Understanding HIV/AIDS: A Gender and Rights Perspective

29-30 November, 2005

Workshop Report

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Women's Health Training Research and Advocacy Cell

Women's Studies Research Centre (WSRC)
Faculty of Home Science
The Maharaja Sayajirao University of Baroda

December 2005

WOHTRAC Report Series. No. 7

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Introduction

Background

The HIV pandemic is increasingly being viewed the world over as a strongly gendered health, development and human rights issue.

Evidence from across the globe shows the changing pattern of infection rates by sex and age. Not only are more women than men being infected and are dying of HIV/AIDS, there are profound differences in the underlying causes and consequences of HIV/AIDS infections in both sexes, reflecting how differences in biology and gender norms are affecting both sexes differently. Therefore gender analysis is crucial to understanding HIV/AIDS transmission and it forms the basis for effective strategies for prevention.

Human rights are central to all aspects of an effective response to HIV and AIDS. A "rights-based approach" to HIV/AIDS starts from the premise that respect for human rights forms a coherent basis for programs to address the pandemic, and that abuses of human rights contribute to the spread of the virus and undermine attempts to contain it. When human rights are not promoted and protected, it is harder to prevent HIV transmission and the impact of the epidemic on individuals and communities is worse.[1]

Women's Health Training Research and Advocacy Cell (WOHTRAC) has incorporated the *Human Right to Health* perspective in its current 'Gender, Health and Development Project'. The Human Right to Health perspective includes the right to highest attainable standard of physical and mental health, including reproductive and sexual health. It also includes right to equal access to adequate health care and heath related services regardless of any other status, and advocates equitable access and distribution of various resources necessary for people's development. The rights perspective also stresses that the State has the obligation to ensure access to health including the enabling conditions before this right can be fulfilled.

WOHTRAC's mandate is to develop and institutionalize a gender and rights perspective on health and development in The Maharaja Sayajirao University of Baroda and advocate a gender and rights perspective for health and development policies and programs.

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[1] Amnesty International, *Women HIV/AIDS and Human Rights.* Accessed from: http://web.amnesty.org/library/Index/ENGACT770842004

WOHTRAC, organized a state level workshop on "Understanding HIV/AIDS: A Gender and Rights Perspective", on 29 and 30 November, 2005.

Objectives of the Workshop

- Sensitization of persons working in the areas of women's health and HIV/AIDS on gender and rights issues in HIV/AIDS.
- Development of a gender and rights perspective of HIV/AIDS in them.
- Identification of gender and rights issues in existing intervention programs and recommendations for addressing these issues.

Participants

Over 35 participants, representing NGOs working on women's health issues and HIV/AIDS including the Gujarat State AIDS Control Society (GSACS) partners providing Targeted Interventions for HIV/AIDS prevention and control in Gujarat, the Departments of Skin and Venerology, Preventive and Social Medicine, Obstetrics and Gynecology of the Medical Colleges of Karamsad and Baroda, and other individuals working in the area of women's health and HIV/AIDS took part in the discussions. (See Appendix A for the List of Participants)

Resource Persons

The resource persons for the workshop were:

Prof. Yogesh Marfatia, Head, Department of Skin and Venerology, Baroda Medical College and core team member WOHTRAC,

Ms. Renu Khanna, Founder Trustee SAHAJ – Society for Health Alternatives, Baroda, and core team member WOHTRAC,

Prof. Prakash V. Kotecha, Head, Department of Preventive and Social Medicine, Baroda Medical College and core team member WOHTRAC,

Dr. Uma Nayak, Associate Professor, Department of Pediatrics, Baroda Medical College, and core team member WOHTRAC,

Dr. Radium D. Bhattacharya, Director, GAP-ISRCDE, Ahmedabad.

Methodology

The two-day workshop was conducted over six sessions at the Women's Studies Research Centre, Faculty of Home Science, The Maharaja Sayajirao University of Baroda. The methodology was primarily presentation and discussion (see Appendix B for the program outline).

Epidemiology of HIV/AIDS in India and Gujarat

Presenter: *Prof. Prakash V. Kotecha*

HIV (Human Immunodeficiency Virus) and AIDS (Acquired Human Immunodeficiency Syndrome), often used in the same breath and interchangeably are *not* the same. HIV is an infection, while AIDS is a disease. HIV infection occurs first and then over a period of time it develops into AIDS. Having HIV infection is not fatal, whereas having AIDS means certain death. Thus one must consciously avoid using the two acronyms HIV and AIDS interchangeably.

Modes of Transmission

HIV spreads

- Through unprotected sex: the virus is present in the semen, menstrual blood, and vaginal fluids.
- Through use of contaminated injection and syringes, and transfusion of contaminated blood.
- From mother to child – during pregnancy, labor and delivery and through breastfeeding,

HIV does not spread by the following:

- Touching an HIV positive person
- Taking care of HIV positive person
- Working with an HIV positive person
- Studying or working with an HIV positive child
- Air, water, or mosquito bites
- Sitting together and eating/sharing food

Signs and Symptoms of AIDS

It takes about 4-6 months of incubation of the virus for a person to test positive after infection. This period is known as the 'window period'. HIV tests will fail to detect infection during the window period.

Secondary symptoms of AIDS are:

- Persistent cough for over 1 month
- Boils and itching on the skin
- Ulcers in the mouth and other parts of the body
- Painful ulcers on the waist
- Sores on the body and throat
- Swelling in the lymph glands for over two months
- Opportunistic infections

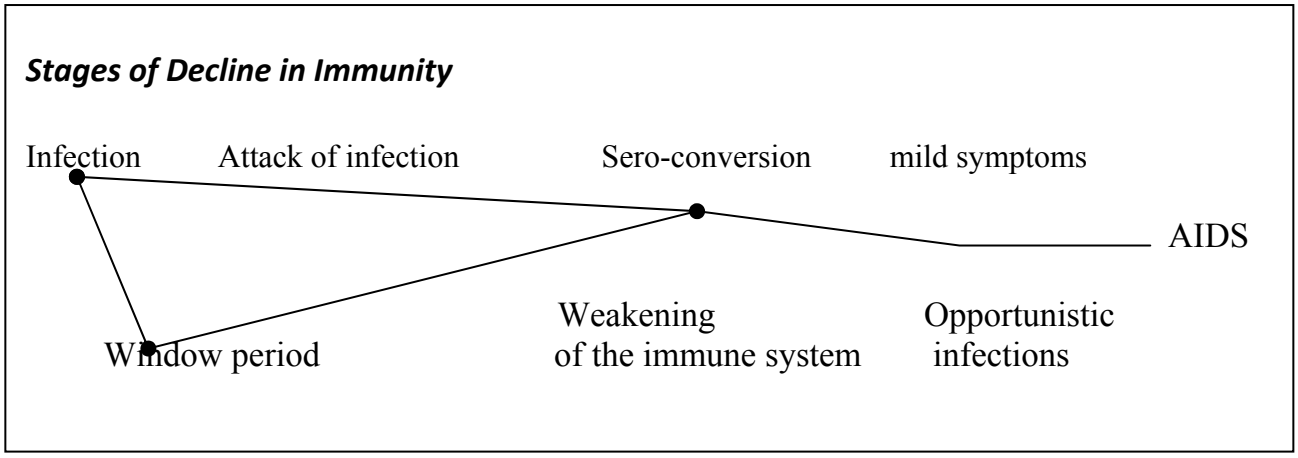
The common diseases which affect persons with AIDS are:

- Infection in the lungs, e.g. tuberculosis and pneumonia
- Infection in the brain, i.e. mental imbalance, severe headache and excessive stress.
- Intestinal infection: prolonged diarrhea
- Cancer: especially skin (Kaposi's Sarcoma, which is not very common in India)

Opportunistic Infections

There are many opportunistic infections such as:

- Pneumocystis carinii pneumonia (PCP), a type of pneumonia affecting the lungs
- Kaposi's Sarcoma: a rare and fatal form of cancer
- HIP Encephalopathy: affecting the interiors of the brain
- Tuberculosis
- Candidasis: a type of yeast infection
- Herpes Simplex: a type of viral disease
- Primary Lymphoma of the Brain: A type of brain cancer



History HIV/AIDS in India and Government Response

The first case of HIV infection in India was diagnosed among commercial sex workers in Chennai, Tamil Nadu, in 1986. Soon after, a number of screening centers were established throughout the country. Initially, the focus was on screening foreigners, especially foreign students. Gradually, the focus moved on to screening blood banks. By early 1987, efforts were made up to set up a national network of HIV screening centers in major urban areas of the country.

A National AIDS Control Program was launched in 1987 with the program activities covering surveillance, screening blood and blood products and health education. In 1992 the National AIDS Control Organization (NACO) was established. NACO carries out India's National AIDS Program, which includes the formulation of policy, prevention and control programs.

The same year that NACO was established, the Government launched a Strategic Plan for HIV/AIDS prevention under the National AIDS Control Project. The Project established the administrative and technical basis for program management and also set up State AIDS bodies in 25 states and 7 union territories. The Project was able to make a number of important improvements in HIV prevention in the country such as improving blood safety.

Prevalence of HIV/AIDS: The Global and Regional Scenario

HIV/AIDS – Global Scenario, 2005 (in lakhs)

People living with HIV/AIDS

Total persons: 403
No. of adults: 380
Children <15yrs: 23

New cases of HIV/AIDS

Total persons: 49
No. of adults: 42
Children <15yrs: 7

No. of AIDS Deaths

Total persons: 31
No. of adults: 26
Children <15yrs: 5.7

As of 2005, globally, there are 403 lakh people living with HIV/AIDS, there 49 lakh new cases of HIV/AIDS and 31 lakh AIDS deaths occurred in the same year.

Every 6 seconds, around the world, a new HIV infection occurs, i.e., about 14000 new HIV infections each day.

More than 95 percent of these infections occur in low and middle-income countries. Almost 2000 out of these 14000 new infections that occur every day are in children under 15 years of age. About 12000 of these infections are in persons aged 15 to 49 years, of whom almost 50 percent are women and about 50 percent are 15–24 year-olds.

Regional estimates for the number of deaths due to AIDS show that majority of the AIDS related deaths are in Africa and the lowest number of deaths occur in North America. The number of women living with HIV/AIDS, is highest in Africa, possibly because the detection in men may be better. HIV/AIDS progresses much faster in children and ironically, children are mostly not responsible for the infection. In 2005 alone, there were 23 lakh children below the age of 15 years, and there were 5.7 lakh children who had died due to AIDS.

Prevalence of HIV/AIDS in India and Gujarat

In India HIV prevalence among adults is 0.9 percent. As of July 2005, there were 51.34 lakh cases of HIV and 1,11,608 (cumulative) cases of AIDS reported in India.

Estimates of People living with HIV/AIDS in India			
Group			
Adults			5,000,000
Women			1,900,000
Children			120,000
Total			5,100,000
Adult HIV prevalence estimate			**0.9%**
HIV cases in India, as of July 2005			**In lakhs**
Urban			21.27
Rural			30.07
Male			31.32
Female			20.02
Total			**51.34**
Number of AIDS cases in India			
Cumulative			
Males			79041 (70.8%)
Female			32567 (29.2%)
Total			**111608**
In the month of July 2005			
Males			556
Females			196
Total			**752**
Age and sex wise distribution of HIV cases			
	Male	*Female*	
0-14 yrs	2860 (3.6%)	1994 (6.12%)	4854 (4.3%)
15-29 yrs	21782 (27.5%)	14405	36187 (32.4%)
30-49 yrs	48342	14508	62850 (56.3%)
>50 yrs	6057	1660	7717 (6.9%)
Total	**79041**	**32567**	**111608**
Modes of transmission as of July 2005			
Sexual			85.96
Perinatal transmission			3.64
Blood and blood products			2.00
Injecting drug users			2.39
Others (not specified)			6.01
Total			**100.00**

Distribution of the cases of HIV by age, sex and residence shows higher prevalence in men, in persons in the active reproductive age of 15-49 years and in the rural population.

AIDS cases: Distribution in India	
State/Union Territory	AIDS cases in 2004
Andhra Pradesh	11,819
Gujarat	5,561
Madhya Pradesh	1,347
Maharashtra	13,402
Manipur	2,866
Rajasthan	1,153
Tamil Nadu	52,036
Uttar Pradesh	1,383
West Bengal	2,397
Ahmedabad M C	520
Mumbai MC	7,223
Total	**109,349**
State/Union territory	**AIDS cases in 2005**
Tamilnadu	52036 + 7484
Maharashtra + Mumbai MC	13747
Andhra Pradesh	12349
Gujarat + AMC	5636 +621
Karnataka	2896
Manipur	2866
West Bengal	2397
Total	**111608**

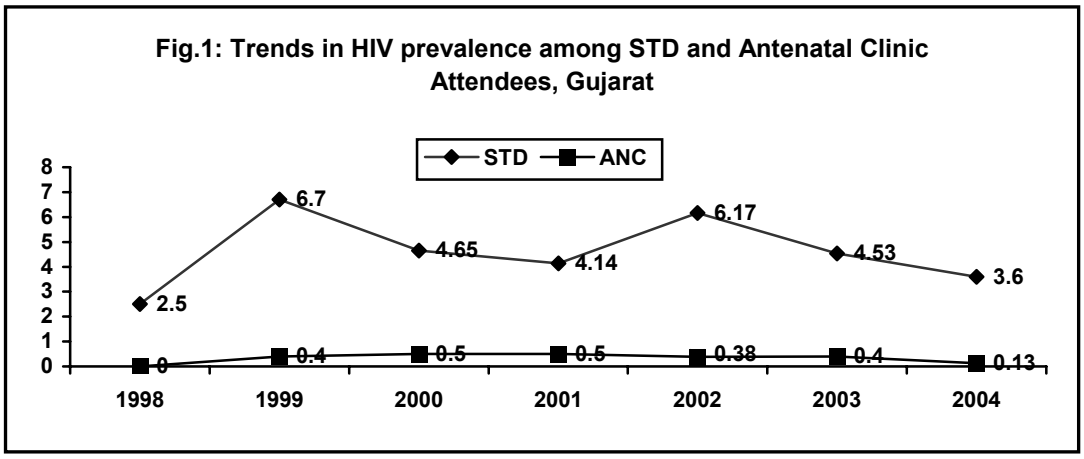
Inter-state variation in HIV prevalence (2004)	
State/Union Territory	**HIV prevalence (%)**
Andhra Pardesh	2.25
Arunachal Pradesh	0.17
Assam	0.00
Bihar	0.00
Goa	1.13
Gujarat	**0.13**
Tripura	0.30
Uttar Pradesh	0.25
West Bengal	0.50
Chandigarh	0.50
Daman & Diu	0.38
Pondicherry	0.25

About 80 percent of the cases are from the three states of Tamil Nadu, Maharashtra and Andhra Pradesh.

Error!

In 2005, with regard to distribution of AIDS cases across states/union territories, Tamil Nadu ranks the first, followed by Maharashtra, Andhra Pradesh. Gujarat ranks fourth. This data needs to be examined more closely.

HIV prevalence in Gujarat is 0.13, as per 2004 data. The trend in prevalence among STD and Antenatal Clinic (ANC) attendees shows the prevalence in the general population and in high-risk behavior groups. The data in the graph (Figure 1) show a decline, which indicates that either some intervention must have been very effective or the data is suspect.



Sentinel Surveillance System

The prevalence estimates for India are based on sentinel surveillance conducted at public sites, i.e., public sector facilities. In 2004, the total number of sentinel sites stood at 659 and this includes 171 STD sites, 269 ANC sites, 24 IDU (injecting drug user) sites, 15 MSM (men seeking sex with men) sites, 42 FSW (female sex workers) sites, 132 ANC (rural) and 6 tuberculosis sites.

However, the public sector provides only 20 percent of the health care in the country. There is no system to collect information on HIV testing from the private sector, which provides 80 percent of the health care in India.

India racing for the spot of No. 1

In absolute numbers, India continues to stand second, next only to South Africa having 5.3 million HIV infections and has not overtaken South Africa. In terms of prevalence percentage India has HIV prevalence of 0.91% among adult population as compared to 21.5 % in South Africa. Given India's large population, with most of the Indian states having a population larger than the populations of majority of the countries in Africa, even a 0.1 percent increase in the prevalence rate would increase the number of adults living with HIV/AIDS in India by over half a million people. India is racing for the position of number 1 in the prevalence of AIDS and will soon overtake South Africa.

HIV in India: Current and Future Trends

The National AIDS Control Organization (NACO) has estimated that the number of Indians living with HIV increased by 500,000 in 2003 to 51 Lakh. Around 38 percent of these people were women. By the end of May 2005, the total number of AIDS cases reported in India was 109,349, of whom 31,982 were women. These data also indicated that 37% of *reported* AIDS cases were diagnosed among people under the age of 30. However, many more cases of AIDS go *unreported*.

