



ICMR

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## LIVE AND LET LIVE : ACCEPTANCE OF PEOPLE LIVING WITH HIV/AIDS IN AN ERA WHERE STIGMA AND DISCRIMINATION PERSIST

South and south-east Asia is the epicenter of the HIV epidemic, with majority of the infections expected to be occurring in this region. Within the region, India is estimated to have the largest burden of the epidemic in terms of the numbers, with about 3.97 million people reported to be infected with HIV<sup>1,2</sup>.

Within about two decades the epidemic has emerged as one of the most serious health problems in the country. The initial cases of HIV/AIDS were reported among commercial sex workers in Chennai and Mumbai and in injecting drug users in north-eastern state of Manipur. However, the infection has since then spread rapidly in the areas adjoining these epicenters and by 1996, Maharashtra, Tamil Nadu, and Manipur together accounted for 77% of the total AIDS cases in the country. Varied cultural characteristics with reference to the sex related risk behaviours make the estimation of HIV prevalence difficult.

Maharashtra and Tamil Nadu, the two worst affected states, accounted for nearly half of the total number of HIV infections in the country and Manipur, a small state accounts for nearly 8% of HIV infections in the country<sup>2</sup>.

Of all the HIV infections, nearly 87% are contracted sexually and are transfusion associated and intra venus

drug (IVD) use driven. Vertically transmitted infections make up the remaining<sup>2,3</sup>. These are, however, only the reported number of cases, as the estimated number may be still higher. The fear of stigma related to the disease itself dissuade many individuals from getting themselves tested.

### AIDS and HIV Related Stigma

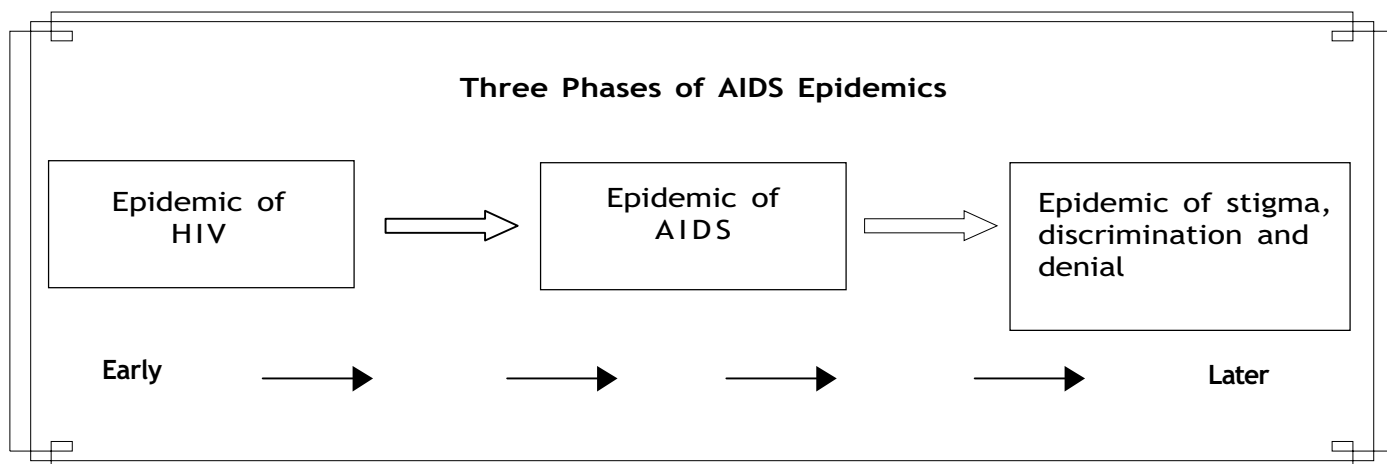
The organized global sector responded to the HIV/AIDS epidemic much earlier, in eighties itself and ever since there has been a serious concern regarding how the epidemic would impact on the community. Jonathan Mann, founding Director of the World Health Organization's Global Programme on AIDS, stressed on the existence of three phases of the AIDS epidemic in any community<sup>4</sup>:

**Phase I:** The epidemic of HIV infection that enters a community silently and unnoticed and often develops over many years without being widely perceived or understood.

