

WOMEN AND HIV
ISSUES, CONCERNS, RESPONSES AND COPING

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Abbreviations:

AIDS	: Acquired Immunodeficiency Syndrome
AZT	: Zidovudine
HIV	: Human Immunodeficiency Virus
IEC	: Information, Education and Communication
MTCT	: Mother to Child Transmission
NGO	: Non-Governmental Organization
PHC	: Primary Health Center
PLWHA	: People Living With HIV/AIDS
RCH	: Reproductive and Child Health
RTI	: Reproductive Tract Illnesses
STD	: Sexually Transmitted Diseases
STI	: Sexually Transmitted Infections

Index

I. Introduction

Certain facts have emerged quite clearly in the recent past. First, HIV epidemic is spreading very fast in our country. We estimate that there are minimum about 3.7 million persons infected with HIV in our country. Sexually transmitted infections (STIs) and other reproductive tract infections have intricate and intimate relationship with HIV, with effects on causation, vulnerability and effects on women. It is said that the STIs and RTIs exhibit a "biological sexism". The classical reasons cited are, in societies undergoing socio-economic transition, women's early onset of sexual activity, lack of ability to negotiate sexual contacts and, in comparison to men generally lower levels of education and exposure to health information and services. These render them vulnerable to recurrent RTIs and STIs. (Wasserheit, J.N., 1989, The significance and scope of reproductive tract infections among third world women. *International Journal of Gynecology and Obstetrics*. Suppl.3: 145-168). Nearly 40% of Indian women are married between 15 and 19 years of age and well over half of women in this age group have experienced a pregnancy or birth (National Family health Survey (NFHS-2), International Institute of Population Sciences, 1998-99, 19). Little else is known about adolescent sexual and reproductive health, despite the fact that adolescents make up nearly 25% of the population (Jeejeebhoy S. 1998. Adolescent Sexual and Reproductive Behavior: A review of the Evidence from India. *Social Science and Medicine*. 46(10): 1275-1290). The strong associations of STI with HIV in urban setting have been confirmed through studies showing a dramatic rise of HIV infection in sex workers and patients attending municipal STD clinics in Pune. Mehendale and colleagues found that the incidence rate of HIV infection among patients attending STD clinics in Pune was much higher in women than in men (14.2% and 9.5% per year respectively). (Mehendale S.M., Shepherd M.E., Divekar A.D.,et al. 1996. Evidence for high prevalence and rapid transmission of HIV among individuals attending STD clinics in Pune, India. *Indian Journal of Medical Research* 104:327-335).

Women are at the center of the 'hot-spot' as far as HIV epidemic is concerned, with around 50% of the new infections occurring in the women, more than 80% of these being seen in women below 35 years of age i.e. in the prime of their reproductive careers. It has also been observed that the rate of new infections among apparently monogamous married women, with no other identifiable risk factor, is on the rise (Gangakhedkar R. R., Bentley M.E., Divekar A.D.,et al. 1997. Spread of HIV infection in monogamous women in India. *Journal of the American Medical Association* 278(23):2090-2092). Women of younger age are often more at risk than their male age mates are, because they are sexually active with older men. These women are also likely to give birth to children who could be HIV infected and even if not infected they are destined to become orphans soon. Quite often these women being the index cases in the families they have to bear the brunt of the stigma and discrimination. There are also unmarried girls detected to be HIV positive. In these cases unprotected sexual encounters are the risk factor. There are few studies available informing the extent of this kind of sexual activity. Lack of proper sex education puts these girls at increased risk of getting pregnant or acquiring STIs and HIV.

It is also very important to note here that in Indian culture, which is claimed to be highly conservative, though people do not talk about sexual behaviors there is vast complexity in sexual behavior as well as networking. Though little studied and documented, this is evident from the observation that STIs are said to be the third major communicable disease. The highest concentration of STI cases reporting is estimated at 32.6% in Maharashtra and is likely to be due to a relatively higher level of urbanization, a higher level of commercial sex work, and a larger number of STD clinics.

(Government of India, 1988, Health Information India. Director General of Health Services, Ministry of Health and Family Welfare, New Delhi).

Responses to the HIV epidemic have to focus on dealing not only with the causes of the epidemic but also the impact. The HIV control programs have invested heavily in the conventional strategies like IEC (Information, Education and Communication), safe blood supply, condom promotion, etc. In spite of these efforts the epidemic is still progressing rapidly. This informs us about continuous evaluation of our strategies and materials. At the same time more and more number of HIV infected individuals have now started developing symptoms. Care and support for people living with HIV/AIDS (PLWHA) needs different types of services, which may be difficult to estimate, conceptualize and design.

It is estimated that of all PLWHA

- 50% are asymptomatic and hence will remain undetected
- 10% will develop tuberculosis
- 20% will have acute HIV illness within one year
- 10% will develop chronic illness
- 10% will die within one year.

With our experience in dealing with PLWHA over last 10 years we now firmly believe that the prevention programs can now succeed only if we also put in place appropriate care and support facilities. The typical message of "No cure, No vaccine. Certain death!" certainly strikes a different note for PLWHA. How can we support someone and tell, "it is not the end of the road and one can lead a healthy and productive life in spite of HIV" when media are screaming around with these kind of frightening messages? There are also the issues of stigma and discrimination. In a highly moralistic society, egged on by the media describing HIV as the disease of the immoral, promiscuous it is not easy for the PLWHA to come forward and lead a 'normal' life.

As Jonathan Mann put it " AIDS is the first pandemic of its kind to occur during the post-World War II era of human rights. Accordingly public health officials have dual responsibility in confronting AIDS: they must protect public health and respect human rights." There is still some debate in the minds of many that consider this dual role as adversarial. It is however emerging that not only are they mutually compatible but inextricably linked. It is now clear that individual, community, and national vulnerability to HIV is directly connected with societal discrimination.

Women who as it is are more vulnerable in our patriarchal society certainly are more at risk of getting infected with HIV, and once infected will have to face different and often more severe consequences of the reality.

To quote from the book 'Until the Cure' edited by Ann Kurth (Yale University Press, 1993),

" I am the face of the HIV virus. You see me every day, you pass me on the street, and you work next to me, yet you don't know my secret. We are invisible. Statistics are not kept, can not be kept, on those who live with HIV disease. Women are an invisible component of this disease for several reasons: fear of losing custody of children, fear of losing jobs, fear of negative judgement." On being told about HIV positive status, " My world, my life as I knew it changed completely. Your life feels like a piece of glass that shatters to the ground, and the pieces seem impossible to pick up. It doesn't go away. But gradually I learned to cope with the reality. Today, I am happy to say, my life is very full, very content, and filled with joy." (Anonymous)

It is obvious that the problem of HIV can not be tackled from a medical point of view alone. Unless the other issues affecting the causation and perpetuation of the environment surrounding the epidemic of HIV/AIDS are identified, recognized and addressed to the control might just remain a distant dream.

Despite the growing importance of HIV/AIDS as a major cause of increased morbidity and mortality, especially in young women, it has been understudied. Perhaps the attention is lacking because " women and children are politically weak groups" in the society. In a society where there are several restrictions, discussing these issues considered to be a taboo, we lack tools to intervene effectively to bring the situation fast under control.

There have been a lot of changes in the women's health programs and shifts in policy. In 1952 the Indian government instituted a Family Planning Program (FPP). However, with growing pressure from international population policy makers, it gradually became "population control" program, paying little or no attention to women's general health needs. In 1977, FPP was renamed the Family Welfare Program (FWP) and expanded to include special components such as Maternal and Child Health (MCH) Services, again focussing on pregnant women and children and neglecting morbidity concerns outside the realm of Motherhood. In 1992, the National Child Survival and Safe Motherhood (CSSM) program was introduced, combining immunization with MCH interventions.

In October 1997, the government launched the Reproductive and Child Health (RCH) Program. The RCH program entails a change not only in program policy but in management and implementation as well.

The goals of the RCH program include:

- Removing all targets
- Phasing out incentive payments to both providers and acceptors of family planning methods;
- Increasing utilization of existing facilities rather than creating new structures; and

- Using the voluntary and private sectors to increase access to services and fill gaps left by public-sector providers.

The RCH program utilizes district-level planning and monitoring to make it more responsive to local needs, and it focuses on improving the quality of care by emphasizing the needs of the client, involving the community, improving the client-referral system and providing local oversight for female health workers. The program strives to revitalize the existing network of rural health facilities by improving supplies of drugs and equipment and enhancing training so workers can provide better information and counseling to clients and communities.

Under the RCH program, the government is implementing national initiatives for information, education and communication activities, for training and for program monitoring while also introducing reproductive and child health interventions. Besides addressing quality of care and informed choice, the RCH program also promotes the creation of forum for policy dialogue and for periodic program reviews. The program also stresses that states should have flexibility when implementing recommendations emanating from evaluations and reviews. While the detail of the RCH program can be debated and discussed, it does attempt to address several issues that have thus far been neglected in India's Family Welfare Program.

In our primary health care set up one of the mandates of reproductive and child health (RCH) programs has been prevention and treatment of reproductive tract infections (RTIs) and sexually transmitted infections (STIs). The various components are:

- At community level: 1) IEC, counseling for awareness and prevention, 2) Condom distribution, 3) Creating awareness about usage of sanitary pads by women of reproductive period, 4) Creating awareness about RTIs and personal hygiene
- At sub-center level: No. 1 to 4 and 5) Identification of cases of vaginal discharge, lower abdominal pain, genital ulcers in women and urethral discharge, genital ulcers, swelling in scrotum or groin in men, 6) Diagnosis of RTIs and STIs by syndromic approach, 7) referral of cases not responding to usual treatment, 8) partner notification and referral.
- At PHC level: Nos. 1-8 and 9) Treatment of RTIs and STIs, 10) Syphilis testing in antenatal women.
- At first referral unit/district hospital level: Nos. 1-9 and 10) Laboratory diagnosis and treatment of RTIs and STIs, 11) Syndromic approach to detect and treat STD in antenatal, postnatal and at risk groups.

We are at the threshold of an impending crisis with HIV epidemic looming large. It will be most appropriate to understand the various issues that have evolved or are likely to evolve with rapid unfolding of the HIV epidemic. We should be prepared to face the onslaught with proper systems and defenses already in place rather than running around for fire fighting measures when the fuse has gone off. This is not a phobic reaction. Many communities especially in the Sub-Saharan Africa have had to face this kind of crises and the toll claimed has been irreparable for many a country.

The present study intends to understand the position of the situation as it stands today, to understand the peoples perspective of the situation, the availability, utility and utilization of the services provided and requirements perceived in the fast changing situation. This will help to develop a model, through the participation of the stakeholders; to integrate HIV/AIDS related issues in the RCH programs.

II. Objectives

- 1) To document the problems, concerns and felt needs of the women directly and indirectly affected due to HIV epidemic in the project area.
- 2) To document the understanding and perspective of the service providers about the issues and the needs of HIV affected women.
- 3) To understand the level of awareness and attitudes of the community and study its relation to care, support, stigma and discrimination.
- 4) To organize a workshop of the stakeholders to discuss strategy for integration of HIV/AIDS issues in RCH service.
- 5) To propose a model of integrating HIV/AIDS related issues in the RCH Services.

III. Conceptual framework

" Our understanding of the way in which psychosocial and cultural factors affect the incidence, course, experience and outcome of a disease is crucial for clinical medicine, both in the determination of what data are clinically relevant and where therapeutic interventions should occur." (Good B.J. 1977. The Heart of What's the Matter: Semantics of Illness in Iran, Culture Medicine and Psychiatry, 1:25-58).

There are several factors determining effects on the health of an HIV infected woman. From the data on our files and our experience of dealing with HIV infected women in our clinic as well as in the counselling center we did a retrospective analysis of the issues faced by these women. We based our conceptual framework on these observations and developed research instruments to use in our data collection. Our conceptual framework, as shown in the following figure, was like this.