The UN Population Division has projected that HIV prevalence among adults in India will peak at 1.9% in 2019. According to UN estimates, there were 27 lakh AIDS deaths in India between 1980 and 2000. During 2000-15, the UN has projected 123 lakh AIDS deaths and 495 million deaths due to AIDS during 2015-50. Further, a 2002 report by the CIA's National Intelligence Council has predicted 200 to 250 lakh AIDS cases in India by 2010, more than any other country in the world.

Orphans in India

Obtaining data on the number of children orphaned by AIDS is difficult. It is believed that the proportion of children in India orphaned by AIDS is far lower than in sub-Saharan Africa, but because of India's huge population the actual number of children already orphaned by AIDS is very high. In 2001 the number of orphaned children was already estimated to be 12 lakhs.

Women at Stake!

The epidemic continues to shift towards women and young people. It has been estimated that 38 percent of adults living with HIV/AIDS in India at the end of 2003 were women. What the available data show is both shocking and moving. In 2004, it was estimated that 22 percent of HIV cases in India were housewives with a single partner. The increasing HIV prevalence among women can consequently be seen in the increasing cases of mother-to-child transmission of HIV and pediatric HIV cases.

To Sum Up

HIV/AIDS has no cure, the long wait for an effective vaccine continues. On the positive side, we very well know what causes it to spread, the various modes of transmission, so we can raise awareness, educate people, and motivate everyone to protect themselves.

The ABCD approach is the most popular prevention strategy, wherein A is for abstain, B is being faithful, C is consistent and correct use of condom and D is avoiding drugs, completely.

Discussion

- *Why is it said that mosquitoes do not spread HIV?*

Mosquitoes or other sucking and biting insects do not transmit HIV. For a mosquito to infect someone, it would have to bite a person who was infected. Then, it would have to either immediately travel to someone else and infect that person from tiny drops of infected blood left on the sucker, or it would have to process the virus in its saliva and inject it into the next person. Mosquitoes do not do either of these things.

They do not travel from person to person. They do not carry enough blood on their suckers to infect anyone else they bite. And, they do not process the virus in their

saliva. Once inside a mosquito, the virus lives for only a short time. Thus, the saliva mosquitoes inject into people cannot have HIV. If HIV were spread via insects like mosquitoes, there would be a high infection rate in people of all ages.

- *How are sentinel sites selected?*

The HIV sentinel surveillance system of NACO has been put in place to gather data and monitor the trends of HIV in specific high- and low-risk groups. A few selected sentinel sites representing various groups are screened for HIV prevalence and the trends are monitored over a period of time. The population groups and sites are chosen based on information of behavior of various risk groups for HIV infection. The high-risk population groups include patients attending STD clinics, men seeking sex with men (MSM) and injecting drug users (IDUs), while low-risk populations include mothers attending antenatal clinics. The rationale of choosing sentinel sites in these clinics is that data about people with risk behaviors, such as those engaging in multi-partner sex and injecting drug use, who make use of clinic services, will be collected at regular intervals. Moreover, a sentinel site has to be a place where people would consent to give blood samples. Usually, those who attend STD and ANC clinics, blood banks, voluntarily give blood, for the purpose of pathological investigations. It would not be possible to set up sentinel sites in schools, as few schools would volunteer, and thus it is not possible to monitor the prevalence among school-going children. Because sentinel sites are selected on the basis of information of behavior of various risk groups for HIV infection, the number of sites for each group would vary across various states. For instance, sites for IUD users would be more in certain states like Manipur.

The sentinel surveillance method has been criticized because samples are drawn from sites that are not uniformly spread across the country. For example, states which have a greater number of sites for STD and ANC will show higher prevalence trends, than those that have lesser number of sites, thus showing uneven trends across the country.

- *When we highlight the increasing rate of mother-to-child HIV infections among antenatal women, we stigmatize only women for no fault of theirs!*

As highlighted in the presentation, 22 percent of the HIV cases in India are women, with a single partner, they do not belong to any of the high risk behavior groups, they are married, and are faithful to their husbands. They have been infected by their husbands. It is true that classifying any group as high risk behavior stigmatizes the entire group. For instance, about 26 percent of Indians are migrants, however, mostly single migrants, and not all who migrate, show high risk behavior. But treating migrants as a high-risk group stigmatizes the entire migrant population.

Recently, there has been a change in the term mother-to-child transmission to de-stigmatize mothers. This mode of transmission is now called parent-to-child transmission.

Gender Analysis of HIV/AIDS

Gender Concepts: Importance and Role in Health and HIV/AIDS

Presenter: *Renu Khanna*

What is gender?

The term gender is defined as widely shared expectations and norms within a society about appropriate male and female behavior, characteristics and roles which ascribe to men and women differential access to power, including productive resources and decision making authority. Gender roles vary over time and by class, caste, religion, ethnicity and age.

In short,
Biological sex (i.e. being male and female by birth) + value = Gender

By birth we are born as males or females, while social construction of femininity and masculinity turns males and females into 'men' and 'women'.

Gender concepts

The various dimensions of gender that construct 'men' and women' in particular societies are:

- ***Social beliefs about men and women:*** Certain beliefs exist in society about men and women. E.g. men are strong, women are weak, men are rational, and women are emotional.
- ***Gender norms for behavior:*** These social beliefs about men and women define different norms which govern the behavior of men and women in society, e.g., men can express themselves, men can be articulate, women must not express themselves or be articulate.
- ***Gender roles, sexual division of labor, different activities and tasks:*** These define different gender roles for men and women, e.g., men must be breadwinners, and women must be carers, nurturers. This in turn results in sexual division of labor – which is generally productive for men – like earning income/wages, and reproductive for women – caring, nurturing, social reproduction; community leadership for men, e.g. Sarpanch, informal leadership without public or formal recognition for women, e.g., as *dai*, wise woman, etc. There are different activities and tasks for men and women. Women's tasks are undervalued and invisible, e.g. cooking, cleaning and women's work is fragmented. The public domain is reserved for men, and the private for women.

- ***Access to and control over resources:*** Resources like money, land, technology, knowledge, self-esteem, time, and space.
- ***Decision-making and power:*** Those who make decisions and have power are the ones who influence social beliefs and gender norms for behavior, sexual division of labour, and access to and control over resources.

Thus, this is a system, which feeds on its sub-systems and perpetuates itself. The beauty of the system is that it can be broken anywhere – either by changing social beliefs, or by changing norms for behavior of men and women, or by changing the work that men and women are supposed to do, or in the allocation of resources. Thus it can be said that gender constructs can be changed over time, over space, and over contexts.

All the above dimensions of gender construct 'men' and 'women' in particular societies and each of these dimensions needs to be examined while doing a gendered analysis of any situation or problem.

Gender is commonly reduced to 'women' but the term is *not* synonymous with women. It has to do with differences between men and women, gender relations, power, and it is one more basis of discrimination and inequality.

Sex, gender and health

A gender perspective in health recognizes that while some health conditions are biologically determined (e.g. menstruation or pregnancy), **Biological susceptibilities and vulnerabilities** (sex) interact with **Gender and social factors** (gender) to produce health conditions which

- are **sex specific:** For example pregnancy and breast cancer in women, prostate cancer and hydrocele, in men.
- have **different/higher prevalence in one or other sex:** For example, anaemia due to iron deficiency, osteoporosis (8 times more in female than in male) in women; cirrhosis associated with alcohol abuse, lung cancer associated with tobacco consumption, excessive mortality from violence, homicide and accidents in men.
- have **different characteristics for men and women,** different manifestations or symptoms as well as outcomes in men and women: For example, sexually transmitted diseases (STDs) are 'asymptomatic' for longer periods in women and have more severe consequences in women such as sterility and even death, in cases of pelvic inflammation. Malaria during pregnancy is an important cause of maternal mortality, spontaneous abortion and stillbirths, particularly during pregnancy, malaria contributes significantly to the development of chronic anaemia in women.
- **generate different responses** at the levels of the individual, family, community and the health care system: For instance, cardiovascular problems. The notion persists that these are typical men's diseases. As a result, symptoms are not recognized in

women. Data indicate that cardiovascular diseases are one of the main causes of death, in some population groups, among women older than 49 years. Further, very few male sterilizations are done as compared to female sterilization, despite the fact that vasectomy is a simpler, more economical and less invasive procedure than sterilization for women.

Therefore a gendered analysis of any health condition, disease, health programme would include: examining sex-disaggregated data; identifying gender related factors affecting who falls ill, when and where; and identifying gender related factors affecting responses to illness.

Sex, gender and HIV/AIDS

Differences in biological vulnerability of men and women

- Women are more likely than men to become HIV positive after a single intercourse, especially if they are young.
- Male-to-female transmission of HIV appears to be 24 times as efficient as female-to-male transmission. This is due to a large mucosal area exposed to virus in the case of women and greater viral inoculums present in semen as compared to vaginal secretions.
- Young girls are particularly vulnerable as their immature cervix and relatively low vaginal mucosal production presents fewer barriers to HIV.
- STDs in women are often asymptomatic.

How gender norms for behaviour increase women and men's vulnerability

- There is high value placed on virginity of girls.
- Girls/ women not supposed to know about sex, men are expected to know much more. Girls/women are kept ignorant about sex and ways to negotiate safe sex.
- Women have to please men, defer to male authority. Therefore women cannot refuse sex or negotiate safe sex.
- Men are socialized to be adventurous, risk taking so they have higher rates of partner change and are more likely to have concurrent or consecutive partners. Women more likely to be faithful.
- Poverty interacts with gender norms to promote risky sexual practices. Construction of masculinities, notions of virility, pressurise men to ‘prove’ themselves through promiscuous sexual activity.

How gender roles, sexual division of labour put men and women at risk

- Men are supposed to be the breadwinners. Out migration of men for work, occupations that require them to live for long periods without their families, increases the likelihood of their engaging in unsafe sexual practices. Men (more likely than women) have multiple partners, relations with sex workers, and desire

sex without condoms, all of which predispose them to sexually transmitted infections and HIV.

- Economic instability also forces women to migrate. Women migrate and come into a range of occupations categorized as the 'flesh trade' - from bar girls, to sex workers**.** Young women entering the manufacturing sector, face increased vulnerability to sexual exploitation in factory work. For instance, sexual exploitation of migrant women workers from Kerala in the prawn industry in Gujarat has been reported recently.
- In their traditional role as caregivers and nurturers, the burden as carers in HIV affected households is greater for women.
- With the out migration of men, many women are left alone, heading their households and vulnerable to sexual exploitation.

Gender differences in access to and control over resources

- Awareness and information both in men and women. Several studies have shown a marked lack of awareness and knowledge of HIV/AIDS and risk factors and modes of transmission. As the National Family Health Survey shows, awareness of AIDS is particularly low among rural women, poor women, scheduled-tribe women, and illiterate women.
- Women's economic dependence on men makes it difficult for them to negotiate safe sex. Negative economic consequences of leaving high-risk relationships is more serious than health risks of staying.
- Laws and policies prevent women from owning property and productive resources.
- Control of household and reproductive decision-making lies mostly with men. Women are denied opportunity of protecting themselves.

Power

Because women lack access to and control of over resources, they have less or no power to make decisions regarding their lives. Demonstration of power by men manifests itself in the form of violence against women, sexual coercion and violence, sexual exploitation and trafficking, which in turn negatively impacts on women's health.

Research gaps in HIV/AIDS and gender: Some unanswered questions

- How do gender roles and societal pressure put men at risk?
- How do we measure reduction in gender inequalities leading to vulnerability to HIV/AIDS?
- How can change be brought about to make HIV/AIDS institutions more gender sensitive?
- How to bring about convergence between the RCH Program, comprehensive primary health care and the HIV/AIDS Control Program?

HIV/AIDS: Gender Differences in Vulnerability, Outcomes and Responses

Presenter: *Dr. Yogesh Marfatia*

Dr. Marfatia began his presentation reiterating that gender is not just about being a male or a female, but has to do with the socio-cultural roles assigned to males and females and the dynamics between them. Gender is a very important factor in health. Gender differences in women's and men's roles and responsibilities, in their access to resources, information and power are reflected in the gender differences and inequalities in women's and men's vulnerability to illness or disease, their health status, access to preventive and curative measures, and burdens of ill-health.

Feminization of the HIV Epidemic

% of HIV infected women	47 %
• Women age 15-29 yrs.	60 %
• Mean age	29 yrs.
• Married	95 %
• Housewives	81 %
• Monogamy	88 %
• Awareness	50 %
• Female Literacy rate	53.7 %

Biological and social vulnerability of women

Biologically, women are more vulnerable to RTI/STI and HIV due to their anatomy (large vaginal mucosa to interact with infected material) and physiological reasons (pregnancy/delivery/abortion, etc.) right from menarche to menopause. Younger women have immature cervix and low vaginal mucous production, which presents fewer barriers.

HIV Transmission Potential

Mode of Transmission	**Infection/100 Exposure**
Male to female unprotected vaginal sex	0.1 - 0.2
Female to male unprotected vaginal sex	0.033 - 0.1
Male to male unprotected anal sex	0.5 - 3
Needle stick (Female Health care worker > Male)	0.3
Injection drug equipment	0.67
Mother to child	13 – 48
Exposure to contaminated blood products	90 – 100

Women also bear the burden of contraception, and the use of non-barrier contraceptives, like hormonal contraceptives, which are known to increase their vulnerability. Hormonal contraceptives are known to cause cervical ectopy. It is a condition in which a specific type of cell that lines the inside of the cervical canal extends on to the outer surface of the cervix, where exposure to sexually transmitted

pathogens is greater. Cervical ectopy appears to increase vulnerability to certain sexually transmitted infections, which in turn increase a woman's risk to HIV infection. Hormonal contraceptives have been associated with changes in the immune system and theoretically could weaken it. Also, use of progestins alone results in thinning of the lining of the vagina (vaginal epithelium) possibly leaving it more susceptible to tears or abrasions through which STI pathogens could enter the body. Finally while progestins alone may inhibit infection, by thickening cervical mucous, they can decrease vaginal acidity, a condition that facilitates infection, like vaginal candidiasis, chlamydial infections, etc., and results in faster disease progression.

Initially, a high number of women acquired HIV through blood transfusion. Women require blood transfusions mainly for obstetric and gynaecological related indications. A recipient of HIV infected blood progresses slowly towards developing the disease, and hence can have a longer healthy life, be sexually active and experience reproductive events without any indication of being infected. Presently the potential for transfusion induced HIV transmission during the window period is more in women.

Social vulnerability of women is higher as they have limited choices as far as sexual and reproductive activities are concerned. Women start sexual activity at younger age when their genital tract is immature. Their partners may be older and sexually active. Women lack control over their own bodies and over the sexual behavior of their partners. They are also more vulnerable to non-consensual, coercive sex. This is further compounded by their lack of awareness and knowledge about contraception, prevention of RTI, STI and HIV.

Lack of education results in low awareness and low economic self-sufficiency, which in turn act as push factors for women getting into sex-trade. Economic necessities also hamper enforcement of condom use among sex workers, who are equally at high risk of acquiring HIV infection from their clients.

Women have fewer opportunities to benefit from reproductive health and other such health and development programs, while men face gender related barriers to their reproductive health. Some of the important gender issues and factors that directly or indirectly affect women's reproductive health status and utilization of health services are:

- Educational status and media exposure, freedom of movement
- Control of household and reproductive decision making
- Employment status, control over earnings, money and assets.
- Spousal communication
- Attitudes about gender roles
- Attitudes about the right to refuse sex
- Violence and coercion
- Attitudes that reflect self-efficacy, self worth and entitlement

Differences in outcomes for men and women when infected with HIV

- Women have shorter survival rates than men primarily because they come later for treatment or are less likely to seek it. For instance, as a study at the Skin and VD department of the Baroda Medical College shows, there is low turnover of female patients at the clinic. There is also low level of spousal communication. Hardly one percent of the female patients who attend the STD clinic come for partner treatment or risk reduction.
- Being HIV positive has an impact on child bearing in women.
- The brunt of all social inequalities is borne by women: e.g., Taking care of positive husband/child, being the head of the household, being the breadwinner as well as the caregiver.
- Though both men and women face stigma and discrimination when infected with HIV, women are stigmatized more and blamed for spreading HIV/AIDS, i.e., labeled as 'reservoir of infection' and 'vectors of transmission'.

