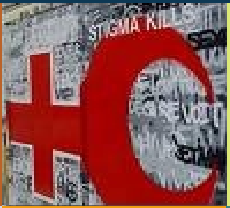
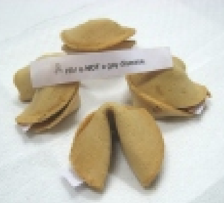
HIV/AIDS –Related Stigma and Discrimination in three districts of Maharashtra





Fear ignorance blame my this and misinformation all contribute within different cultures and communities to create stigma and discrimination that directly affect positive people

सत्यमेव जयते

SHARWAREE GOKHALE
Additional Chief Secretary

GOVERNMENT OF MAHARASHTRA
Public Health Department
1st Floor, Mantralaya, Mumbai 400 032.
Phone : 91-22-2287 3848 / Fax: 91-22-2204 5150
E-mail : sec_pubhealth@maharashtra.gov.in

Message

HIV/AIDS has remained a management challenge in the state of maharashtra. The dynamic nature of the epidemic necessitates evidence based strategic planning and intervention. One of the strategies was the formulation of Avert Society which was formed as a tripartite agreement between the Government of India (NACO), Government of maharashtra and United State Agency for International Development (USAID) to provide technical inputs to the state.

The broad objective of Avert Society is to ensure increased use of effective and sustainable response to reduce the transmission of HIV and to mitigate the impact of STI/HIV/AIDS and related infectious diseases in Maharashtra.

The Society had carried out five preparatory research studies as quntitative enquiries focusing on diverse aspect of HIV/AIDS management from year 1999-2001. The present qualitative study on Stigma and Discrimination of HIV infected and affected population is a natural sequel to previous social researches undertaken.

This study provides invaluable insights into the marginalization of the HIV infected and affected. It guides state policy makers and implementers to incroporate strategic approaches to systematically eradicate the overwhelming contradictions of fundamental rights of people living with HIV in the broad spectrum of health care, community and at the an individual level.

I must appreciate the task undertaken by Avert Society in conducting and collating the findings of the study in this summary report. I sincerely hope that the study would be widely utilized by every individual concerned with the rights of PLHIVs, by policy makers, implementers and providers of health care services to institutionalize necessary steps in abolishing stigma and discrimination in the state of Maharashtra.

(Sharwaree Gokhale)

PREFACE

Prejudice is the child of ignorance.

~William Hazlitt

One of the guiding principles of National AIDS Control Program (NACP) III is upholding the rights of the individuals infected and affected by HIV/AIDS to live a life of dignity. Unfortunately for many who are relentlessly fighting encumber of the disease realize that Stigma and discrimination emerge from ignorance and misconception. It vitiates the surroundings making it less conducive to egalitarianism and justice.

To minimize the impact of stigma and discrimination in the process of care for infected and affected individuals, Avert Society initiated a systematic enquiry into the issue by spearheading a qualitative research study to understand the existing forms of stigma and discrimination, its origin among various defined groups. Measures were taken to ensure the active involvement of PLHA in the project stages of conceptualization, research and analysis of data. In addition civil society representatives were consulted in the planning and implementation process to foster social ownership and community involvement.

The study covering three districts of Maharashtra indicated the presence of diverse forms of stigmatization within health care institutes, the community and family. It highlighted the need for interventions that strengthens human resources to act as a link between infected and affected individuals and the community at large.

One of the critical findings of the study indicated building capacities of the infected and affected individuals by means of networking and strengthening of group formation. This is fundamental to addressing the concern of stigma and discrimination in a practical way.

This study would not have been possible without Action Research Centre and Network of Maharashtra Positive (NMP+) who undertook the study. I thank all PLHIV and CSO members who were involved in the study. I take this opportunity to thank Dr. Vandana Bhatia and Ms. Shabana in providing valuable technical guidance, support and for monitoring the entire process of the study. I appreciate the hard work extended by Dr. Neeta Rao, Research Specialist, Avert Society in finalizing the summary report. I would like to thank all the Avert Staff - Technical, Financial, Administrative and Secretarial for their cooperation in completion of the study. I express my heartfelt gratitude to all the respondents whose valuable inputs have provided insight through this study.

Anna Joy

Ms. Anna Joy
Project Director / In Charge
Avert Society

Table of Content

EXECUTIVE SUMMARY

Stigma is a common thread intertwined with all aspects of HIV/AIDS management. The socio-cultural dimension with differentiation based on caste, religion, gender and class offers a fertile ground for the stigmatization process to survive and reveal itself in different forms. HIV/AIDS-related stigma and discrimination are manifested at different levels-societal, community and individual; and in different contexts. This leads to internalization of being deviant by the infected and affected individuals, thereby breeding low self esteem. Such instances of self alienation only make implementation of HIV/AIDs intervention programs difficult.

HIV-related stigma and discrimination are known to interact with the pre-existing stigma and discrimination associated with sexuality, gender, and poverty. HIV/AIDS-related stigma and discrimination also interrelate with preexisting fears about contagion and disease. A study was therefore undertaken in three districts of Maharashtra by Avert Society to explore the causes and forms of stigma and discrimination, such as to provide inputs to the ongoing programmatic intervention. In order to gain a holistic perspective about the issue respondents were selected from general population, people living with HIV/AIDS and Health Care Providers' groups. The study findings have been categorized into the following sections:

Causes of stigma and discrimination

Limited knowledge about modes of transmission and prevention methods, certain beliefs, prejudices and fear cause discriminatory behavior towards infected and affected. Most of the respondents from the general population exhibited good levels of knowledge and attitude towards PLHA, except few who mentioned that shaving in a saloon should be avoided as it could spread infection. Some respondents blamed sex workers and truck drivers for spreading the infection. They indicated that the sex workers should be tested for HIV regularly as they were a major threat. PLHA respondents showed good knowledge about prevention methods and modes of transmission. Very few HCPs stated that the virus remains viable outside the body for 45 seconds to an hour depending upon the condition, though most of the HCPs did not feel the need to use gloves or keep distance from PLHA patients. There was a universal approval for testing before marriage.

HIV testing and disclosure

Most of the PLHA respondents reported to have got tested for HIV due to the repeated sickness of themselves or their spouse. Many respondents complained that their consent was not taken before testing. Health care providers often revealed the test results to the family members expecting them to provide support to the infected individual.

Stigma: Self-stigma among PLWHA, in the household, Community and Health care set up

Sadness was the strongest emotion experienced by the PLHA which was compounded by shame, fear of discrimination and isolation by some. Few respondents expressed that their status affected their jobs and travel. Most of the PLHA respondents felt that they could not marry and have children and favored the idea of marriage among the infected couple. Some PLHA reported that their family members behaved differently leading to self-isolation, instances of insult, abandonment, loss of property, and children taken away from them and stated that they suffered more inside their homes than in the society. Some PLHA respondents complained about people behaving differently with them and quoted instances of humiliation and their children being discriminated. Most of the respondents who accessed government hospitals complained about the poor facilities, including no adequate space to sit, long waiting time, and lack of privacy. Instances were quoted about the refusal of treatment by providers, bed sheets were not being changed and isolation.

Some Health care providers admitted to refusing and referring PLHA patients to other doctors due to the fear of infection, excessive precautions by the providers while handling PLHA patients and refusal by the support staff to handle the dead bodies of PLHA patients. There were no reports of health care providers getting stigmatized. Due to the fear of stigma, most of the PLHA had not disclosed their status at workplace.

Stigma and media/communication

Some PLHA stated that the media focusing on sex and prostitution perpetuated stigma and discrimination against them. They condemned campaigns like 'Balbir Pasha,' 'Manjula ka boyfriend,' and 'Vetal Vikram.' However some appreciated advertisements showing celebrities like Amitabh Bachan and Sachin Tendulkar talking about HIV & AIDS and suggested the need to focus on emotional support to PLHA using media of television, radio, and street plays.

Knowledge of rights among PLHA & Gender Issues related to Stigma

Although most of PLHA respondents could not relate well to their rights, some of them mentioned that they were entitled to different rights including, right to work, right to be member of an organization, right to education, voting right, right to exist, right to avail doctor's services, right to independence, and right to decision making.

Many respondents indicated that women suffered more stigma and discrimination when compared to men and faced more hindrances in testing and disclosing their status.

Recommendations

Along with educating people about HIV/AIDS; modes of transmission and prevention, myths and misconceptions, risk perception and secondary prevention for PLHA need to be adequately addressed. There is an urgent need to educate PLHA about their rights and services available for them. HIV/AIDS communication strategy should focus on prejudices, self stigma and discrimination at health care set up. Health Care Providers need to be sensitized and trained to handle PLHA cases. Interventions at workplace are essential to de-stigmatize HIV and provide greater acceptance to the infected. Since PLHA women are likely to suffer more, interventions should instill mechanism to address specific vulnerabilities of women.

Chapter 1

INTRODUCTION

The HIV/AIDS epidemic has been a gathering force in the past few decades and it continues to be a major global threat. AIDS finds its victims in both rich and poor countries. There is no region of the world where HIV/AIDS is not a potentially serious threat to the population.[1]

It is estimated that there are about 2.31 million people infected in India. The largest number of infection are seen in Maharashtra and Gujarat in the west; Tamil Nadu and Andhra Pradesh in the south; and Manipur in the northeast. The infections are mostly due to heterosexual contact except in case of injecting drug users of northeast.

Stigma is a common thread intertwined with all aspects of HIV/AIDS management. The socio-cultural dimension with differentiation based on caste, religion, gender and class offers a fertile ground for the stigmatization process to survive and reveal itself in different forms

a) Interaction with pre-existing stigma and discrimination

HIV-related stigma and discrimination are know to interact with the pre-existing stigma and discrimination associated with sexuality, gender, and poverty. HIV/AIDS-related stigma and discrimination also interrelate with preexisting fears about contagion and disease. Early AIDS metaphors such as death, horror, punishment, guilt, shame have exacerbated these fears; reinforcing and legitimizing stigmatization and discrimination.

HIV/AIDS related stigma and discrimination are most closely related to sexual stigma. This is because HIV is mainly sexually transmitted and in most areas of

---

[1] *United Nations (2005), Population, Development, and HIV/AIDS with particular emphasis on poverty. United Nations, New York.*

the world, the epidemic initially affected populations whose sexual practices or identities are different from the “norm.” HIV/AIDS related stigma and discrimination has therefore reinforced pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution, and sexual “deviance.”

HIV/AIDS related stigma & discrimination are also linked to gender-related stigma. The impact of HIV/AIDS related stigma & discrimination on women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to information and services. In settings where heterosexual transmission is significant, the spread of HIV infection has been associated with female sexual behavior that is not in conformity with gender norms.

Racial and ethnic stigma and discrimination also interact with HIV/AIDS related stigma and discrimination. The epidemic has been characterized both by racist assumptions about “African sexuality” and by perceptions in the developing world of the West's “immoral behavior.” The HIV/AIDS epidemic has developed during a period of rapid globalization and growing polarization between rich and poor. New forms of social exclusion associated with these global changes have reinforced pre-existing social inequalities and stigmatization of the poor, homeless, landless, and jobless. As a result, poverty increases vulnerability to HIV/AIDS, and HIV/AIDS exacerbates poverty.

The various metaphors associated with AIDS have also contributed to the perception of HIV/AIDS as a disease that affects “others,” especially those who are already stigmatized because of their sexual behavior, gender, race, or socioeconomic status, and have enabled some people to deny that they personally could be at risk or affected.

b) Manifestation of HIV/AIDS related Stigma and discrimination

HIV/AIDS-related stigma and discrimination take different forms and are manifested at different levelssocietal, community and individual; and in different contexts.