Personal issues like **age, education, economic and social status, and rural/urban background.**

Family issues like **support (parental family, in-laws family, spouse, others).**

Sexual behavior related factors like **being married or unmarried, first exposures to penetrative sex, sexual abuse, age at marriage, arranged or self decided marriage, dowry, divorce, destitution, widowhood, having or not having children, knowledge, awareness, consent, choice of partners, access to contraception, etc.**

Health status determinants like **diseases (STIs, HIV, other infections, psychological illnesses), pregnancy, delivery, breast feeding, abortion, violence, etc.**

Issues regarding access to health care like **availability and attitudes of counselors, health care providers (public or private sector), voluntary and confidential HIV testing facilities as also the treatment seeking behaviors.**

Social issues like **stigma, discrimination, dis-empowerment.**

Availability of social support systems in the form of **institutions, organizations, legal advise, etc.**

Figure *

IV. Methodology:

The study was conducted in rural and semi-urban areas of Pune district and other areas under the GTZ program where NGOs are involved in RCH programs.

The data were collected from various players in the 'act'.

These were the persons, the family, the society (general population, health care providers, other support systems etc.) The most important aspect was to gather data regarding their perceptions, concerns and felt needs, and also the perceived solutions.

For this we followed the following methodology:

- 1) In-depth interviews of (n = 42) HIV infected women from rural background of Pune district. The interviews were with special emphasis on the profile of problems faced by them (with reference to our conceptual framework) and their life histories. One can understand the difficulty in identifying HIV infected persons in the community and then randomly sampling them. We interviewed the women who reached our clinic or were referred to us by NGOs working in the field areas covered by the project. Therefore though the sample is selective, and clinic based our analysis shows that it does represent women from all the parts of Pune district. With the given small size of the sample it was not possible to conclude any thing about the relative distribution of HIV cases in the district as well as the incidence and prevalence, yet it was definitely seen that there are certain pockets in the district with higher infection rates. Also, the issues they talked about were representative of those faced by most women with HIV.
- 2) In-depth interviews of women in discordant couples where the woman was infected (n = 3). This was an important aspect as these women faced different situation as compared to the women in families where both the partners were infected.
- 3) In-depth interviews of women in discordant couples where the woman was not infected (n = 3). Here the woman was in the role of a supporter and caregiver. She however had to face problems regarding relationship, secrecy, and confidence from a different plane.
- 4) Interviews (n = 5) of family members affected by persons living with HIV in the family, there coping mechanisms, resource management, behavior, etc.
- 5) Key informant interviews (n = 11): Among the persons interviewed there were 4 persons associated with NGOs working in the fields and providing support to women. One was from a mother NGO providing infrastructure to others in the field for their RCH related activities. One was lab technician providing diagnostic services in a rural set up. There were 4 counselors working with different organizations. Within

them they had vast experience of talking to HIV infected women and men. There were 2 social workers that have put numerous years dealing with the women's issues. They have always been in the frontline raising issues affecting women's lives, and who have seen the HIV epidemic unfold in front of the rural backdrop and its multilateral effects on the lives of people, women in particular.

- 6) Focus group interviews with women's groups in order to understand their perception (n = 14). These were conducted in different parts of the district and with a variety of groups. These discussions provided the richness, the variety and the depth to our data. Focus group interviews were conducted with women at:

Indian Institute of Education: women's small saving group members from Ratnagiri, Sindhudurg and Thane,

Wade Bolhai near Wagholi: women members of small saving group,

Karvenagar: women recently settled in semi-urban areas and migrated from villages,

Bavdhan budruk: women from Neo-Buddhist community

Bhugaon: mothers of school children

Agakhan palace: group of rural health workers

Gawadewadi: women from small saving group

Saswad: women belonging to specially trained health workers from an NGO – 'Masum'

Sadkechi wadi: tribal women from Ghodegaon taluka beneficiaries of an NGO – 'Shashwat'

Pimpergane: tribal women from Ghodegaon taluka beneficiaries of an NGO – 'Shashwat'

Baramati: women teachers from a play center – 'Balsankul'

Patas: young girls from 18 – 22 years' age group

Welhe: women attending 'Jana Prabodhini Gramvikasan' group

Marakal: women attending 'Nari Samata Manch' activities

- 7) Interviews with health care providers (multi-purpose health workers, nurses, and medical professional in both private and public sector).
(22 doctors and 5 health workers).
- 8) We also carried out a knowledge and attitudes study on a sample of 403 randomly selected individuals from the project area. The data analyzed helped us in focussing on the issues that need to be addressed to while implementing the programs.
- 9) We have also used information from some letters written to us by a women attending our clinic describing several issues affecting her.
- 10) At the end of the study before submitting a proposed model we plan to conduct a workshop of different involved agencies to discuss our analysis.

V. Ethical Considerations:

- All instruments used were pre-tested in pilot phases and modified to ensure their cultural acceptability in terms of language, approach and topics addressed. The field workers were extensively trained to use these instruments.
- Informed consent was solicited from all individuals participating in the qualitative data collection phase. After explanation of the purpose of the study the consent form was either read out to the participant or given to read. Written consent was obtained from all. A complete confidentiality was assured and the participant was given absolute choice to participate or withdraw from the study. Those who consented to record we tape-recorded the interviews. The interviews were then transcribed. Whenever possible the contents were confirmed by the concerned person.

VI. The Women:

When HIV/AIDS enters the family and community it immediately affects women. They are in the frontlines of health care regardless of their own sero-status. As the strength of women living with HIV/AIDS to cope with their problems reduces they have to count on someone else to look after them. They become a dependent member at an early age. The dependence is for health, psychological and financial needs. They have to deal with the fear of illness and/or death of their partner, children and themselves. It is so often seen that their major concern is for their children or even paradoxically, for the desire to have more children knowing death is imminent. When women are increasingly being infected with HIV we have to look at the factors contributing to the increased vulnerability of the women. Short and long term prevention strategies must be promoted, taking into account the specific needs of women. New caring strategies need to be developed to meet the needs of women both affected and infected by HIV/AIDS. In order to understand the needs of these women we conducted 42 in-depth interviews with HIV infected women. The basic background characteristics were as follows.

Profile of the sample

Profile of the HIV infected women (n= 42):

As already stated, because it is difficult to identify PLWHA in the community we had to rely on a self-selected sample. The HIV infected women selected for in-depth interviews either came to our clinic or counselling center on their own or through referrals from different sources; or they were contacted through the NGOs working in their areas. However analysis of the background features does give us an impression that the issues presented by them would more or less be representative. Out of these 42 women 30 were referred to us by other doctors and other health care providers, 8 by NGOs, 2 by friends and 2 had come on their own.

Out of the sample of 42 women 32 were below 30 years of age. We shall be looking at their marriage related issues later, but we may note here that all of them were married. Almost 45% (19) were already infected before reaching the age 25. It would also be pertinent to note here that 5 of them were below the age 20. It is seen that HIV epidemic is affecting very young women in our country.

Table 1: Distribution according to age

15-20	5
21-25	14
26-30	13
31-35	9
36-++	1

HIV does not spare anybody, especially women. Awareness about HIV and possibility of avoiding getting infected may have correlation with educational status but here we find that women of all educational categories were infected. This could be because of two reasons. One, the overall literacy rates in women are high in the area where we worked; two, it could also mean that education is not good enough a tool for women as far as prevention of acquiring HIV from their spouse is concerned.

Table 2: Educational background

Illiterate	3
< 4th std.	2
4th to 12th	29
> 12th std	8

Most women were housewives. Being from rural area this also included working in the farms of their own or as farm labors, this is not considered as an occupation. Three worked as domestic servants, 9 had jobs in various capacities (school or college teachers, travel agency operator, lab technician, etc.)

Table 3: Occupational status

Housework	28
Service	9
Maid servant	3
Others	2

The same is the case with economic background. Women from all types of economic backgrounds were infected. However it is, probably, only the vulnerability that is common. HIV disease being a very long drawn process, requiring quite a bit of monetary resources, if not psychologically those from upper economic strata have a better chance of availing the available treatments. Nearly half, even out of this self-selected sample did not have enough resources to manage the investigations and the treatment for HIV disease.

Table 4: Economic background

Extremely poor	4
Poor	14
Middle class	19
Upper middle class	4
Rich	1

As the sample is self-selective it is likely that extremely poor women rarely reached the care providers. However it may be presumed that given the present social scenario their problems would generally be worse than the sample represented here.

We planned to do the study concentrating on the women out of the metropolitan areas of Pune district. Of the 42 women 35 were from classically rural settings, 2 were from small towns and 5 from urbanized centers.

Twenty-seven of the women stayed in joint families while 15 were staying in nuclear and small families.

All of these women were married at least once. We did not have any interviews with unmarried HIV infected women. Most such patients are very young girls, infected because of mother-to-child transmission or slightly older girls infected due to blood transfusions. They have their own issues and problems but we felt these were out of the context of this study. It will not be absolutely correct to say that women always got infected from their marital partners. We know that the issues in pre-marital sexual behaviour are complex and as a few of the cases illustrated the HIV infection was acquired through pre-marital sex. However unmarried girls brought for HIV diagnosis or care is a rare phenomenon. Data from large sized cohorts will be able to throw light on the exact proportions. Our analysis of 700 consecutive cases of HIV seen in our clinic during last 3 years shows that 114 were women (16.3%) and of these only 7 were unmarried. Of these 7, 5 were girls infected due to mother to child transmission and of these 2, one was transfused blood in the past and the other had history of high risk sexual activity. May be they are already getting married before any symptoms appeared. Though people talk and discuss the issue of pre-marital testing only a few are volunteering for the same. So as far as the present data are concerned most issues could be understood with special reference to marriage. It is also not rare women having out-of marriage relationships.

" All the time I was worried about my relation with him, he was from lower caste. I tried to keep everything secret. Having extra-marital relationships was condemned and that too with a man from lower caste was almost criminal."

However in the clinical setting it is neither possible nor desirable to prove who infected whom. It was interesting to note that even the men generally accepted that the infection must have originated from them. There are some different issues as far as discordant couples are concerned and the same will be discussed later.

Looking at the current marital status of these women, 23 were currently married, 15 widowed, 3 separated and 1 divorced. Of the 23 currently married women 4 were between 15 to 20 years of age, 16 between 20 and 30 and 3 were above 30. Of the widows 10 were between 20 and 30 and 5 above 30 but below 40. One woman below 20 was already separated.

When we looked at the cause of death of the partner in case of the widows, husbands of 13 had died of AIDS, 1 due to tuberculosis (probably associated with HIV) and 1 due to some other cause not related to his HIV infection. The age distribution of these women is even more telling. Seven (7) were widowed before the age of 25 and the remaining before 35. This can be seen in the light of the facts brought out by the NFHS-2 which states that the proportion of the divorced, separated, or deserted is small and widowhood is quite limited until the older ages. Forty-three percent of women age 50 or older is widowed. But the proportion of widows below the age 30 in the NFHS-2 has been 2.6 percent.

Looking at the age at first marriage of these 42 women, 25 were married before the age of 18, 11 before the age of 22 and only 5 after the age of 22.

The age of the partner at the time of first marriage, in contrast, was between 19 and 22 in 6 cases, between 23 and 28 in 24 cases, and in 2 cases it was above 28. (In case of 9 the women they could not tell about the age of their partner at the time of marriage.) These proportions are congruous with those represented in the NFHS-2.

These data tell us quite a few important facts.

- Women get married at an early age.
- They get married to relatively older men.
- They get infected with HIV at a younger age.
- They are facing the problems of widowhood, separation, and desertion at a young age. Though these phenomena are not very rare in the society these women have an added burden of HIV infection.

We have tried to look at these data more closely.

Out of these 42 women 38 were married in an arranged marriage, only 3 had had love marriages (i.e. they knew their spouses before marriage). In case of one she was remarried the first marriage was an arranged marriage and the second one decided by her own. This tells us that in arranged marriages there is hardly any enquiry about the health status of the person, discussion about past sexual history is unthinkable. But, even in 'love marriages' the partners did not discuss sexual matters, health matters with each other.