Difference in responses to men and women living with HIV/AIDS

Disease management strategies have also been less well developed for women.
HIV prevention strategies have the ABC approach. A – Abstinence, B – being faithful, and C- consistent and correct use of condom. This approach however overlooks the fact that women lack the power to negotiate sex, that they are faithful in monogamous relationships, but are infected by their partners; and that condom is a male driven protection, not in the hands of women to enforce its use, and that it is used less frequently with regular partners. Thus one may question the relevance of the messages for prevention of HIV. Women constitute two thirds of the world's poor; they are less educated, more overworked and underpaid, and financially dependent on men. All this limits their ability to access information on HIV/ AIDS prophylaxis, care and treatment.

"Behind most females with AIDS there is a male without condom"

Female condom and vaginal microbicides are the female control methods now available for HIV prevention. The female condom is a prelubricated polyurethane sheath. It covers the vagina completely and is an effective contraceptive as well as protective against HIV and all other STI. The drawback of this method is that it is not easily available or affordable. The acceptability is also less because of difficulty in insertion and objection by the male partner. Though it is difficult to procure and use, more so in the Indian context where female literacy is low, there is potential for re-use. Vaginal Microbicides kill HIV and other pathogens, they can even offer contraception. Effective microbicides are still under trial. Their safety, efficacy, acceptability and availability are still issues that remain unanswered.

Women face discrimination at the levels of the individual, family, community and the health care system. The following instances of discrimination have been witnessed in the STD clinic of the civil hospital in Vadodara:

Discrimination at the individual/family level

- If a couple is tested positive, treatment of the husband always takes precedence over that of the wife. Much of the discrimination against women is by their in-laws.
- Positive women are shown as the culprits who have brought the infection to the family. Discrimination by in-laws intensifies after the death of the husband.
- Widows are forced to leave their homes without money or their share of property.
- Even HIV positive husbands misbehave with their wives.

Discrimination by the health care system

- All pregnant women are tested for HIV without appropriate counseling, without their consent, and refuse services to those who test positive.

Discrimination at the community level

- Employers of deceased HIV positive employees deny jobs to their widows in their place. For example, a driver of a nationalized bank died of AIDS. The wife was tested without her consent and found to be HIV positive. The report was not kept confidential. The driver's widow was then denied employment in the bank. Her in-laws demanded that the job be given to their younger son, i.e., the younger brother of the deceased and not to his widow.
- Social pressure to bear children and prove fertility forces childless HIV positive women to become pregnant. An instance of this was a 26-year-old recently married male who was admitted to the Skin and VD. Department ward with Psoriatic erythroderma. The young man tested positive. His wife too tested positive. Both were advised about the potential for vertical transmission, i.e., from the wife to the child. During the discussion, the couple said that, "if we don't have a child, our family members and the community won't let us live in peace." The couple did not come for antenatal care fearing that they will be advised to have the pregnancy terminated. A year later, they came with a baby, and the husband was terminally ill.

Thus stigma and discrimination commonly results in ostracism and rejection by the family, affecting women more than men. It also leads to secrecy, denial of their sero-status, and they risk infecting others. Negative responses in the health care setting lead people to conceal their HIV status in treatment facilities for fear of being denied care. Individuals who are sick may also delay seeking treatment till the last moment, harming their own health in the process.

Call for action

Sexually transmitted/transmissible diseases have become not just biological and medical problems, but also social and political problems. Both medical and public health interventions fail to address the full complexity of these social diseases. There is a need for complex models of disease prevention and integrated approach for the prevention of HIV/STI. Dr. Marfatia concluded his presentation with the following recommendations and raising some pertinent questions:

1. *Guarantee access to HIV/AIDS prevention and treatment*
    - Ensure availability of female / male condom to all
    - Incorporate gender balance and gender equality in all policies
    - Set up women friendly centres for care.

2. Make research gender sensitive
    - Accelerate research to develop women controlled preventive methods like microbicides and affordable female condoms.

3. Educate and inform
    - Disseminate HIV / AIDS and STD information to each and every adolescent girl and woman.

4. Address gender inequality in policy

5. Address HIV transmission in conflict situations
    - Ensure gender sensitive HIV/AIDS awareness and preventive care and treatment programmes in humanitarian assistance.

HIV/AIDS in Children and Prevention of Parent to Child Transmission (PPTCT)

Presenter: *Dr. Uma Nayak*

Diagnosing HIV infection in children is difficult. While children constitute a small proportion of the HIV infections, the proportion of children in the number of deaths due to AIDS is substantial. In 1997, out of 2.2 million AIDS deaths, 20 percent of the deaths were among children below 15 years of age. The reason for the higher number of deaths among children is that HIV infection progresses much faster in children as compared to adults. On an average, it takes 8-11 years for an adult living with HIV to develop AIDS. In children however, HIV infection can develop into full blown AIDS within a span of 8-17 months.

In children, the main modes of transmission are from an infected mother and transfusion of infected blood. Mother to child transmission (MTCT) is when an HIV positive woman passes the virus to her baby. This can occur during pregnancy, labor and delivery, or breastfeeding. Without intervention, i.e., treatment, around 5-10% of babies born to HIV positive women will become infected with HIV during pregnancy, 15-20% will become infected during labor and delivery, and a further 5-15% will become infected through breastfeeding. Over all the risk of transmission from mother to child is as high as 25-45%.

The efficiency of transmission from the mother to child is greatest at the time of labor and delivery.

Testing children for HIV is difficult task. Children are tested for HIV only if their mothers test positive for HIV during the antenatal period. In that case, the child is tested for HIV after the age of 18 months because until that age, the same maternal antibodies are present in the child and testing the child before the age of 18 months would not show the true results. If a child has fungal infection for a long period, being immune suppressed the child may test positive. Where the HIV status of the mother is unknown, children are tested for HIV if they show persistence of a list of diseases of unexplained causes like – TB that is resistant to treatment, blood disease, skin diseases, chronic fever episodes, etc.

Nutrition and immunization of positive children are important areas, which need great care. An infant who is tested positive for HIV cannot be administered a live vaccine, as it can have a negative effect on the child.

Prevention of HIV Transmission

Rationale for PPTCT in India

27 million pregnancies per year

↓ 0.6% prevalence

162,000 infected pregnancies

↓ 30% transmission

Annual Cohort of 48,600 infected newborns per year

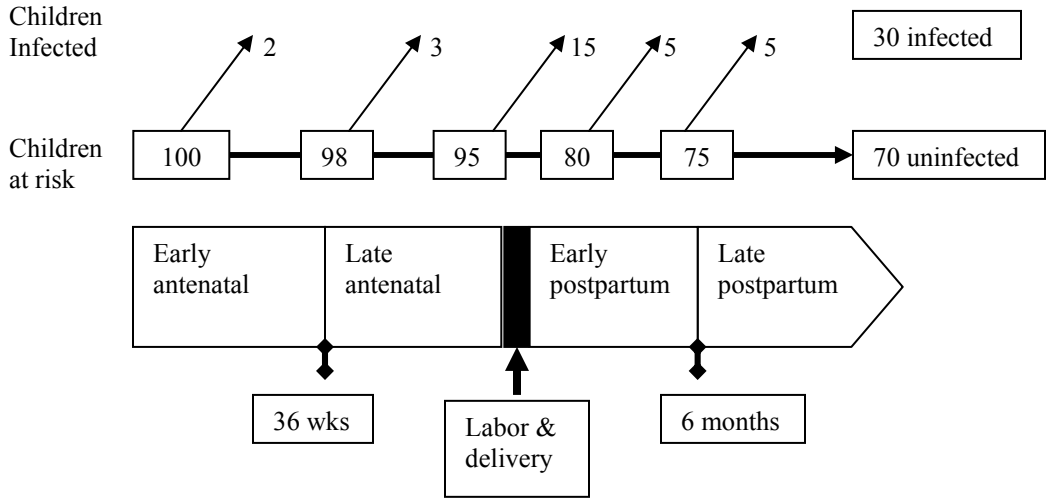
↓

Most of these children die within 2-5 years

HIV infection in children is transmitted by mothers, but mothers are not the source of infection. The term "mother to child transmission" (MTCT) puts the blame on the mother, the woman – who is herself a victim of the HIV epidemic as earlier presentations have clearly shown. Women are often looked upon as vectors and blamed for the spread of HIV infection. Not only are stigma and discrimination against the women much stronger, women also face the risk of violence neglect, abandonment, and destitution when infected with HIV.

Therefore the "mother-to-child" mode of transmission of HIV/AIDS is now being referred to as "parent-to-child" transmission. Before we discuss, prevention, let us first understand mother-to-child transmission of HIV infection. It is now established that even without any intervention, majority of the children of positive mothers do not get infected. This can be understood with the help of a hypothetical cohort of 100 HIV positive mothers, as shown in Figure 1.

Figure 1: Mother-Infant HIV Transmission in Hypothetical Cohort of 100 Children of HIV+ Mothers



The figure illustrates the timing of HIV transmission from the mother to the infant. As can be seen from the figure, HIV transmission occurs during pregnancy - between early and late antenatal period (36 weeks), during labor and delivery, and in the postpartum period through breastfeeding. In this hypothetical cohort of 100 HIV positive mothers, all 100 children are at risk at the beginning of the pregnancy, but 5 get infected during the antenatal period. During labor and at the time of delivery, 15 children get infected, and in the postpartum period 10 children get infected through breastfeeding. Thus, majority of the children will remain uninfected, although all of them are at risk at the start of the pregnancy.

The risk of HIV transmission to the infant can be decreased:

- *During pregnancy*: by decreasing the viral load in the mother, by administering anti-retroviral prophylaxis and treatment, monitoring and treating infections and supporting optimal nutrition of the mother.
- *During labour and delivery*: by avoiding premature rupture of membranes, invasive delivery techniques, unresolved infections such as STIs, and by providing elective caesarean section when safe and feasible.
- *During postpartum period:* by promoting safer infant feeding, i.e., through replacement feeding, or through exclusive breastfeeding for limited time, avoiding mixed feeding, reporting breast problems (e.g. mastitis, abscess, bleeding nipples), and supporting optimal nutrition.

NACO Guidelines on Breast Feeding

The issue of breastfeeding is complicated. By depriving the child of breast feeding, we may cause its death by diarrhea if top feeding is not given properly. Hence the present guideline by NACO is to give the choice of breast feeding/top feeding to the mother. Top feeding if well managed, can decrease transmission of HIV to the child through breast milk. However, if not well managed, it can result in diarrhea, and cause death of the baby. The mother after proper counseling, takes the decision whether or not to breast feed. However, if she chooses breast feeding, she must breast feed exclusively, i.e., without any top feeding. If she chooses top feeding, then she must give only top feeding; mixed feeding in this situation is more dangerous (as the disadvantages of both methods will be compounded).

Prevention of Parent to Child Transmission (PPTCT) Program of NACO

PPTCT program is going on in many hospitals. Under this program, the drug Nevirapine is given as a single dose to the HIV positive woman during labor, the mode of delivery is not necessarily cesarean section (though for an individual, this mode would be preferred), the choice to breast feed is given to the mother after counseling, and the baby is also given a single dose of Nevirapine after birth. This is presently an ongoing project and results are yet to be published.

Comprehensive Approach to Reducing HIV Infection in Infants and Young Children

A comprehensive approach prevents HIV infection in infants and young children. It is a four-pronged strategy for prevention of parent to child transmission (PPTCT), which includes:

1. **Primary prevention of HIV infection:** A strategy focussing on parents-to-be, it uses the ABC approach, wherein A = Abstinence; B = Be faithful to a single (HIV) uninfected partner; C = Condoms, using them consistently and correctly.
2. **Prevention of unintended pregnancies in HIV-infected women:** A strategy that ensures women's access to counselling and referral for family planning, to safe, consistent, and effective contraception.
3. **Prevention of HIV transmission from HIV-infected women to their infants:** The core interventions under this strategy are: HIV counselling and testing, provision of antiretroviral (ARV) prophylaxis, promotion of safer delivery and infant feeding practices.
4. **Provision of treatment, care and support to HIV-infected women, their infants and their families:** This strategy includes prevention and treatment of opportunistic infections, provision of ARV treatment, palliative and non-HIV care, nutritional support, reproductive healthcare, psychosocial and community support, comprehensive MCH care (antenatal care, essential obstetric care, emergency obstetric care, postnatal care and support, family planning services, counselling and testing for HIV, nutritional care, ARV prophylaxis, early recognition and treatment of HIV).

To Sum Up

- Without interventions the risk of PTCT is 25-40%.
- Combination interventions can reduce PTCT rate by up to 40% in breastfeeding populations.
- Because ARV prophylaxis alone does not treat the mother's infection, ongoing care and support is needed.
- Maternal and Child Health services can act as an entry point to the range of services to provide care and support to the HIV-positive women and affected family members.
- Linkages to community services can provide enhanced care and support.

Discussion

Dr. L. N. Chauhan, Head of the Department of Obstetrics and Gynecology, Karmsad Medical College shared with the participants his Department's experiences in running a PPTCT program.

There are three kinds of positive women who approach the department:

1) who neither know that they are pregnant nor their HIV status,
2) those who know they are pregnant but do not know about their HIV status, and
3) those who know they are pregnant and also that they are HIV positive. Each group needs different treatment. In India, abortion is legal under the Medical Termination of Pregnancy (MTP) Act and under this law, MTP can be provided to women after 5 months of gestation. Women are informed about this option and are provided MTP, if they want. Depending on the economic status of the women, treatment is given. Treatment can be started at 4 months, 6 months or at 8 months of gestation, or nothing is done. In the United States, women begin treatment at 4 months because their economic status is better. If the economic condition is good, there are better options available to women.

A few simple measures ensuring that maximum care is taken during labor and delivery, can help prevent transmission of HIV by 10 to 15 percent.

If the couple are both HIV positive and do not want the pregnancy, they are given the option of MTP. If the woman is not married, she is counseled. If the couple is married and is HIV positive and still wants to keep the baby, they are offered the best of the services possible. Dr. Chauhan welcomed questions from participants.

Dr. Marfatia remarked that majority of the deliveries still take place at home, women come to health facilities only in the last stage or pregnancy or at the onset of labour, when it is too late to test them and provide treatment if they are found HIV positive. The RCH program has to be expanded to reach the last woman so that they are detected early.

- *Where in Gujarat is PPTCT provided?*

It is provided in all government hospitals, corporation colleges, Karamsad Medical College is one. In Vadodara District, it is provided at the Jamnabai Hospital. Now there is a plan to upscale it at the district level.

- *What is the scope of the PPTCT program?*

We have to appreciate Smt. Sushma Swaraj, who changed the name of the program from 'mother' to 'parent', because the father is equally responsible for the infection. The transmission happens in three stages, during pregnancy, delivery, and postnatally through breastfeeding. All government medical colleges and hospitals conduct

voluntary testing and counseling. When women come to the ANC clinic, they are counseled for testing and tested with their consent. The test record is kept separately. Women who are found HIV positive are administered 200 mg of Nevirapine at the time of delivery by the nursing staff in the presence of the doctor and a pediatrician, and the child is given syrup within three days of birth, and the child is followed up. All this information is kept confidential. Children who are at high risk are followed up separately and special care is taken. We look out for opportunistic infections in the children. However, transmission can happen in spite of all care and precautions.

- *Are ARVs available for free mothers and children?*

No. Not as part of the PPTCT program.

- *What if the woman who comes to the antenatal clinic is still in the window period?*

If the woman is in her window period at the time of the first test, the routine test will naturally show negative. However, pregnant women usually have to test again after 3 or 4 months of the first test. At that time the true result would emerge.

- *Is it dangerous to give vaccine to children who are HIV positive?*

HIV positive children cannot be administered live virus vaccines, like the polio vaccine. So we need to give the vaccine in syrup form. In that case, care is taken, but all other routine immunizations can be given, but with great care.

- *Can the HIV positive mother continue ARV treatment beyond 4 months of pregnancy?*

Yes. But not under the present government program. Women are given ARV from the fourth month to prevent the transmission to the child. If the woman wants to continue after that, she has to bear the cost own her own, if she happens to be HIV positive but has not developed AIDS.

- *How can women in the rural areas be tested?*

The testing is offered under the ANC services. However, since it is a hospital based service, ANMs are not trained to do it. ANMs can only motivate women to go for testing to the hospitals.

It will take a long time before this service is provided as an outreach service.

- *The question before CBOs is - what can we do with all this information shared today?*

CBOs can play an important role in many ways: raising awareness in community, preventing unwanted pregnancies in HIV positive women by providing counseling, they can ensure regular follow up of women enrolled in the PPTCT program.

Even today, tetanus, which can be prevented by vaccination is claiming the lives of new born children, because it is still difficult to reach the last woman, despite high level or awareness in the community, we miss out on those who need the awareness and service the most, those who live in the remote areas, people who do not approach the health facility.