**Phase II:** The epidemic of AIDS itself, the syndrome of infectious diseases that can occur because of HIV infection but typically after a delay of a number of years.

Phase III: The epidemic of social, cultural, economic and political responses to AIDS, described as potentially the most explosive, as reactions that have been characterized, above all, by exceptionally high levels of stigma, discrimination and at times collective denial. These are central to the global AIDS challenge as the disease itself.

this epidemic, and gain insight into why this stigma exists and discrimination occurs. This would address the issues surrounding stigma and discrimination in the HIV/AIDS prevention and control programmes. An understanding of how and why AIDS stigmatization occurs and affects research, diagnosis, treatment and prevention efforts is



The stigma has continued as a challenge even subsequently and has been included as one of the five most pressing items of UNAIDS. Peter Piot emphasized that, effectively addressing stigma removes what still stands as a roadblock to concerted action, whether to local community, national or global level, so action against stigma ramifies across every single aspect of HIV work<sup>5</sup>.

Despite the gap of over one decade between the two statements made globally the similarity in the statements underscores the fact that the issue of stigma continues to stand at the center of the fight against the global AIDS pandemic. This is despite the huge resources that have been mobilized to control the epidemic at a global level. The human immunodeficiency virus is a biologically complex organism, but this complexity pales in comparison to the complexity of the social forces involved in the generation and reproduction of stigma in relation to HIV/AIDS<sup>4,5</sup>. But the issues related to stigma, discrimination and denial have been poorly understood and very few attempts have been made to understand this very complex problem.

Thus, the theme for the World AIDS Day-2002 “Live and let live” aptly focuses on the issues related to stigma and discrimination. This will also mobilize us to look with greater concern about people infected and affected by

critical for developing effective public health programme<sup>6</sup>. An attempt has been made to discuss these issues in the present write-up.

### Defining Stigma

AIDS and HIV stigma can be better understood when the perspectives are realized both from the outsider’s and the insider’s viewpoints.

A description of stigma incorporates an acknowledgement of cultural values: it is a depiction of life as an individual within the social and cultural milieu experiences it. In the context of HIV/AIDS, the stigma is associated with the devastating medical progression of opportunistic infection, moral transgressions in the context 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 infection.

### AIDS and The Risky Group

AIDS is not a general public health problem. It is considered to be a problem of those ‘others’ with risky behaviours and those who are considered to be

susceptible to risks, are primarily considered important because of their potential to spread and to leak out of the afflicted population to the general population. The epidemiological categories to conceptualize the risky groups, has had no impact in the containment of the HIV infection as the infection still continues to spread among those with no risk. However, by such categorization, it has further alienated those individuals who are on the margins e.g. the sex workers, the migrants, women, etc. This is especially when research has shown that poverty and associated high risk behaviours may be far more predictive of disease risk. The public health concerns associated with risk group stigma arise because of the false sense of security people assume when they identify some groups of 'others' with risky behaviours as potential disease bearers who can transmit the infection to those with whom they share similar risky situations e.g. unsafe sex, sharing needles for intra venous drug use (IVDU), etc. There is still another group of individuals who have no risk of their own but their risk is because of these others with risky behaviours. This group is considered as the 'innocent victims' e.g. the spouses of HIV infected persons, children of infected parents, the recipients of HIV infected blood from a blood bank.

### Stigma and AIDS

The AIDS epidemic has often been associated with severe negative public reactions to persons who are assumed to be infected by HIV. These reactions have ranged from isolating an individual in the family to deserting a pregnant wife 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 death.