" As soon as completed my 10th standard examination I discontinued my education. Our neighbor's nephew used to visit every summer. I fell in love with him. My parents did not

approve of my relations with this man, who was a rickshaw driver and had studied only up to 8th. I ran away with him. My parents disowned us. I have never met them again."

Why were they tested for HIV?

Out of these 42 women 6 were currently pregnant. Of these 5 were tested HIV positive during routine ANC check-ups, and one was tested because of clinical symptoms. In case of the others 4 were tested during ANC check-up, 4 because of clinical symptoms, 4 after their children were tested HIV positive, and 22 after their partners were diagnosed to be HIV infected. Two were tested during investigations for infertility.

The problems of women detected positive during ANC are complex. They are the index cases in the family. Most often the testing is done without their consent and proper information. Though ideal medical ethics demand that the investigations should be done only if they are likely to be beneficial to the person undergoing the investigation; most ANC testing for HIV, unfortunately leads to exclusion of the positive women from the care. Doctors find it very difficult to convey the results to the woman, the spouse is not around, the parents- if informed - find it extremely difficult to inform her husband or the in-laws. In such situations decisions are taken mostly in ad hoc manner and not necessarily in the best interest of the woman. The health care provider wants to 'get rid' of this patient and so, quite often, does not even provide proper guidance. So often have the women been told very bluntly to just disappear.

" The doctor was not even ready to hold my case paper in hand."

As we have already seen these women are very young. In the Indian culture first pregnancy is an occasion for celebration. Too many values are attached to fertility so that the young girl is in no mood to take any such pressure.

" Abhalach kosalalya sarkhe watle!" (Felt as if sky had fallen!)

" On one hand I felt relieved that I shall not be called Wanz (childless) and would not be bothered by the relatives all the time, but on the other hand I am very much worried about the possibility of the baby getting infected. I think decision to get an abortion (MTP) is difficult but the decision to continue is even more difficult."

" The doctors told me not to breastfeed, but then what shall I tell my mother and my mother-in-law. They don't know anything. The mother-in-law keeps on complaining about these new fads of young girls. 'Amachya weli navhati asli ther!'" (During our times there were no such fancies!) *Now you tell me what can I do?"*

In a hospital which has been providing good obstetric care for many years now, however, the doctors feel that the situation is changing. *" The response of HIV positive patients has changed over time. Previously they used to be very secretive. Now they do not mind to disclose their status in front of students, assistant nursing staff. This change is seen past 2-3 years. This could be because they are being better informed before being referred for obstetric care. They however seem to be very confused about the options regarding the mode of delivery and breast feeding."*

The issue of breast-feeding is also very tricky. Knowing the risk a doctor or a counsellor can not take a simplistic view that " women in developing countries should continue to breast feed." The issue of absolute breast feeding protecting the child has not yet been conclusively scientifically resolved, and it is not practically field studied too. There could be several options to breast-feeding like expressing breast milk and the autoclaving/boiling before feeding, breast milk banking, animal milk and tinned milk substitutes. Unfortunately these have not been studied, their feasibility has not been evaluated, so the costly option of tinned substitutes is being forced on to the women.

The child being an index case in the family is an even more traumatizing experience. The shocks come out of blue, successively and devastatingly. In a typical situation a young child is admitted for fever/diarrhea/pneumonia. By second day it is found that the child is HIV infected. So the parents are tested and at times the other sibling. By the third evening a whole, hitherto happy family, is informed that all or most of it are HIV infected.

It was interesting to note that, despite all these odds all 6, currently pregnant women decided to continue with the pregnancy. This was, of course after they were explained about prophylaxis for prevention of mother-to-child transmission, and all of them opted for it, irrespective of the social status.

Apart from pregnancy there are other issues surrounding marriage. A cross sectional analysis of the data provided important insights.

Three of these forty-two women have had abortions in the past, in case of one multiple. All of these were managed with the private sector doctors. One woman had got an MTP done at a government RH.

There are several problems in the way advice is given to these women regarding continuation of pregnancy. Because of attitudinal reservations most health care providers feel that these women should not have the right to have any children. The whole aura of discussion about population explosion, innocent victims, killer disease, unfortunate orphans surrounds the advice. The health care providers are at times ill informed but well meaning, but at times are extremely exploitative too. We know of women whose pregnancies were terminated in the 7th and 8th month at great expense without informing any of the options.

" The doctor told me that I must have the abortion. "

A discussion with a doctor,

" What about the rates of abortion in HIV infected women? "

"Initially all of them come for an abortion. They have this fixed thing in mind that there is 100% chance that the baby will be infected. Unfortunately 9 out of 10 will decide to continue the pregnancy when explained about the reality and possibility of prophylaxis. "

"Why you call this unfortunate?"

"It is my personal view that these women should not have children. In fact they should be compulsorily sterilized."

Who accompanied these women when they visited the clinic for the first time?

In case of the married women (n=23) 12 came to the clinic with their partner, 2 with partner and brother, 6 alone, 2 with brother, and 1 with other than a family member. In case of 15 widows 3 came with father, 2 with mother, 5 with brother, 1 sister, 3 alone, and 1 with other than a family member. NONE CAME WITH ANYONE FROM THE IN-LAWS FAMILY.

The mother-in-law is a definite pattern in itself. This is a well-established 'tradition', but HIV worsens the situation.

"They started harassing me. They wanted me to walk out. My mother-in law refused to look after our children. She also organized a meeting in the community to throw me out."

"She cursed me because he started falling sick only after our marriage. She made me do all the work. She called me names, insulted me and sometimes hit me."

"I wanted to go home and take some rest but my mother-in-law was reluctant, she did not want to lose this Hakkachi molkarin ('rightfully yours' maid servant.)"

Whom are these women staying with?

Of the currently married 23 women 22 are staying with partner (8 along with parents-in-law.) One is staying with parents. Of the 15 widows only 2 are staying with the in-law families. Four are staying alone, 7 with parents, and 2 with siblings.

Apart from their own problems women are expected to be the caregivers in the family, not only to the husband but also to the in-laws.

"I knew my husband was having an affair with this woman. My children used to call her 'Gori Gori Aai' (the fair looking mother). In the initially years of marriage I often felt disgusted with his indifferent, unloving and callous attitude, but stayed on because I did not want the stigma of being called a divorcee. I cared for him till his death. His brother bothered his father over money matters. So much so that ultimately the old fellow died. My mother in law came to stay with me. I am looking after her now."

Divorce, separation and destitution bring in even different problems. All have their own stigma. The stigma not necessarily correlates well with the cause of the situation. Men get away relatively easily, without having to face much of social wrath but women are not only blamed, but are often more likely to be looked at as objects of desire. A single woman has to take that extra care in the society to protect her. These women become dependent at a very young age. They are not happy at in-laws place nor are they welcome at their paternal home. Their brothers by this time have gotten married and their wives do

not want this woman now with them, as she requires her share of resources. If they come to know about the HIV status the situation is even worse. As, in spite of all the information, they remain worried about themselves and their children. The widespread fear that HIV may spread to others if they washed clothes, cooked food, shared utensils prevents them from working and then brothers family feels that this is an 'unproductive burden'. The issues of property rights also do come up.

There are other issues of violence, abuse and substance use in the families and women have to bear the brunt. There were no women in this group who admitted of substance use by themselves. However of the 42 women 20 faced problem of alcoholism of their partners. Alcoholism has complex links with HIV. It is now established beyond doubt that alcohol influences the risk taking behaviour. Number of sexual partners is more among those who consume alcohol than in non-alcoholics. Safe sex practices are more likely to be adopted by non-alcoholics than alcoholics, especially if the sexual acts are taking place while inebriated. The physical violence against women is directly related to alcohol consumption. It was seen that occasionally alcohol consumption reduced after detection of HIV but more often the worries and tensions of the disease became an additional reason to go on binges. This not only eroded the already scarce resources but also affected the physical and mental health of the whole family.

" He used to bring prostitutes and have sex with them in front of me. I could not say a word, as I was terribly afraid of his beating. I also always thought about our neighbors. I could not seek help from parents, as they were already helpless. He never bothered about any contraception, even when we did not know about HIV. I had 3 children in 3 years. I could not tell him anything then, how could I discuss it now? He has had all types of Guptarog (Sexually transmitted diseases) in the past and has also made me suffer from that."

There are several behaviour-related problems associated with alcoholism, they are both the cause and the effect.

" Alcoholic husbands are very suspicious of their spouse, wife or otherwise. They torture them."

" My father-in-law was a teacher and the family was quite well-to-do in the beginning. But he (my husband) and his brother both developed habits of drinking, gambling and going to prostitutes. Whatever money their father had saved got over soon. But habits don't change."

"He was sober when not drunk, very loving; but when drunk he would beat me, kick me, he did not spare beating even when I was pregnant."

"I felt disgusted with his behaviour. I have to bear the brunt of his drinking. My mother-in-law will always protect him."

" Tu kon vicharnar? Mee paise milwato, mee udawnar!"(Who are you to ask me? I earn money; I shall spend the way I like!)

" Even today the grandfathers and great grandfathers in our area are having extra-marital affairs. It is in the soil. These things are not considered bad as in other places. The men get away but the women do not have the liberty to behave like this. Women can not make any noise about this. Now, if grandchildren see their grandfathers do something then they do not feel wrong if they have their own keeps and affairs."

Dowry related violence and abuse is also a part of women's lives. In-laws who did not know about the HIV infection continued asking for more money from her parents, and when they came to know about the infection the need for resources even increased further. In case of widows the in-laws rarely provided financial support.

The abuse and violence against women also takes several forms. It has both the face-domestic violence and social violence. From our small sample of 42 women we could see that 32 almost 76 %)of these had to face beating, kicking, slapping, using foul language, demanding extra work, mental torture by refusing sex, refusing money, having sex with other women at home in front of her, rape, molestation, incest, etc.

We take a look at the data regarding the disclosure. To who is the fact that she is infected disclosed?

It is seen that in case of the 23 married women only 6 have disclosed it to the in-laws, 3 to parents and rest have kept it to themselves. In case of the widowed 12 have disclosed it to parents and 10 to the in-laws. Overall, of the 42 women, in case of 18 the parents are aware and in 17 the in-laws are aware. However the support provided is not the same. Of the 18 parents who know 16 are ready to provide financial support to the best of their ability while in the case of the in-laws only 3. As far as the psychological support is concerned 17 parents are readily providing support as against only 4 in-laws. Those who have disclosed to others like siblings, other relatives, and friends have generally got very good support. In fact the decision to disclose must have been taken after careful consideration of the situation.

It was however obvious that HIV demands a lot of psychological support and financial resources too. HIV creates a lot of psychological problems. There is denial, anxiety, depression, anger, resentment, absent mindedness, frustration, fear, phobia, obsessive compulsive behaviour, sorrow, grief, suicidal thoughts, violence, mania, forgetfulness, detachment, dissatisfaction, revengefulness, anguish, frustration, confusion, unhappiness, guilt, blame, shame, oppression, despair, acceptance, and so on. Management and care of HIV positive women and men can not be seen in totality without realizing that the disease occurs in this atmosphere. The health providers not only need to be aware of this but need to be equipped to deal with it. The ground reality is, however, that we are not at all geared up to face this challenge.

What about safe sex practices?

Of the 23 currently married women 13 said they are following safe sex practices. Of these 10 couples are using condoms and 3 'no sex' practice. In case of 3 couples not practicing safe sex there is very strong correlation with alcoholism of the husband. Those using condoms have got used to it. The overall sexual activity reduces, there are in-built tensions in the relations. When both partners are infected the issue is discussed more openly among the partners as well as with the counsellor or the doctor. The situation is more complex in discordant couples, as we shall see later. There are also problems with the 'no sex' option, even if it is mutually agreed to. If the decision is being forced by one onto the other it creates tensions.