The difficulty in creating a rational approach towards HIV management got accentuated with linking of HIV infection with promiscuous and same sex relationships. The possibility of infection through infected needles, infected blood transfusion and other surgical vulnerability did not get much attention either in the media or the mindset of public. As a result every infected person became a promiscuous and questionable character in the eyes of community at large.

HIV/AIDS related stigma and discrimination in society is commonly manifested in the form of laws, policies, and administrative procedures, which are often justified as necessary to protect the “general population.” Examples of stigmatizing and discriminatory measures include compulsory screening and testing, compulsory notification of AIDS cases, restrictions on the right to anonymity, prohibition of PLHA from certain occupations, medical examination, isolation, detention and compulsory treatment of infected persons.

Children with HIV/AIDS or associated with HIV through infected family members have been stigmatized and discriminated against in educational settings in many countries. There have been many reported incidences from health care settings of HIV testing without consent, breaches of confidentiality, and denial of treatment and care. HIV/AIDS policies and programs may inadvertently contribute to stigmatization and discrimination by differentiating between the “general population” and “high-risk populations,” prioritizing actions to prevent HIV spreading to the former from the latter.

In societies with cultural systems that place greater emphasis on individualism, HIV/AIDS may be perceived as the result of personal irresponsibility, and thus individuals are blamed for contracting the infection.

Stigmatization and discrimination in the home and community setting is seen in the separation or desertion by legal partner and the denial of right of - property / finance. Alienation continues even upon demise, when infected or affected individuals and children are denied right to take part in last funeral rites.

In contrast, in societies where cultural systems place greater emphasis on collectivism, HIV/AIDS may be perceived as bringing shame on the family and community. HIV/AIDS-related stigma and discrimination in families and communities is commonly manifested in the form of blame, scapegoating, and punishment.

The family is the main source of care and support for PLHA in most developing countries. However, negative family responses are common. Infected individuals often experience stigma and discrimination in the home, and women are often more likely to be badly treated than men or children.

Workplace discrimination is discernible as - employment is discontinued, one is forced to resign, benefits of health and insurance are withdrawn, social distancing, infected persons are called names and sharing of common spaces restricted. Discriminatory practices such as pre-employment screening, denial of employment to individuals who test positive, termination of employment of PLHA, and stigmatization of PLHA who are open about their sero-status have been reported both from developed and developing countries.

In contexts where HIV/AIDS is highly stigmatized, fear of HIV/AIDS-related stigma and discrimination may cause individuals to isolate themselves to the extent that they no longer feel part of civil society and are unable to gain access the services and support they need. Even when laws exist to protect PLWHA rights and confidentiality, few individuals are willing to litigate for fear that this will result in disclosure of their identity and HIV status. Individuals who are already marginalized may be fearful of negative or hostile reactions from others, regardless of their serostatus.

Stigma and associated alienation/discrimination found its base at first among the non-infected. Given the fact that human beings are social animals and to a large extent their social interaction is shaped by local social-cultural realities, many of the infected and affected internalized the feeling of alienation and discrimination. It meant infected hid their HIV positive status till they became dysfunctional. Such instances of self alienation only made implementation of HIV/AID intervention programs difficult.

1.4 Objectives of the Study

The main aim of the study was to understand causes and forms of HIV/AIDS related stigma and discrimination in the general community as well as hospital setting.

The specific objectives are:

- To assess the cause and forms of stigma and discrimination associated with HIV/AIDS
- To understand the fear and misconceptions associated with the discrimination of PLHA
- To understand the knowledge of rights against discrimination among PLHAs
- To discern stigma and discrimination in private and government health care providers
- To understand various measures adopted by the private and public sectors to avoid PLHA

Chapter 2

RESEARCH METHODOLOGY

The study was conducted in three districts of Maharashtra; Mumbai, Nagpur & Sangli in the year 2006 predominantly using a qualitative research approach.

In-depth interviews and focus groups and were employed to explore and understand HIV/AIDS related stigma and discrimination. In both focus groups and in-depth interviews, respondents had the opportunity to express themselves freely sharing their experiences and perceptions.

In all, 97 in-depth interviews, and 29 focus groups were conducted among the three respondent groups in the three aforementioned districts. Theoretical sampling method was used considering the willingness of the respondents to participate in the study. The sample distribution is given in Tables 1 and 2.

Table 1: Sample distribution of in-depth interviews

	Respondent Type	**Mumbai**	**Nagpur**	**Sangli**	**Total**
1	PLWHA	14	9	14	37
2	General population	18	11	10	39
3	Health care providers	11	5	5	21
	Total	43	25	29	97

Table 2: Sample distribution of Focus group interviews

	Respondent Type	**Mumbai**	**Nagpur**	**Sangli**	**Total**
1	PLWHA	5	3	3	11
2	General population	5	3	2	10
3	Health care providers	4	2	2	8
	Total	14	8	7	29

Three respondent groups were further divided into sub-groups to get a wider representation within a group. PLHA respondents included both members and non-members of the positive network. General population respondents included men, women, male and female youth. Health care providers represented both governmental and private sectors, and different streams of treatment practices (allopathic, non-allopathic, and non-qualified). Non-allopathic providers included those with Bachelor degree in Ayurveda, Unani, and Homeopathy. Non-qualified providers were those who did not have a first degree in medicine (either allopathic or non-allopathic). Almost all the health care providers were doctors except one nurse in a government hospital.

2.3 Data collection

A brief discussion on the development of instruments, recruitment and training of PLHA investigators, and data collection process has been presented in this section.

a) Development of Instruments

Data collection instruments included interview guides for various categories of respondents, profile sheets, consent form, and information sheet. A detailed interview guide with specific open ended questions helped in gathering consistent but in-depth information by different interviewers in different study districts.

b) Involvement of PLHAs in data collection

One PLHA investigator was identified from each study district to carry out the task of data collection. Experienced researchers trained the PLHA investigators adequately before initiating the field work. However, some respondents representing health care providers and general population were interviewed by the researchers themselves.

c) Training of PLWHA investigators

Three-day residential training was conducted for all the investigators. The training methods included sessions, group discussions, mock interviews and first hand exposure of interviews at the field level. Training curriculum comprised of basics of HIV/AIDS, forms and context of stigma and discrimination, instruments of data collection, the process of conducting in-depth interviews and focus group discussions and recording the responses.

2.4 Data classification and Analysis

Thematic guides were developed for data classification. The thematic classification was guided by the research questions being addressed in the study. The data classification reports were the basis on which the data was analyzed.

Chapter 3

FINDINGS OF THE STUDY

3.1 Profile of the Respondents

a) General population

Among the general population respondents included - men, women, male and female youth, college youth, slum youth, and sex workers. About half of the respondents were below 25 years of age, and remaining respondents were above 25 years. Further, half of the respondents were females. Nearly half of the respondents had studied between 2 to 10 years. Except two illiterate sex workers, the remaining half of the respondents had studied for more than 10 years. About half of the respondents were not married. Occupation of respondents included business, office work, company work, construction work, housewife, self-employed, student, and sex work. As evident, the general population respondents represented a wider spectrum of the society (across age, education, marital status and occupation).

b) People living with HIV/AIDS

PLHA respondents consisted of men, women, male and female youth, slum youth, and sex workers. About half of the respondents were males. About 1/3rd of the respondents were youth in the age group of 14-24 years. Respondents were HIV positive for years ranging from one to eight. While about half of the respondents were HIV positive for less than 3 years, the remaining respondents were positive for more than 3 years at the time of interview. Respondents had varied educational background; six were illiterates, about half with matriculation, and few with higher secondary and graduate degree. Respondents also had varied marital status a dozen married, and another dozen unmarried, four widowed, and some others deserted, divorced, and widower. Some of the PLHA respondents were members of the networks working for PLHA.

c) Health care providers

Health care providers represented both government and private health care facilities. Among the private providers there were allopathic, non-allopathic, and non-qualified providers. The proportion of different types of providers was almost equal. While some providers did not have first degree in medicine (non-qualified), others had varied educational background in medicine MBBS, MD, BUMS, BAMS, BUMS, and one nurse. Almost all the providers practiced medicine as a main source of income.

Only allopathic providers (three MDs and some MBBS) reported to have had some training in treatment of HIV patients. Most of the non-allopathic providers did not have such training. Only an Ayurvedic provider (BAMS) treated PLHAs based on the knowledge he had gathered from other providers and counselors. A nurse reported that that she was trained to care for HIV patients. Almost all health care providers interviewed treated HIV patients. Most of the providers treated HIV patients for opportunistic infections and counseled for further treatment.

3.2 Knowledge of HIV/AIDS

Knowledge about HIV/AIDS plays an important role in forming opinion about people infected and affected by the disease. It is believed that the incorrect knowledge about the disease leads to stigmatization of people infected or affected by it.

3.2.1 Knowledge of HIV transmission

a) General population

Most of the respondents from the general population thought that HIV/AIDS was a dangerous disease, and contracted through unprotected sex with unknown partners. Blood transfusion, infected needles, and mother to child transmission were also mentioned as other means of transmission of HIV/AIDS. However, some respondents thought that the infected razors, blades, mosquitoes, and kissing could cause HIV. Two commercial sex workers were well informed about the HIV spread of the disease and prevention methods. A degree student did not know much about the HIV transmission dynamics. Some said HIV and AIDS were one and the same, while others thought HIV was a virus which later caused AIDS. A few thought it was brought to India by foreigners, and originated in monkeys in Africa. Interestingly, a respondent said it was a disease spread by the truckers in India.

Most of the respondents thought that there was a possibility of child getting infected from an infected mother. Some respondents indicated that a pregnant mother having sex with an infected person could pass the infection to the child. However, a few believed that child could be saved from getting infection by medication, and separation at the time of birth.

> *"Yes. If the mother has infection, it will also affect her child. If husband is having HIV and wife had sex with him and gets pregnant, she can spread it to her child because mother and child have one umbilical cord which supplies the blood to child."*
>
> *- Female youth, 19 years, Mumbai*

Most of the respondents indicated that there was no threat of HIV by casual contact with the infected person.

> *"No, not at all. In my village two of my friends are HIV positive. We have the same friendship going on as before. Today also I shake hands with them and I eat with them."*
>
> *- College youth, 24 yrs, Mumbai*

b) People living with HIV/AIDS

Some of the PLHA respondents mentioned about how HIV gets transmitted (2 to 4 routes of transmission); when they were asked about what they understood by HIV/AIDS. Some other dominant responses were "AIDS is a dangerous disease;" "immunity decreases;" and "it has come from Africa." Other meanings attributed to HIV/AIDS were "blood gets infected;" "first HIV and then AIDS;" "means death;" "having fever for long;" "HIV is one disease and AIDS many;" "no problem for 8-10 years' "incurable disease;" "can't live longer;" "sex without condom."

> *"HIV/AIDS means it is transmitted through sexual relationship, with needle prick, and also with blood transfusion."*
>
> *- Sex worker, 25 yrs, Sangli*

Most of the PLHA respondents knew at least two routes of transmission of HIV and several of them mentioned all the four routes of transmission (unprotected sex, infected needle, blood, and mother to child). Two women thought that shaving blade also caused infection. A sex worker indicated that eating food together and drinking from the glass used by PLHA can spread the infection.

Most of the PLHA respondents also indicated that there was no threat of HIV through casual contact. However, a woman and a sex worker thought that eating together or wearing the clothes of infected person could cause HIV.