- *We need to look from the perspective of the positive people. Clinicians expect women to prevent unwanted pregnancies, but they overlook confidentiality related issues, like fear of disclosure or exposure, which stop women from taking the necessary care. For example, by refusing to breast feed or to have a child, the woman would be disclosing her HIV status in the community.*

- *Many a times only the husband and wife know about their HIV status in the family and do not tell others in the family about it. At the health care facility, the nurse looks at the papers and when she comes to know that they are HIV positive, they are given a separate room, even the cleaners come to know and they tell the relatives of the couple about their HIV status. Confidentiality is never kept. Many a times, patients are not even told what drugs they are being given.*

As doctors we teach all our students that we should treat everyone as if everyone is HIV positive so that we can take care of ourselves as well as other people in a much better way. Doctors, at least in the public sector, do not write on cots, there are no separate wards or labour rooms now as it was the common practice earlier, doctors now use universal precautions, and information is likely to be leaked more in private practice.

Experiences of NGO Interventions in Gender and HIV/AIDS

Select NGOs working in the area of HIV/AIDS were invited to present their experiences of implementing HIV/AIDS control and prevention programs in a panel session. The NGOs represented at the panel session were implementing targeted interventions for various groups such as commercial sex workers (CSW), men having sex with men (MSM), migrant workers, general population, and prison inmates. The Gujarat State Network for Positive People (GSNP+) was also represented in the panel session.

Working with Sex Workers

Presenter: *Vaishali Ajmera*, Project Officer, Vikas Jyot Trust, Vadodara

Ms. Ajmera's began her presentation with the remark that gender constructs and gender roles are assigned by society, but the family as the smallest unit of society, consciously or unconsciously ensures that these are adhered to. As a girl nears puberty, parents prescribe how she should behave and the norms she should follow because she is a female. When she grew up and was in college she developed an intense dislike for all this, but then she realized that unconsciously she was following all those rules, which she otherwise did not like to follow.

Ms. Ajmera recounted the problems and field constraints her organization used to face and continues to face in implementing their HIV/AIDS prevention program for sex workers.

She also recounted the change in her own attitude towards sex workers and their profession. When she joined Vikas Jyot Trust five years ago, she had a very different view about sex workers. However, when she came in contact with them, her entire perception changed. She became aware of many realities of their lives, which she earlier would not have imagined.

When the Vikas Jyot team began its HIV/AIDS education program for sex workers, they felt that their efforts were in vain. A sex-worker, who is well aware about the protective use of condom, would still not use it to protect herself because there are other people such as pimps/madams and the client, who are involved in this trade, and have more power over her. In one such incidence, which Ms. Ajmera witnessed, a sex worker was being forced by the brothel owner to engage in oral sex with a client. All that she and her team could do was to advise the woman on wearing a condom.

Pimps and madams do not think about protection of sex workers against diseases or insist on condom use, because for them, it is just a business. The client too usually thinks only of experiencing pleasure, which he has paid for. No one, not even the client who is also at risk, thinks about protection. Clients try to extract the value for every penny they pay and for this they exploit them to any extent possible.

Sex work is dominated by men, though it is the sex workers, who are mostly women, who face social and legal consequences. In the entire network – right from the bottom to top – at every stage there is a male involved; be it the broker or the pimp, the lodge owner who provides the space, the client, or the policeman who harasses the sex workers, and extorts money from them. So the question arises, how much power does the woman have at all to protect herself?

Like all other women, sex workers too have inhibitions in consulting a male doctor. The assumption that they are used to 'opening up' to men and should therefore feel no shame is wrong. As they are uncomfortable in consulting a male doctor, it is important that they have access to female doctors.

Rehabilitation is one issue that has been much bandied about. Ms. Ajmera asked the audience to honestly introspect whether and how many of them would really be ready to offer sex workers respectable jobs or jobs in their proximity. She reminded the audience that rehabilitation should not be understood as charity. Rehabilitation does not mean that sex workers must accept whatever society has to offer to them. What sex workers need is the right to a respectable job, which will provide them financial security at the least. The reason why rehabilitation programs fail to deliver is their approach. In nearby all such programs sex workers are given livelihood options that provide them neither financial security nor respect, not even acceptance, from the community.

Another point that Ms. Ajmera made was that of self-respect. According to her self-respect is something that comes from within. One cannot expect or force someone to have it. Also, each one has his or her own perception about such concepts.

Ms. Ajmera ended her talk underscoring that other than sexual beings, all of us are also emotional beings. Sex workers are not different from us. They too live in the hope that someday they would find a compassionate companion from among their clients. It is this hope that makes them continue in their profession.

Working with Men who have Sex with Men

Presenter: *Sylvester Merchant*, Lakshya Trust, Vadodara

Core group: Homosexual and bisexual men

Sylvester Merchant began his presentation stating that the HIV/AIDS pandemic has in fact come as a boon for marginalized groups such as commercial sex workers, homosexuals and bisexuals. Though it may seem as a paradox, but it is only the spread of the pandemic that has opened up space for open discussion on taboo topics such as alternate sexuality, sexual preferences and behaviors.

The presentations made thus far have talked about gender and patriarchy, and male domination. However, the presentations have been one-sided, in that they have looked at gender only from the women's perspective, ignoring the fact that men are also affected. The pressure to be a 'man' is a major issue for men who have 'feminine' qualities in them. Just as girls have to follow norms set for them by society, boys too have to follow the norms set for them by society. However, the pressure of social and gender norms on girls is visible and much talked about, the pressure that boys or men face is rarely discussed.

Society does not accept men who are not 'masculine' and they also face discrimination in society. They are rejected by even their own families. Mr. Merchant illustrated this with the example of a mother who called up Lakshya Trust late in the night. The mother had heard about the Trust working with homosexuals and wanted her son to be "cured". The son had attempted suicide four times and was under psychiatric treatment. When the mother came to know that her son was homosexual and she wanted him to be cured.

Even parents themselves do not want to accept their children the way they are. Parents are in turn blamed by society for their children's sexual preference behavior, which is termed as unnatural and is considered a consequence of poor upbringing, lack of proper guidance and orientation to their own culture.

One cannot imagine how suffocating it is for a long who cannot share his sexual identity even with his parents or even with his mother who has given birth to him.

A popular belief among people is that homosexuality is not an Indian phenomenon, rather it is spreading in India due to the influence of Western culture. There are however, sufficient examples from our own culture, including treatises like Kamasutra, which show that it was not uncommon. Homosexuality was criminalized by the Indian Penal Code in 1860. Under Section 377 of the Indian Penal Code, any sexual intercourse against the order of nature is an unnatural act and is punishable. This includes anal and oral sex. Heterosexual intercourse for the purpose of procreation was

considered as natural and normal behavior therefore any other sexual relation was declared as unnatural or deviant. Section 377 is also applicable to heterosexuals who engage in anal intercourse, because oral and anal sex are both acts that will not result in procreation, therefore engaging in such acts is also unnatural. However, Section 377 has so far been used to harass homosexuals.

In India, marriage is a successful institution. Because of the immense social pressure to marry, there are several homosexual men who are married and continue to have sexual relations with other men. So the threat of infection is ever present. These men infect their partners, their wives and their children. Thus homosexual men as well as their wives are a very vulnerable group.

Lakshya Trust has been working in Baroda and Surat for homosexual and bisexual groups. Mr. Merchant gave a brief overview of their activities and the promotional materials created by them, samples of posters and key chains (containing a condom in a plastic box) were shared with the audience.

When Lakshya Trust started functioning, their main focus was to fight against Section 377; it was a rights-based approach. Later it shifted its focus to the health-based approach. Since the last few years, Lakshya is also working on HIV/AIDS awareness and prevention. Lakshya believes that both approaches - awareness and prevention and rights based approach must be merged. Beginning with a rights approach may not work, but when sufficient people have been mobilized for the common interest of preventing the spread of the pandemic, the rights based approach can be adopted.

The Marginalized Group: Same Sex Relationships amongst Women

Presenter: *Maya Sharma*, Vikalp
Subject area: Rights
Core group: Women

Ms. Maya Sharma, Vikalp, began her presentation with an endorsement of the view expressed in the previous presentation that HIV/AIDS has created space for open discussion on forbidden topics, it has narrowed the distance between the private and the public. However there are still issues around sexuality that are not fully understood. Vikalp is an organization working primarily for women's rights. It has formed an informal group, PARMA, which works with homosexual and bisexuals. Ms. Sharma's paper has been reproduced in the following.

An ambivalent silence layered with stigma prevails around women's sexuality, the emerging context of HIV/AIDS, with its focus on penetrative sex and condom driven safe sex does not make it any simpler to talk about women. As a group women continue

to be the embedded objects or the recipients rather than subjects of the HIV/AIDS discourse.

In this context of HIV/AIDS, talking of women's same sex relationships, runs the danger of raising eyebrows, more shame, rather than awareness on the issue. But in choosing to speak we take a risk of being identified as 'that strange other,' in a world run by naturalized heterosexual norms. But choice too is a matter of privilege. Between finding a voice and getting stigmatized, and not speaking up at all, we chose to speak. This paper talks about the emergence of PARMA, a lesbian support group and through our engagement with men and women who have same sex relationships, the questions/challenges that have come up.

PARMA (refers to the concept of the name of *ardhnarishwar* in Hinduism, to the name of Shiva representing the male and female as being indivisible) is a support group for tansgender/ lesbian women. As an informal group it is supported by the women's group, Vikalp. Subsumed, diffused or indirectly women's sexuality has always been part of Vikalp's work - through women's reproductive health, and violence in different forms, sexuality issues were integral to our work. However it was our involvement around the single women issues that really brought 'sexuality' upfront. Many women who chose to stay out of marriage showed a sexual orientation that challenged the limited understanding of women's sexual choices. Situated within culturally acceptable norms of female friendships, women lived out their deep involvement with one another. While, many we learnt ran away from homes/families there were others who committed suicides to resist the patriarchal norms.

Vikalp supported the compilation of life stories of working class women in Northern India taken up initially to present the real faces of women who only occasionally appeared in the media, to have women's own voices and the context within which they lived their daily lives. We ourselves had no idea what happened to the women following the exposure and the outcry raised by public scandal. We also became aware that amongst the groups involved in gay rights activism, working-class voices were almost completely missing. The irony was that the women who came into public gaze were mostly women from the working class. Some of us felt the need to fill the gap. Vikalp actively supported the idea and the effort of collecting everyday stories of women who loved women. In the course of writing the lives we felt the need of a support group

The Identity 'lesbian' Influenced, and in fact goaded, by society's denial of same-sex relationships, we founded Parma and our use of the word lesbian does mean women who are sexually involved with one another. We often find ourselves caught between telling the full or half-truth about 'Parma' we are at an intersection both as part and separate from Vikalp.

Most of our subjects we work with are not familiar with the word "lesbian." In many ways it reminded us of a time when we began to come out to ourselves, and amongst our friends had began to identify as lesbians. This utterance changed our perceptions of self and the society, and also functioned as an act of claiming. It became imperative to assert our identity within the women's movement and assert that we too were valid political subjects entitled to rights, freedoms, protections, benefits. In several instances the laws discriminate against women who live with women. The Employees' Provident Fund (EPF) scheme 1952, Insurance laws, Sec 292 of the Indian Penal code which punishes obscenity, Indecent Representation of Women Act 1986.

Therefore identities become crucial for gaining rights and on the other hand a single category is restrictive, and unrepresentative—of the complexities of the same-sex relationships, as well as of the realities that intersected with caste, class and other factors (which often included marriage, husband and children). The homosexual as a category of sexual being and homosexuality as a sexual practice are generally rendered invisible by Indian culture in general. Therefore it is only to be expected that the terminology necessary for the inclusion of homosexuality within the parameters of the discourse on sexuality is itself largely absent. This has remained the case for centuries. Modern activists have begun to use the word "sanglaingik" (same-sex) in Hindi contexts, but somehow it remains abstract. Is this because the verbal signifier itself and the activity it signifies are so rarely included in modes of public discourse that when one actually encounters the word, one does not know how to respond?

We do not claim to have answers to this question. Most of our subjects do not speak English and were equally unfamiliar with the words "lesbian" and "sanglaingik". Neither did they use a parallel, politicized term from any other language. In their own contexts, the male form of address and gender-ambiguous plural forms in Hindi is used both by the masculinized subjects and by people around them. The words used were Babu, Bhai. These are generic male form of address. Most often the same-sex partners referred to each other as "dost, saheli, sathin, sakhi", terms which, like the term "female friendship" itself, are general in nature, non-threatening to the heterosexist paradigm, and socio-culturally acceptable. One same-sex couple we interviewed was uniformly referred to by their neighbours and colleagues as "miya-bibi jodi" (husband-wife pair).

We have made a conscious decision to use the word "lesbian" precisely because it was a word "so loaded with fear and embarrassment and prejudice, a word shrouded in silence, a whisper that spoke of an identity that must be hidden from others, that frightening word that dare not cross any threshold." (Caleri Report, 17).

Lesbian rights, which by their very nature foreground women as autonomous sexual beings imbued with selfhood, reason and desire, thus do not confine the issue to a particular sexuality or identity category but open up possibilities for an overall

redefinition of women, women's rights and human rights. We hope our work with the lesbian women contributes in some way towards the larger processes of rendering human rights fundamental and inalienable for all women.

Newer learning and challenges

Our work on issues of sexuality particularly, with the lesbian women and the transgender people have created challenges in learning and fostered a newer understanding on gender and sexuality.

Personal sharing and experiences on field led us to move away from a bipolar understanding of gender to acknowledging the presence of multiple genders. The lines between sex and gender are not so sharply divided as one being nature/al (sex) and gender to mean the socialization of roles. Same sex relationships amongst the women and men together have redefined the meaning of biological sex as being 'purely natural'.

We also learnt naive as it may sound that differences exist in the way same sex relationships are perceived amongst the women. Just as women while sharing a common identity of women are set apart from one another due to various factors same sex relationships too have differences amongst them. Though arrayed to question heterosexuality we saw our limitation of falling back upon those very same parameters.

Developing an understanding on sexuality has enabled us to better analyze ground situations. Working with transgender people created a heightened awareness of heterosexuality as being the privileged institution. During the time of making posters on HIV/AIDS with the support of Gujarat Aids Control Society, Vikalp/Parma conceived of bringing positive aspects of sex. Showing two plaits tied together we wrote sex is a beautiful experience when it is safe, based on love, equality, and consent between adults – GSACS response was to add the following line, *"Samaj anay Kayadani marayada ma hoy ……"* the translation would read , "Sex should be within the acceptable parameters of law and the society*"*. Our negative response to the particular line stemmed from our work on issues of sexuality. Vikalp's wording for the poster had deliberately kept away from words such as, 'should' to erase the moral connotation implicit in them. We worded our response to GSACS, "At the policy level Vikalp cannot agree to the change. Since the larger society being patriarchal supports the legal system which also denies sexual rights and choices to women." Fortunately, our adherence to the original wording of the poster was acceptable to GSACS.

Perhaps it is the beginning of new affirmative spaces opening up of solidarities building up. Even though NACO acknowledges gay people (Sec 377 is used to harass men who have sex with men, Often women too are threatened by it as it reads, " Whoever voluntarily has carnal intercourse against the order of nature with any man, woman or

animal shall be punished....,") the home ministry continues to criminalize consensual private adult sex. The Delhi High Court stated that Indian society disapproves of homosexuality and disapproval was seen strong enough to justify it being treated as criminal offence, finally it is spaces like these workshops and conferences that will wear down upon the system and create an awareness of enriching diversities that exist amongst us human beings, diversities that open new possibilities for articulating a rights perspective in the discourse HIV/AIDS and gender.

Working with Vulnerable and Marginalized Groups

Presenter: *Amudha Ranganathan*, SAHAS, Surat.

SAHAS is a Surat-based NGO, working on HIV/AIDS since 1998. The objectives of its HIV/AIDS program are to:

- prevent HIV/AIDS transmission among vulnerable and marginalised groups (migrants, adolescents, sex workers and MSMs) and the general population,
- provide comprehensive HIV/AIDS care and support services to people living with HIV/AIDS (PLHA) and affected individuals/ families,
- build capacity of PLHA for peer counseling, livelihoods, networking, etc.

The gender-specific rights issues that SAHAS often encounters in its program are:

- *Right to information:* lack of access to information. It is true that boys and men have access to information, but the converse would also be true – boys tend to exaggerate their knowledge while girls tend to underplay what they know, especially when it comes to matters related to sex. Even where women are informed they are not able to negotiate safe sex.
- *Right to equality:* issues relating to testing for HIV. Women are automatically tested for HIV when they go for antenatal care. Men are called for a test only if the woman is found to be positive. Both men and women should be tested at the same time.
- *Right to healthcare and protection:* access to treatment being denied/ delayed. Women do not go for treatment, they first try some home treatment. An HIV positive man refused to have his wife tested, because if she tested positive he would have to bring her for treatment. In another case the husband would not let his wife go to the hospital saying that she would die anyway.
- *Right to decision-making:* in relation to sex, child bearing, abortion etc; A 15-year-old wife and her 20-year-old husband are both HIV positive. Despite being advised against it they had a child, buckling under pressure from their family. Another case is of woman who wanted an abortion and was offered the services against the adoption of a family planning method. When her family refused to let her adopt family planning; she had to go through the unwanted pregnancy.