" He is more of Aadhyatmic type. So he has decided he would control himself. He sometimes gets upset but controls himself. For me? It is very difficult. I get very upset when the desire comes up. I get headaches, my body shivers. It takes very long to cool myself down."

" Whenever I told him not to have sex he abused me saying I must having a hidden lover satisfying my needs."

A positive husband in a discordant couple literally pleaded, *" Doctor please tell her that there is no risk in having sex using condoms."*

"There are hundreds of people at home, and our home is not very large. There is so much lack of privacy that we hardly used to meet and talk. Sexual relations occurred only occasionally in such a situation, but I can not enjoy them"

The problems are not completely solved by suggesting use of condoms. There are several hurdles starting from awareness, promotion, availability, distribution, quality and cost, actual use and negotiation for sustained use. There are also several misconceptions about the pleasure in sex being reduced by condoms.

" Government distributes the condoms free of cost and probably thinks couples are using it but may be they are more used in sonography clinics than in bedrooms! (Laughs)"

"The quality of condoms provided by the government is very poor. The commercially available ones are costlier than the government supply. If I were to use the government supplied condom I would not feel safe."

"Even the doctors spread misconceptions about condoms. A doctor told in an awareness program that the virus is so small that it will pass through the rubber. He wanted to emphasize that people should not have risky sexual behavior but was spreading a wrong message by saying that avoiding sex is the only answer."

"The health workers, sisters feel shy talking about condoms and they do not distribute. People do not ask for them. If distributed children are found playing with them, making balloons."

" It is not enough to just inform about condoms. Many people will not know how to use them. You will have to demonstrate."

" The condom use in red-light areas has definitely gone up. The number of patients with STIs has reduced dramatically. However the efforts need to be sustained. We interviewed a few young men in the red light area. We asked them if they knew about HIV and about condoms. They rushed towards the brothels brushing us aside, saying that was not the proper time to discuss about condoms."

Many of the issues are related with available information. From where the information is acquired?

The radio and television are the most important sources. Newspapers come next in the line. Most felt that the television serials are glorifying or glamorizing the promiscuous behaviors. The total commercialization, the way women are looked at only as objects of desire, the way their status in the society is portrayed all is causing a lot of damage to women's live. The print media are also not less irresponsible. Things in print are remembered for a long time. The neo-literate almost believes that anything in black and white is like a gospel truth. There are no good films, novels or other literature that would discuss the issues in a humane way.

What about the treatment of these women?

Most women from our sample were infected recently. The correlation between their age and age at which HIV was probably acquired is almost linear. As seen from the data only 5 were tested due to their clinical status. Remaining 37 were all asymptomatic. Of the 5 clinically symptomatic 4 were above the age 25 years. So most young HIV positive women probably had long symptom free years ahead of them.

In contrast, most women felt that this was an incurable, invariably fatal disease. They also felt that once diagnosed they were going to die very soon. Invariably the first question that most women (and men too) asked was, "how long I am going to live?" In our fear based approach we have created this myth. We have not informed the people that there is a long gap between infection and death. Which means at least in case of the women there are long years of asymptomatic life ahead. This myth is strengthened by the information that there is no cure. We have confused between "no cure" and "no treatment". Aren't there so many other diseases, which have no cure? Do we not treat patients with other incurable diseases? Then why ostracize this disease? Even the message " hate the disease not the patient!" is wrong in this context. It still reinforces 'our' agenda that this is a disease that needs to be hated, because it is acquired through behaviour, which 'we' do not approve of. Is not each and every disease which brings ill health not hate worthy? The misconceptions are all pervading. **The patients think they are going to die; the family feels it is not worth caring for them; the society feels it should not spend resources on these people; the doctors feel given a choice they would not have treated them, the governments feel (or have felt in the past) that HIV should not be a priority.** However, once these patients and their families are counseled their fears are usually laid to rest and then the response is usually very positive.

It has been now proved beyond doubt that even if only the opportunistic infections are treated adequately, aggressively and promptly the quality (and quantity) of life definitely improves. If the counselor is empathetic, the doctor is caring and the hospital atmosphere humane the patients do very well.

" Ya hospital madhye manuskee, mayecha olava milala jo itaratra disat nahi!"(The humane attitudes, and warmth of care seen in this hospital is not seen anywhere else.)

"We had to do a lot of financial adjustments to get the tests done and start treatment. We sold a buffalo, some soybean and rice to raise the money. Even if we are required to sell some of our land we will do it for her treatment."

Fortunately the costs of the anti-retroviral drugs are coming down very fast. Though still quite costly more and more people can now afford the treatment.

The treatment seeking also needs to be seen in light of several alternative medicines offered. Of the 5 already symptomatic women 3 had tried some alternative treatment or the other. Of these 2 had taken the very famous and costly treatment from Ernakulum, Kerala. They told that when they reached there they saw long queues. People have described travel agencies running regular bus services, carrying 'thousands' of people there. This is not only a sheer waste of resources but playing with lives of people. From community perspective this is playing with fire. As these promised cures and fake reports infuse a sense of false security in the minds of people who are likely to indulge in unsafe sexual activities again, if not outside definitely in marital relations, we have known people getting married because they were 'certified' to be cured. The question is not of 'a Majid.' Sensing this potential now there are such exploiters in every nook and corner. PLWHA, in a 'mad' hope to get cured keep on running from pillar to post. The media have played very irresponsible and irrational role in all this. Just because they want the revenue from the advertisements they say that the correctness of the contents of the advertisements is not their responsibility. They don't even confirm the claims before publishing news items and press releases. To site a recent example; there was this news from Ahmadnagar which claimed that even National AIDS Research Institute (NARI) has accepted their claim. For the first time NARI came out with an explanation later that this acceptance only meant that NARI had received their letter. Neither the claims were verified nor authenticated. Such explanation has little value as rumors spread faster than the news and PLWHA already start thronging these places. It is not to say that there will be no medicines in alternative systems but we definitely need to have better systems of testing the hypotheses and controlling the rumors doing the rounds.

VII. The Discordant Couples

When both the partners, in a marital relationship are HIV infected the reaction patterns are complex. The situation becomes even more complicated if only one of the partners is infected. These are called the discordant couples. There are two types, either the man is infected or the woman is infected. The complexities dramatically change depending upon the patterns. It was our observation from sample that the situations are rare. In most cases both partners were infected. We could interview only 6 women in discordant couples. Three each, from the two types of discordance.

Woman not infected

The 3 women whose husbands were infected were 21,23 and 55 years old.

In case of the 21-years-old, her husband knew at the time of marriage that he was HIV infected. He in fact told her about it, but she was so ignorant that she did not understand anything. He hailed from a very rich farmer family and also owned a wine shop.

" Money was no problem. He used to drink regularly. As the youngest son was always pampered a lot at home. His is a very large joint family. He had heard a lot about stigma attached to HIV so did not want to disclose it to any body, except to her and his elder brother. I ask him often- why at all did he marry? He says because of pressure from his family. We are married for 2 years now. The pressure to have a child is mounting. We are using condoms, but my mother-in-law is blaming me for not having a child. We can not tell her anything. There is a lot of harassment. We are also asked to visit different doctors to solve the problem of infertility. I also want a child desperately, but am not ready to take slightest risk of my child getting HIV from me." At times the pressure and harassment was so much that she considered getting divorced, but she understands the additional problems that she will have to face as a young divorcee. Her husband took to heavy drinking as a means of reducing the pressure and that has added to her woes. She says, " I am totally entrapped. My existence is meaningless. I see no hope from the future."

The 23-years-old woman is already married for 8 years and has a 7 years old son. Her husband was detected HIV positive during a pre-operative check up for the treatment of his kidney stones. She felt her husband was infected due to un-sterile injection needles. Her husband is a waiter in a hotel. He used to consume a lot of alcohol but has completely stopped ever since he came to know about the HIV infection. They have told the fact only to her brother, who has been very supportive. After the birth of her first son she has had 3 natural abortions. They have been using condoms now. Both of them were extremely scared, depressed and anxious initially. It took a while for them to get over the shock, but after repeated counselling sessions and with good support from their doctor and counsellor they now felt much more optimistic. He became more responsible, more communicative and more caring. He said, *"I would have felt miserable had my wife and child been infected because of me."* She occasionally felt sad and scared, but did not have anyone to talk to.

The 55-years-old woman has been married for 31 years. It was an arranged marriage. They do not know how he got infected. It was 6 years ago, when he was admitted in a hospital for prolonged fever, extreme weakness and severe weight loss that his infection was detected. It was a great shock for both of them, very, very difficult to accept. They did not know whom to talk to since her husband was 65 years old then. They felt it very awkward even to discuss with their doctor. They were worried that even the doctor might think that he was promiscuous. Their children were grown up, but they were also not told, they did not want any misunderstanding. She went through the feelings of shame, anxiety, fear, guilt, doubt and confusion, financial worries, persecution. She felt, she had to bottle up her emotions. She became impatient, irritable and depressed. She started getting recurrent headache. She at times felt like *rushing to the bathroom and holding her head under cold running water*. She knows that their doctor has never blamed her husband for anything, he would certainly talk to her but never could gather the courage to do it. It was for the first time that she ever let her emotions flow, she certainly felt better after 6 long years. She also specifically mentioned that she was so comfortable because she was absolutely confident that the confidentiality will be maintained.

To summarize:

Uninfected women in discordant couples

- Do suffer from tremendous psychological stress,
- They also have to suffer harassment if the family, especially the in-laws family, is not aware of the infection,
- A good psychological support and counselling is needed, at times they may need treatment for psychological problems,
- Perceived threat of stigma and discrimination, and also possible breach of confidentiality (even at the hands of health care providers) prevents them from accessing support, which is any way lacking to a large extent,
- Issues of fertility, contraception, safer sex, disclosure are complex and difficult to solve without good and continuous counselling support.
- The issues of safe sex practices are important but assume secondary position in the discussion. The men do demand sex, but women do feel scared to have sex, do not enjoy it, even when condoms are used, as the fear of imminent risk of infection always lurks in their minds.

Woman infected

Women in this group were 20, 35 and 42 years old.

In case of the 20-years-old woman it was their son, who was diagnosed to be HIV infected. He died in a hospital of severe pneumonia. She was tested after that and her husband was not infected. She had had sexual contacts with a neighbor when she was just 15-16 years old. He had ditched her later. She had not disclosed this to anybody. She had also forgotten everything. She occasionally felt like disclosing this to her husband after marriage but never did, out of shame, guilt and fear of losing the confidence. However

the most traumatic part was when a counsellor in a large hospital made her confess all this to her husband. He found it very difficult to digest and abused her. It was his sister who dissuaded him from disowning his wife. She herself passed through a torrid time. When he saw that despite his anger and abuse she was extremely caring, he came to terms with the situation. He, however, desperately wanted to have a child. She was ready to sacrifice anything for him. They thought of several options including artificial insemination from her husband, when they came to know about preventability of mother to child transmission. With the help of a gynecologist she tried artificial insemination a couple of times, which failed. By this time they had understood the fertility cycle. They decided to take a chance with unprotected intercourse at the time of ovulation. She conceived, he was not infected, she was put on AZT prophylaxis. She delivered a healthy uninfected child.

In case of the 35-years -old woman it was a blood transfusion and in case of the 42-years-old an unknown source of infection. Husbands of both were extremely caring. Both couples have not disclosed it to anybody. Husband of the younger of the two is an engineer, has political and social background and is from a well reputed, rich, conservative, very large joint family. They have excellent communication with each other. It was difficult to digest the thought of HIV when it first struck, she was in such a bad shape that he did not want her to be told. In fact she was tested without counselling and consent. As finances were no problem she was put on multi-drug anti-retroviral treatment. She recovered gradually. She used to curse and abuse her doctor for prescribing so many medicines. In one of the follow-up visits she asked her doctor about how long the medicines were to be continued, to which he answered- lifelong. After going home she read her medical records. She was terribly depressed. When she confronted her husband he was shocked, he was taken aback but then felt much relieved as he wanted to do it sometime. When she realized that she was recovering very well from the illness and drugs was her only solution she started adhering to the treatment even more religiously.