> *"You will not get the infection through a handshake. Even if you embrace an infected person you will not get it."*
>
> *- Man, 35, Married, Nagpur*

> *"They say that this woman has HIV/AIDS and nobody should go with her and nobody should wear her clothes and nobody should eat and drink using the same place and glass used by her."*
>
> *- Woman, 29 yrs, Nagpur*

c) Health care providers

All the providers said that the virus did not survive outside the human body long enough to cause infection later. Health care providers said that the virus lived for 45 seconds to an hour outside the human body. One MD practitioner mentioned that although the virus could not live at atmospheric temperature, the fear of infection still remained.

> *"When the HIV virus is out of the body in liquid form i.e., in blood, it survives till the clotting of blood (approx. 5-7 min.,) and as soon as it comes into contact with the atmosphere it dies."*
>
> *- Govt. allopath, Sangli*

Most of the health care providers said that it was not necessary to use gloves while examining PLHA patients unless they were dressing skin lesions, wounds, cuts or giving injections. During invasive procedures (operation, delivery, etc.) gloves, goggles, masks were felt to be necessary by the providers. A nurse said that there was a separate ward for HIV patients where gloves, gown, mask and aprons were used while providing care. She also indicated that two gloves were used for handling PLHA patients instead of one glove as in case of other patients.

When probed about the extent of risk from different body fluids, blood was termed the most infective one by the health care providers. Only half the respondents mentioned that semen and vaginal fluids harbored infection. Saliva in case of injury/wounds in the mouth or ulceration, sweat, secretions, mother's milk was cited as other factors of HIV transmission.

> *"The most infective factors are sexual secretion and blood for the transmission of HIV. In sweat, saliva and tears the percentage is very low (less than 0.3%). It is found in mother's milk in very low percentage 0.001%."*
>
> *- Govt. allopath (MBBS), Sangli*

3.2.3 Knowledge of prevention, cure and treatment among the General Population

How one can prevent from getting HIV infection?

Almost all the respondents among the general population knew about different methods of HIV prevention. Different methods of prevention mentioned by the respondents were "using condom;" "abstaining from sex;" "avoiding infected syringes;" "going to a good qualified doctor;" "transfusion of tested blood only;" "sex with wife only;" "avoiding outside (marriage) sexual relationship." 'Not using the used blade in saloon' was also one of response.

> *"Control over sexual desire is a must, he must have safe sex with his wife only, and the blood transfusion should not be taken without testing. "*
>
> *- Man, 36 yrs, Nagpur*

> *"One should not have sex if he or she does not have condom. One should buy a new needle whenever he or she goes to the hospital."*
>
> *- Sex worker, 32 yrs, Sangli*

Is there a cure for HIV?

Respondents were asked whether HIV/AIDS was a curable disease. Many respondents believed that there was no cure for HIV. They also mentioned that the infected person could live longer with medicine and with the support of the family members. Two respondents thought that there was a cure for HIV. Some thought that HIV could be cured if treated at an early stage.

> *"Yes to a certain extent it can be cured if good food and fruits are taken on a regular basis, and by avoiding alcohol and eating non-vegetarian food."*
>
> *- College youth, 18 yrs, Mumbai*

> *"Yes I have heard that by taking medicines they can prolong the life of a PLHA by a few years; they can live a little longer."*
>
> *- Woman, 37 yrs, Nagpur*

Is there a treatment to prolong the life of PLWHA?

Almost half of the respondents from the general population mentioned that there was a medicine to prolong the life of HIV infected person. Almost 12 of the respondents emphasized on the need for supporting PLHAs with love and care to prolong their life.

> *"We must give them happiness. And if we ignore them they will become more depressed, and therefore die earlier."*
>
> *- Female youth, 24 yrs, Mumbai*

> *"That I don't know, but I know that to increase the immunity inside the body, there are medicines available in the market."*
>
> *- Youth, 25 yrs, Sangli,*

Know any HIV infected person?

Most of the respondents knew some or the other HIV infected person. Such known people living with HIV/AIDS were either family members or neighbors.

These PLWHAs included friends, neighbors, policemen, husbands, HIV patients in hospitals, etc. Youth respondents reported not knowing any HIV infected persons in general.

3.3 Causes of stigma and discrimination

3.3.1 Shame, blame and responsibility

Upon disclosure of positive status the individual is perceived to be a deviant and then the attempt is to fit in the person within known deviant groups who have been stated to be vulnerable to HIV by prevention programs. Opinions on shame, punishment and blame were explored with the aid of open ended questions administered to General Population and Health Care Provider respondents.

You think HIV infected people should be ashamed?

a) General population

Most of the respondents from the general population said that the infected persons should not be ashamed if the infection is due to infected husband, infected needle, and caused by doctor, etc. However, some respondents mentioned “People should be ashamed if they got it due to sex.” Reasons quoted by the respondents in support of such view were “they knew about the danger;” and “they brought it on their own;” and “because there is no cure.”

> *“According to me people should not do such things which make them feel ashamed and get this kind of a disease.”*
>
> *- Man, 32 yrs, Nagpur*

b) Health care providers

About half the health care providers said that PLHAs should not be ashamed because of their infection. However, some providers said that if the infected person got the disease by going to sex workers then the person should feel ashamed.

> *"It is ok with patients who have sexual exposure but the people who do not have sexual exposure and have been infected accidentally, why should they be ashamed of themselves?"*
>
> *- Govt. Allopath (MBBS), Sangli*

Who is spreading AIDS?

a) General population

Sex workers and truck drivers were considered to be spreading HIV/AIDS in the society. Some respondents blamed all those not taking precautions in sexual encounters as responsible for spreading HIV/AIDS. While some blamed men, others held women responsible for spreading HIV/AIDS. Rich people, bar girls and doctors were also seen as responsible for spreading the disease.

b) Health care providers

Health care providers indicated that the sex workers, truck drivers and cleaners, eunuchs were responsible for spreading HIV/AIDS. However, some providers held illiterate people, villagers, lower class people and migrant population responsible for spreading the disease (because of lack of knowledge). Some other providers indicated that drug addicts, youngsters, bus and auto drivers, and school teachers are responsible for spreading the disease. Many health care providers felt that the promiscuous men and women were responsible for spreading HIV/AIDS.

> *"Sex workers are the high risk group in our society. Truck drivers and cleaners are the people who have high rate of HIV infection"*
>
> *- Govt. allopath (MBBS), Sangli*

Is it a punishment for bad behavior?

a) General population

Most of the respondents among the general population did not believe that the HIV infection was a punishment for bad behavior. However, three men from varied socio-economic background said that it was a punishment for bad behavior (“indeed a bad deed;” “against the rules of the nature”). Reasons for endorsing 'not a punishment for bad behavior' were “it can affect anybody;” “act could be a mistake;” “innocent people also get the infection;” “it is our deed and God has nothing to do with it;” “it is our fate;” “sex is a need;” and “we are responsible.”

> *“Yes. If any body breaks the rules of Nature, then Nature will punish him.”*
> *- Male, 31 yrs, Mumbai*

b) Health care providers

One Unani health care provider mentioned that it was a punishment from God for bad behavior.

> *“To avoid HIV, one has to be faithful, honest and trustworthy”*
> *- Pvt. Non-Allopath (BAMS), Sangli*

Blame PLHA for causing havoc in the society?

a) General population

Some respondents from the general population expressed that because of PLHA the disease is spreading and the government has to spend large amount of resources to control it. While, some respondents considered sex workers and slum dwellers as threat to the society in the context of spreading HIV/AIDS.

b) Health care providers

Some health care providers suggested that the HIV patients should take preventive care not to spread the disease to others in the society.

Opinion about people who get infected through sex vs. blood transfusion

a) General population

Many respondents blamed the one who got infection through sex while letting the other person (who got infection though blood transfusion) off. Reasons for blaming the person who got the infection through sex were "person knew about the danger;" "person's own mistake;" "less responsible;" "not using condom." Further, such person was treated as a culprit, and the infection was seen as a punishment for his/her bad behavior. One respondent felt that the negligence played role in causing the havoc. Several other respondents did not blame both for different reasons "Need support;" "just a mistake;" "both are equally responsible;" "other's fault." Infection due to sex was not blamed by some respondents for the reasons that sex is a need, and the person did not know that partner was infected.

> *"A person who contracts AIDS through sexual behavior, it is his/her own fault, but if a person contracts it through blood transfusion, then it is not his fault. It is the fault of the person who has given him blood i.e. the technician without testing in the laboratory."*
>
> *- Male youth, 22 yrs, Nagpur*

b) Health care providers

Some providers felt that those who got the disease though the blood transfusion could not be blamed while others who got the disease by visiting sex workers were blamed.

> *"No. We do not differentiate between these two patients. Both of them are mere patients who approached us for treatment"*
>
> *- Govt. Allopath (MBBS), Sangli.*

> *"I will not go and find out the cause of HIV/AIDS. I will first see how the infected person will be relieved from HIV".*
>
> *- Pvt. Non-allopath (BAMS) Sangli*

3.3.2 Fear of contagion, and risk perception among the general population

When asked if they would wear a washed sweater previously worn by a PLHA, most of the respondents agreed because they thought HIV/AIDS did not spread by wearing a sweater or by touching a person. Only three respondents refused to wear a washed sweater previously worn by HIV positive person for the fear of getting infected.

> *"Yes, why not? HIV does not spread through clothes, talking or eating together. HIV spreads only in two ways - one is by sexual contact and the other, by blood transfusion."*
>
> *- College male youth, 18 yrs, Mumbai*

When enquired if they would be willing to drink water from the washed glass previously used by PLHA, most of the respondents did not exhibit any apprehension. Only five respondents (mainly youth) were not sure. However, the same five respondents were willing to wear the sweater used by PLHA.

> *"We will be afraid. We will wash it again and drink from it."*
>
> *- Female youth, 18 yrs, Mumbai*

> *"Yes. Because roaming with an HIV infected person or eating with him does not cause HIV - AIDS."*
>
> *- Woman, 35 yrs, Married, Sangli*

Would you care for a HIV infected relative?

Some of the respondents indicated that they would take care if the infected person does not have anybody to care or based on the advice of the doctor. Most of the respondents were willing to care for the HIV infected close relative.

> *"If there is nobody else, then I will do it. I should have the place, money and facilities to look after them. Then only I can do it."*
>
> *- Woman, 25 yrs, Nagpur*

> *"Yes. Because if he or she stays in our house or if he or she sleeps with us then we will not be affected by HIV because the virus is present only in the blood."*
>
> *- Woman, 35 yrs, married, Sangli*

3.3.3 Fear of casual infection among the health care providers

Would you be comfortable giving injection/dressing/putting a drip?

Almost all the health care providers claimed that they were absolutely comfortable treating PLWHAs without any discrimination. However, a non-allopathic provider (BAMS) said that providers avoided minor surgeries and sent them to doctors who specialized in treating HIV patients.

> *"Now we are accustomed with all this"*
>
> *- Govt. Allopath (MBBS), Sangli*

Would you mind drawing blood from PLHA?

Almost all the providers (except a BUMS doctor) indicated that they were comfortable drawing blood from PLHA. They further reported that they were already undertaking such procedures in their daily practice. However, some providers said that they took precautions, like wearing gloves, while drawing blood from PLHA.

Would you be comfortable sharing bathroom with infected colleague?

All the health care providers reported that they would be comfortable sharing toilet with an infected colleague, as they thought HIV was not a contagious disease.

Would you assist in the delivery, surgery, suturing of PLHA?

Almost all the providers said that they would assist in the delivery, surgery etc. of a PLHA person. However, some respondents mentioned that they would do it with adequate precaution. A group of allopathic providers (Sangli) said that there were other doctors who did deliveries of HIV patients.