- *Right to security:* protection against violence, sexual exploitation, abuse, harassment, etc; the husband of a positive woman made the doctor say that he got the infection from his wife. The brother-in-law of the woman, taking advantage of this marital conflict was forcing the woman to have sex with him. The mother-in-law ignored her claim saying her son was a good person. Now the woman is forced to live with her natal family. In another case, an HIV positive husband was forcing his wife to have sex with him and complained to SAHAS that his wife was discriminating against him as he had TB.
- Right to justice: legal issues (related to property, divorce, children, etc;)
- Right to be protected from stigma and discrimination.
- Right to employment and livelihood opportunities.

Strategies and activities to address gender and rights issues:

- Addressing the young through school programs and out of school programs. Many young girls do not even recognize that they are being abused.
- Awareness programs for women in the community, sex workers, adolescent girls, etc;
- Provide support and counseling for abuse, violence, dowry harassment, etc; Linkages for referrals for legal issues.
- Create enabling environment for empowerment of PLWHA both men and women to form networks. Women are always blamed for their HIV status. One positive woman associated with SAHAS who was being harassed by her neighbors was empowered to one day openly declare her status and challenge anyone to harass her. All harassment stopped from that day.
- Provide support to PLWHA for treatment (ARV), livelihoods, nutrition, skill building.

Problems faced:

- Changing the low status of women requires the support and commitment of opinion makers, particularly the men.
- The police and anti–social elements also hinder efforts to reach women.
- Laws are not effective enough and women are not aware of the existing laws.
- Cultural expectations.

Lessons learnt:

- Need to reach out to all women.
- Access to information regarding laws, support systems to redress violation of rights.

Working with Prison Inmates

Presenter: *Kamlesh Meswania*, Project Support Unit – Partnership for Sexual Health Project, Ahmedabad

Mr. Kamlesh Meswania shared his experiences of working with prison inmates at the Sabarmati Jail.

Many of the AIDS awareness programs for prison inmates are generally not very successful on account of lack of cooperation from the prison authorities. When the Targeted Intervention for prison inmates was started in the Sabarmati Jail, Ahmedabad, initially the project team encountered a lot of resistance and disinterest from the authorities as well as the inmates. To a great part it was the wariness on the part of the inmates who did not look favorably on those wearing a "Khakhi" uniform and viewed the project team with suspicion of being on the 'other' (police's) side. The police authorities were also skeptical about the program. Initially, the team was harassed by officials who refused permission, instructed them to seek permission from the Home Ministry and the Superintendent of Jails, despite the fact that GSACS had been working directly with Prison Department.

The two major hurdles that came in the way of implementation of the program were:

- Having sex was banned in the prisons, so there was no question of carrying or demonstrating the use of condom in the prison.
- Since the inmates were men, it was found that there were several men who were engaged in bisexual or homosexual relationships, so the intervention had to address issues of non-heterosexual relationships among men and counsel them on non-penetrative sex and condom use. By doing so they were violating Section 377 of the Indian Penal Code, which criminalizes these relationships, on the very premises of law enforcers!

Under these circumstances, carrying a condom within the jail premises was against rule. After determined and persistent advocacy with the prison authorities, the project team was granted permission to demonstrate condom use on the computer for the prison inmates.

Being understaffed was another constraint in implementing the program. The project team consisted of the project officer and only one outreach worker.

Gradually the program has come to be accepted by the prison authorities. The project team has succeeded in creating a receptive environment for such intervention programs among both the authorities and the prisoners. Presently, the project activities such as record keeping, Management information System (MIS), conducting FGDs, and

counseling are being carried out by the prisoners themselves who are assisted by an outreach worker.

The prisoners were involved in the preparation of IEC materials. By working with them the team realized that prisoners are not such ogres as depicted in films, but very creative. Their involvement in the preparation of IEC materials brought out the artist in them and they came up with innovative messages for condom promotion.

The project team has also conducted awareness programs with women prisoners and has conducted health check-ups for them in the prisons.

Mr. Meswania displayed the slides created by the prisoners. The major learning from the program was that working among prison inmates requires a lot of effort first, to create an enabling environment, especially when we know there will be resistance, and second, to make the program sustainable to ensure that it is successful. Peer education and involvement of the target group in the program not only sustained their motivation and interest in the program, but also ensured that the program would be carried out by inmates themselves without much 'outside' intervention. Unfortunately, so far no dent has been made with regard to changing the perspective of law enforcers on rights of prisoners, with reference to Section 377.

Working with Positive People: Role of the Gujarat State Positive People's Network

Presenter: *Asha Ghodke,* President, Women's Forum, Gujarat State Positive People's Network

The Gujarat State Network for Positive People (GSNP+) was established in February 2003, by a group of positive people. It has its headquarters in Surat and is a part of the Indian Network of Positive People (INP) situated in Chennai. It is run by volunteers.

The goal of GSNP+ is to create an enabling environment for PLWHA in Gujarat, wherein they would have timely access to care and support and treatment without any discrimination, upholding their human rights. The main principle of the GSNP+ is to ensure that PLWHA are at the center of all decision making, to ensure that their lives become better.

To this end the GSNP+ works towards mobilizing and creating a network of PLWHA, enhancing their skills and capacity, providing counseling services, creating awareness among PLWHA about their human rights, providing information on the various income generation and livelihood programs and services of the government. Besides conducting advocacy and sensitization programs, the Network helps widows and children affected

by HIV/AIDS, maintains personal interaction with PLWHA in hospitals, runs a "Positive Speaker Bureau" and a "marriage bureau" for positive people.

Positive speakers are PLWHA who address the public to share their experiences about their experiences as people living with HIV/AIDS. The Positive Speaker Bureau was set up in response to several incidences of discrimination and violence against PLWHA, like stoning and immolation, due to which many of the PLWHA fear to reveal their identity in public. The Positive Speaker Bureau has been set up to address discrimination, dispel misconceptions regarding HIV/AIDS and PLWHA in society, help them gain acceptance in society, encourage voluntary testing, and to prevent the further spread of HIV. Instead of speaking about unreal or imaginary things, the Bureau provides living examples to control the spread of HIV/AIDS. It helps other PLWHA in society to adopt an optimistic and positive approach to life. PLWHA themselves work towards preventing the spread of HIV/AIDS.

The participation of women is also high in this organization and they participate in important decisions of the organization.

GSNP+ is also associated with other organizations working with positive people. All PLWHA residing in Gujarat state can become members, regardless of whether they are members of GSNP+ as well as take part or assist in its activities.

Discussion

The discussion that followed focused mainly on the failure of rehabilitation of sex workers, the need to challenge and change the popular concepts of masculinity, and the limitations of targeted interventions for the so-called 'high-risk' behavior groups. The points made by the participants are briefly reproduced below:

Failure of rehabilitation programs for sex workers

- Rehabilitation of sex workers has been tried at various places, without much success. The reason is that they cannot be compensated with the same pay packet as they make in their profession as sex workers. The government schemes have only sewing and knitting to offer as training programs we want them to do savings, without providing them avenues for livelihoods that provide them the same standard of living.

- Sex work is now increasingly being looked at as a service. The concepts of chastity are now changing, sex workers now ask, why do we need to be rehabilitated? Everyone has the right to choose their own work.

- A woman's body is a place for consumption. How can the commodification of women's bodies be stopped? The pattern of sex work is also changing, Internet pornography, migrating sex work, etc. It is a nexus of several powerful forces, which we are not looking at.

Challenging and changing existing concepts of masculinity

- The posters made by the prison inmates (shared in Mr. Meswania's presentation) are very masculine.

- The posters are the views and perspectives of the prisoners. It is true that the poster are very masculine, but this is the way that they understand the issue.

- The purpose of this meeting today is to question the popular concepts of masculinity. We have to find ways to turn the concepts of masculinity at the ground level. The point is that all the models of masculinity have to be questioned. In the short run, using the existing models or notions of masculinity to convey messages may work, but we need to realize that these notions are very deeply embedded in our consciousness and need a long time to change. We have to go beyond and challenge the existing notions of masculinity. We have promote male responsibility.

- There is a positive change happening in this direction. Recently there have been several TV spots and advertisements that show the caring side of men. In one such ad, the husband tries to make his wife comfortable on the first night instead of trying to force her.

- The whole concept of the meterosexual male is now spreading and getting more acceptability.

- There is a perspective change happening at the higher level, but must also permeate the ground level.

Limitations of targeted interventions

- There is so much emphasis at the ground level on condom promotion, which need to be changed. Let us not forget that condom use is not 100 percent safe and human beings are not machines.

- Presently, the targeted interventions are being implemented by many NGOs simply because there are funds available. Also, there is a lot of quantification of work and related paper work involved, to facilitate monitoring. As a result often the actual

intervention or outreach work suffers. Further, targeted interventions restrict the work of implementing organizations within a framework of activities to be completed.

Regarding the last point, one of the participants felt that implementing NGOs had the freedom to use targeted intervention programs as a framework and go beyond the scope of work to bring in innovative programs and approaches.

Rights Issues in HIV/AIDS*

Rights Perspective to HIV/AIDS

Presenter: ***Renu Khanna***

What are human rights?

Human rights are rights that universally belong to people regardless of their sex, race, color, language, national origin, age, class, religion, or political beliefs. These are rights that are legally guaranteed by human rights law, protecting individuals and groups against actions that interfere with fundamental freedoms and human dignity. They encompass what are known as civil, cultural, economic, political and social rights (WHO, 2002). Human Rights are vital to human dignity and to an individual existence.

Rights-based approach to HIV/AIDS

Human rights are central to all aspects of an effective response to HIV and AIDS. HIV strikes hardest where human rights are least protected: sex workers, MSMs, migrants.

A "rights-based approach" to HIV/AIDS starts from the premise that respect for human rights forms a coherent basis for programs to address the pandemic and that abuses of human rights contribute to the spread of the virus and undermine attempts to contain it. When human rights are not promoted and protected, it is harder to prevent HIV transmission and the impact of the epidemic on individuals and communities is worse (Amnesty International).

Safeguarding people's fundamental rights improves when their ability to protect themselves and others at risk of HIV infection, helps reduce their vulnerability to HIV, assists them in dealing with the epidemic's impacts. Public health strategies and human rights protection are mutually reinforcing. Prevention and Control Strategies driven by fear of infection cannot succeed. In the long term, success can only come through an approach based on values – the values of

Box 1

Human Rights related to HIV/AIDS

- Rights to be free of discrimination
- Rights to health
- Rights to marry
- Rights related to Parent-to-Child-Transmission (PTCT).
- Rights to information, education, work, found a family, enjoy benefits of scientific knowledge.

Several international treaties and covenants include these:

- International Conference on Population and Development Program of Action (ICPD- POA)
- Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)
- Convention on the Rights of the Child (CRC)
- Millennium Declaration, MDCs.

* On account of shortage of time, participants were provided handouts of this presentation.

human rights and human dignity. The Universal Declaration of Human Rights also places human dignity first. Thus integration of the public health strategies and human rights protection reduces HIV transmission and improves quality of life of People Living with HIV/AIDS.

International human rights standards and HIV/AIDS

The centrality of human rights in effectively responding to HIV and AIDS in has been emphasised in international and national programs since the creation of the World Health Organization's Global Programme on AIDS in the 1980s. The importance of human rights to protecting and promoting health has also been recognized within the UN system through the work of the treaty-monitoring bodies, the rights-based work of health-related UN agencies such as WHO, UNAIDS, UNIFEM and UNFPA, and the creation of the posts of UN Special Rapporteurs on the right to health and on violence against women (Amnesty International).

A number of international agreements, statements and standards relate specifically to human rights in the context of HIV/AIDS. UNAIDS and the Office of the United Nations High Commissioner for Human Rights (OHCHR) convened an International Consultation on HIV/AIDS and Human Rights in Geneva in 1996. This meeting adopted the International Guidelines on HIV/AIDS and Human Rights, which were endorsed by the UN Commission on Human Rights in 1997 (see box 2).

The International Guidelines on HIV/AIDS and Human Rights form a sound basis to ensure that the full range of human rights, including those outlined above, are at the heart of an effective and accountable response to HIV/AIDS.

Box 2

International guidelines on HIV/AIDS and human rights

Governments should:

- establish a national framework that is coordinated, participatory, transparent, and accountable across all branches of government;
- ensure consultation with communities and enable community organizations to carry out their activities;
- review and reform public health laws so that they address HIV/AIDS adequately, in a non-discriminatory way, and in accordance with international law;
- review and reform criminal laws and correctional systems so that they are not misused, are not targeted against vulnerable groups, and conform to international law;
- enact or strengthen anti-discrimination laws or other laws dealing with discrimination, privacy, confidentiality, and ethics in research;
- ensure by law that quality goods, services, and information are available and accessible for HIV/AIDS prevention, care, treatment, and support; [this guideline was subsequently expanded]
- provide legal support and services to educate people affected by HIV/AIDS about their rights, enforce those rights, and develop expertise in HIV-related legal issues;
- promote a supportive and enabling environment for women, children, and other vulnerable groups;
- change discriminatory and stigmatizing attitudes through education, training, and the media;
- develop, implement, and enforce professional and ethical codes of conduct in accordance with human rights principles;
- establish monitoring and enforcement mechanisms to guarantee that HIV-related human rights are protected;
- co-operate with the UN system to share knowledge and experience of HIV-related human rights issues and protection mechanisms at international level.

Source: *Amnesty International*

In 2002, following a further consultation, a revised *Guideline 6: Access to prevention, treatment, care and support* was adopted, providing up-to-date policy guidance based on current international law and best practice at country level.

Right to highest attainable standard of health

General Comment 14 on International Covenant on Economic, Social and Cultural Rights, specifies enabling conditions and health services which are: Available, Accessible, Acceptable, and of Quality.

Interpretation of this Article in the context of HIV/AIDS

In our opinion, fulfilling the requirements of General Comment 14 in relation to HIV/AIDS first implies a need for convergence between the Reproductive and Child Health Program and the National AIDS Control Program. This would mean that from District Level downwards the health care facilities would address needs of HIV/AIDS persons. Placing HIV/AIDS squarely

within comprehensive health care would fulfil the 'enabling conditions' specified by General Comment 14. 'Enabling conditions' for health also refer to determinants of health. In the case of HIV/AIDS determinants are migration, sex trade and trafficking, sale of blood and blood products. Polices and legislations preventing or regulating all these to bring in elements of safety and/or prevention of HIV/AIDS would be some measures of fulfilling the 'enabling conditions' clause of General Comment 14.

Box 3

Enabling Conditions for Reproductive and Sexual Health

- Educational status and media exposure, freedom of movement
- Control of household and reproductive decision making
- Employment status, control over earnings, money and assets.
- Spousal communication
- Attitudes about gender roles
- Attitudes about the right to refuse sex
- Violence and coercion
- Attitudes that reflect self-efficacy, self worth and entitlement

HIV/AIDS testing facilities and Voluntary Counseling and Testing Centres (VCTCs) should be available in sufficient numbers, as also trained and sensitive health care providers. Health services should be accessible without discrimination and stigma. Antiretroviral drugs should be available free to these who cannot afford to pay. Quality comprehensive cost of antiretrovirals should be brought down through price control measures as described in PPTCT section. PPTCT services should be available and accessible to all women who need them. Information on HIV/AIDS and rights of persons living with HIV/AIDS to affordable quality health services is an obligation of the government and the Health Department. Availability of good quality condoms (male and female) as well as vaginal microbicides is part of prevention.

HIV/AIDS and women's human rights

A number of international human rights standards – including those agreed to by, and binding on, governments – are relevant to protecting women's rights in the context of HIV/AIDS, both in terms of the prevention of HIV/AIDS and the response to it. International human rights law requires governments to take a range of measures to protect the right to the highest attainable standard of health (also known as the 'right to health'), and the right to freedom from discrimination, among others. There are other rights, which are also important to the consideration of HIV, including rights to information, to education, to work, to found a family, to enjoy the benefits of scientific knowledge and other rights. The relevance of human rights standards to HIV/AIDS prevention, treatment and support has been elaborated by international consultations on the subject, and independent experts within the UN human rights system have also commented on women's human rights and HIV/AIDS (Amnesty International).