"HIV has changed my life in more than one way. It has strengthened bonds between us. In our family women are not supposed to go out of the four walls, but as all are caring for me- they have been told that I suffer from lung cancer-they allow me to do anything. I go out to the office, I wear Punjabi dress, I travel with my husband. I am freer now. If I had had no problem, I would still have been confined to those four walls." Adjustment to safe sex has been taken care of. Both of them want now to take part in social work, especially related to HIV awareness.

In the third case also the husband is very caring and sensitive person. For his own problems he regularly attends counselling sessions. The two have very good communication.

These three cases where the woman is infected are in a way unusual because the reactions of the husbands are more or less very supportive. We have heard of many cases where infected women were thrown out of the families. Both the key informants and focus groups have emphasized the fact that the inferior status of the women in the society makes them more vulnerable to both acquisition and the effects of HIV infection. The

sexual partners, who are not infected, have to make several choices regarding their sexual life, children, resource allocation, dealing with psychological pressure, etc. Men in a patriarchal society will behave differently and would have a different set of expectations about love, caring, etc.

To summarize from our data:

- Men in discordant couples faced a lot of stress needing tremendous amount of counselling support. The anxiety about the men's reactions was an additional burden for women.
- Men from our group were all from financially well off backgrounds, which could be another factor.
- It is also possible that HIV infection getting detected at a relatively later date in marital life can change the reactions. If HIV infection gets detected very early in the course of married life the reactions may alter.
- The issue of safe sex in this situation is generally resolved in a different way. There is more guilt about not being able to satisfy 'his' needs, so whatever he says is agreed to. Men seemed to be more confidently convinced about the efficacy of condoms. It is possible that men found out alternative partners for their sexual needs.

VIII. The affected

Some people make this distinction between the 'infected' and the 'affected' individuals. We feel this distinction is not very perfect, as the infected individuals are the ones 'primary affected'. The spouse could be called 'secondary affected' and the others who have come to know about the infection as 'tertiary affected'. The spouse, apart from other problems has to deal with sexual needs and the problems are more complex. The tertiary affected persons are generally those, who are involved in providing support, psychological and monetary. Their reactions may be providing positive or negative feedback. We hear stories about discrimination, stigma, and harassment. Such episodes were narrated by many during the focus groups and also by the key informants. Interviews of the tertiary affected relatives who reached a doctor or a counsellor to seek more information are thus definitely biased yet we summarize here the data from interviews of 7 'tertiary affected' relatives.

There were 3 mothers, 3 brothers, and a father. It is worth noting that we do not have interviews from the in-laws families. It does not mean they never accompanied patients to the clinic. Their role in care, however, always remained peripheral. Mostly mothers-in-law came when issues about pregnancy were settled. Occasionally fathers-in-law came, generally when their son had already perished because of HIV. They always expressed a detached feeling about the proceedings, none of them agreed to interviews. They were always more concerned about the health of their son's health and mostly looked at the problem of the daughter in law as a matter of duty than of concern. It could be that they were a bit worried that they may get blamed for the situation.

The various components that emerged from our interviews are:

- Guilt: In case of arranged marriages the parents feel, they are primarily responsible for the fate of their child, especially the girl child,
- Fear: they might get infected, if they have a patient at home (especially a woman - she cooks)
- Lack of resources: "*I will do everything to help my daughter except offering money. I do not earn much and have two more children to support.*"
- Anxiety: About ones dear persons fate,
- Anger: against the in-laws family. *It is their son that gave this disease to my child, and now they do not look after her.*
- Helplessness: in the matters of marriage, treatment meted out at the in-laws place, lack of care and support, lack of resources,
- This helplessness cut across the spectrum of education, economic status, social status,
- Expensive marriages: most resources were spent on the marriage leaving behind debt, now how to pay for treatment,
- Managing pregnancies: especially HIV being detected during ANC, also the problems that many doctors at periphery do not manage pregnancy with HIV. There are also issues of testing without consent and counselling and attitudes of health care providers. Traditionally the woman is with her parents for the first delivery. If she

gets detected HIV positive the whole issue of partner notification and his testing becomes very complex.

- Wasteful expenditure: on unproven medicines,
- Misconceptions about mother-to-child transmission: *"If both parents have HIV then child will definitely have the infection. If only one parent is affected there is only 50% chance."*
" I was told that after delivery baby can stay with the mother but I started sleeping with the baby, so that my daughter may not touch her."
- Secrecy and decision-making: taking decisions about treatment without informing the infected person about the status.

IX. Their stories

Katha 1

BP, 28 years, B.Com. Works in a bank. Nuclear family consisting of husband and son. At present she has called her mother to stay with them especially for their son. She comes from a middle class family. She has mother and an elder married sister who is very close to her. Her's is a love-marriage. She underwent curettage in 1994 in a hospital. The conditions there were very unhygienic. When she was pregnant, during ANC she was asked to undergo test for HIV. She was reactive. So both of them got tested and were confirmed to be having HIV infection. Both of them did not have any clue as to how they acquired the infection. Both of them were shocked and very much depressed knowing about it. They knew very little about AIDS, so they searched for more information. She told her sister about it and took her in confidence. Her sister was a science graduate. She also took keen interest in knowing more on HIV. They decided to go in for an abortion, but she already had completed 5th month of her pregnancy, so abortion was out of question. They decided not to disclose their status to his parents and her mother, as all of them were old and had some health problem or the other. Also his parents were very traditional and old fashioned. They felt that the parents may not be able to understand the problem and would react in a negative way. Both had deliberately decided to stay away from his parents in order to avoid clashes, as they were certain about his parents' difficult nature. Her sister introduced her to Dr. XX for his guidance and advice. They discussed about the possibility of prevention of MTCT and started with AZT prophylaxis for BP. She underwent an elective cesarean section had a son. She did not breastfeed her child. She did feel deprived but she was very concerned about her son. Her son was tested when he completed one and half years and he was not infected. Both of them were very happy. Throughout their marriage both shared very good communication. According to her they were more like friends to each other than husband and wife. She always had her sister's, and her husband's support. Initially when they came to know about HIV infection during her pregnancy, they were under lot of tension. They were very worried as to what would happen to their child if they die of AIDS. They wanted to avoid their native place for her delivery, as his parents would have had questions they wanted to avoid answering. So, her sister took her to her house in her last trimester and looked after her. Her sister asserted that they would look after her child and in case of any mishap would not hesitate to adopt the child. She was relieved of her anxiety regarding her child. She felt indebted to her sister and her husband, but they assured her not to feel so. Her brother-in-law was equally supportive. She felt that she has gone through tremendous change due to HIV. She became very mature, understanding. HIV infection increased the communication between the couple. They supported each other and came still closer. She felt 100% confident about her husband that he did not get the infection through sexual relationship. She felt very angry and depressed for months together and found it difficult to get over the negative feelings. Having a child made a lot of difference in their life. She considers it as a blessing that her son is negative. She was also very particular about her doctors. She had seen one doctor who spoke about how stigma has to be removed, and he himself

asked his domestic servant to quit the job when he came to know that her son expired of AIDS. He also refused to give certificate of death. She started reading all the news items on AIDS and listening carefully if people talked on that subject. She feels incidence of deaths has increased in their area but awareness has not increased. Awareness programs are conducted only in schools and colleges and majority of the population is left out. People have very strong negative attitude about HIV infected people and they gossip about sexual behaviour of infected people. She feels infected individuals have a need for counselling and good counselling can make qualitative difference in standard of life of HIV infected individual. She keeps herself very busy. She expressed the wish to join the group of infected individuals to share her problems with them and to seek support, provided the confidentiality is taken care of. She also expressed the wish to help other HIV infected people, especially women. She feels her current job takes most of her time, so she would like to leave it one day in order to have spare time for her hobbies. She also wants to spare more time with her son. She likes to read. Sexually she felt they were always compatible and enjoyed very good sexual relationship. At present, they regularly use condoms. It was tiresome in the beginning but later they got adjusted to it.

Katha 2

Mrs. MD, 35 years, B.Com. and Mr. DD, 40 years, (engineer). Married for 12 years, arranged marriage. Joint family of 30 – 35 members. Very well reputed, rich conservative family, but education is considered as very important and is encouraged. “*KHANDANI, SUSANKRUT*” (from a traditionally well-cultured family). He has been involved in social and political work. He is also a member of the local *Grampanchayat*. Wife is also from very rich and reputed family. She is the youngest of the children and only daughter after 3 sons, so all the family members pampered her.

Both got adjusted very well with each other. They could not spend much of time together in the joint family because of having too many people around all the time and also because of his varied social and political interests. Also it was not a custom in rural area for a couple to go out together for a stroll. They used to compensate it by visiting various hill stations or by often visiting Pune and Mumbai. Her wife used to be involved in all the day to day activities at home but used to get bored, as she could not put her education to use. She often used to request him to involve her in his office work but he said that traditionally it was not allowed for the woman of xxx household to go out of the threshold. They were supposed to be covered from head to toe. His wife used to find it oppressive. He could not think of breaking the tradition but considered her request and decided to start women's group for her. Health wise she was not keeping well. She had pneumonia and she was anemic also. So she was given blood transfusion in 1996. Their family members gave her blood and said it was directly transfused to her. She was given various medicines and injections but that did not improve her health and she was not keeping well. Seeing her symptoms, the treating doctor asked him to get her tested for HIV. No pretest counselling was done and she was tested without her knowledge and

consent. She was detected reactive. At that time she had become very ill. One of his close friends, who knew about the test, advised him to go to Dr. XX at Pune, as the friend had sent HIV infected individuals to him who were doing well. She was admitted in a hospital for the treatment. Various tests and procedures were performed for her illness. She was re-tested for HIV for confirmation. He was also tested and he was detected non-reactive. Her reports were not disclosed to her immediately because of her ill health.

He was shocked to learn about her HIV reports. He had heard about AIDS and had known about the routes of transmission but he never had had any doubts her sexual behaviour. He decided to ignore the mode of transmission and concentrated more on improving her health. They immediately started the anti-retroviral drugs as they could afford the cost. Gradually she improved, gained weight and started feeling better. He had disclosed her serostatus only to his uncle and a friend. He was not sure of the reaction of the family members so he decided not to tell them. His uncle also was shocked, when he came to know her serostatus, but he also agreed to keep the news to himself. She had to take a lot of tablets and suffered from acidity, nausea, vomiting and she was taking time to get well. She used to get very annoyed with the doctor who was making her take so many tablets. One day he told that she had to take them lifelong. So, she was very depressed. She went through the reports and came to know she was HIV infected. He had told his relatives that she was suffering from lung cancer. Her first thought was, "what is the use of going on living?" She became very upset. She did not want to take the tablets throughout the life. She did not know much about HIV / AIDS except that she had contracted a dreaded disease. She could not face the people, felt like avoiding them, so she cried a lot. When he came to know that she had read the reports he was taken aback. He was very worried for her. But then he felt much relieved, because from the moment he came to know about her reports he was under tremendous pressure. *"Manantlya manat kudhat hoto kee tila kase sangayache."* (I kept on thinking all the time, how to tell her!) He constantly felt that he was hiding the news from her. So, on one hand he wanted to protect her from the bad news and on the other hand he wanted her to know. Also he felt that doctor should prepare the person before sending the person for HIV test. It should not come as a shock. He also expressed that the doctor should break the news to the infected person as soon as possible and should give support and help. Instead of talking only about modes of transmission the doctor should talk about new drugs, possibility of prolonging the life and how one can manage the illness effectively. He felt that the first doctor never thought of these things and he just asked the test because according to him HIV test was necessary. The second doctor talked to him about all the issues. So with that information he could talk his wife out of depression and could encourage her to take medicines regularly and she gradually got adjusted to treatment. He spoke very positively about his experience with the hospital. He spoke of his experience with one pediatrician who was their family friend, who after knowing his wife's HIV status started avoiding them. He expressed that instead of having separate hospitals for HIV infected individuals they should be accommodated in the general hospitals to avoid stigma and discrimination.