> *"We don't differentiate among patients while checking or at the time of delivery, also even if we know that they are HIV+ patients we see to it that their delivery is done in a normal way like any other mother"*
>
> *- Govt. allopath (MBBS), Sangli*

Would you fear touching the sweat or saliva of PLHA?

None of the health care providers (except a nurse) were scared of touching the sweat or saliva of a PLHA as they indicated to know the chances infection through such fluids were low, and they took adequate precautions (gloves, masks, glasses, etc.,) in handling fluids.

> *"As a medical practitioner if I am scared of touching, I can't practice"*
> *- Pvt. Allopath (MBBS), Mumbai*

3.3.4 Avoiding contact with PLHA

A large number of respondents from the general population mentioned that they had no problem shaking hands with the HIV infected person, and sending their children to a school where PLHA child was studying. However, two respondents indicated that there could be a problem if they sent their child to a school where PLHA child was also studying. A few respondents were willing to send their children with caution to avoid fighting or causing injury to them. Most of the respondents had no problem working with HIV infected persons except two people who said that they would not eat with the PLHA person, and keep a distance. In general, the respondents from general population indicated that they would not avoid contact with the HIV infected person in personal situation, and school and work environment.

3.3.5 Supporting coercive policies against PLWHAs

Do you think the names of PLHAs be made public?

A large number of respondents from the general population were against the idea of making the names of HIV infected persons public mainly due to the fear of stigma and discrimination against such persons. However, some respondents (7) thought that the names HIV infected persons should be made public. Ascribed reasons for making the names public were "give their example to create awareness;" "if they were willing to come out open about their status without shame."

> *“Yes. The names of the PLWHAs should be made public, so that people are careful while dealing with them and they also may be able to get help from social organizations.”*
>
> *- Woman, 32 yrs, Nagpur*

Testing sex workers regularly for HIV?

Many respondents felt that the sex workers should be tested for HIV because “they spread the disease and should be removed out of the profession;” “to provide care to them;” “so that people do not go there;” “so that people use protection if they go there.” A few respondents felt that it was not necessary because “it was of no use because people go to sex workers inspite of knowing the risk;” “sex workers would be forced to close their business.”

> *“Yes. Sex workers generally spread HIV to men as they have sexual relationships with many men. Clients do not know what kind of diseases sex workers have. If tests are done, both the sex worker and the man will benefit.”*
>
> *- Female youth, 23 yrs, Mumbai*

HIV test before marriage, and testing foreigners?

There was a universal approval among the respondents of the general population for testing for HIV before marriage. Similarly, most of the respondents felt that the foreigners should be tested for HIV when they come to India. Reasons for endorsing testing foreigners were “HIV is more in other countries;” “they have sex in India;” “AIDS has come through foreigners.” A few indicated that there was no need for such test because “of fear of discrimination;” “they are our guest and will go back in a month or so.”

> *“Yes, this is very good. Today people see the 'kundali' before marriage. Instead of that an HIV test should be done before marriage and if it is negative, then only they should marry - because two lives depend on that.”*
>
> *- Man, 35 yrs, Mumbai*

3.4 HIV testing and disclosure

a) People living with HIV/AIDS

PLHA respondents recounted their experience on disclosure of their HIV status and Health Care Providers were questioned on their opinion about confidentiality and disclosure of status.

Why did you test for HIV?

About half of the respondents were infected for more than three years at the time of the interview. Several respondents tested for HIV because of the repeated sickness. Further, most of the women tested for HIV at the time of pregnancy or because of the sickness of their husband or child. Some respondents tested based on the advice of the health care providers. Two other respondents tested for the HIV because all members in the family were asked to test.

> *"My husband had fallen sick in 2004 and at that time blood was tested for me and my husband."*
>
> *- Woman, 23 yrs, Mumbai*

Was your informed consent taken?

Only about a dozen respondents mentioned that their consent was taken before taking their blood for testing for HIV. Testing was done on a compulsory basis for some respondents during the pregnancy and at the time of hospitalization for other illnesses.

> *"My husband was too sick, and no treatment was working; so we wanted to admit him in Shastri hospital. There, they wouldn't admit him without these tests."*
>
> *- Female, 23 yrs, Mumbai*

How was your status revealed?

About half of the respondents were told directly about their HIV status by the health care providers. Among them, some got counseling (6), and many others (12) did not get any counseling. Almost a dozen respondents mentioned that they were either told in the presence of their family members or privately to their family members (mother, brother, wife, etc.). A few respondents got to know about their status with substantial delay.

> *"No, nothing. Just they gave the report in my hand and said that I was HIV positive."*
>
> *- Woman, 36 yrs, Mumbai*

Testing policy used by the health care providers

Some of the health care providers interviewed reported to have sought consent from the patient before testing for HIV. In case of emergencies consent was not taken in general, while it was mandatory for pregnant mothers. Some providers got their patients tested thrice for confirmation, while some reported to have referred them to the laboratories. Providers also reported about the requests from persons to conceal the personal identity.

How did you (PLHA) reveal your status?

More than a dozen PLHA respondents revealed their HIV status to their family members only. Some of them revealed their HIV status to select members of the family (mother, brother, grant parents, wife, etc.), which was subsequently known by other members in the family. Some respondents (particularly sex worker, and youth) never revealed their status to anybody fearing stigma and discrimination.

> *"First of all I told my grand-parents and my father. However, I did not tell anybody immediately after the testing. Because people would ill-treat me and discriminate me so I didn't tell anybody."*
>
> *- Male youth, 17 yrs, Mumbai*

What was the reaction to your revealing the status?

Only about half of the respondents got support from their family members. Some respondents (8) got a negative response from their family members to whom they revealed their HIV status.

> *“They told us to live separately. My father-in-law told me to live separately. My brother-in-law and sister-in-law kept us separate, and never helped us when my husband was hospitalized.”*
>
> *- Woman, 23 yrs, Sangli*

What encouraged you (PLHAs) to reveal?

HIV infected persons revealed their status for various reasons. Responses to this question were “cannot be hidden;” “was drunk and told;” “family members should know;” “to get their support;” “if I get too sick I will get help;” “it was important to tell mother;” “they will take care of my kids in the future;” “wanted someone to know about it.”

> *“I trust a friend of mine. At that time I was very nervous as to what I should do. I was broken inside, already because of lack of treatment for this. I had TB also, and was in such a bad condition that I would have died. I also wanted someone to be informed about it.”*
>
> *- Man, 35 yrs, Nagpur*

Reasons for not revealing their status by PLHAs

Fear of stigma and discrimination was the strongest motive for not revealing the status to others (in the society). Sex workers thought they would loose business if they revealed their status to others in the community. Some other respondents thought if they reveal to others they would be heartbroken. Most of respondents had revealed HIV status to their doctors.

> *“I thought if everybody comes to know about my HIV status then my business of sex work will go down. Therefore, I didn't tell any body. It is better I shouldn't tell other sex worker, otherwise she will tell everybody about my status.”*
>
> *- Sex worker, 25 yrs, Sangli*

b) Health care providers

Do you find difficulty in maintaining the confidentiality of HIV status?

Several health care providers contended that it was not difficult to maintain confidentiality of HIV status of PLHAs. However, some providers confessed that it was difficult to maintain confidentiality in the health care set up. An HCP maintained that the nursing staff should be told, as they had to treat them and need to be cautious. In one case, the HCP said that the person giving the report, loudly said, “Where's the report of this AIDS patient?” and “This person is having AIDS.” In some cases, rather than telling the patient they tell their close relatives so that the patient does not get depressed. In one case confidentiality was maintained by segregating the HIV report from the remaining case papers of the patient

Do you think people hesitate to test because of stigma?

Some health care providers indicated that people hesitated to test due to the fear and dilemma of dealing with it if the status turns out to be positive. However, providers indicated that there was less fear among the public in the recent times. Some providers attributed social stigma as one of the reasons for apprehension for testing. A provider indicated that it was more of a problem when the patient was a lady (whose chastity is questioned). Some other provider felt that the cost of testing could be a deterrent for people to test for HIV.

How do you reveal the status of a person after testing?

Health care providers reported that they revealed the results of HIV tests to the person who tested. Some of the providers mentioned that the persons were often counseled before revealing the results. Many health care providers reported to reveal the results to the relatives of the persons who tested for HIV, particularly if the person is emotionally vulnerable. In case the laboratories did HIV testing, the results were not revealed directly to the person tested. Instead laboratories sent the results to the health care provider who in turn revealed the status to the person. Only one government health care provider in Mumbai indicated that counselors revealed the HIV test results to the persons testing for HIV.

> *“Counseling is a must for them; we can't directly drop a bomb on them. In case of STD patients, mostly we tell their relatives and they tell them. They get support from the relatives”*
>
> *- Govt. allopath (MD), Sangli*

You think you should counsel? (HCPs)

Health care providers where asked whether they thought they should counsel the person who tests for HIV. Most of the providers felt that it was necessary to counsel the patient adequately before revealing the results, and most of them did such counseling. Two MD doctors said that the counselors should do the counseling as they had more time and training for such tasks. A Unani doctor said psychologists should do the counseling. Some providers asked the patients to bring their close relatives along with them for testing with an intention to reveal the results to the relative instead of the person who tested for HIV.

Do you think PLHA should reveal their HIV status to others?

Most MD doctors felt that HIV positive persons should reveal their status to their family members for their support and also to prevent them from getting infected. However, health care providers indicated that the friends of PLHA should not be told unless they kept it confidential and are nice to the person. One HCP felt that it was up to the patient to decide whether to reveal or not. A few HCPs felt that HIV positive person should not reveal their status as they may be deprived of even basic rights by the society and even their own family members.

> *“They should tell their family members as they need someone to take care of them when they are suffering”*
>
> *- Govt. allopath (MD), Sangli*

3.5 Self-stigma among PLWHAs

Ever felt ashamed or inferior, and blamed yourself?

Sadness was the strongest emotion felt by the respondents after knowing their HIV status (10). Several respondents (7) felt ashamed that they were positive because of the thoughts “it happens due to sex;” “had sex outside marriage;” “people think I had sex with other men;” “knew about it and married without revealing.” Some others felt shocked, tensed about it, and felt that it was big mistake. Some respondents (7) did not feel ashamed mainly because they thought it was like any other disease.

> *"I was very sad and depressed. Sex work is my source of livelihood, and if I loose this business who would take care of me."*
>
> *- Sex worker, 25 yrs, Sangli*

> *"Yes. That I have done wrong and how will I tell my family. I felt I had fallen on the ground, and I had no right to live. I thought it must have been my fault to get such a disease."*
>
> *- Man, 29 yrs, Nagpur*

Do you think a person you know (also who knows you) would react to you if you reveal your HIV status?

Several respondents (13) felt they will not be accepted if they reveal their HIV status to a known person. While five of the respondents were not sure, only three said that they would be accepted if they reveal their status to someone they knew. Few of the PLHA respondents were apprehensive that they would be secluded from the community especially with regard to financial transactions.

> *"He will cut contact with me and avoid me. He will avoid doing any financial dealings with me, and end friendship with me."*
>
> *- Man, 35 yrs, Sangli*

> *"I think they will accept me; they love me very much and they know that I am a good natured person. And I think if they come to know that I have HIV they will not discriminate against me."*
>
> *- Woman, 36 yrs, Mumbai*

Do you think you have isolated yourself and withdrawn from your family?

Many respondents (14) did not isolate themselves from others for reasons, such as "family support was there;" "had good health;" "living in a joint family;" "not revealed status to many people;" "praying to god;" and "not ashamed." However, some respondents (10) reported that they isolated themselves and withdrew from the surrounding environment for different reasons "did not know what to do;" "perceived discrimination;" "aloofness of others;" "self hatredness."