### Sources of Stigma

In eighties, AIDS was perceived as a lethal disease that can be contracted by specific behaviours and was considered to be a disease of gay men and intra venous drug users in the west and persons with promiscuous behaviours in other countries. The definition of the syndrome resulted 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<sup>7,8</sup>. This dual stigma of the HIV infection and the associated behaviour make the life difficult for an infected individual

### FACTORS CONTRIBUTING TO HIV/AIDS RELATED STIGMA

- HIV/AIDS is a life-threatening disease
- People are scared of contracting HIV
- The disease is associated with behaviours (such as sex between men and injecting drug-use) that are already stigmatized in many societies
- People living with HIV/AIDS are often thought of as being responsible for becoming infected
- Religious or moral beliefs that lead some people to believe that HIV/AIDS is the result of moral fault (such as promiscuity or deviant sex) that deserves to be punished.
- Sexually transmitted diseases are well known for triggering strong responses and reactions in the community.
- Early in the AIDS epidemic a series of images were used that reinforced and legitimized stigmatization. These are:
  - à HIV/AIDS as a punishment (e.g. for immoral behaviour)
  - à HIV/AIDS as a crime (e.g. innocent and guilty victims)
  - à HIV/AIDS as horror (e.g. in which infected people are feared)
  - à HIV/AIDS as otherness (disease as an affliction of those set apart)

Together with the widespread belief that HIV/AIDS is shameful, these images represent ready-made but inaccurate explanations that provide a powerful basis for both stigma and discrimination. These stereotypes also enable some people to deny that they personally are likely to be infected or affected.

Source: file://A:AIDS stigma.htm

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to cope-up with, in his/her individual capacity and as a member of the family to which he belongs and the community as a whole.

As happens with other life threatening illnesses, AIDS confronts even the non-infected individual with the reality of death. The fear of death due to an incurable disease is a psychological burden for the infected individual and coping with the disease is a challenge. The psycho-social impact of the disease falls on the significant others of this infected individual, viz the spouse, family members, children, etc. The fact that the disease is due to a virus that is most frequently transmitted sexually, poses risk to many individuals as in sexual transmission multiple partners of at least one partner are often involved. This happens in majority of the cases and it is socially not acceptable. As a consequence of coping with the infected individuals the healthy individuals distance themselves by defining the illness as an affliction of others whose death is certain within a stipulated time. In addition, they give a moral judgment to rationalize their distancing from the HIV infected individual.

Early news reports in USA identified the disease to be associated with homosexuals, the heroin addicts (through IVD use), the Haitians and haemophiliacs. This identification of an illness with groups of individuals, defined as risk groups gave an opportunity to others to see themselves as protected from the epidemic and protected from HIV/AIDS<sup>9</sup>. This form of distancing and discrimination was in a way the starting point of differentiating the infected from the uninfected individuals. The attempts to continue with these attitudes towards such serious illness lead to attributions of individual character flaws to diseased persons. Although victim blaming on the basis of individual characteristics has occurred with AIDS, blaming the social groups has been much more common and thereby the response to the AIDS epidemic has wider social impact rather than being considered as only a medical problem.

### **Illness and Stigma**

AIDS has been considered as incurable and having a progressive condition, and since it is transmissible, people infected with HIV are often perceived as placing others to risk of acquiring the infection. The infected people are blamed for being responsible for their condition through riskful behaviour<sup>10,11</sup>. The symptoms of AIDS related illnesses are frequently visible to others and are

often disfiguring. These are likely to disrupt an individual's social interactions and thereby lead to a feeling of isolation.

### **AIDS and Pre-existing Stigma**

Initially the epidemic had been socially defined as a disease of the marginalized groups, especially gay men, thereby the stigma attached to AIDS as an illness was layered upon a pre-layered stigma. Such attitudes towards the disease were observed in several countries which resulted in public perceptions of AIDS being tied closely to the perceptions of the groups among which it is most prevalent.

The AIDS was labelled as a disease of the already stigmatized group of homosexuals (63%), IV drug users (19%) and about 7% cases fitting in both groups, and blacks and Hispanics were disproportionately represented in all transmission categories<sup>12</sup>. The only exception was the group of haemophiliacs who did not represent any of the stigmatized groups.