He tried to be more sensitive to his wife's need. At home family members thought that she had lung cancer so they became very cooperative and encouraged her to get herself involved in the activities of her interest. He helped her to start a woman's group.

Initially he felt very depressed and sometimes irritable with all the pressure he had to bear with. He also felt frustrated regarding his sexual needs and found it difficult to get adjusted to not having sex with his wife. He was apprehensive of condom failure. He consciously decided to avoid even thinking about sex and concentrated more on religious rituals to divert his physical needs. He avoided physical proximity with his wife as much as possible. She also felt very frustrated and irritable as she was deprived of sex. She used to get irritated with him. He managed to pacify her by telling her that they were nearly forty years old, had their children and enjoyed good sexual life for twelve years, so it was time for them to change their priorities and concentrate more on their children and other activities.

Both of them wanted to get involved in social work especially for HIV infected people but did not dare to directly start anything for the fear of identification.

He felt HIV infection made him more understanding and patient. She felt her nature underwent change in terms of being less irritable and impatient after having HIV. Their communication increased in terms of quality. Both of them felt the need of counselling and expressed that counselling provided by their doctor has helped them a lot to cope up with their fear, anxiety, depression and frustration. He feels that Government should take definitive steps to help HIV infected individuals in terms of offering counselling services and reducing the cost of medicines. The awareness programs are only focused on prevention. Something needs to be done for already infected individuals instead of making them more fearful, the programs need to be focused on talking about support and optimistic future regarding treatment on HIV. People should be made aware of needs of infected individuals. The general belief that HIV infected individuals are of bad character needs to change. He felt that media especially TV serials on various channels are responsible for giving glamour to extra-marital sex and young generation is getting affected with ideas projected through these serials. Wealth does not necessarily affect behaviour in a negative manner. Education can be a positive factor in terms of awareness of HIV / AIDS as educated people can have the choice of getting right information on prevention.

Initially they were worried about spreading the infection to other family members. Now they are sure that infection can not be spread easily. She has improved quite a lot in the last one and half years, physically and emotionally. She has become stronger than before and only occasionally she felt depressed and sad. Sometimes she feels guilty when people at her home talk about AIDS. She feels she is having that disease and is hiding it from her own family members. She has stopped thinking about death and is concentrating on enjoying her present as far as possible. He has decided to spend his life in social work, especially related to HIV / AIDS.

Katha 3

MS, 27-years-old, slum dweller, from a suburb of Pune, 4th Std. Poor financial background. Husband is an electrician who earns approximately 2000/- per month.

She was from upper caste family who used to stay in one of the suburbs of Pune City. She was not very good in school so she dropped out after studying up to 4th Std. She belonged to a poor household and did not have father to support so she had to help her mother in her work as a domestic servant. She was married to an older person from her own community. It was an arranged marriage. She was 16 years at the time of marriage. They shifted to a village after marriage where he used to work as a RTO agent and also used to do some odd jobs on contract basis. He never told her much about his work or salary.

Within first 2 years she conceived and had a son. First two years of their marriage were comparatively better than afterwards. During the initial years of marriage she was suspicious of his behaviour. They used to have quarrels as he used to drink and come home very late. If she protested about his behaviour then he used to get very angry and beat her up. They did not have much of communication, as he did not care for her. Gradually his drinking habit increased. He used to give very little money in her hands, so it was very difficult for her to manage the household expenses. Her mother used to feel very bad about her and her son; so she used to help her financially. But she had her own limitations.

He used to have lesions on his genitalia, so once she tried to confront him for his behaviour. He was drunk at that time, he beat her up and told her it was none of her business if he chose to sleep with hundreds of women. He told her that he was earning his own money and had every right to spend it as he wished. She had no right to ask about his behaviour. Then he bragged about his various affairs and how he was a “man” who needed several women for his sexual appetite. He told her that she was not enough to satisfy him so he was keeping other women.

He used to beat her black and blue. She suffered from reproductive tract infections often for which she took treatment from private doctors near her mother’s house. Whenever she used to be sick she used to go to her mother’s place for rest and for a change from her miserable life with her husband. She never received any support from her in-laws as he never got on well with them and they never bothered about them. When life became too unbearable she left him and went to stay with her mother. There she started working as a domestic servant and supported her son. Though she left her husband of 5 years she felt that she had made a right decision as she was happier with her mother, even though she had to work hard at other people’s houses. She had no wish to think about other men or marriage as she had very bad experience with her husband. Gradually she got over that experience but frequently she used to think about what was she going to do in her life. She got introduced to an electrician who was working at the place where she worked as a domestic servant. He was sympathetic towards her and liked her. She was attracted to him but he belonged to a lower caste. So she did not think about marriage. She told him

about her first marriage and her son. He did not mind that. He proposed to her but told her that he could not manage to look after her son and his mother would not accept her son. She was in a dilemma. Her mother assured her that she would look after her son as she thought MS was young and deserved some happiness. So despite the caste difference she gave her permission for marriage.

MS got married to RS and came to live with him. Her son remained at her mother's place. She visited him occasionally and he also got adjusted to her absence. RS was a much better husband. She was happier with him. Her new mother-in-law used to stay with her three other sons in Mumbai. She was an old woman who accepted her son's marriage to a divorcee with some reservations. She used to visit them and occasionally stay with them. After two years of their marriage she conceived. During her ANC the doctor tested her for HIV. She was reactive and was re-tested for confirmation. She was asked to call her husband for the test. She was shocked to know about her HIV status as she had heard about it. She knew that people die of AIDS, so she became very worried for herself, her unborn child and her husband. She knew that her first husband must have been the source of the infection. She was counseled by the social workers of the hospital but they wanted to inform her husband. She was sure that her second husband will not be able to take the shock and if her mother-in-law came to know about it then she would ask her to leave their house. The counselors at the hospital advised her to get an abortion done. That was out of question, as her husband and her mother-in-law were very happy when they came to know about her pregnancy. For abortion she would have to tell her husband the reason for the abortion. Therefore she decided to continue with her pregnancy but she was under tremendous pressure, as she could not tell her husband about the infection. She could manage to go through the ANC and delivery with the help of her mother and her husband did not know anything about her positive serostatus. She was told not to breastfeed her baby son to avoid transmission. She managed to give some excuse to her mother-in-law, who came to stay with them after her delivery. Her mother-in-law was so happy to have a grandson that she took charge of the baby. MS was trying her best to avoid being with her son as she felt miserable about not being able to feed him. She worried about her elder son also. She thought that there was no one who would take care of him after her and her mother's death.

She was very worried about her husband demanding for sexual contacts. She felt that after 2-3 months of delivery her husband would ask for physical relationship and she did not know how she was going to say no to him. She was already feeling very guilty and ashamed that she already might have passed on the infection to her husband when she did not know about it. If not after knowing about it, it would be criminal. She felt very sorry for him, but could not find any solution. It was becoming very difficult to leave the house for the doctor's visit as she could not tell why she was visiting a particular doctor who is dermatologist and a HIV expert. MS felt that she had no right to live if she infected her husband who was like a God to her. (*To agdee Devmanus aahe!*) But then she thought that she had to live for her small son. If she committed suicide her husband would be in deeper trouble. So she was extremely upset and had no other thoughts other than HIV. She constantly worried for her newborn son who was underweight and was falling sick. Off and on. She used to worry about him to such an extent that once when she came back

home from somewhere and saw crowd near her house she immediately thought that something had happened to her son and because of that fear and anxiety she fainted on the road. When she came to senses she realized that the people had gathered at the house because of one minor accident and people were just onlookers.

She decided firmly that instead of living under so much pressure and thinking about death all the time she would take life as a day at a time. She decided to inform her husband only when it became absolutely unavoidable. She would cross the bridge when she came to it. The counsellor put forth all the possibilities and alternatives in front of her. They discussed the possibilities at great length with her. She motivated her for disclosure to her husband. But she was firm on her decision. She said, "*Aajach maranyapeksha udyawar maran dhakalata aale tar pahate!*". (Instead of dying today I will try to postpone it to tomorrow!) The counsellor suggested her to take up some course in order to be independent financially in case she needed to do so. She thought about learning to sew. She decided to take her husband and her son for HIV testing under some pretext after a few months.

She requested the counsellor not to intervene as she was already under pressure. She discontinued the follow up that was suggested by the counsellor, as the social worker insisted on partner notification. MS felt very threatened by the counselor's stance. She sought help from another counsellor who assured her of confidentiality and suggested her to keep a regular follow up.

"Devani mala sukh dile, pan sukh mhanaje kay te kalayachya aatach dukhat lotale. Itakya varshani kahitari bare zale ase wateparyant aabhalach kosalale!" (God gave me happiness but before I got the proper taste of happiness again pushed me into the grief. After all these years I thought that everything became fine and suddenly I felt like the sky had fallen on me.)

She looked very pathetic and helpless. She expressed a lot of anger towards her first husband who gave her HIV infection. She cursed him for spoiling her life. (*Maaze shaap tyala lagoodet.*)

X. From the letters of a friend

This is a 30-years-old lady. She is not included in our sample. She is also not a patient. In fact her husband died of HIV under a doctors care. She is not infected. These are excerpts from some of the letters she wrote to the doctor whom she treated as her friend. She is post-graduate and is working as a professor in a rural college.

"Just because he got infected he was declared guilty, but I don't think that all those who are not infected are as if very faithful, monogamous Ramas. Secondly, I am sure that since I came into his life he was faithful to me. If anything had happened before I am not aware of. I have not tried to inquire also. While marrying if I accepted someone with his strengths and weaknesses I cannot leave him just because he is HIV positive."

"Dear doctor, though you suggested to me many times that I should take a practical view about the situation, I did not. If we start looking at our life with our partner practically then what would be the meaning of love and relations?"

"I am a rural girl educated in a small village. My childhood passed like a butterfly. We were a lower middle class family, but were very rich as far as good moral values. I was intelligent and was doing well in the school. My father allowed me to learn further and go to college. My expectations from life were not very far fetched. They were just like those of a rural girl. But I was fortunate to get good education and a good job too. I got married to S. He was well educated, smart, handsome man. He had a good job. He was 6 feet tall and had curly hair. I felt as if I met the prince of my dreams. He was very sensitive and considerate. We got two sons. We had excellent communication. We treated each other as friends and not like spouse. We were so happy that anybody would envy us."

"When we came to know about his disease we had decided to commit suicide. But my two kids and myself were not infected. And we got tremendous support and encouragement from you to live on. Secondly, we were not worried about our lives but felt that it will not be possible for us to do the same with our beloved kids, and we changed our decision. We did everything for him. I wanted him in whatever shape he was. But when his health started deteriorating I felt as if someone was destroying the colorful picture of our life that I had painted, in front of my eyes. If it were to be destroyed in a single stroke it would have been easier to accept, but here the painting was being undone line by line. I was never worried about my physical hardships. My only aim was to see my husband survive."

"In the last days he had become like a child to me. I would bathe him, comb his hair, and feed him with my hands. He felt very secure only when he would be with me. I cared for him, as a mother would do for her child. I never ever thought about anything happening to me when I cared for him. With out him our life is like an empty sanctum sanctorum of a temple. Everything else is there; there are flowers, there is all the decoration, but there is no god's idol. Nobody else can understand my sorrows, my concerns, but it may be possible for you to understand so I am writing this to you."

"When he breathed his last people suggested that my kids should perform the last rites and fire the pyre. I objected. I did not want my small kids to go through this torture. There is one more ritual. When the corpse is lying there they would put vermilion on my forehead and as soon as the dead body would be lifted some widows would wipe it off. I did not allow this. They were annoyed, but I remained firm. As a far as widowhood was concerned I was already a widow for last four years. Now when I look back I think, if the society expects such inhuman things from an educated woman like me what would be the plight of thousands of ordinary, uneducated women who become widows at an early age."