The Millennium Declaration and Millennium Development Goals (2000), which represent a "road map towards the implementation of the United Nations Millennium Declaration", elaborate eight goals with measurable targets for the international community to achieve by 2015 and calls on nations to (among other things) "promote gender equality and empower women" (Goal 3) and to "combat HIV/AIDS, malaria and other diseases" (Goal 6).

The Declaration of Commitment adopted by the UN General Assembly Special Session on HIV/AIDS (UNGASS) in 2001, referred to previous international and regional commitments made on HIV/AIDS. It stated at para. 14 "that gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS" and called, at para. 59, for the "empower[ment of] women to have control over and decide freely and responsibly on matters related to their sexuality to increase their ability to protect themselves from HIV infection".

Expert comment and interpretation of standards is also important in the fight against HIV/AIDS. The Global Reference Group on HIV/AIDS and Human Rights provides expert commentary and recommendations to UNAIDS; many NGOs, including those bringing together women and men living with HIV/AIDS, regularly contribute expert refinement of human rights analysis; the UN Special Rapporteurs on the right to health and violence against women have both made specific reference to the gender dimension of HIV/AIDS; and other important sources of interpretation of UN standards make important points for the protection of the rights of women and girls in the context of HIV/AIDS.

The recommendations of numerous international documents on HIV/AIDS and women's rights have reiterated the following:

- End violence against women
- Address women's social and economic disempowerment
- Eliminate stigma and discrimination against people affected by HIV/AIDS
- Enable access to prevention, treatment and care for people affected by HIV/AIDS
- Increase international cooperation so as to meet the goals set by the international community and to enable all states to meet their international human rights obligations.

Human rights of sexual minorities

In 1994, the UN Human Rights Committee (HRC) condemned unequal treatment based on sexual orientation in its landmark judgment in a case and held that sexual orientation be understood to be a status protected against discrimination under articles 2 and 26 of the International Covenant on Civil and Political Rights. The HRC has continued to be concerned with sexual-orientation based discrimination in its comments to a number of countries.

In 2001, the Special Rapporteur on Torture raised issue of torture against sexual minorities, that "members of sexual minorities are disproportionately subjected to torture and other forms of ill-treatment, because they fail to conform to socially constructed gender expectations. Indeed, discrimination on the grounds of sexual orientation may often contribute to the process of dehumanization of the victim, which is often a necessary condition for torture and ill treatment to take place. In 2004, the Special Rapporteur on Right to Health noted that "discrimination on grounds of sexual orientation impermissible in international law" and

observed a "basic duty of state to respect an individual's freedom to control his or her health and body."

In 2003, the Brazilian delegation introduced a resolution on "Human Rights and Sexual Orientation" at the 59th Session of the UN Commission on Human Rights (UNCHR). After being postponed for two successive sessions of the Commission, the draft resolution was tabled for the 61st Session of the United Nations Commission on Human. Discussion and voting on the resolution has once again been postponed.

Fundamental rights promised in constitution of India

The Constitution of India provides for human rights guarantees, in the form of the following fundamental rights promised in the Constitution:

- Right to Equality: before law, prohibition of discrimination, equality of opportunity, abolition of untouchability, abolition of titles.
- Right to freedom: Of speech, protection in respect of conviction for offences, of life and personal liberty, against arrest and detention.
- Right against Exploitation: Prohibition of trafficking and forced labor, child labor.
- Cultural and Educational Rights Protection of interests of minorities, etc.

HIV related law in India

Section 377 of the Indian Penal Code criminalizes homosexuality, as being 'against the law of nature.' A comprehensive HIV Law has been proposed by the Lawyers' Collective, which focuses on

- Anti discrimination
- Transforming systems of power to be more equitable.
- Rights vis-à-vis MTCT: Consent for testing, Confidentiality issues

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Stigma and Discrimination

Presenter: *Dr. Radium Bhattacharya*

Dr. Radium Bhattacharya, Director, GAP ISRCDE, Ahmedabad, a physician by training, has been working in the area of HIV/AIDS prevention since the last 18 years. Her presentation on stigma and discrimination surrounding HIV/AIDS was based on her experience of working with people living with HIV/AIDS.

Magnitude of the Problem

There are an estimated 5.8 million HIV infections in India for the year 2005, of these around 4 million are in 15-49 years of age group, and about 50 percent of the adults infected with HIV are women.

> *"HIV related stigma and discrimination remains an immense barrier to effectively fighting the most devastating epidemic humanity has ever known"*
>
> **Peter Piot**

Nearly three-quarters of those living with HIV/AIDS in India say they have faced stigma.

Stigma and Discrimination at Various Levels: Case Studies of PLWHA

The following life stories of people clearly demonstrate the stigma faced by people living with HIV/AIDS at various levels.

Family/Society

At the level of Ms. Archana (name changed) a 30-year-old mother of two young daughters ages 7 and 9 years respectively is well-educated and belongs to a well-to-do family. She shared a good relationship with everyone in her family. When she broke her hand, she had to undergo HIV test and was tested positive. Her relationship with her family members changed overnight. In spite of being educated and 'enlightened', she was isolated in her own home by them and was forced to live separately. Her husband refused to undergo HIV test and Archana was blamed for contracting the infection. One day her husband left the house with their two daughters without disclosing where they were going. Now Archana lives alone in a big house and is not getting any support, financial or otherwise, from her in-laws. Fortunately, however, her natal family is helping her.

She is not allowed to meet her daughters in school as the school authority has been instructed, not to allow her to meet her daughters. Archana's sister is encouraging her to come out of her situation, but Archana has lost all courage to fight. She does not want to approach the court of law as she loves her family, despite the treatment meted out to

her by them. She lives in the hope that her in-laws will accept her, she will get her family back, and things will once again be like old times.

Health care system

At the level of the Mr. and Mrs. Barot, are a couple living in Patan district, Gujarat. A few years ago Mrs. Barot had received blood transfusion while being treated for some illness in a small town hospital. Mrs. Barot fractured her leg and had to undergo surgery of her leg in a hospital. She underwent HIV test and was found positive. As soon as the doctors came to know her HIV status, they asked her to leave the hospital and advised her to go to a larger hospital for operation, even though Mr. and Mrs. Barot had already paid Rs. 33,000 in advance as charges for the operation in that hospital. In violation of existing laws on confidentiality, the doctors wrote on the *case paper* that she is HIV positive. The couple however, were never informed what HIV is nor were they counseled.

After a visit to GAP, they came to know more about HIV/AIDS, and most importantly that it is not an infectious disease. During group meetings at GAP, they saw HIV positive people and HIV negative people sitting and eating together. It changed their life and they now say that GAP has given them a new lease of life. They feel that they had lost a very important chapter in their life and from now onwards they are going to live together and nothing on this earth can change their feeling of togetherness.

Workplace

At the Mukesh Marvadi, working as a peon in an office, and his wife, Sushilaben Marvadi, both are HIV positive. They have no idea about their HIV status and what HIV means. Their two-and-half-year-old son is also positive. The child's growth is stunted and he cannot speak. So they had another child, a son. When they lost their second son at the age of six months, their employer sent someone to the hospital to know the cause of the death. The hospital unfortunately did not maintain any confidentiality and the employer came to know that the child died of an AIDS related disease. Immediately, the employer sent a person to Mr. Marwadi's house with an advance salary and told him never to come back to work again. Interestingly, the employer is owner of a pharmaceutical company. Because Mr. Marwadi was not employed in the organized sector he did not get any provident fund or other security that workers of the organized sector get.

These three stories clearly depict that STIGMATIZATION shows its omnipresence. Apart from infected and affected people, even organizations working in the field of HIV/AIDS are also stigmatized.

What is Stigma and Discrimination?

The term stigma has its origins in the Greek civilization, where it was a practice to tattoo or brand people for a wrongdoing. So stigma is prejudice and discrimination against a set of people who are regarded by others as being "flawed", "morally degenerate" or "undesirable" and who are treated in a negative way.

Prejudice is an attitude, while discrimination is overt behaviour. And these two usually go together - thus a stigmatized person is away from the mainstream society. Prejudice and stigma are feelings, whereas discrimination is acting out of these feelings. Stigma is a process of devaluation.

Discrimination occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong to a particular group making a boundary in the society between "normals" and "outsiders", between "us" and "them".

Stigmatization: First leprosy… now HIV/AIDS

In the last century, when the world had just managed to overcome the stigma of Leprosy, which causes deformity, there was an outbreak of HIV/AIDS. The type of HIV/AIDS related stigma differs in different countries depending on the existing prejudice against certain groups like the gay community, commercial sex workers, or injecting drug users. In the Western world, stigmatization began with the gay and injecting drug users, whereas in India, the stigmatization is related to "sex", as 80% of transmission of HIV infection is through heterosexual encounters, and because sex is taboo in Indian society. In India, having HIV/AIDS is associated with immoral, multi partner sexual relationships.

Causes of stigmatization: phobia – ignorance

Perhaps the most important stigma attached to HIV/AIDS is the ignorance about the route of transmission, which produces the fear of transmission. In many situations, this fear is perpetuated by the medical fraternity, whom patients approach for treatment and care. The attitude and behaviour of the service providers like refusing to operate, do dressing of HIV positive patients, often creates the image in the minds of their relatives that they are untouchables. These relatives carry back such messages to their homes and behave negatively towards the positive person.

For instance, a documentation by GAP, shows how an adolescent boy was advised not to touch his HIV positive mother without wearing gloves, "if she happens to bleed in case some accidents occurred etc., before attending the mother in an emergency you should run for a pair of gloves." But the boy asked "Is this the way that I should treat

my mother". This boy had been trained by GAP and was well aware of HIV/AIDS and its modes of transmission. Therefore he had no fear in taking care of his mother. The message that the doctors were giving him did not scare him, as it would have any other person who lacked the correct knowledge about HIV/AIDS.

Public interest vs. individuals rights

In the beginning, when India was going through a period of denial about HIV/AIDS. It was viewed as that a problem of the West and not of a predominantly monogamous society like India. The initial response of the government therefore was to test foreign students, mainly those of African origin. This was followed by an announcement that certain categories of long-term residents also had to go for HIV test. The concern was that foreigners could transmit the infection to locals. This prompted the preparation of a draft bill prohibiting marriage between foreigners and Indian nationals. Fortunately, the proposed legislation did not see the light of the day.

In 1991, about 40 countries required proof of HIV negative status before allowing foreign visitors to enter.

Homophobia is an important reason for stigma in many nations. In India, Section 377 of the Indian Penal Code criminalizes homosexuality, though there is a significant population of homosexuals who are vulnerable to HIV/AIDS. Organizations like NAZ Foundation International have reached MSM population successfully, both in urban and rural areas. Here the stigma is towards the sexual behavior of the group, which is 'abnormal' or 'deviant' in the eyes of the mainstream population.

Targeted interventions and stigmatization

Targeting a group, as a risk group is also a process of stigmatization. While targeting truckdrivers, commercial sex workers, MSM groups as high-risk behavior groups we are stigmatizing them. It is to be understood that within the so called 'risk groups' too not everyone is practicing risk behaviour.

We need to realize that the intervention components of HIV prevention and control programs should focus on the risk behaviour of the people as a whole, and not as groups. The program on truck drivers intervention programme has already developed immense stigma against the truck drivers. It is as if they are spreading the virus on the highway, as a result many are facing the consequences of such programmes and it is now becoming increasingly difficult for single truck drivers to find a wife. Truck drivers are concerned about this given the fact that at any given time not more than 45% of truck drivers indulged in high risk sex behaviour.

This is also true when the programmes are targeted at the commercial sex workers (CSW). Only sex workers are targeted but what about their clients who are responsible for further transmission to the other groups? People who have sex with sex workers may practice safe sex but having sex with an unknown partner who is not labeled as sex worker makes people complacent and safe sex is not practiced. Therefore interventions should target Risk Behaviors and not Risk Groups to avoid stigmatizing these groups.

Because HIV/AIDS has intimate relationship with sex, in the Indian context often the disclosure of the status becomes a complex issue.

Stigma and gender: Are women more stigmatized than men?

Girls and young women show a higher rate of acquisition compared to men of similar age.

Can women be really sexually assertive than men?

> *"The gender dynamics of the epidemic are far reaching due to women's weaker ability to negotiate safe sex and their generally lower socio - economic status."*
>
> Kofi Annan

Can a woman even think of differing from the concept of mutual fidelity when she has been socialized and brought up on the principle that her husband is God?

Can a woman ensure safe sex by suggesting that her sexual partner wear condom - when the very suggestion of condom use carries with it an indication of infidelity that could threaten her personal security and destroy the relationship? Such a woman would be stigmatized - **"She is promiscuous."**

If the woman did have sex using a condom, how would she be able to prove that she is fertile to the society where her status is dependent on her being able to bear a son? Once again she is stigmatized - **"She can not become a mother."**

Women, young, or old, are facing the dual brunt of HIV/AIDS epidemic- those living with the virus and those who are caring for the sick. These are women who are plagued by host of ethical questions: Should I conceive a child? Will I be able to terminate my pregnancy, if I so decide? **Or** Should I have the access to AZT (Azido Thymidine, a retroviral drug) so that I can bring a child on this earth without infection? But, once the child is born - will I be able to see the child grow up -or is child going to lose both parents and become an orphan?

These are real concerns, which need to be addressed in programs.

Emerging Issues and Problems

Prevention strategies

The Female Condom, a symbol of women empowerment, has been launched twice since 2001 by the Government of India, yet it is not available in the market. GAP has found two kinds of reactions among men regarding the female condom. One group of men resisted the use of female condom feeling that their wives would become more promiscuous. The other group felt that introduction of the female condom in a relationship provided an opening for communication on sexual matters, which are otherwise never discussed. A study from GAP among rural women also pointed out that the female condom increased women's knowledge about their own body and gave rise to discussion between men and women on sexual and reproductive health, at times reinforcing women's bargaining power.

A study with sex workers on the accessibility of Microbicides and female condoms also found favorable reactions. In the words of a sex worker, "As sambhar (South Indian curry) is different everyday depending on what vegetables you are adding, sex will also be different depending on what types of preventive methodologies you are using!! It is now like going for shopping with a big shopping bag".

What is interesting is that the preventive technologies have been triggering these changes in gender relations. This change has come about without violence.

Government of India has decided to provide **free AZT** to the pregnant mother and children below 15 years. What does it mean to the women? Where does she stand? There is a multitude of problems and many of those are not yet answered. Have we done enough homework before launching such programmes? The reality is that only 1200 people are on ARV in Gujarat and there is no consistent counseling.

Laws against discrimination

There are laws existing in many countries, outlawing discrimination. However laws seldom successfully change the behavior and attitude of the people where stigma is very deep rooted and it can only be modified over period of several generations even when laws and policies demand such changes**.** Therefore, it is absolutely essential that efforts should be made *now* to root out the stigma and discrimination against HIV/AIDS.

Given the existing discrimination, social acceptance is particularly crucial for the effective implementation of HIV related legislation. There is evidence that in the existing social structure in India human rights violations and violence is greater against individuals who have been traditionally marginalized, especially poor and

disempowered women, those belonging to scheduled castes/scheduled tribes, and other stigmatized groups.

Adolescents: The future of nations

India is the second most populous country in the world with a population of 1.03 billion. An estimated 400 million are children, i.e., persons below 18 years of age. Acceleration in economic growth has placed India among the 10 fastest growing developing countries in the world. Yet the country's per capita income remains low and 26% of the population lives below poverty line. The Planning Commission of India estimates that as of March 2000, adolescents (aged 10–19) accounted for 23% of the Indian population, that is, almost 230 million. Such a large group represents a major human resource that can and must contribute to the overall development of the country.
As India witnesses the entry of the largest ever generation of adolescents, representing one-fifth of India's population, we are faced with the ever compelling need to target programmes centered on prevention of HIV/AIDS in this group.

Gendering AIDS: Women, Men, Empowerment, and Mobilization

The gendered face of HIV/AIDS is evident in the fact that women bear the major brunt of psychological, social, and economic consequences resulting from to loss of livelihood, poverty and taking care of the sick. Gender norms impact the way in which the infected men and women are perceived thus influencing the ways in which individuals cope with HIV/AIDS. Effective implementation of gender sensitive programmes in HIV/AIDS requires an analysis of the differential political economy of risk in the region.

An active role can be played by civil societies including local decision-policy making institutions in protecting the rights of the individual. Community partnership/ involvement/participation is critical in sustaining the socio-cultural fabric of any community.

Reduction of stigma and discrimination is central to any effort aimed at HIV prevention; the program would essentially need to be developed within a rights based approach. This requires sensitization of the community including service providers to gender and human rights issues.