> *“Yes. I have reduced my visits to my brothers and mother's houses. They discriminate; do not let me touch their children, and other things.”*
>
> *- Woman, 28 yrs, Nagpur*

Not applied for job/ promotion or travel to another country?

While some (5) reported that HIV status had NO effect, others reported that it affected while applying for job or traveling. Two respondents discontinued work because of their repeated sickness due to HIV. Two respondents reported that they could not travel to other country or place for work due to HIV. Four respondents mentioned that they were not getting job because of their positive status. Some respondents (12) from the general population knew HIV infected persons who could not apply for job or did not get promotion.

> *“I am living the same life, but the difference is first I used to go for work and now I am not working.”*
>
> *- Man, 40 yrs, Mumbai*

> *“I wanted to go out of country so I had asked the agent about it, he said because you are PLHA you cannot go. The salary was 20,000 rupees.”*
>
> *- Woman, Mumbai.*

Did you decide not to marry or have children because of your infection?

Almost a dozen respondents mentioned that they could not marry and have children because of their HIV status. Some of the respondents (3) were already married and had children. A respondent mentioned about a HIV positive lady who re-married (dead husband's brother) to have children. However, some other respondents, who were already married and had children, wished that they were not married and did not have children. Many respondents (13) from the general population knew HIV infected persons who could not marry or have children because they were positive.

> *“I wanted to have a child who would call me daddy, but now it is not possible and it is very hard to digest.”*
>
> *- Man, 30 yrs, Mumbai*

> *"Yes. I have not married because of my status; and if I marry I will marry a HIV positive girl."*
>
> *- Man, 26 yrs, Nagpur*

Did you avoid going to public places such as restaurants and teashops?

Nineteen of the total PLHA respondents did not avoid going to public places such as restaurants and teashops. Respondents reported that they did not feel any threat because they had not revealed their HIV status to the public. Only two respondents mentioned that they avoided going to public places due to stigma and discrimination.

> *"I would avoid going there if I had revealed my status. They would start treating me differently."*
>
> *- Male slum youth, 25 yrs, Sangli*

> *"Yes, I avoid going to my mother's place, it is because people know me and about my HIV status. That is why I avoid going there."*
>
> *- Female youth, 23 yrs, Sangli*

Do you think a PLHA person should marry?

Most of the respondents (21) supported the idea of PLHA marrying. However, they also indicated that "both should be positive;" "there should be true love;" "other person should be told about the status;" "should take precautions" "person needs sex;" "should take care." Some respondents (6) did not agree to PLHA marrying stating "concerned about the lady and child;" "would be nuisance to wife;" "spread the disease."

> *"If man and woman both are positive there is no problem in marrying. But they should take precautions though they are married."*
>
> *- Male youth, 17 yrs, Mumbai*

> *"Yes, they can become helpful to each other - lonely life is a very difficult. If a man remains unmarried - he may be a nuisance to society, as he cannot suppress sex and spreads HIV. If he gets a HIV positive partner he may not spread HIV to others. So such marriages should be encouraged."*
>
> *- Woman, Sangli*

3.6 Stigma and discrimination in the household

The fear of the unknown and perceptions of deviance may find expression in family life, as seen in some instances, with regard to HIV infection.

Do family members behave differently?

About half of the PLHA respondents reported that their family members behaved differently. These behaviors included "husband deserted wife;" "brother and sisterin-laws did not accept;" "father neglecting and getting angry and irritated;" "physical isolation of the infected person;" "not invited for the function in the family;" "not allowed to touch children, driven out of the family;" "not talking and eating food together;" "stopped visiting them." About half of the respondents mentioned that their family members did not behave differently, for reasons like "the infected person was the only daughter;" "all were positive in the family;" "not revealed the status;" "are very supportive."

> *"We were asked to get separated from the family thinking that it could affect the marriage proposal of another family member. They hate us; do not like us doing chores in the house. They spray water after we clean the utensils, not allowed in family functions. Our daily routine chores are denied. They say that they would give food to us and no need to do any work."*
>
> *- Woman, Sangli*
>
> *"No change at all. I even got helping hands from family and the society. I have not revealed my status to anybody."*
>
> *- Man, 35 yrs, Sangli*

Were you isolated in the household?

Several PLHA respondents (18) indicated that they were isolated in their houses by their family members. Isolation was in different forms "bed thrown away;" "not allowed in the house, by in-laws;" "driven out of the house;" "separate utensils for drinking and eating;" "not allowed to participate in the engagement ceremony;" "not touching, keeping all the belongings separate;" "separate bathroom and soap;" "separate pot for drinking water;" "kept in tabela (cattle shed);" "not allowed to cook, clothes separated."

> *"My wife didn't do anything, but other family members ill-treated me. I was seriously ill and I had no guarantee of my life, and at that time they didn't touch me, and they didn't come near to me."*
>
> *- Man, 30 yrs, Mumbai*

Similarly, about half of the respondents from the general population reported knowing some PLHA abandoned by their family members. Different forms of abandonment mentioned by the general population respondents were "keeping the person outside the house;" "keeping in a separate room;" "giving food through the window;" "ignoring the person;" "separate plates and food;" "separating clothes from others;" "separate toilet;" "sending the person to a village to die."

> *"They left him to sleep outside Sometimes they may have ignored him also."*
>
> *- Woman, 28 yrs, Mumbai*

Were you teased or insulted by your family members?

More than a dozen respondents indicted that they were insulted or teased in their own house by other family members. Different forms of insulting were "you have not done anything for us;" "troubling us instead of dying;" using words 'chinal' and 'randi,' told to get out of the room," you are going to die and no one will touch your body," "calling a guy eunuch." The respondents (8) who did not face such discriminatory treatment at home quoted "not revealed status" and "the infection due to blood transfusion" as reasons.

> *"Yes, they told us - you are going to die and no one will come and help you."*
>
> *- Female, 23 yrs, Sangli*

Abandonment, loss of child or property

Several respondents mentioned that they were abandoned (husband/ regular partner deserted, wife sent back to parents' house, separation from the family, abandoning after the death of husband). However, about a third of the respondents indicated that their spouse or family did not abandon them. Some other respondents indicated that the family of their spouse took their children away. Some women respondents reported that they did not get any property from their spouse or family.

> "Yes. My husband (regular partner) left me after knowing my status."
>
> - Sex Worker, 24 yrs, Mumbai

> *"First of all, my in-laws had hidden the status of my husband. When I got the infected, they filed for a divorce, and took away my daughter."*
>
> *- Woman, Mumbai*

3.7 Stigma and discrimination in the community

Stigma and disclosure is closely linked, the fear of stigma ensures HIV positive person and their immediate family members would think twice about making the status known to others in the community.

When information of status was made known, the experiences were diverse. While certain individuals did not face discrimination, others were confronted with discrimination and rejection of various kinds.

Treatment meted out by the society

About a dozen respondents reported that people did not behave differently in the community. Responses of these respondents were "if the status is not revealed to others;" "not happened to me;" "does not happen these days;" "educated people do not do that." Some respondents (9) indicated that people behaved differently with them ("they have no value for people;" "kept a distance;" "cleaned bathroom repeatedly after use;" "not greeting when met;"

and “refused to eat together”). Seven other respondents said that it had happened to some other person.

> *“Since I have not revealed my status to anybody, I have no problem.”*
>
> *CSW, 28 yrs, Mumbai*

> *“Yes, not much but some discrimination is there, they wouldn't drink water or take tea with us.*
>
> *- Female youth, Mumbai*

More than half of the respondents felt that they lost respect or standing in the community (“no value to us;” “people avoid us;” “no one talks to me or greet me;” “when I visit somebody they talk only about disease;” “not wanted in social events;” “suspicious attitude;” “scared of us;” “they think we are rascals”). However, ten respondents mentioned that they did not loose respect in the community.

> *“Yes it is less now, my father used to invite me to visit him often earlier, but now he tells me not to come at all”*
>
> *Man, 36 yrs, Mumbai*

> *“No, it has not affected my respect it is going on as before.”*
>
> *Man, 37 yrs, Mumbai*

Some PLHA respondents (8) reported that they were insulted, teased or sworn at by others (abused by sister-in-law, other patients and in some instances by doctors; instructed to stay away by others). However, about half of the respondents indicated that they were not insulted, teased or sworn at (“nobody knows the status;” “have fear of that;” “not abused but kept away from me”).

> *“Yes. They (who know my status) scold sometimes; they ask why I do not give away my children to somebody.”*
>
> *- Sex workers, 24 yrs, Mumbai*

> *“They feel the ones who are infected are dirty and I fear that they would insult me.”*
>
> *Male slum youth, 26 yrs, Sangli*

A few respondents from the general population reported to know HIV infected person insulted, abused and beaten. Forms of insults and abuse were “behaving rudely;” “insulting in the public and beating;” “humiliation leading to suicide;” “gossiping about;” “abuse as sinful person;” “taunting;” “terminating relation;” “not touching;” “getting angry with the person;” and “not sitting close.”

> *“Although the husband knew that because of him his wife got infected he still blamed her and had relations with another woman.”*
>
> *- Woman, 25 yrs, Nagpur*

Exclusion from social gathering

About half of the respondents mentioned that they were excluded from social gathering (“does not invite me;” “no marriages in the family;” “nobody talked to me in marriage;” “not allowed in festivals;” “friends do not interact publicly;” “not invited to social functions;” “treated as bad omen during functions/ festivals”). The remaining half of the respondents felt that they were not excluded from social gathering (“not revealed my status;” “never happened to me;” “going on as before”).

> *“They don't talk to them, they don't sit or eat with them, and they don't go out with them.”*
>
> *Sex worker, 27 yrs, Sangli*

> *“No. I go everywhere. I do not reveal my status. So I do not have problem.”*
>
> *- Woman, 36 yrs, Mumbai*

Some respondents (7) from the general population knew HIV infected persons not being allowed to take part in social gathering. Forms of social ostracizing were “not allowed in wedding;” “ignoring in a social gathering;” “not invited;” “relatives avoiding;” “not lifting the dead body of infected person;” “making them sit idle in social functions.”

> *"Yes people attended his funeral but nobody was ready to touch the body fearing that they may contract the disease. With great difficulty some of his relatives and two of his own brothers got ready to lift the body."*
>
> *- Male college youth, 18 yrs, Mumbai*

About half of the PLHA respondents reported that there was no change in friends and people visiting after getting the infection ("they scold me sometimes but the number of people have not reduced;" "my friends are positive like me;" "same as before;" "not affected as yet;" "on the contrary more people are visiting me because I help other PLHA;" "status not known to others"). However, some respondents (8) thought that there was a reduction in friends and people visiting them after they got the infection ("they have fear;" "do not talk or eat with us;" "stopped participating in community events;" "people have stopped coming to see me;" "it happens if you reveal;" "made new set of PLHA friends").

> *"It is same as before, they call me home but I don't go."*
>
> *Male youth, 17 yrs, Mumbai*

> *"Yes, they totally stopped sitting together, talking and even coming close to me."*
>
> *Man, 26 yrs, Nagpur*

About half of the respondents indicated that they experienced gossip/ rumor/ unfair remarks ("talk behind our back;" "it happens because of sex;" "did something bad and because of that my husband died;" "people enquiring about the disease;" "talking among themselves;" and "overheard - he has AIDS and will die"). While several respondents (9) said that they did not experience any gossip, rumor, passing remarks, some respondents suspected that it could be happening behind their back. Only two respondents mentioned that they were physically assaulted. One PLHA indicated that some were afraid to hit him because of the possibility of bleeding and blood coming in contact with them.

