Disclosure of HIV seropositivity. *J Clin Psychol* 1999; 55 : 1041-9.
81. Mason HRC, Marks G, Simoni JM, Ruiz MS, Richardson JL. Culturally sanctioned secrets? Latino men's nondisclosure of HIV infection to family, friends and lovers. *Health Psychol* 1995; 14 : 6-12.
82. Semple SJ, Patterson TL, Shaw WS, Pedlow CT, Crant I. Disclosure of HIV seropositivity to sexual partners: an application of social cognitive theory. *Behav Ther* 1999; 30 : 223-37.

83. Wolitski RJ, Rietmeijer CA, Goldbaum GM, Wilson RM. HIV serostatus disclosure among gay and bisexual men in four American cities: General patterns and relation to sexual practices. *AIDS Care* 1998; *10* : 599-610.
84. Simoni JM, Mason HRC, Marks G, Ruiz MS, Reed D, Richardson JL. Women's self disclosure of HIV infection: rates, reasons & reactions. *J Consult Clin Psychol* 1995; *63* : 474-8.
85. Cole SW, Kemeny ME, Taylor SE, Visscher RR. Elevated physical health risk among gay men who conceal their homosexual identity. *Health Psychol* 1996; *15* : 243-51.
86. Stempele RR, Moulton JM, Moss AR. Self-disclosure of HIV-1 antibody test results: The San Francisco General Hospital Cohort. *AIDS Educ Prev* 1995; *7* : 116-25.
87. Chandra PS, Deepthivarma S, Manjula V. Disclosure of HIV infection in South India: patterns, reasons and reactions. *AIDS Care* 2003; *15* : 207-15.
88. Bharat S, Sanghnetra RA, Aggleton P. Household and community response to HIV/AIDS in Asia: the case of Thailand and India. In: Kaldor J, Brown T, Bharat S, Zhang K, editors. *AIDS in Asia and the Pacific*. 2nd ed. Pennsylvania: Lippincott-Raven; 1998 p. 17-122.
89. Bharat S, Aggleton P. Facing the challenge: household responses to AIDS in Mumbai, India. *AIDS Care* 1999; *11* : 31-44.
90. Kalichman SC, Simbayi L. Traditional beliefs about the cause of AIDS & AIDS related stigma in South Africa. *AIDS Care* 2004; *16* : 572-80.
91. Cobb M, De Chabert JT. HIV/AIDS and care provider attributions: Who's to blame? *AIDS Care* 2002; *14* : 545-8.
92. Bharat S, Aggleton P, Tyrer P. India: HIV and AIDS related discrimination, stigmatization and denial, A report prepared for UNAIDS, Geneva, Switzerland; 2001.
93. SHARAN. The PLHA-friendly achievement check list: A self-assessment tool for hospitals and other medical institutions caring for people. <http://www.popcouncil.org/hiv aids/stigmaR1.html> 14 Dec 2005.
94. Bird ST, Bogart LM, Delahanty DL. Health-related correlates of perceived discrimination in HIV care. *AIDS Patient Care STDs* 2004; *18* : 19-26.
95. Greenwald AG, McGhee DE, Schwartz, JLK. Measuring individual differences in implicit cognition: the implicit association test. *J Pers Soc Psychol* 1998; *74* : 1464-80.
96. Des Jarlais DC, Friedman SR, Hopkins W. Risk reduction for the acquired immunodeficiency syndrome among intravenous drug users. *Ann Intern Med* 1985; *103* : 755-9.
97. Herek GM. Beyond "homophobia": A social psychological perspective on attitudes toward lesbians and gay men. *J Homosex* 1984; *10* : 1-21.
98. GIPA World AIDS Day 2004: Project for personal stories from PLHAs. http://www.gnpplus.net/gipa.stories/GIPA_in_action.
99. Albert E. Illness and deviance: The response of the press to AIDS. In: Feldman DA, Johnson TM, editors. *The social dimensions of AIDS*. New York: Preager; 1986 p. 163.
100. Sahay S, Mehendale S, Sane S, Brahme R, Brown AS, Charron K, et al. Correlates of HIV vaccine trial: an Indian perspective. *Vaccine* 2005; *28* : 1351-8.
101. Mansergh G, Marks G, Simoni JM. Self disclosure of HIV infection among men who vary in time since seropositive diagnosis and symptomatic status. *AIDS* 1995; *9* : 639-44.
102. Goldin CS. Stigmatization and AIDS: Critical issues in public health. *Soc Sci Med* 1994; *39* : 1359-66.
103. Mann J, Tarantola DJM, Netter TN. AIDS in the world - A global report. Harvard University Press, England; 1992.

Reprint requests: Dr Nita Mawar, Deputy Director, National AIDS Research Institute (NARI) (ICMR), Post Bag 1895
73-G, Bhosari Industrial Estate, Pune 411026, India
e-mail: nmawar@nariindia.org, nitamawar@yahoo.com