Conclusion

The variety of experiences of GAP in the last eighteen years evoke many questions and pose dilemmas:
Why are women more vulnerable and discriminated against. If it is societal structure then is it possible to change the structure and elevate the status when societal structures

are part of the state culture and heritage? When there is casteism/racism in a society? How can we change the societal structures?

HIV/AIDS can be prevented if the conflicts and contradictions around "gender" are addressed and restructured by the civil society activists.

Discussion

Following are the important points that were made in the discussion:

- The problem with the present AIDS control program is that it does not give much ownership to the doctors. There is no training provided to resident doctors of government hospitals in the management of patients who have HIV/AIDS. In Vadodara 80 percent of the private hospitals or clinics are not ready to admit people with HIV/ AIDS. As soon as they come to know about the patients' HIV status, they refer them to the civil hospital. It is only recently that some private hospitals have begun to admit positive patients out of commercial interest.
- The paucity of training is compounded by the fact that there is a shortage of doctors. As a matter of fact, there is only one doctor for every 10,000 people.
- It is true that AIDS control programs will continue to have gaps, however, there are many associations of medical practitioners such as IMA, FOGSI. But to what extent are these associations taking the responsibility of spreading the practice of universal precautions among its members? These associations have a very important role as well as responsibility to train its members in maintaining universal precautions.
- Training in universal precautions is now being given to lab technicians and general practitioners who are mostly approached by people first.
- In India we do good work but this model has to spread widely and very quickly. For instance, we need to aim at training of 90 percent of the lab technicians and all the doctors within a span of two years increasing numbers are very important to achieving success of such training programs.
- Mainstreaming of HIV/ AIDS is necessary. Basic training for ANMs and doctors must include training in HIV/AIDS.
- The problem of HIV should not be viewed in isolation, or as an exclusive problem, because its tentacles reach every aspect of life. Therefore it should be addressed as part of all programs.
- Stigma and discrimination have always been a part of one or the other disease. If we look back in the history we will find that Tuberculosis at some point of time had the same stigma and discrimination as HIV/AIDS has today. There are many other diseases like cancer, infertility, etc, which are still stigmatized today. Stigma attached to diseases will keep changing over time as awareness about the diseases spread. It is true that as humans all doctors have the fear of contracting HIV which means certain death, however there are other diseases like Hepatitis

B, exposure to which is equally dangerous. However, HIV/AIDS seems to create a greater fear in the minds of doctors.

- The fear of AIDS stems from ignorance and lack of strict adherence to universal precautions. Despite education and training, doctors are still not willing to operate on HIV positive people. They simply refer such cases to other doctors, who refer them further. While fear of the disease is legitimate, doctors must make efforts overcome this fear.
- The way doctors give messages to the caregivers of persons with HIV/AIDS is also very important. As in the case of the 18-year-old boy who was taking care of his mother, the doctor should have stressed the importance of keeping gloves handy without making it a taboo.
- Removing stigma and discrimination against HIV positive people and preventing further spread of HIV, both must be components of the program and HIV positive people should be involved in the process.
- It is very important for HIV positive people to come out and speak up so that the public can see that they can lead normal productive lives and are not necessarily bed-ridden as is the common belief of people.

Some of the participants posed the following questions to the resource person:

- *Are there any specific policies for HIV positive people?*

No. The Lawyers' Collective has drafted a bill with a rights-based approach to address the issues of people living with HIV/AIDS. There are five key issues in the bill. The bill will be tabled in the Winter Session of Parliament. It is hoped that by 2006 the Bill would become law.

- *Is HIV testing compulsory for insurance policy?*

No. There is no HIV testing for insurance policy because anyone can become positive after testing negative initially because he or she is in the window period. However, people with AIDS are not included in the insurance policy. As long as the death certificate does not explicitly state that the person had died of AIDS, but due to other diseases (that is, opportunistic infections or diseases), a person can claim insurance. There are insurance policies for HIV positive people in the Netherlands and South Africa.

- The scenario has now changed. GAP and the Indian Network of NGOs (INN) with its network of 400-500 NGOs is meeting at a National Convention in February 2006. Insurance is one of the issues which will be discussed. GAP has also received a request for the preparation of a policy paper for insurance companies on this issue.

Dr. Marfatia added that usually insurance claims of smaller amounts are cleared. It is only in the case of large amounts like 20-25 lakh rupees that a lot of probing is done if death of the insured person occurs within three years of buying the policy.

- *Can Mediclaim demand to know the HIV status of the applicant? Does the insurance company have the right to know?*

No. No one can ask anyone about their HIV status, as everyone has the right to keep their HIV status confidential. However, it is the duty of the positive person to inform the examining doctor of his or her status. The insurance company does not have the right to know.

Ms. Renu Khanna brought to the notice of the participants that private insurance companies are excluding people on the basis, of their sero-status for example ICICI prudential has HIV positive status as one of the exclusion criteria.

Participants made the following remarks and suggestions to address women's vulnerability to HIV/AIDS.

- The structure of our society is such that parents behave very differently with their daughters and daughters-in-law in the case of diseases. Parents bear all the expenses of their daughter when they contract a disease, but the same is not done for their daughters-in-law. Therefore structural change in society is very important.
- Social structure will change if we provide women access to information, increase their understanding of their rights - that 'my body is mine'. This will happen only with education and property rights. Men who are sensitive must come forward and raise their voices as their opinions would carry more weight than women activists who have already been labeled as 'home breakers'.
- Men must participate more and play a greater role. Until now, we have not let men to participate. Women are biologically very strong and their empowerment through education and economic independence will make them stronger.
- There is a pressure on women to marry even if they are well educated and economically independent. So, it should be solely the decision of the woman whether she wants to marry and have a family or to be single.

Concluding the discussion, Ms. Renu Khanna observed that there is an increasing consciousness among women. Women across all social classes are coming out and becoming confident that they can live alone. But men are not changing; they still want a traditional wife. She said that if we want to work with men, we need male role models to send across the message. She suggested the creation of a pool of male facilitators to conduct training programs for men.

Addressing Gender Issues in HIV/AIDS Prevention and Control Programs

Participants were divided into three groups to work on the following topics:

- Empowerment of women, addressing stigma and discrimination.
- Rights of People Living with HIV/AIDS.
- Rights and issues of Sex-Workers.

Each group identified the gender and rights issues in their topic and made recommendations for action:

Group 1: Addressing Stigma and Discrimination: Gender Sensitization and Empowerment of Women

The group identified areas of concern and points for action to fight stigma and discrimination against people, living with or affected by HIV/AIDS, women in particular.

1. Spread awareness about gender issues and carry out gender sensitization of the population through:
    - Counseling of parents (including parents-to-be) to sensitize them on the equality of the sexes to reduce gender-based discrimination within the family. Sensitization of parents will help challenge the existing gender norms of behavior for boys and girls.
    - Inclusion of gender issues (including the topic of HIV/ AIDS) in the school curricula. Children learn in schools, about gender roles through examples such as "my father goes to office, my mother is a school teacher…" or that certain subjects such as home science are only for women/girls.
    - Gender sensitization of workers of NGOs and Government Organizations implementing programs for empowerment and prevention and control of HIV/AIDS. Family planning programs run by Government and private organizations at present focus only on women. Under the RCH program, both the woman and her husband are important, but in practice the program as well as the health workers focus only on women. The program must focus on couples and especially on men, in order to promote male responsibility in contraception and disease prevention.

2. Women's Empowerment through:
    - Promotion of their education.
    - Providing opportunities to women to get complete information regarding HIV/AIDS and to have their questions on this topic answered.

- Economic empowerment. Women must be encouraged to step out of their homes and take up jobs, because home-based work is often not counted as work and becomes invisible work. Therefore women must increase their visibility through jobs outside their homes.
- Provision of information, knowledge and support to women to enable them to make their own decisions. For example, a woman who is pregnant and does not want to continue the pregnancy, or is being forced to undergo a sex determination test, must be informed of all her options, and legal and other support should be provided to help her make her decision.
- Ensuring equal status. Reservation for women is a short-term equity measure. The longer-term vision of equality should be kept alive. Along with reservations, all efforts should be made to enhance the status of women. As long as women are not empowered to assert themselves or make their own decisions, reservations will not serve the purpose. The oft-cited example of women Sarpanches being mere puppets of their husbands as failure of women's reservation, is an outcome of reservation without complementary efforts to empower women and enhance their status.
- Encouragement of women to participate in physical activities like sports or physical exercise. This will help boost their self-confidence, besides increasing their visibility in public spaces.

3. Fighting Stigma and discrimination by:
    - Creating awareness regarding health and providing knowledge regarding the health system.
    - Organizing health awareness camps.
    - Using films or other popular media as channels to spread the message about HIV/AIDS.

Discussion

One of the participants raised the issue of gender-discrimination in the health care system. The workload of the female health workers/ANM is greater than that of the male health workers. Moreover, there is no one to supervise the work of the latter while the work of the ANM is continuously supervised. The posts of the male health worker is the responsibility of the state governments, while the ANMs are appointed by the Centre. The state governments are lax in filling up vacant posts. As a result a large percentage of posts remain vacant increasing the workload of ANMs.

Group 2: Rights of People Living with HIV/AIDS

The group identified the important rights of positive people and made recommendations for ensuring that the PLWHA may also exercise or access these rights.

1. **Right to marry**

Do HIV positive people have the right to marry? If yes, then should they be allowed to marry only positive people or also those who are HIV negative? These are some questions that need to be asked. While the group did not take a stand on the right of PLWHA to marry, they strongly felt that PLWHA should not keep their sero-status a secret. Disclosure is the most important part of such marriages. Those who wish to marry should disclose their serostatus to their prospective partners, in order to avoid marital conflicts, separation and divorce later. At the time of marriage the couple should file an affidavit that they are HIV positive and are getting married according to their will, fully aware of their sero-status. In case one of the partners is negative, s/he should provide a letter of consent for the marriage. Marriages that are solemnized this way leave little scope for cheating someone or being cheated into marriage.

2. **Right to employment**

Apart from the right to non-discrimination at the workplace, we have to consider the two types of employment for positive people in the government sector: 1) permanent employment and 2) contract employment (casual labour). The government may consider providing job opportunities to PLWHA in contract employment. Preference may be given to PLWHA in jobs that are non-risky or have low health risks for PLWHA, e.g. the posts of peons. Government must provide opportunities for livelihoods to PLWHA so that they can be self-employed or work/run a small scale or cottage industry. Government as well as non-government organizations must provide them encouragement by providing loans, information and equipment for setting up of their small businesses or industries. Some rules and policies need to be changed to accommodate the needs of PLWHA. For instance, as per the existing norm, to form a self-help group (SHG) a membership of at least 10 persons is essential. However, it is often the case that PLWHA cannot form an SHG because they do not have the required number of members. In such cases, an exception should be made to allow the formation of SHG of PLWHA with even fewer than 10 members. Alternatively existing SHGs could integrate PLWHA into their group as a conscious effort.

3. **Food and nutritional security**

Food and nutritional security of the PLWHA should be ensured, especially for those who are unemployed and living in poverty.

4. **Representation of PLWHA**

When we speak about the rights of PLWHA, it is important that persons who voice their concerns or demands should be from the same community.

Any support or assistance to be provided to PLWHA must be timely and it is important that such assistance be aimed at making them self-reliant. Each individual must be given the right to choose from a variety of options.

PLWHA do not have any special rights, but equal rights as everyone else. Rights applicable to everyone else are equally applicable to PLWHA. It is important to create this awareness among people to combat stigma and discrimination.

At the organizational level, awareness about rights can be spread through various media like posters, wall hoardings, exhibitions, etc.

Increased representation of PLWHA in SHGs can also help spread awareness and address issues of discrimination and stigma.

The group felt that it would be more effective if high ranking government officials, elected representatives, and even religious leaders or religious leaders joined the efforts to spread the message against stigma and discrimination.

Discussion

One of the participants responded to some of the points made in the presentation that ILO's guidelines on the employment of positive persons exists and it have been adopted by the Confederation of Indian Industries and about 60 industrial units in Surat have signed this policy. According this participant, the problem is that workers are unaware of their rights. She felt that in spite of being the appropriate organization to fight for the rights of HIV positive workers, the Gujarat State Network for Positive People (GSNP+) was not participating in many of the advocacy efforts of local NGOs for positive people. She also felt that if positive people want policy changes in their favor, they should be willing to trade off their confidentiality in return.

Another participant, representative of the GSNP+ responded that confidentiality is an issue only for those positive persons who are not yet ready to reveal their positive status. The recommendation to change the current rules for forming SHGs is based on actual experience of positive people, who have not been able to form SHGs on account of their small numbers. It is important to bring about changes in economic policies in favour of positive people, because their numbers are growing and they are careening towards impoverishment. Several of them are already living below poverty line and several on the brink of falling below Poverty Line. The GSNP+ has presently only 4 to 5 people working, all of them as volunteers. The GSNP+ being representative of the

whole state, there is a very high workload on each volunteer. At the GSNP+ counseling centre, the volunteers spend at least an hour talking to each positive person. They work under great pressures of time and human resources. Hence it is not possible for the GSNP+ to participate in all the on-going efforts for positive people being made by NGOs.

It was strongly recommended that:

- GSACS must provide special funds to run the GSNP+. It must support this group, by converting the voluntary efforts of individual members into salaried employment. This way issue of shortage of human resources can be solved.
- NGOs, especially women's health groups, working in the area of HIV/AIDS and providing interventions should not consider themselves as separate from the GSNP+, they must step in to represent and coordinate its activities.
- Capacity building of GSNP+ volunteers is very important, and can be undertaken by NGOs.

Group 3: Rights and Issues of Sex-Workers

This group presented the common problems of sex workers related to their health and social relations and made suggestions to address these.

1. Health problems

- *RTI, STI, and HIV/AIDS:* Creating awareness regarding health and providing knowledge regarding these sexually transmitted and transmissible infections.
- *Unwanted pregnancy*: Counseling, giving them options, including information on safe abortion.
- *Sex during pregnancy*: Counseling on when to pause sex work during the first two and the last three months of pregnancy.
- *Inconvenience in accessing health care:* There should be flexibility in the timings of health facilities/ clinics to enable sex workers to attend them.

2. Social problems

- *Inability to insist on condom use by their clients, due to fear of losing the client:* Counseling for creating of a "pool system", wherein all sex workers pledge to refuse sex without condom. To show solidarity, sex workers who are successful in enforcing condom use can pool in to compensate or share their income with those who have lost their clients on account of insisting on condom use.
- *Harassment by police:* Organization of sensitivity training programs for the police, targeted at all ranks, from the commissioner to the constable. commissioner of police.
- *Non-acceptance by society*: Even if sex workers are willing to change their profession society is not ready to accept them.

3. Economic problems

- Field experience shows that these women are left with no savings when they grow old and are left with no livelihood options. Savings should be encouraged by forming savings groups.

Discussion

One of the participants remarked that sex work exists because society wants it to, but at the same time society does not want to accept its existence. Another participant illustrated with the example of the cleaning up of a famous red light area in Surat, in which about 150 sex workers were to be rehabilitated. Ironically the very person who was leading the peoples' movement (Jumbesh) against the clean up was not willing to keep provide employment to sex workers, even as domestic help. The clean up operation once again proved that rehabilitation is not the answer to the problem.

Ms. Renu Khanna winding up the discussion reminded the group about the changing nature of sex work, which is increasingly becoming non-brothel based. She also shared with the group the increasing self-assertion by the sex workers who are now organizing themselves. VAMP, a Sangli-based organization of sex workers is a very active organization. VAMP organized a conference and presented before an audience of about 1000 people a 45-minute play. The play, suffused with humor, in a simple language attempted the demystification of sex workers and put across their issues to society.

Recommendations for the HIV/AIDS Prevention and Control Programs

Following are the recommendations for policy and programs directed at HIV/AIDS prevention and control.

- **Incorporate a gender and rights perspective in all HIV/AIDS prevention and control policies and programs.**

- **Fulfill the Right to Health,** by ensuring that
    - health services, including HIV/AIDS prevention and treatment, are available and accessible to all without discrimination and stigma.
    - good quality condoms (male and female) as well as vaginal microbicides are available as part of prevention. This calls for acceleration of research to develop effective and affordable women-controlled preventive methods.
    - antiretroviral drugs are available free to these who cannot afford to pay for them. Cost of antiretrovirals should be brought down through price control measures.
    - PPTCT services should be available and accessible to all women who need them.

    - information is provided on HIV/AIDS, on the rights of persons living with HIV/AIDS to affordable quality health services.

- **Fulfil enabling conditions for health.** This includes determinants of health, by addressing issues like migration, sex trade and trafficking, sale of blood and blood products, through policies and legislations; by providing HIV/AIDS and STI education to women and adolescent girls; by empowering women and girls (through access to resources like education, information, livelihoods, and economic assets) for self-determination, taking control of their reproductive health, protecting them from violence and sexual coercion; by changing attitudes and mindsets regarding gender roles, concepts of masculinity and femininity.