> *"They say that I used to go around having sex with others even before marriage and that is why I am affected by this disease."*
>
> *Woman, 29 yrs, Nagpur*

> *"No they have never hit me because they are afraid that if they hit me and I*

> *bleed and they touch my blood then they might also become HIV positive."*
>
> *- Man, 26 yrs, Nagpur*

Had to move out of the neighborhood or not able to rent a house

A few respondents (5) indicated that they had problem with housing ("thrown out of the house;" "children kept away from the house;" "not able to rent"). Some other respondents (5) mentioned that they knew other PLHA having similar problems ("thrown out of the house;" "other members shifting out;" "thrown out of the housing complex;" "not able to rent"). However, several respondents (13) did not have any problems with the housing ("I do not know whether it is happening to anybody;" "such situation has not come to me yet;" "neither heard nor seen"). Similarly a few respondents (8) from the general population did know HIV infected persons who either lost their housing or could not rent one.

> *"I was thrown out of the house in the beginning."*
>
> *- Man, 36 yrs, Mumbai*

> *"When I took this room on rent, my neighbor told the owner not to give the room because I was infected with HIV; but the owner was nice and allowed to stay in the room."*
>
> *- Female youth, Mumbai*

Stigmatization of friends and family members

Only some respondents (6) mentioned that their friends or family were stigmatized ("they would say 'positive has come to the house';" "children are not allowed to play;" "friends told to stay away;" "friends were asked to tell about PLHA friend;" "parents told your son is suffering because of some mistake"). Several other respondents (14) said that they did not have such problem. Some respondents (7) reported that their families had time due their infection.

> *"Some of my friends told me that they had witnessed PLHA being discriminated. They teased by saying positive has come."*
>
> *- Woman, 36 yrs, Mumbai*

> *“PLHA family had to keep the person in the hospital; all the money was spent to pay the bills, and they had to mortgage whatever gold they had.”*
>
> *- Man, Nagpur*

A few respondents (4) reported that their children were discriminated because of their status (“parents protested to take out positive's child;” “not talking to the child;” “respondent himself/herself faced discrimination in college;” “child not picked up by adults”). Six other respondents had heard about other PLHA's children being discriminated. Some respondents indicated that their children did not suffer any stigma and discrimination because they had not revealed their status. There were two incidences where school helped PLWHA children with special care.

> *“There were three HIV affected children studying in a school. Then the parents of the other students protested against keeping HIV-affected children in the school, and demanded that they be removed from the school, and they will not let their children study in that school. The school threw out HIV-affected children.”*
>
> *Man, Sangli*

Denial of medical care and other benefits

Some PLHA respondents (10) reported to know PLHA not given care after accident. Very few respondents (3) mentioned about being aware of other PLHA denied participating in social event. Some mentioned how they were denied medical care.

> *“If they come to know that he is Positive, they do not pay much heed to him. The doctors and sisters would not attend to him even if they are called repeatedly.”*
>
> *- Male youth, 17 yrs, Mumbai*

Several respondents mentioned about the denial of insurance services to PLHA. While some had not revealed their HIV status to the insurance company, others who had the policy feared that they would not get the benefit of insurance on death. There were other cases of denial where PLWHAs were not allowed to make use of the company benefit, and HIV pension benefit, and hospitalization.

> *“We were told that the insurance did not cover HIV. If this facility is refused to us, we cannot do anything for our children's future.”*
>
> *Woman, Sangli*

> *“There is a pension of 250 rupees to a HIV patient. This money is not given properly to the HIV affected people, and they do not give in time.”*
>
> *- Man, Sangli*

3.8 Stigma and discrimination in health care set up

Stigmatization within health care settings can arise from both structural and individual factors and it is often determined by local socio-cultural political reality. This is reflected in the responses of Health care Professionals and the experiences of the HIV infected.

Experiences narrated by PLHIV

Most of the PLHA respondents sought care from the government hospitals (“they know my status;” “get free treatment there;” “get good treatment;” “they know the disease”). A few respondents (4) used both government and private set up in seeking care (“Government for ART, and the private doctors for other illnesses”). Some others (6) reported going only to the private doctors (“I go only for cough and cold;” “doctor knows my status”).

> *“Most of the PLHA go to government hospitals, because they get free treatment there as the medicines and testing is costly outside. Not all doctors are unaware about it. The doctors in Nagpur medical college hospital have good knowledge and provide proper treatment.”*
>
> *Man, Nagpur*

> *“I visit private doctor for small problems like cough.”*
>
> *Man, 37 yrs, Mumbai*

A few respondents (5) complained about the behavior of the doctors and nurses ("do not touch;" "getting angry and asking to leave the hospital;" "bad counseling;" "hesitate to do invasive operation;" "do not bother about patients' needs"). Some respondents (4) were not happy about the quality of the treatment ("poor facilities;" "no new line of treatment;" "not examining properly"). Some other problems mentioned by the respondents were "too much crowd in the hospital;" "higher charges;" "space problem;" "and lack of privacy."

> *"First time I went to ART center, medical counselor did my counseling in a very bad manner. When I thanked him towards the end of the session and shook hands with him, he just gave his two fingers to shake hands."*
>
> *- Man, 26 yrs, Nagpur*

> *"Doctors don't examine me and give me medicine, he only sees me from far and prescribes the medicine."*
>
> *Sex worker, 35 yrs, Sangli*

Experiences at the time of seeking health care services

A dozen respondents complained that they were refused treatment by the providers ("after knowing my status, I was told to go to another doctor;" "not giving good medicine;" "treating from a distance;" "resisted to admit for treatment;" "private doctor sending to govt. hospital;" "refusing to do dental work;" "refusing if the patient had more problems;" "tablets not given in hand but kept on the table"). About half of the respondents indicated that the health care providers did not refuse to treat them.

> *"I had taken medicine for ten days. I was to get operated for teeth, and doctor knew I was HIV positive, so he told me to go to another doctor."*
>
> *- Male youth, 17 yrs, Mumbai*

> *"When we go to private doctors they say it is better you go govt. hospital. And in govt. hospital if we stand in the hospital then it has bad effect on our business, hence we don't go out."*
>
> *- Sex worker, 27 yrs, Sangli*

Health care providers were also asked whether they refused admission or treatment to people living with HIV/AIDS. Most of the providers said that other doctors or hospitals refused admission or treatment to HIV patients. Only one provider admitted to refusing admission to a PLHA since he was scared about his staff getting infected. Reasons cited for such refusal were "it may turn away other patients;" "they feel these patients may not be 100% safe;" "they may not be having adequate facilities or staff to deal with such patients;" "due to misconceptions of doctors about HIV." A health care provider said that they treated HIV patients for common ailments and sent them to specialist for HIV treatment. Some other provider said that there were many doctors who gave reasons like "there are HIV specialists go to them for treatment to ward off HIV patients." Another HCP knew a doctor who did not even talk to or touch PLWHA patients. Four providers claimed that they had not refused admission or heard of any provider doing so. One respondent said providers used to refuse earlier but not nowadays.

Waiting for too long was a problem for about a dozen respondents ("provider do not attend to us;" "we have to stand in line for a long time;" "no water to drink;" "whole day is wasted;" "had to make 3 trips to get some treatment"). However, some respondents (7) did not complain about waiting at the health care facility.

> *"Yes - in government hospital. Because, first of all, we have to fill a form, then they start the treatment at 1.00 pm, and it wastes our whole day."*
>
> *Man, 38 yrs, Nagpur*

> *"We have to stand in the line and the nurse keeps on screaming at us. There is no water and clean toilet. And there is no fan there and the serious patients do not have the place to rest or sleep for sometime."*
>
> *Woman, 29 yrs, Nagpur*

Some respondents (8) reported that they were referred to other providers unnecessarily ("once he knows the status he refers to government doctor;" "government doctor provide good treatment;" "private providers tell us to go to government hospital"). Some other respondents (7) indicated that they were not referred to other providers, unnecessarily.

“Private providers tell us to go to government hospitals.”

Sex worker, 27 yrs, Sangli

“They get angry and say that just for this much fever you come here or what? You can go to the private - if there is any fever then you should go to the private hospital and you should not come here.”

Woman, 28 yrs, Nagpur

Health care providers were asked whether they shunted PLHA patients between wards unnecessarily. Many health care providers said that the HIV infected patients were shunted between wards. Reasons given for shunting were “HIV patients have low immunity when compared to other patients;” “infection should not spread to HIV patients;” “it is better to consult an HIV specialist.”

“There are a few doctors who simply refuse to take HIV patients”

- Pvt. Allopath (MBBS), Mumbai

“The shunting of patients is occurring, including in JJ hospitals. Most of the doctors deny admission in the first place”

- Pvt. Allopath (MD), Mumbai

Further, care providers were also asked whether they passed on HIV patients to other providers because they did not want to treat them. Health care providers admitted that this was done. Reasons cited for such act were - “they do not want to take a risk;” “patients who do not have an idea where to go for treatment will naturally be sent to the concerned department;” “sometimes it is done to get expert opinion.” Only a couple of providers said that PLWHAs were not passed on to others.

“Private clinics and hospitals do not treat positive patients”

- Pvt. Allopath (MD), Mumbai

“Some CME doctors get together and discuss among themselves 'keep distance from these AIDS patients' ”

- Pvt. Allopath (MBBS), Mumbai

Most of the PLHA respondents mentioned about health care providers using gloves ("they use gloves or else do not touch us;" "they always use gloves;" "use gloves to avoid coming in contact with us"). However, some other respondents (6) indicated that providers did not use gloves unnecessarily.

> *"Yes. They have fear that if we touch these patients they might get infected, so they use it."*
>
> *Male slum youth, 26 yrs, Sangli*

> *"They always use those gloves, mask and gown."*
>
> *- Sex worker, 25 yrs, Sangli*

The perceptions of the providers with regard to taking excessive precautions and using gloves for non-invasive procedures were explored. About half of the providers reported not taking excessive precautions. Those who took excessive precautions mostly used 2-3 gloves instead of one, face masks, caps etc. A provider said that these precautions made him uncomfortable while treating the patient.

> *"At least 90% doctors do not take excessive precautions, 10% may be doing this"*
>
> *- Pvt. Non-Allopath, Mumbai*

> *"When we hand over our duty to the next staff we softly tell them this person is sero positive, we don't say HIV +"*
>
> *- Govt. allopath (nurse), Mumbai*

About half of the health care providers said that there was no conditional treatment of HIV patients. A few providers mentioned that they charged HIV patients extra money for the additional precautions that they had to take (the extra articles or for keeping them in a separate room).

> *"Some HIV patients are very rich and ready to pay any amount. So finally doctors are also earning money"*
>
> *- Pvt. Non-Allopath, Sangli*

Did health care providers discuss about your status with others, use derogatory language or treat you in an undignified manner?

Almost a dozen PLHA respondents reported that providers gossiped or made derogatory remarks about them (“scolded that I had too many children;” “asked whether I drank alcohol;” “asked whether we had sex with sex workers;” “asked personal questions in the presence of others”).

> *“According to me counseling should be done in privacy. There were many people sitting in the room. He asked my age and then enquired how many women I had been to and slept with. Was she a girl, a woman or old woman? How did you do it with her? You used condom or not?”*
>
> *Man, 26 yrs, Nagpur*

Health care providers reported that they did not gossip about the PLHA patients, but their support staff, such as nurses and ward boys did that. A nurse contended that class IV employees discussed this, as they had to be careful while washing bedpans, urinals, etc.