AIDS related stigma interacts with pre-existing stigmas in various ways. Identification of a person with AIDS transforms a man from discreditable (secretly gay) to discredited (publicly gay)<sup>13</sup>. The stigma of disease and the pre-existing stigma related to certain behaviours lead to bifurcating individuals with a disease as outsiders. On the other hand, persons who did not contract AIDS through either homosexual behaviour or drug use but are infected due to their partner's behaviour or got it through the infected blood have been categorized as the innocent victim and their sexual partners not considered as part of the general public<sup>14</sup>.

In the developing countries, particularly in African and Asian countries like South Africa, Thailand and India, the most common mode of transmission is the heterosexual contact. Here the high and low risk behaviour groups were identified on the basis of the sexual behaviour and in restricted pockets through the intra venous drug use. In India more than three fourths of the HIV infections are due to the heterosexual contacts, thereby the groups with risky behaviours like the commercial sex workers, the truck drivers, 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 spouses. The other group of concern are children of infected mothers that paved the way for an intervention programme to avoid this transmission on an urgent basis<sup>2</sup>.

## AIDS Stigma and Women

In traditional societies where patriarchy exists, the social norms and cultural expectations of behaviour put women to low risk of HIV infection but men's behaviour are tolerated and to some extent accepted even if it puts them to certain risky behaviours<sup>15,16</sup>. This has resulted in a situation where the women who are at low risk by their own behaviour are at greatest risk from their husband's behaviour<sup>17</sup>. However, in such situations, the women may not be often considered as a victim and the husband as the blamable person due the social hierarchy and the differential power relations that exists and women are still blamed for bringing the infection in the family, especially when the women has been tested for HIV earlier as happens in several ante-natal clinics<sup>18</sup>. In such situations, based on the HIV status, women experience discrimination at home as well as at a health care setting. As a result coping with her HIV status and looking after her child become a double burden that she has to manage along with her own health and other social vulnerabilities.

### DISCRIMINATION IN A HOSPITAL WARD DURING DELIVERY

Ms. Devi, a 24 year old woman, husband a taxi-driver, delivered a baby boy at the hospital. She was found to be HIV infected during her antenatal check-ups and given AZT during last month of pregnancy. Her first child had died during delivery at her native home in the village. For her second pregnancy she had registered in the hospital because of her sickness and was very protective of her new baby; she had information about mother to child transmission of HIV and had taken ample care including preparing to top feed the child. She had disclosed her HIV status to her husband, mother-in-law and brother-in-law who were reportedly supportive.

She felt good about the care she got at the hospital except for one incidence during her delivery when the doctor on duty shouted at her saying why she had not informed the doctor about her HIV status, as others could get infected from her. At that stage, she felt very bad, but didn't say anything<sup>19</sup>.

### PROBLEMS OF A WOMAN WHOSE HUSBAND DIED OF AIDS

Ms Shail is a 26-year-old widow now staying alone and looking after her two daughters. She is a matriculate and works as an office cleaner, a temporary job she got a year ago. Her husband who worked on a temporary job died more than a year ago at the age of 33 leaving behind a five-year daughter and a daughter born posthumously, who is now ten months old. When her husband died of AIDS, it was her fifth month of pregnancy, and the doctor after knowing her HIV status advised her for an MTP. She, however, continued her pregnancy in the memory of her husband, and also with the hope that it may be a male heir in the family. She undertook the AZT treatment and opted for alternate feeding. She had a normal delivery of a female child but started breast-feeding the baby, as it was a no cost food and she could not bear the cost of alternate feeding.

All the family members both at her mother's and in-law's house were aware of her HIV status due to her husband's death. Her in-laws do not take adequate care of her, as she did not bear a male child. She foresees a big problem for her, as she has to look after her two daughters. She has very few friends. However, the only support she has is from her mother and sister. Shail's major concern is her own health, which is important if she has to look after her daughters. Since she is breast feeding her daughter she was taking adequate nutrition. She was offered stale food at her mother- in- law's house another reason for her shifting to her mother's house<sup>19</sup>.

## AIDS as Illness: Stigma, Anxiety and Decision Making

The association of death with AIDS evokes anxiety. It is well known that this infection can remain latent in the body for unknown period of time and is potentially catastrophic even during this period and later as one gets AIDS . Living with an infection and in an environment where ones past behaviour is related to the present state

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makes it further more challenging. Individual judgments and decisions associated with HIV/AIDS under such conditions of anxiety are thus likely to be construed, emerging from irrational thinking.