"When I looked at him dying, I always felt we are all going to die one day but no one should suffer such a horrible death."

"I try to forget him but it is not possible. I try to project myself as a happy person; I try to entertain my kids, but when I am all alone I feel the emptiness. Whenever I feel such emptiness I sit in front of his photograph, and cry. But he is no more and there is no one left to wipe my tears. At such times I remember these lines from a poem I had read some where."

*(The tears in your eyes are worth only if there is some one to wipe them
If there is no one whose eyes will well up, then even death is worthless.)"*

These letters are extremely moving. The love, the compassion, the acceptance, the sensitivity touches and stirs some inner chords in our minds. These are the words that have flown out, out of her own will and initiative. These are not 'data' . We have left the words untouched, except for the translation.

XI. Key Informant Interviews (KIIs)

As discussed earlier, HIV is not a simple medical problem but a complex socio-developmental issue. There are no simple technological solutions that could help us quenching the burning fire effectively and efficiently. In this complex scenario there are various players. The laboratory technicians who do the testing, the counselors who provide the information and support, since we are concentrating on women's issues women's groups and feminist activists, and because it is a social health problem views of a health activist were all exceptionally important.

Since all of them had vast experience in their own fields we wanted to explore their perceptions and views as well as perceived solutions.

The interviews were more in a free flowing format and with less use of structured questionnaires. The talks were detailed and at length, rarely did we interrupt their talk. We requested them to talk about our domain of concern, and tried to understand their way of thinking.

The KIIs provided colorful yet highly subjective insights. Most of the KIIs were very strong personalities, and had distinctive ways of presenting their narratives. The designed 'lack of control' over the interviews at times had a disadvantage, in that the KIIs took off to some tangents that were not directly related to the domain of study. But all of them talked very freely and at times provided us with different exposure and direction of looking at issues, which were not thought before.

Some of the common concerns expressed by all of them can be summarized as follows:

- HIV is a major and complex problem.
- Women's status is lower and secondary in the society; this increases their vulnerability.
- Counselling support is extremely important and at the same time lacking.
- Imparting knowledge should not be a one-time activity; sustained follow up is a must.
- People preferred private sector set-ups for health care to the public sector facilities.
- Alcoholism and other addictions are the most important fuelling factors.

Though there was apparent unanimity over these issues the perceptions about the causative factors were varied. They also mentioned some uncommon special issues. Let us have a look at these issues.

Complexity of the problems arises partly due to the fact that seriousness of HIV is felt only when the patients are seen. This is preceded by almost 8 to 10 years of a silently spreading epidemic of asymptomatic HIV disease. Two of the women KIIs working with a NGO said they perceived the problem only recently, within last couple of years. One of them working in the area for over a decade said, *"If you had asked me these questions ten years ago, I would have told you that it was not a problem of my area. It could have been*

a priority even then but I did not feel it then. But now, it definitely is an important issue and can not be overlooked any more."

As regards the secondary status of the women in the society one feminist activist said, *"Women are never given importance in a family. It doesn't make any difference whether they are present or not in terms of decision making. They do not own anything (neither house nor land) on their names. If anything goes wrong she is the one to be blamed first. The fault may be her or her husband's; or nobody may be at fault (as in issues related to not having children), but she is blamed for everything, always and she is thrown out of the house. Then husband getting married for the second time is another problem, which leads to further negligence of a woman. The couple has no privacy/space for communication. Also alcoholism/addictions in men is another major problem. There is lack of the power of negotiation, especially in first 15 years of marriage. After that the women gradually can negotiate to some extent, but before that they do not have any say in important matters."*

All KIs working directly with HIV related issues also expressed these feelings. A counsellor however said that though men felt that they were more important, they carried a feeling of guilt about having infected the spouse. She also mentioned that men behaved very nicely in front of others but beat up wives after going home. A community worker said that women are allowed to stay at husband's place only till such time that he is alive. After his death she loses all her space in the family.

Most of the KIs felt that the awareness programs lacked quality. Many expressed a concern that there was undue emphasis on the number of programs. That is why they are proving to be ineffective. A director of an NGO doing numerous such awareness programs said that most such programs were done very casually, they lack seriousness. He agreed that their NGO also did not have any effective modules but they called in experts. This was detrimental because then there was absolute lack of consistency of messages. One of the NGO directors said that they had no system of evaluation or noting the feedback, so they do not know whether their efforts made any dent. This confirmed the casualness of approach. A very experienced counsellor spelt out the reasons: the information was given in highly technical language, it was not people friendly as many concepts were discussed in English terminology, even the doctors speaking in such programs lacked correct information so they spread misconceptions. Another counsellor said that due to various problems the issues were not discussed in totality, e.g. after discussing about unsafe sex, people avoid talking about condoms. So the information is inadequate, if partially provided it is not likely to translate into behaviour change also is likely to spread misconceptions. The two health activists said that most people doing such programs themselves have very negative attitudes that are naturally passed on into the community. In spite of these odds there is a feeling expressed that the proportion of unsafe sex has reduced. The three activists suggested some means for improving the quality of these programs. Most important is that the persons doing this must have very correct technical knowledge and very good attitudes. Using effective posters, street plays, etc must enrich the campaigns.

Facilities for good and effective counselling were essentially mentioned by all. The director of the NGO mentioned that counselling should not be just looked at as pre- or post-test counselling. Apart from the patient his/her spouse, the family, friends, society and even the health care providers would need good counselling support. The shock of the news about HIV infection evokes multiple responses. Some even go to the extent of committing or attempting suicides. A good counselling support in such crises is very essential. Only good counselors can do the job of convincing people that there is still productive life beyond HIV infection. A director of an NGO, who also runs a lab, opined that there is no culture of counselling. Many patients are referred to his lab for HIV testing but few are counseled about it. He can not intervene and offer the services, as the doctors feel offended. He has started a counseling center but hardly any patients are referred to this center directly. A counsellor working in a government project mainly doing MTCT intervention research feels that counseling is very important and difficult too. She talks to almost 5 women per week. She said that women sometimes ask such complex questions that it is impossible to answer them. One of the HIV positive women had told her,

"Madam, you take everything so lightly because neither you nor your husband nor your son is infected. When you tell me that my son is progressing satisfactorily I can not be happy for such small things. I know very well that I will not be there to see him grown up as you will be able to do with your son."

Who could be called a good counsellor?

The counsellor should have been trained properly before they start working with the patients, refresher courses are necessary for the counselors as otherwise there is the possibility of stagnation.

"With HIV counselors there are increased chances of a burn out, as we have to listen mostly to morbid and sad stories all the time. We should have opportunities to relax and at the same time have some platform to share our experiences."

Counselor should be able to help at all levels medical, social, psychological and economical. On the other hand a very senior counselor says,

"formal training is not essential to be a good HIV / AIDS counsellor. One needs to be very open, nonjudgmental and without negative attitudes to be a good counsellor. She has seen many trained workers spoiling the cases mainly due to their negative and rigid attitudes about morality. Anyone who is familiar with counselling, having enough knowledge and willingness to learn more, and most of all having enough sensitivity and empathy can be a good HIV / AIDS counsellor irrespective of being formally trained."

She feels formally trained counselors sometimes develop superiority complex and instead of focusing their attention on the client they become self centered and can potentially harm the client by not giving attention or neglecting them and force their own values and moralistic ideas on the client. According to her HIV orphans is going to be another major social issue and both infected and affected children are going to have problems regarding treatment, care and rehabilitation. Partner notification, is another serious issue. She said that some infected individuals are not willing to disclose their HIV status to anyone, mainly due to the fear of stigma, discrimination and isolation. After counselling many of them disclose their status to their partners. If they decide not to inform anyone, then

concerned doctors, counselors should motivate them for partner notification but in any case should not force them to disclose.

She tells the importance of counseling in a very concise and precise manner.

Counselling services are extremely important for HIV infected individuals and their family members. Right from obtaining the correct information up to dealing with psychosocial issues, helping in decision making, making appropriate adjustments, bringing change in behaviour in terms of changing unsafe practices, preparation for treatment, hospitalization and death, a counsellor can offer support and strength required to deal with the problems. Good counselling can bring a lot of positive and qualitative change in the life of the individual and the family members.

As regards other issues that women have to face the several issues mentioned were malnutrition, over exertion, RTIs, alcoholism and addictions, migration, and violence. The most important of these, mentioned by all, were alcoholism and violence. These two had also a direct bearing on the problem of HIV/AIDS. One of the health worker looking after a poor urban locality and other one working mainly in the Adiwasi area, both mention that the problem of alcoholism is on the rise, with more than 90% men being habitual drinkers.

All these issues come up again with new presentations when they are closely related to HIV/AIDS. For example lack of negotiation in the matter of sex or use of condoms. If the husband dies due to HIV, the woman is kicked out of house. Previously they used to kill her as 'Sati' or kick her out because she became the widow, and now they do so because the husband dies of HIV disease. The things are same, only now they are having a new face/disguise.

Counselling services are extremely important for HIV infected individuals and their family members. Right from obtaining the correct information upto dealing with psychosocial issues, helping in decision making, making appropriate adjustments, bringing change in behaviour in terms of changing unsafe practices, preparation for treatment, hospitalization and death, a counsellor can offer support and strength required to deal with the problems. Good counselling can bring a lot of positive and qualitative change in the life of the individual and the family members.

If HIV/AIDS is to be implemented in new RCH program, can you give any suggestions to make it more effective?

It can be made effective provided the Govt. does not treat it as an extended family planning program. Or it is not just changed name of the same program. As initially it was called as family planning, then family welfare, then CSSM, then GOBI, (growth monitoring, oral re-hydration, breastfeeding and immunization), then GOBI FM etc. If it is the same kind of program, then it will be like 'old wine in new bottle', then you may add HIV/AIDS to it or whatever else you feel like adding, it is not going to be effective. If you are going to focus only on family planing, by casting the net wider with the view that those people will come for FP who escaped till today, then it won't be effective. But if really they were going to add these components as abortions, violence ('Hinsa'),

HIV/AIDS in RCH and work on it, then it would be effective. Tell me one thing how can one work today on RCH without a component of HIV/AIDS in it?

During our survey we noticed that immunization is being carried out very seriously and is successful in reaching to people, but other services are not reaching to people and people aren't aware of them. People don't make use of them even when things are available. In such circumstances what will be the response to issue of HIV/AIDS that carries a lot of stigma?

It is difficult to work for this issue. What is it we are going to do, when there is no cure for AIDS? What are we going to tell them? If we are not going to change the circumstances, then are we going to just label them? That is the reason why we need to decide very carefully about what programs we are going to conduct and plan them properly. If it is going to be test oriented then again it is going to be problematic as health workers will be interested in completing the target and that's all, and would not bother about what happens to the person's life. A sero-reactive to the HIV is going to suffer but a non-sero-reactive is also going to suffer just because he/she went for testing. That is the reason why we need to think a lot about it. In case of immunization we were giving them something to prevent disease or in TB we give them curative therapy, in this case what are we going to give them? If such is the case then the other components need to be very strong. The important issues as ethics, confidentiality, pre-test counseling, post-test counseling, behaviour change, attitude change, social change, all these things need to be thought about seriously.

To implement HIV related issues in existing services of RCH is really difficult, unless there is proper training and changes in terms of attitudes. Camps are arranged and information is given to people. But that is given only once and there are no follow-ups. Another very important thing is attitudinal change, about which nobody is talking.