> *“Nurses gossip about PLHA patients. As they lack adequate knowledge and understanding, they might do this kind of thing”*
>
> *- Pvt. Non-allopath (BAMS), Sangli*

> *“I tell my staff, 'look he is positive, better be careful' and most of them think of them as immoral, alcoholic, womanizer, AIDS positive. There was a case where a patient was getting blood transfusions and now he is positive; then it was a case of sympathy”*
>
> *- Pvt. Allopath (MBBS), Mumbai*

Several PLHA respondents (10) indicated that the bed sheets were not changed as required (“not provided fresh sheets;” “family members had to clean the sheets;” “bed sheets were discarded;” “sheets not changed for three days”). However, some respondents (6) said that the bedpans and sheets were changed as per requirement. Both these experiences have occurred in government hospitals.

> *“Last time when my husband was in the hospital, he had loose motions and the ward boys refused to touch the bed sheets, I used to wash them. He was in his last stage so no one was willing to touch him.”*
>
> *- Female youth, Mumbai*
>
> *“My brother used to change the bed sheet.”*
>
> *- Man, 36 yrs, Mumbai*

Some PLHA respondents (9) reported that they were kept in isolation in some way or the other. The isolation of the patient occurred in many ways “keeping the patient on the floor;” “a gallery near the toilet;” “making the patient sit in the corner;” “separate bed away from other patients.” However, some other PLHA respondents (9) reported that they were not kept in any kind of isolation.

> *“Wards are same but the cots are different. In the front row, there are normal patients, and in the opposite row, positive patients are kept.”*
>
> *Man, 40 yrs, Mumbai*

> *Yes, it is true, we don't get admission in government hospital, and if they give admission, they are kept separate or near the bathroom.”*
>
> *Man, Nagpur*

Health care providers were also asked whether they isolated PLHA patients for some or the other reasons. About half of the providers said that HIV patients were kept in some kind of isolation. Some other providers said that PLHA patients were kept separately in a side-row in a ward if not in a separate ward. One provider reported that even the bed sheets, linens and bathrooms were kept separately. However, if the HIV wards were full, the patients were kept, for some time, in other wards. A nurse from a government hospital in Mumbai said that HIV patients had special beds in the verandah. Almost all the providers said that PLHAs did not have restricted access to toilets and bathrooms.

Some respondents mentioned that they were asked to pay in some cases (“when medicines were bought from outside;” “saying that the cost has been increased by the govt.;” “terminally ill patient was asked to spend for treatment;” “charging more because of HIV”).

Health Care Providers' perspective:

> *“A private doctor said 'paisa feko tamasha dekho.' In govt. hospitals, if we tell them that we are HIV positive then they don't give any attention. They just write prescription and tell us to buy from the shop. We think that dying is better than giving them so much money.”*
>
> *Female, 28 yrs, Nagpur*

Almost all the health care providers contended that the PLWHA patients were not asked to pay for free services. A private non-Allopath (BUMS) mentioned about greedy doctors who treated HIV patients with an eye on their pockets.

> *“No, the nominal charges that they are paying. No extra fee is charged”*
>
> *- Govt. allopath (MD), Sangli*

About half the health care providers said that HIV patients were not discharged earlier than required. Among those who contended that these patients were discharged earlier than required said it happened mostly in government hospitals. Reasons cited for early discharge were “maybe to avoid infection to others;” “to prevent other patients from turning away.”

> *“When I discussed with HIV patients they said, 'I wanted to stay there for some more days for treatment but they didn't allow me”*
>
> *- Pvt. Non-allopath (BAMS), Sangli*

> *“If he does not want to keep them then he will not admit them in the first place.”*
>
> *- Pvt. Non-qualified, Mumbai*

Half of the health care providers said the support staff refused to lift the dead body of HIV patients. Some of the responses of providers to this question were “maybe this happens or could happen in government hospitals;” “it is due to non-awareness and will slowly change in future;” “they take excessive precautions (4-5 gloves, caps, masks, gowns).” Some provider also stated that that the body of PLHA was wrapped in plastic covers and it was burnt along with all the clothes. A HCP said that some families did not take the body of a PLHA home and straightaway cremated it. One government nurse reported that the practice of wrapping the body in a plastic bag had changed to wrapping it in a white bed sheets and labeling with red ink as HIV+ so that the mortuary staff could exercise enough care. Reasons cited for this was "to prevent getting infection."

> *"The staff is careful not to touch the body. Staff does not have much knowledge. They even hesitate to pick up a normal dead body"*
>
> *- Pvt. Non-qualified, Mumbai*

Health care providers stigmatizing and getting stigmatized

Health care providers reported that they never stigmatized PLHA. A MD doctor from a government hospital said private and non-medical doctors stigmatize more. A private homeopath and a Unani doctor said, "Some doctors refuse to treat PLHA and hospitals discharge them earlier than required." All except one provider said that doctors were not stigmatized for treating PLHA. Only a private Non-allopath doctor said he knew a doctor whose patients were only prostitutes. "Once prostitutes start coming then no other patient will go to him."

3.9 Stigma and discrimination in Workplace

Most of the PLHA respondents who were working did not disclose their HIV status to others in their work places. One respondent even unsuccessfully tried to hide his status at the time of recruitment. Of all the PLHA respondents, only one sex worker had revealed about her HIV status to fellow sex workers. PLHA respondents reported that they were scared about loosing their jobs if they revealed their status at workplace. Further, they were also scared about the potential stigma and discrimination by their colleagues and the management.

> *"If disclosed to any employer, he will remove me from the work. They will exploit us, give us more work and then they will remove us."*
>
> *- Woman, 23 yrs, Sangli*

> *“I am scared my employer would sack me, I don't know how my colleagues would behave with me, so I didn't reveal my HIV status.”*
>
> *- Man, 30 yrs, Sangli*

3.10 Stigma and discrimination Media and communication

What media and messages perpetuate stigma and discrimination?

While some PLHA respondents (10) were of the opinion that media perpetuated stigma and discrimination, other respondents (5) thought that media did not perpetuate stigma and discrimination. PLHA respondents condemned the poster advertisements of earlier years where AIDS was portrayed as deadly disease and almost equated with death. Further, they did not like the media campaign focusing on sex, prostitution, and associating HIV with danger in any form.

> *“In the beginning government had made propaganda with the stickers. In that they said AIDS means death, and the posters were stuck on the walls of government hospital and in villages, so doctors are making more fuss about it.”*
>
> *- Man, 30 yrs, Sangli*

Some respondents criticized the Balbir Pasha campaign because they felt that it had negative connotation that exacerbated stigma against the infected. Some other campaigns like Betal- Vikram and Manjula ka boyfriend were also criticized. In general, PLHA respondents liked communication which focused on emotional support to HIV infected persons, not those with focus on sex, prostitutes, and associating HIV with death.

> *“Balbir Pasha is one example, you may have heard about it. The ad questions who would be the next Balbir Pasha, it creates fear for HIV as Balbir Pasha had died of AIDS. This instills fear in the minds of people. They should not show the ads of prostitute.”*
>
> *- Man, Nagpur*

> *“In train a poster was displayed with a message of 'Be Aware of AIDS - it is dangerous.' We feel so sad when we see that.”*
>
> *- Woman, Mumbai*

What kind of media and messages are effective in reducing stigma and discrimination?

Most of the PLHA respondents believed that both television and radio were the most effective media for reducing stigma and discrimination. A respondent mentioned how a cable television with access even in slums would be useful in communicating HIV/AIDS messages. Another respondent mentioned that he liked the interviews of doctors on television because it helped him know more about positive living. Another respondent mentioned that the media should portray infected person like any other normal person. One of the respondent mentioned that the street plays were more effective means of communication in reducing stigma and discrimination. PLHA respondents liked television communications focused on emotional support to HIV infected persons. Some of the advertisements showing celebrities like Amitabh Bachan and Sachin Tendulkar speaking about how shaking hands and eating with PLHA does not spread AIDS were liked by the respondents. Another respondent indicated that he liked the advertisement 'keep away from AIDS not from AIDS affected person.'

> *“Radio and TV. Nowadays there is cable in every house even in slums; we should give the message through national channels.”*
>
> *Man, Mumbai*

> *“Nowadays Amitabh is coming in an advertisement where he says shaking hand doesn't spread AIDS, Tendulkar in another advertisement says eating and shaking hand doesn't spread AIDS. This is very good thing that is happening now.”*
>
> *- Woman, Mumbai*

3.11 Knowledge of rights among PLHAs

Only some respondents were able to discuss about the rights issues when the interviews were conducted. Most of the respondents who discussed about the rights indicated that they were entitled to equal rights like anyone else. A respondent mentioned how employers removed PLHA from the jobs due to the pressure from other employees in workplaces. A female PLHA respondent mentioned about her right to be a member of Women's organization (Mahila Mandal), right to speak and to go anywhere she wants to without any restrictions. Some other respondents mentioned about right to education, voting right, right to exist, and right avail the services of doctors, right to independence, right to making decision in the family, etc. Further, a respondent mentioned that it was his right to get insurance policy like anybody else.

> *“We are entitled to equal rights. Since we are positive, we face restrictions. Other workers pressurize the employer to remove the infected worker from job.”*
>
> *- Male youth, 17 yrs, Mumbai*

> *“I have the right to be a member of a Mahila Mandal and I have the right to speak and go anywhere. I can do all the works that a normal person can do.”*
>
> *Woman, 29 yrs, Nagpur*
>
> *“I should get insurance policy, I should get good treatment, and education and should not be discriminated in the society.”*
>
> *Man, 30 yrs, Sangli*

3.12 Presence of PLHA friendly services in health care set up

Most of the Health Care Providers interviewed reported to have undergone some sort of training on care and counseling of PLWHAs. Only a Unani doctor and a group of non-Allopathic providers reported no exposure to any such training. One private Allopath (MBBS) also did not have training, and he had only one support staff. All the providers contended that counseling facilities existed within their premises. However, most of the providers reported to counsel themselves. Only one group of private non-qualified providers admitted that they had no counseling facility.

Most of the Allopathic providers had sufficient stock of drugs. A few providers (2 private Allopaths-MBBS, most non-allopaths) said that they only prescribed drugs and did not stock them. A Unani doctor said that he ordered drugs from a company, as and when required. All the providers reported to have adequate supplies, such as, gloves, and mask. Only a government nurse said that they needed better infrastructure for themselves.

Most of the health care providers said that they had required facilities to treat PLHA. However, some said that they needed a separate unit, a few more ICUs and ventilators for providing better care to PLHA. A few providers said that they did not have sufficient facilities (a Unani, a private MD, a govt. MD, a non-allopathic).

> *"We need a full-fledged HIV care centre. There are a lot of patients not getting admissions in the government hospitals"*
>
> *- Pvt. Allopath (MD), Mumbai*

3.13 Gender issues in stigma and discrimination

Many respondents (13) from the general population indicated that women suffered more from stigma and discrimination. Reasons quoted were "she has to go out for shopping for vegetables;" "not invited to participate in social gathering;" "being at home;" "suspecting her moral characters;" "blamed for diseases;" "transmitting to child;" "cook of the family." While some had no opinion, other few thought men suffered more for reasons like "men work outside to earn a living;" "men mix with friends and family outside;" "men are suspected of bad behavior."

> *"It is more difficult for women since she only needs to go outside to buy vegetables and groceries. Moreover, if there is any function nobody invites her."*
>
> *- Woman, 35 yrs, Sangli*

> *"A male is condemned more. If a male knows he gets scared as he only goes outside to work, roam around and sit with friends."*
>
> *- Man, 42 yrs, Sangli*

More than a dozen PLHA respondents said that it was difficult for women to disclose their status for different reasons. Some respondents thought that both men and women get the same treatment irrespective of their gender. However, some other respondent mentioned that it was difficult for man to reveal the status because man was considered to be an earning member and the head of the family, and it affected the status of the family.