- **Converge the Reproductive and Child Health Program and the National AIDS Control Program** to address the needs of persons living with HIV/AIDS from the District Level downwards.

- **Adopt a comprehensive approach to reducing HIV infection in infants and young children** through prevention of parent to child transmission (PPTCT), which includes: primary prevention of HIV infection (the ABC approach for parents-to-be), prevention of unintended pregnancies in HIV-infected women, prevention of HIV transmission from HIV-infected women to their infants (HIV counselling and testing, provision of antiretroviral (ARV) prophylaxis, promotion of safer delivery and infant feeding practices), and provision of treatment, care and support to HIV-infected women, their infants and their families.

- **Provide comprehensive Maternal and Child Health services** (antenatal care, essential obstetric care, emergency obstetric care, postnatal care and support, family planning services, ccounseling and testing for HIV, nutritional care, ARV prophylaxis, early recognition and treatment of HIV).

- Enforce legal provisions to protect the human rights of people living with HIV/AIDS and those belonging to sexual minority groups.

- **Decriminalize homosexuality.** Section 377 of the Indian Penal Code, which criminalizes homosexuality as ‘against the law of nature’ must be repealed. The comprehensive HIV Bill proposed by the Lawyers’ Collective should be passed by the Parliament at the earliest.

- Include People Living with HIV/AIDS in all HIV/AIDS related policy making and program planning.

- **Address research gaps in HIV and gender.** There is need for research on how gender roles and societal pressure put men at risk; how to measure whether reduction in gender inequalities leads to reduced vulnerability to HIV/AIDS; what changes are required to make HIV/AIDS institutions more gender sensitive; how to bring about convergence between the RCH Program, comprehensive primary health care and the HIV/AIDS Control Program.

Appendix A

Understanding HIV/AIDS: A Gender and Rights Perspective" from November 29-30, 2005.

List of Participants

Outstation Participants

Sr. No.	Name	Organization
1.	Ms. Sonal Shroff, Secretary	Lok Vikas Sanstha, L-28, 1st floor, Jai Raj Society, Ichhapore-3, Hazira Area, Surat-391 510. (O) 0261-2840146, 2861878 E-mail: lvs_surat@yahoo.co.in
2.	Ms. Nimisha Choudhary, Leader & Committee Member	Aga Khan Rural Support Programme, Dadia Pada. (O) 02623-222293 (O) 952649234181
3.	Ms. Rekha Choudhary, Leader & Committee Member	Aga Khan Rural Support Programme, Dadia Pada
4.	Ms. Reva Vasava, President of Women Organisation,	Aga Khan Rural Support Programme, Mandvi. (O) 952623222293
5.	Ms. Champa Vasava, Convenor Aarogya Samitee	Aga Khan Rural Support Programme, Mandvi.
6.	Dr. Uday Singh,	PSM Dept. Karamsad Medical College, Karamsad. (O) (02692) 221429
7.	Dr. L.N. Chauhan (M) 9427350226	Dept. of Obst. & Gynaec. Karamsad Medical College, Karamsad.
8.	Mr. Jignesh Panchal (M) 9825083383	Samanvay Resource Centre, Godhra P O Box 14, Beside Nagar Palika, Devgadh Baria, Dist Dahod Panchmahal, Gujarat- 389380 (O) 02678-221025; (02672) 570912
9.	Mr. Ashok Kangad, Project officer,	Gramya Vikas Trust, Near S.T. Bus Stand, Okha Highway, Dwarka-361335. (02892) 236551, 236552

Sr. No.	Name	Organization
10.	Ms. Hemangi Trivedi, Counsellor	Gramya Vikas Trust, Near S.T. Bus Stand, Okha Highway, Dwarka-361335. (02892) 236551, 236552
11.	Mr. Satish Macwan, Project Coordinator	Sneh Prayas, 401, Simandhar Avenue, 8, Kailash Society, Behind H.K. House, Off. Ashram Road, Ahmedabad (O) 079-55450877 E-mail: info@snehprayas.org
12.	Mr. Rajiv Kumar, State Program Manager	Sneh Prayas, 401, Simandhar Avenue, 8, Kailash Society, Behind H.K. House, Off. Ashram Road, Ahmedabad (O) 079-55450877 E-mail: info@snehprayas.org
13.	Ms. Jayshree Ahir, (M) 9825476289	Prayas, 60, Maruti Nagar, Near Yadavnagar, Meghpar Road, New Anjar, Anjar. (R) 02836-246493 E-mail: prayas_anjar@hotmail.com / prayasmail@rediffmail.com
14.	Mr. Ashwin Patel, Project Officer, (M) 9825415223	Gharda Foundation, C/o. Gujarat Insecticides Ltd., Plot No. 805/806, GIDC, Ankleshwar-393001, Dist. Bharuch. (O) 02646-222271 / 220032 / 223914 Extn: 247 E-mail: giledp1@sancharnet.in

Local Participants

Sr. No	Name	Organization
15.	Ms. Manisha Salunke,	AP+, G-10, Nishant Flat, Nagarwada, Salatwada Road, Vadodara. Ph: 5583664 E-mail: applusvadodara@yahoo.com
16.	Ms. Pratiksha Ravalji, Field Worker (M) 9426486855	Peoples Training and Research Centre (PTRC), 26, Shyam Nagar, Nr. Dairy Teen rasta, Baroda-390 011. Ph: 2631815; E-mail: jagdish.jb@gmail.com
17.	Ms. Shubhda Kanani, Director	C-2 Biren Apartment Above Punjab National Bank Fatehgunj Char Rasta Vadodara. Ph: 0265-5592184; Fax 0265-2750139 Email: s_kanani@yahoo.co.uk/ aarogya28@eth.net
18.	Ms. Sushma Oza, Director	United Way, 9th Floor, Sidcup Towers, Opp. Pizza Hut, Race Course Circle, Baroda-7. Ph: 23580911/ 5527715 E-mail: admin@unitedwayofbaroda.org
19.	Mr. Viral, Field Officer	SAHAJ - SHISHU MILAP, 1, Shree Hari Apartment B/h. Express Hotel Alkapuri, Vadodara. Ph: 2358307
20.	Mr. Noel, Field Officer	SAHAJ - SHISHU MILAP, 1, Shree Hari Apartment B/h. Express Hotel Alkapuri, Vadodara. Ph: 2358307
21.	Ms. Deepa Bordevarkar, Proj. Coordinator(M) 9825169684	SAHAJ - SHISHU MILAP, 1, Shree Hari Apartment B/h. Express Hotel Alkapuri, Vadodara. Ph: 2358307
22.	Dr. Bhavesh Modi/Avni Pathak, Tutor (M) 9426233639	PSM Department, Medical College (0265) 2422808

Sr. No	Name	Organization
23.	Dr. Shilpa Kapadia, Course Coordinator	Center for Adult Education, M.S. University of Baroda. (O) 2795510

Panel Presenters

Sr. No.	Name	Organization
24.	Vaishali Ajmera, (M) 9825821704	Behind Bharat Flour Mill, Nagarwada Chaar Rasta, Nagarwada. Vadodara. E-mail: vaishali.ajmera@gmail.com
25.	Ms. Maya Sharma	A-5, Saptagiri, Opp. Taj Residency, Akota, Baroda. Ph: 2352589 E-mail: vikalpgroup@hotmail.com
26.	Mr. Sylvester Merchant, (M) 9825311997	105, Rajmandir Apartment, 62 Alkapuri Society, Alkapuri, Baroda-7. Ph: 2331340 E-mail: lakshya121@rediffmail.com
27.	Ms. Asha Ghodke	GSNP+ Room No. 35, SMIMER Hospital, Near Sahara Darvaja, Surat. (O) 0261-5594700 E-mail: gsnpplus@yahoo.co.in
28.	Ms. Amudha Ranganathan	Sahas, 301, 3rd Floor, Meghani Towers, Old Capital Cinema, Station Road, Surat-395 003. Ph: (0261) 2423132 E-mail: sahasorg@yahoo.co.in
29.	Mr. Kamlesh Meswania, (M) 9427071114	GSACS, Gujarat State Aids Control Society O-1 Block, New Mental Hospital Complex Meghaninagar, Ahmedabad – 380 016. E-mail: gsacs@icenet.net

List of Resource Persons

Sr. No.	Name	Organization
30.	Dr. Y.S. Marfatia, (M) 9825917442	Dept. of Skin & VD, Baroda Medical College, Vadodara.
31.	Dr. Uma Nayak, (M) 9327214065	Dept. of Pediatrics, Baroda Medical College, Vadodara.
32.	Ms. Renu Khanna, (M) 9427054006	SAHAJ – SHISHU MILAP, 1, Shree Hari Apartment B/h. Express Hotel, Alkapuri, Vadodara. Ph: 2358307 E-mail: sahajbrc@icenet.co.in / sahajbrc@yahoo.com
33.	Dr. P.V. Kotecha, (M) 9825683556	Dept. of Preventive and Social Medicine Baroda Medical College
34.	Dr. Radium D. Bhattacharya, President	INDIAN NETWORK OF NGOs on HIV/AIDS GAP – ISRCDE, B-01, Siddhachakra Apartments, Ellisbridge, Ahmedabad-380 006. Ph: 079-26575282; Fax: 079-26575962 E-mail: inn94@icenet.net / radium@icenet.net

WOHTRAC Core team

35.	Dr. Shagufa Kapadia, Principal Investigator (M) 9825781934	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
36.	Dr. N. Rajaram, Co-Investigator (M) 9824253554	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
37.	Dr. Niti Chopra, Core Team Member (M) 9376230324	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
38.	Ms. Urvi Shah, Core Team Member	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2. (O) 2795569
39.	Ms. Bhavna Mehta, Core Team Member (M) 9376225001	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.

WOHTRAC Staff

Sr. No.	Name	Organization
40.	Ms. Yamini Venkatachalam, Advocacy & Documentation Coordinator	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
41.	Ms. Swati Joshi, Training Coordinator	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
42.	Ms. Jaya Singh, Research Assistant	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
43.	Ms. Mandeep Jajwa, Research Assistant	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
44.	Ms. Falguni Maniar, Computer Analyst	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
45.	Ms. Varsha Mistry, Computer Operator	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
46.	Mr. Hasmukh Parmar, Account Officer	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
47.	Mr. Paresh Pagi, Support Staff	WOHTRAC, M-1, New Vikrambaug, Pratapgunj, Vadodara-2.
48.	Mr. Mukesh Solanki, Support Staff	WOHTRAC, M-1, New Vikram baug, Pratapgunj, Vadodara-2.

Appendix B

Understanding HIV/AIDS: A Gender and Rights Perspective

29-30 November 2005

Program Schedule

29 November 2005

Time	Topic	Methodology	Resource Person
10:00 am	**Registration and Tea**		
10:30 am – 12: 00 pm	**Introduction** **Objectives of the workshop** **Epidemiology of HIV/AIDS in India and Gujarat** • History of HIV/AIDS • Prevalence and Trends • Predominant modes of transmission in India and Gujarat • Opportunistic Infections • Factors underlying transmission • Limitations of existing data	Presentation and Discussion	Renu Khanna/Dr. Yogesh Marfatia Dr. P. V. Kotecha
12:00 – 1:00 pm	**Gender Analysis of HIV/AIDS** • Physical/biological vulnerability • Socioeconomic factors and socio-cultural determinants of risky behavior	Presentation and Discussion	Dr. Yogesh Marfatia Renu Khanna
1:00 pm – 1:45 pm	LUNCH BREAK		
1:45 – 3:15 pm	**Panel on *Experiences of Interventions in Gender and HIV/AIDS***	Presentation and Discussion	**Moderator:** GSACS Representative **Presenters:** Representatives of NGOs implementing TI/PLWHA - Vishali Ajmera, Vikas Jyot Trust - Sylvester Merchant, Lakshya Trust) - Maya Sharma, Vikalp - Asha Ghodke, GSNP+ - Amudha Ranganathan, Sahas
3:15 – 4:15 pm	**Mother to Child Transmission**	Presentation and Discussion	**Presenter:** Dr. Uma Nayak
4:15 – 4:30 pm	TEA BREAK		
4:30 pm – 5:30 pm	**Rights Perspective to HIV/AIDS**	Presentation and Discussion	**Presenter:** Ms. Renu Khanna
5:30 – 5:45 pm	BREAK		
5:45 – 6:45 pm	**Symposium on the topic "Understanding HIV/AIDS: A Gender and Rights Perspective".**	Open Discussion	**Speakers:** Dr. Uma Nayak, Dr. Y.S. Marfatia, Dr. L.N. Chauhan, Ms. Renu Khanna, Dr. P.V. Kotecha

30 November 2005

Time	Topic	Methodology	Resource Person
9:30 – 11:30 pm	**Stigma and Discrimination**	Presentation and Discussion	Dr. Radium Bhattacharya
11:30 – 11:45 pm	TEA BREAK		
11:45 – 1:00 pm	**Addressing Gender and Rights Issues in HIV/AIDS Prevention and Control Programs** • How NGOs and CBOs can respond within their existing intervention programs	Group exercise and presentations	Dr. Yogesh Marfatia/ Ms. Renu Khanna
1:00 pm – 1:30 pm	**Evaluation and Future Directions: Recommendations for Prevention and Control Programs**		Dr. Yogesh Marfatia, Ms. Renu Khanna
1:30 pm –2:15 pm	LUNCH and DEPARTURES		

Appendix C

Workshop Evaluation

Twenty evaluation forms were received from the participants. Overall the participants evaluated the workshop positively in each of the following aspects.

Quality of Presentation: Most of the participants rated the quality of presentations as excellent (n=9) and good (n=9), and two evaluated it as average.

Though the resource persons had made all efforts to speak in the most commonly understood language (Gujarati) and it was kept as the medium of communication, as far as possible through out the workshop, there were suggestions by a few participants for keeping Gujarati as the medium of communication.

Selection of topics and coverage of individual topics: The topics selected for presentation and discussion were rated as excellent (n=11) or good (n=8) by the majority of the participants. Two participants expressed the need for more in-depth information on some of the topics and the need to include more topics.

As regards the coverage of individual topics, 6 participants found it excellent, 2 found it good and 3 found it average. One of the participants felt that the coverage of topics could have been more exhaustive.

Quality of handouts: Majority of the participants rated the quality of handouts as good (n=10) and excellent (n=6), while 3 found it average, one did not respond. There were requests for more resource materials in Gujarati language to facilitate better understanding of the topics under discussion.

Timing and duration of the workshop: Out of 20 participants, 10 rated the timing of the workshop as good and 8 rated it as excellent, and 2 rated it as average. Similarly, duration of the workshop was rated as good (n=11) and excellent (n=8) by most participants. Two rated it as average.

A few participants felt that more time could have been spent and that the workshop could have been extended over more days, but fewer hours per day.

Time given to each topic: Majority of the participants were satisfied with the time devoted to each topic under discussion (excellent = 7; good=11). Again there was a suggestion that more time could have been spent on each topic.

Management of the workshop: All the participants were satisfied with the overall the management of the workshop, which they rated as either excellent (n=10) or good (n=10).

All but one participant found the sitting arrangement excellent (n=11) or good (n=8). Similarly, the hospitality provided to participants was rated as excellent (n=9) or good (n=9).

Other Remarks/Comments/Suggestions

- There is a need to organize more such workshops to spread awareness on such sensitive issues in society.
- If such a workshop is organized more often, with more in-depth coverage of all related issues, its impact would be felt and the importance of these issues would be recognized.
- Such workshops are needed as they enable interaction with heterogeneous groups.
- Such workshops should be organized for graduate and postgraduate students of medicine to enable them to view medical problems (communicable disease, maternal and child health, psychiatric problems) from a gender perspective. This will help medical practitioners to diagnose these conditions from a gender perspective – social diagnosis with clinical diagnosis – to serve the patients better.
- It is important to ensure participation of government officials (GSACS and PSU) in such workshops. Representation of GSACS would have enabled participating organizations to table their issues and come up with immediate solutions.
- The workshop could have been made more participatory by increasing the number of group activities and group work, so that all participants could express their viewpoints more freely. More group work would have helped in extracting more information.
- More time could have been spent for in-depth discussion on topics that were taken up.
- There is a need to include Positive People in such workshops and increase their participation in discussions on issues around HIV/AIDS.
- Greater coverage of the legal aspects of HIV/AIDS is needed.
- The medium of presentation as well as resource materials should be in Gujarati.
- A review of the of the workshop should be conducted so as to know the extent to which participants have been able to deliver the message to the public both at a personal and societal level.