Anxiety evoked by the HIV/AIDS may lead people to believe that not enough time is left to weigh carefully the strengths and weaknesses of various alternative solutions to an HIV/AIDS related problem. These beliefs are likely to foster a vigilant style of decision making in which the easiest or most readily available perceived solution is adopted without considering its consequences<sup>20,21</sup>. The decisions taken under such hypervigilance may result in behaviours that can isolate HIV infected still further.

### **Developing Strategies for Eradicating AIDS Related Stigma**

HIV/AIDS stigma exists at both individual and societal level and attempts to eradicate this stigma must target the both. Education programmes must be designed not only to impart information to individuals, but also reduce the stigma attached to HIV/AIDS. It is significant that the community understands how important it is for them not to stigmatize people with HIV infection and AIDS as they require social acceptance, compassion and support and not blame and social distancing. There is a need that the public policies should address issues of treatment and prevention and also establish social norms of acceptance, respect and compassion for HIV infected persons.

Eliminating AIDS related stigma would require action in the following areas:

- Individual's HIV status must remain confidential and unauthorized disclosure of this information should be condemned.
- Discrimination on the basis of HIV status should be prohibited.
- Public education efforts must directly confront HIV/AIDS related stigma and should 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 care and other services.

AIDS related stigma poses a problem for all in the society. This imposes severe hardships on the people

who are its targets and it ultimately interferes with the treatment and prevention of HIV infection. Emphasis on the eradication of AIDS related stigma in the community through aggressive efforts at the government and the non-governmental level are the need of the hour. These inputs would help in creating a social climate conducive to a rational, effective and compassionate response of the general community to this epidemic<sup>9</sup>. This would further help in normalizing the epidemic through acceptance, support and care of the HIV and AIDS cases in the community.

Public health managers and the government need to essentially address, the following types of AIDS stigmatization<sup>22</sup>:

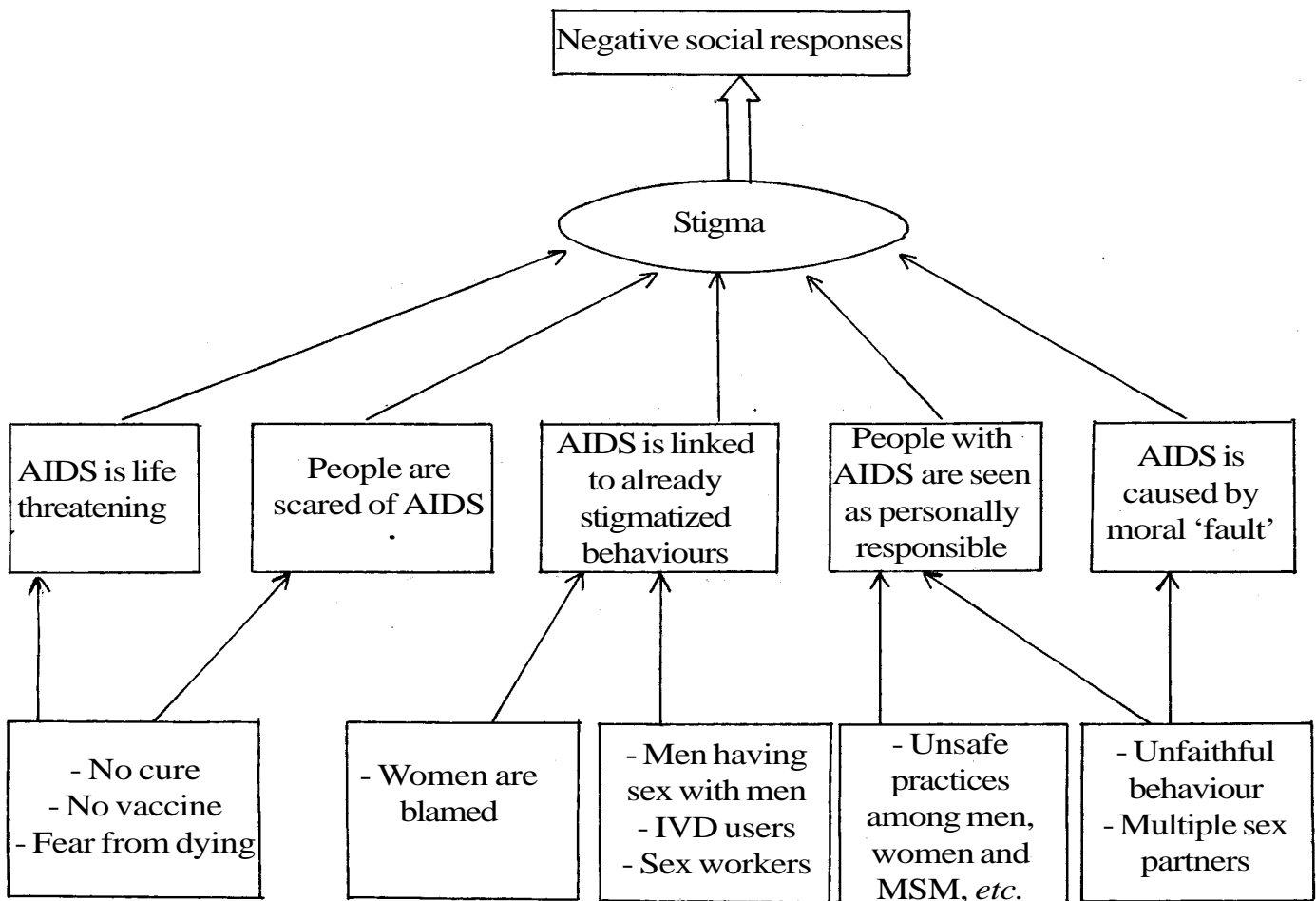
- (i) Theologically/morally based blame on those who are infected;
- (ii) The concern for the health of those not afflicted by disease;
- (iii) Eliminating risk group categories as it gives false security to its marginalized group; and
- (iv) The civil rights problems-human rights centered approaches be enforced, though it is a major challenge requiring frequent debates. However, this would prove to be a long term investment.

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 which is potential threat to the individual's well-being and quality of life, and the rights of the rest of the society for the effective development of large-scale effective public health programmes<sup>22,23</sup>.

### **AIDS Stigma and Research**

There is a need for research that should address the extent to which stigmatization of those with AIDS affects social responses, including health and medical care, employment, housing, *etc.* Research is also needed to elucidate the ways in which public health decisions are taken in view of the epidemic. 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

## Key Determinants to AIDS Related Stigma





Source: Adapted from Parker *et al*<sup>24</sup> and de Bruyn<sup>25,26</sup>

AIDS. A study carried out in Mumbai and Bangalore<sup>27</sup> focused on the negative consequences of living with HIV/AIDS. This study was useful to document the forms of stigma that takes place at individual, family and community level and also identified the forms of stigma that occurs in the hospital setting. The study highlighted the existence of prejudices and the associated fears in both the HIV infected individuals and the care providers and showed that interaction of the dyad of the infected and the care provider can give rise to extreme forms of discrimination starting with being resistant to providing care to isolation for the HIV positives.

This study used qualitative methods of data collection among a vast range of care providers in two cities from high prevalent states. The study was able to identify

several forms of stigma, discrimination and denial, the operating factors leading to these forms and the resultant outcomes of the negative consequences of HIV/AIDS. While the study has given useful insights through the systematic use of qualitative methods and contributed to the recommendations for prevention programmes, however, the generalization based on this data may not be adequate to influence policy. More studies to quantify the varied forms of stigma existing in varied hospital settings are needed to influence policy changes for providing good quality health services. Research focusing on these issues of patient care would increase the scope of studies and become useful advocacy tools to influence policy changes. Few such studies are in progress in India which are likely to contribute in developing prevention strategies that focus on minimizing the social