> *“Women participate in social functions like 'haldi kumkum' and she can't reveal her status because they will not invite her for that. For man, he does not care about anything.”*
>
> *- Man, Sangli*

> *“Man is reluctant to disclose as it affects his status. Women's positive status does not make much difference. Man is an earning member and head of the household. So it affects the family status, while in case of women, it does not make any difference in the family life.”*
>
> *- Man, 35 yrs, Sangli*

Several PLHA respondents (9) indicated that women suffered more of self stigma for reasons like “husbands desert wives;” “blamed more (kalankit)” “women cannot fight” “does not have freedom like men” and “women are disgraced more.” While three respondents said both women and men suffered the same level of stigma, one person said it was more among men.

> *“Women have to bear more stigma because they suspect her character especially if her husband is negative.”*
>
> *- Female, 36 yrs, Mumbai*

Many respondents (10) from PLWHA group including men and women thought that women suffered more in the households (“because women are scared;” “infection is blamed on her by the in-laws;” “less respect to women”). Interestingly two respondents felt that men suffered more because they were seen as cause of the infection and men had to go out in the society to earn a living.

> *If a lady suffers from HIV then the society says, because of this lady her husband also got infected but I don't think like that.*
>
> *- Man, 38 yrs, Nagpur*

More than half of the PLHA respondents felt that women suffered more in the community for different reasons (she is always blamed and harassed, women suffer more, image of women is less, people gossip about her character, underestimated, widows are abused). Some other respondents (4) thought that both women and men suffered the same level of stigma and discrimination (stigma is the same there is no reason why they will be good to her and not to me).

> *“Man has to suffer very less because he earns and a woman has to suffer a lot because she is alone. If any woman is working and she is earning good then she will not suffer.”*
>
> *Man, 40 yrs, Mumbai*

Chapter 4

SUMMARY AND RECOMMENDATIONS

Causes of stigma and discrimination

Knowledge of HIV/AIDS transmission and prevention

Most of the respondents from the general population and PLHA knew about the modes of HIV transmission. However, there were some respondents who thought that shaving in a saloon and eating with infected persons caused infection. Health care providers reported that the virus lived outside the body for 45 seconds to an hour depending upon the condition. Most of the respondents did not feel threat in a casual contact with infected person. Health care providers considered blood as most infective, and did not feel the need to use gloves for simple examination of PLHA patients.

Most of the respondents from the general population and PLHA knew about the prevention methods. However, not shaving in a saloon was a one of the prevention method mentioned by the respondents. Except a few, all the respondents thought that there was no cure for HIV. About half of the respondents thought that the PLHA could live longer with medication. Another dozen respondents mentioned about the need for emotional support to the PLHA. Most of the respondents from the general population knew some or the other PLHA (friends/neighbors, etc.).

Shame, blame and responsibility

Most of the respondents (both general population and HCPs) did not blame or put PLHA to shame for getting the infection. However, some respondents blamed the infected persons if they had got it through sex. Sex workers and truck drivers were blamed for spreading HIV/AIDS in the society. Except a few, most of the respondents did not think that the infection was a punishment for bad behavior. Most of the respondents (general population) blamed the persons who got the infection through sex while pardoning the ones who got infected through infected blood (transfusion). Health care providers indicated that any act did not warrant blaming. Respondents also did not blame housewives since the infection was considered be through their spouses.

Fear of contagion and risk perception

Several respondents from the general population (except a few) mentioned that they did not have problem wearing a washed sweater and glass previously used by the PLHA. Many of them mentioned that they would take care of HIV infected relative. Further, it was felt that pregnant nurse or doctor should take care of PLHA patient because it was their duty. Many respondents mentioned that they would not have problem shaking hands with a PLHA, and sending their child to a school where PLHA child was studying, and working with HIV infected colleague in a workplace. Most of the health care providers indicated that they would be comfortable giving injections/ dressing and putting drip, assist in delivery or surgery in case of PLHA patient. Further they also reported that they would not have problem touching the saliva or sweat with requisite precautions.

Supporting coercive policies

A large number of respondents from the general population did not support the idea of making the names of PLHA public because of the potential stigma and discrimination. However, the respondents indicated that the sex workers should be tested for HIV regularly as they were a major threat. There was a universal approval for testing before marriage.

HIV testing and disclosure

PLHA respondents tested for HIV due to recurring episodes of illness, either themselves or their spouse. Several of them complained that they were not consented before testing, and the results of the tests were revealed in a confidential manner. Health care providers often involved the family members of the person testing for revealing the results. Although providers mentioned about taking consent, there were instances of mandatory testing and testing without consent. About a dozen respondents revealed their status to their family members from whom they expected support. They did not reveal to others due to the fear of stigma and discrimination. Several providers indicated that people feared testing because of widespread stigma and discrimination. Further, they were of the opinion that PLHA should not reveal their status to others unless the confidentiality is maintained.

Self-stigma among PLHA

Sadness was the strongest emotion experienced by the PLHA after knowing their status. Several respondents felt ashamed that they were infected with HIV. Further, they thought that they would not be accepted if they revealed their status to someone they knew. While some did not isolate themselves, others isolated themselves from the surrounding environment because of aloofness of others, perceived discrimination, and self-hatredness. Some of the respondents mentioned that HIV status impacted their jobs and travel. Many PLHA reported that they could not marry and have children because they were infected. However, PLHA respondent favored the idea of marriage among the infected couple. Most of the respondents did not avoid going to public places since they had not revealed their HIV status.

Stigma in the household

PLHA suffered more inside their homes than out in the society. Respondents reported that their family members behaved differently leading to self-isolation. There were instances of insult, abandonment, loss of property, and children taken away from the infected persons.

Stigma in the community

Some PLHA respondents complained about people behaving differently, and felt that they lost the respect in the community. Some of PLHA were excluded from participating in social gathering and were insulted or teased. Some other respondents reported about the problem of housing, family members suffering, and their children discriminated. Many PLHA were concerned that they would not get the benefit of insurance.

Stigma and discrimination in health care set up

Most of the respondents who accessed government hospitals complained about the poor facilities (no space to sit, long waiting time, and lack of privacy). About a dozen respondents complained about the refusal of treatment by providers. Some health care providers admitted to refusing and referring PLHA patients to other doctors due to the fear of infection. Excessive precautions by the providers (2 to 3 gloves, mask, etc.) were reported by both PLHA and providers themselves. There were no reports of conditional treatment except overcharging in some cases. Providers indicated that mostly nurses and ward boys gossiped about the PLHA. Many PLHA complained that the bed sheets were not changed as required. Some PLHA reported that they were isolated in the health care set up. Health care providers admitted that the support staff of the hospital refused to handle the dead bodies of PLHA patients. There were no reports of health care providers getting stigmatized.

Stigma in workplace

As most of the PLHA with employment had not disclosed their status, there were no reports of widespread stigma and discrimination in workplaces. Several PLHA respondents were worried about the potential threat of stigma and discrimination by their colleagues of they revealed their status.

Stigma and media/communication

Some PLHA reported that the media (particularly some campaigns through large hoardings) perpetuated stigma and discrimination. They did not like media focusing more on sex and prostitution in HIV/AIDS communication. Some of them condemned campaigns like 'Balbir Pasha,' 'Manjula ka boyfriend,' and 'Vetal Vikram.' PLHA respondents thought that television, radio, and street plays with messages focused on emotional support to the PLHA would reduce stigma and discrimination. Respondents liked the recent advertisements where Amitabh Bachan and Sachin Tendulkar talked about how AIDS does not spread by shaking hands and eating together.

Knowledge of rights

Although several PLHA respondents could not relate well to their rights, some of them mentioned that they were entitled to different rights including right to work, right to be member of an organization, right to education, voting right, right to exist, right to avail doctor's services, right to independence, and right to decision making.

Presence of PLWHA friendly services

Several providers indicated to have received sufficient training to treat PLHA patients. While some providers reported to stock sufficient drugs, other simply prescribed. Several providers made efforts to counsel on their own, and reported that they had adequate stock of supplies like gloves, masks, etc.

Gender issues in stigma and discrimination

Many respondents indicated that women suffered more stigma and discrimination when compared to men for different reasons (suspecting her moral character, women are blamed more, less respect to women; women cannot fight for their rights, etc.). Further it was considered difficult for women to test and disclose their HIV status for similar reasons.

4.2 Recommendations

Providing Information

- The fear of the unknown can be dissolved by reducing the perceived differences through facilitating care of the infected persons, clarifying myths and misconceptions facilitating early detection and providing quality health care services.
- In addition to providing information about the routes of HIV/AIDS transmission, myths and misconceptions need to be addressed.
- Since relatively fewer respondents knew about the medication for prolonging the life of a PLWHA, there is a strong need for creating awareness about the availability of ART treatment among the public. Enough care should be exercised to avoid people construing ART as cure for HIV.
- Respondents blamed people who got the infection through sex as an

irresponsible act. However, they did not blame those who got the infection through other routes. Therefore, efforts should be made to create awareness so that there is acceptance of the infected, irrespective of the routes of transmission.

- Both sex workers and truck drivers were blamed as cause of spreading HIV/AIDS in the society. Therefore, HIV/AIDS awareness should focus on de-stigmatizing these groups and convey that anybody with risk behavior can get the infection.

Strengthening Systems

- A visit to the ART center leads to immediate identification as being HIV positive and warrants associated stigma and discrimination. The fear of being identified as HIV positive leads to infected persons postponing the first visit to the ART center till unavoidable; this further deteriorates their health condition.
- Media needs to be sensitized about the emotional response of PLHA to the HIV/AIDS communications. As indicated by the PLHA messages carrying emotional support to PLHA should be included in the campaign.
- Programmatic intervention for reducing stigma and discrimination should address the different vulnerabilities of women as infected persons.

Capacity Building & Sensitization

- Training programs among health care providers should focus on alleviating the unfound fears of infection. Although providers know the levels of risk involved in different procedures, some providers still fear treating PLHA patients.
- Further, health care providers were also known to stigmatize and discriminate PLHA. Therefore, it is essential to sensitize the support staff about the extent of risk of infection in dealing with PLHA patients.
- Although health care providers indicated that they had a conducive environment for providing care to PLHA, there were several complaints

about the problems at health care facilities. Attitude of the providers need to change for better, and the
facilities at the hospitals need to be improved. ART centers should provide free treatment for the opportunistic infections as well.

- Several private providers who are treating PLHA for their opportunistic infection need to be trained on HIV/AIDS medication.

Support structures for PLHA

- Self-stigma was quite evident among the PLHA respondents. Efforts should be made by the programs and positive networks to provide appropriate emotional support to the PLHA to overcome the problem of self-stigma.
- There have been reports of widespread stigma and discrimination in the households and communities. Therefore, there is a need for concerted efforts through programs to reduce such stigma and discrimination. Self isolation of PLHA could be tackled by developing support systems through family members and networks.
- For more people to reveal their status and avail of services, workplaces need to have HIV/AIDS policy which is well canvassed among the employees. PLWHAs should be assured about the job, and their colleagues sensitized on stigma and discrimination.
- Knowledge of Right is poor among the PLHA. Therefore, programs and networks should focus on educating the PLHA about their rights as a citizen of the nation.

Avert Society
AcWorth Complex, R. A. Kidwai Marg
Wadala (West), Mumbai 400 031 Maharashtra, India
Website: www.avertsociety.org, Email: info@avertsociety.rog
Tel. No.: 022-24164510/ 16/28/ 24155943/ 48
Fax No.: 24163996