## OUTCOMES OF DISCRIMINATION, STIGMATISATION AND DENIAL

		<b>Levels</b>	
		<b>Individual</b>	<b>Societal</b>
<b>Nature</b>	<ul style="list-style-type: none"> <li>· Fear, anxiety</li> <li>· Depression, suicidal thoughts</li> <li>· Internalization of shame</li> <li>· Self isolation</li> <li>· Secrecy, non disclosure</li> <li>· Concealment in health care settings</li> <li>· Anger</li> </ul>		<ul style="list-style-type: none"> <li>· Climate of fear, suspicion of positive members</li> <li>· Stressful social/group relationships</li> <li>· Status quo maintained on prejudiced attitudes</li> <li>· Hidden, silent epidemic</li> <li>· Societal backlash, polarization of groups (HIV positive vs. HIV negative)</li> </ul>
	<b>Constructive</b>	<ul style="list-style-type: none"> <li>· Acceptance of one's HIV status</li> <li>· Courage to challenge discrimination and stigmatization</li> </ul>	

harm resulting from stigma and discrimination (NARI: Unpublished observations).

### UNAIDS Campaign for the World AIDS Day

Live and let live is the slogan of the World AIDS campaign for 2 years (2002-2003), which will focus on eliminating stigma and discrimination. It is well recognized that stigma and discrimination are the major obstacles to effective HIV/AIDS prevention and care. The World AIDS Day campaign encourages people to break the silence and the barriers to effective HIV/AIDS prevention and care.

### *Issues that need to be addressed through the campaign*

Only by confronting stigma and discrimination will the fight against HIV/AIDS be won. Fear of discrimination may prevent people from seeking treatment for AIDS or

from acknowledging their HIV status publicly. People with, or suspected of having HIV may be:

- Turned away from health care services,
- Shunned by their friends and colleagues,
- Denied housing and employment,
- Turned down for insurance coverage, or
- Refused entry into foreign countries.

In some cases, they may be

- Evicted from home by their families,
- Wives be deserted by their husbands, in-laws,
- HIV infected divorced by their spouses, and
- Suffer physical violence or even murder.

The stigma attached to HIV/AIDS may extend into the next generation, placing an emotional burden on children who may also be trying to cope with the death of their parents from AIDS<sup>28</sup>.



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## RECOMMENDATIONS FOR REDUCING DISCRIMINATION AND STIGMATIZATION

An UNAIDS study in India proposes the following broad recommendations with a view to reduce discrimination and stigmatization associated with HIV/AIDS specifically in health care setting.

- The concept of universal precautions needs to be promoted
- Human rights principles of informed consent and confidentiality need to be incorporated
- Newer concepts and labels such as, barrier nursing, immune compromise patient are becoming synonymous with HIV/AIDS and hence not to be used for all types of infections.
- Urgent need to spread legal education and awareness among medical professionals and staff about their duties and responsibilities.
- Mandatory testing must be discouraged.
- Counselling services must be made available in all health care facilities to take care of the psychosocial needs of HIV positive patients.
- To challenge beliefs in causal mode of HIV transmission and address the diffused and irrational sense of personal risk to HIV infection among health functionaries to reduce levels of discrimination of HIV/AIDS patients within the health care sector.

It has been recommended that there be more proactive responses that address the root cause of discrimination and stigmatization namely AIDS related misconceptions, ignorances, prejudices and biases.

### *Hope through the campaign*

The HIV epidemic can be contained, when HIV prevention and care are tackled seriously through community-wide efforts and with the full support of governments, community organizations, religious institutions, and business groups. The World AIDS Day campaign for 2002-2003 is all about stigma and discrimination. Tackling this challenge at the health care settings, workplaces, educational centers, places of social gathering would only help to win the fight against AIDS. To succeed in this global fight, it is important to understand that only virus is the common enemy, not those affected by it<sup>28</sup>.

To sum up, in the words of Kofi Annan, UN Secretary General "On this World AIDS Day, let us resolve to replace stigma with support, fear with hope, silence with solidarity. Let us act on the understanding that this work begins with each and every one of us.

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