Sensitization of health workers and attitude change of health workers is important because information is not inversely proportional to stigma. If one gets more information, that does not necessarily bring the change in attitudes and acceptance of HIV infected individuals in the society. *In early 80s we had conducted a survey related to social aspects of leprosy and we found highest negative attitudes existed among the doctors, which means in spite of having information and knowledge there was high rate of negative attitudes. Hence having only the information is not enough. Other possibility is that those who don't have negative attitudes may start having so after getting the information that is not having any ideological content. The information contents should have some ethical base/values. Otherwise it will wander off its limits like a kite. Then the needs of people regarding HIV/AIDS should be assessed just like what you people are doing at present, which is very important. People are dying so do they need home-care, what are the needs? The needs need to be assessed on a large scale.*

There are many obstacles in reaching the program/information to the people. When we start talking of any of these components, the issue goes very close to the use of contraceptives, because you are talking about RTI. When you start talking about RTI you

are so much into reproductive and sexual language that people are afraid of it and they would avoid coming to you. If you were not reaching to people then why would people come to you for anything?

In case of STDs many women are infection carriers. Unless we give them information that they can be asymptomatic carriers, how will they come for treatment? The problem in the first place is that women are not having easy access to the medical service. They are not taken to the doctors, as they do not appear to be suffering. If they suffer from such illness they may be treated badly, beaten by their husband with a question that with whom did she sleep to get that? If such are the conditions and circumstances then the govt. health services should make efforts to win the confidence of the people, they should maintain that much confidentiality and people should have faith in them, which is not seen happening at all. At least I have not seen RCH program, reaching people as an integrated program. That can be my lack of knowledge, as I don't stay in village, I would say, if I try to be fair to them. But that's not true, because we have our health centers and health workers in so many villages. If something really noticeable was going on we won't miss it by any chance. As we are working in the same field there is really no chance that we would miss it.

Why people do not prefer PHC as the treatment is free of cost?

"You know something? The PHC locations are all political. Therefore instead of being in needy areas the PHCs are in areas that are vote banks. So why will people go there at 5-km distance if they are not sure whether they will get service? Why won't they take bus in opposite direction to city where they are at least sure that they will get some service? Other main problem is that the first ST reaches the village at around 11am to 12 noon, when the PHC OPD gets over and the last ST starts at 4-4.30pm the OPD is yet to start. People come back from work at around 5.30 to 6pm, by that time the OPD closes. If a woman in labor goes there after 5pm she is send back saying that the delivery is difficult, because who is going to wait for that after OPD timings?"

There were two very sensitive questions about which we asked the KIs. These were relating to the **right to marry and right to have children**. All of them expressed unanimously that the PLWHA have both these rights. However the director of a large NGO said that the decision has to be taken after considering the support system the child may have in case the parents would die. "AIDS orphans should not become a burden on the society." The counselor dealing with many women in a MTCT research set up said, "I theoretically agree that it is her right, but in my personal opinion she should opt for termination."

"HIV sero-reactive person should have right to marry and also have the right to have children. But we need to revisit these issues because the picture at present is not just black and white, but there are shades of gray in it."

HIV has thrown up all these issues. A look at them might make one feel really depressed. But there are certain nice things that have happened due to HIV. A counselor an field worker who himself is HIV infected says,

" I feel helping HIV positive people has given the much needed meaning to my life. I, myself, have taken care of people dying on the streets. I have touched them, physically picked them up and carried them to the vehicle. I have dressed their wounds. Every time I help some HIV positive person I feel very satisfied at the end of the day. I feel I have served the God."

XII. Focus Group Interviews

In order to obtain semi-structured normative data on women's health concerns, their awareness and understanding about HIV/AIDS and perceptions about health care facilities provided by the government in public health sector with reference to health in general and RCH in particular, focus group interviews (FGIs) were conducted.

Total 14 FGIs were conducted . In 12 of these women were from Pune district. Two additional FGIs were conducted with women social workers from different districts of Maharashtra. Some of them also worked in the field of health. These women had come to Pune to attend training workshops. One group was from Ratnagiri, Raigad and Sindhudurg areas and the other was from Thane, Sangli and Kolhapur areas. Although these women were from outside Pune district area, we could correlate the situation and ground realities in their areas with our observations through this exercise. Pune district has definitely been one of the best-served districts in Maharashtra as far as public health is concerned. We could compare our observations with those in less-than-the-best situations. As the women in these groups were already attending HIV/AIDS training workshop we have analyzed their views separately. Also a separate mention needs to be done of a FGI with a group of women who had had a training for almost 18 months on women's health issues. The issues, concerns, understanding, attitudes, and directions expressed by them were exceptionally different from others. This group demands special attention while drawing conclusions. It also tells us as to how informed and empowered women can be if sincere and serious efforts are put in.

In the remaining 11 FGs women were from different geographical, social, educational and cultural backgrounds. Different NGOs helped us in organizing these FGIs. In nearly all cases the women in the group knew each other well. The discussions were facilitated by our coordinator Meghana Marathe and were helped by one or two field workers. Women were shy and sometimes hesitant to begin with, but were very co-operative as we went through the sessions. In addition to very useful qualitative data we could understand that they were very eager to learn more about HIV. Almost all of them requested for awareness program which was conducted subsequently.

From the FGIs we tried to understand the following:

- Awareness about HIV/AIDS with correct information about modes of transmission and preventive measures,
- Source of this information,
- If from awareness programs, then who arranged these?
- Information about nearest PHC.
- What type of health facilities they preferred (public or private)?
- Did anybody from public health facility do regular visits? What kind of services was provided?
- What were their perceptions about the health care providers in public as well as private sector?

- What were their and other women's attitudes towards HIV +ve people?
- What were other social issues faced by people and women in particular?

Observations

Only 3 groups were aware about all the 4 modes of transmission of HIV correctly. Groups of women, who were mainly illiterate, were from Adiwasi area totally lacked correct information. Those who knew something about HIV mostly got the information from television and newspapers. Naturally these were women from relatively upper social strata and had access to mass media. However the information about prevention was lacking in all the groups. One group for whom an awareness program was conducted by an NGO mentioned that though television showed advertisements about HIV it did not give clear information. Four groups felt that it was a dreadful incurable disease spread through sexual contacts. They did not know about any other mode of transmission. A group from semi-urban area mentioned that this is a disease transmitted through handling of blood and due to immoral activities of people. This correlation to immorality was more from the side of educated class of women. They gave the feeling that they perceived the disease as of poor, immoral, 'bad' people. A group of Neo-Buddhist women mentioned that they insisted on use of boiled syringes whenever they visited a doctor. They also told that this was informed to them by an NGO working with them. They did not have any other information however. Many groups shared quite a few mis-conceptions, like HIV being spread by sharing toilets, swimming in the same water in which HIV positive person has swum, dog bite and mosquito bites. They discussed a lot about several rumors floating around. All the groups except one voluntarily expressed the need for more information. The one group, which consisted of educated working women from semi-urban area, did not desire more information.

Seven groups mentioned that they never had any opportunity to attend any awareness program. They had not even heard of any programs being conducted in their areas. Four groups mentioned that some of them had attended such programs. NGOs or individuals organized all of these. None mentioned about any government initiatives.

When asked about any HIV infected person if they had come across some mentioned about cases in their neighborhood. They felt that there was no stigma or discrimination at least in their areas. Some mentioned that even though there must be cases around "*but then who will tell?*"

All groups mentioned that generally the public health care facilities were nearby, generally within a range of 5 Kms. However only one group mentioned that they preferred public facility. They said, "*We have to go there. There is no alternative. We have to walk 3-4 kilometers. Private doctors are even further away. We even conduct deliveries at home. Only if there is a problem we go to the Arogyakendra.*" Quite a few said they do not prefer public facilities, as they are not satisfied with the services. A group of women gathered at a PHC for ANC clinic said, "*Government hospitals do not have enough facilities, so we prefer private doctors. We come here only for ANC. We are not going to come for deliveries.*" About the quality of private care they felt that though

not very good the quality of care was slightly better than at PHC. All were however unanimous in mentioning that the private care was very expensive.

All of the groups mentioned that the PHC staff did visit villages for vaccinations, malaria diagnosis, *to draw blood for investigations and writing something on the door*, and finding cases for sterilization. They never give any information. They provide medicines only if asked for. Never does anyone inquire about women's genitourinary problems.

The various problems of women mentioned by these groups were low back ache, weakness, white discharge, prolapsed uterus, burning urination, different menstruation related issues. Few of them were addressed to by the health facilities. Women also were not very keen to seek help in the initial stage. "*Only when it becomes really difficult to carry on with the work we take treatment.*"

There were several other issues mentioned by these women which also required urgent attention. They also had deleterious effect on women's wellbeing. These issues were: alcoholism, wife beating, malaria, water scarcity and lack of safe drinking water, unemployment, stray dogs, dowry, open drainage and woman's secondary status. "*Woman's position is always secondary. People believe that one must have a son so they do not practice family planning till they get one. They say Wanshala diva pahije! Nahitar pani kon pajnar? (One must have a son as a 'lamp' of the family tree, otherwise who will do the rituals after my death!).*"

As already mentioned there was a group of women who were extensively trained about issues of women's health for a period of 18 months. They were providing health care to rural women. Their interview needs special emphasis. Here we are presenting an edited version of their interview.

There were 4 women.

Age	Education	Working since	No. of children
57 yr.	2 nd	5 yr.	5
49 yr.	6 th	5 yr.	1
33 yr.	8 th	9 yr.	3
32 yr.	7 th	7 yr.	3

In their program there is at least one trained health worker available in each village. These women being from the same villages they are always available.

These women were very co-operative, open to talk and informal in approach. They were sharing their experiences freely and joking and laughing, telling about themselves, telling

about the superstitions they had before this training and they had the ability to laugh at themselves.

- What is the type of work you are involved in?

Our work is related to women's health. We also take programs for adolescent girls.

-1: People talk about illness/disease but we try to find out reason behind it.

-3: Women usually don't talk freely. We try to give them a platform where they can speak out.

-2: Women don't talk about menstrual problems, problems related to genital tract as white discharge, prolapsed uterus. We try to convince about the need for examination and treatment, and encourage them to speak.

We talk with them in detail about their life, their problems. We keep a regular follow up and provide maximum support.

- What type of training you have gone through for this work?

Yes. We have had training for 18 months.

-4: Establishing a rapport and winning confidence of women, Encourage them to speak out, assure them of confidentiality of whatever they tell us, all these things were considered to be an important part of the training and this part itself took 4 to 5 months. Other part was learning about a woman's body systems, about various illnesses, their symptoms, commonly available herbal medicines, etc.

-2: For minor illnesses people can't afford going to the doctor or to the PHC. We give them basic medicines (as per requirement).

- How was your training?

-1: It was really very good. The atmosphere was friendly and informal. We participated in all the activities. The teaching was not like in a class room. Our lessons were in the form of practical and games.

-2: Because of this we could remember the things better.

- Which problems of women were focussed on?

Per vaginal white discharge, excessive bleeding, prolapsed uterus, anemia and weakness.

- Would you tell us more about your training?

We were taught about the internal examination of female genital tract. So we were told in very beginning of our training that we should learn to examine ourselves first and then each other, in front of the group. During this training we discovered that 4-5 members amongst ourselves had certain infections and diseases. Now how were we to know about them without examination? As our organs are well inside of our body and it's difficult to see the symptoms of the genital tract. As per our training, we took treatment ourselves and got cured. So we were convinced of its use.

- Did you face any problems during the training?

-2: Yes. First difficulty was examining us without clothes in front of everybody. We were told to do breast examination and speculum examination in small groups. We were not ready for this. So we were told that if we were not allowing ourselves get examined, we

didn't have the right to examine others and therefore we could not continue with the training. Initially we were 24 trainees, out of which only 12 continued with the training after this condition. We thought we must complete the course so we stuck to it.

- Then how did you manage?

-3: Women don't look at their own body and don't take care. We discovered many of us had anemia. They taught us what are our different systems and where they are situated. They asked us to map our bodies. We drew only the outline. Then they taught us about different organs of our body, by actually asking one of us to lie down and drawing outline, then drawing organs inside. Till that time we didn't know that there are so many organs in our body. (All of them laughed merrily.)

The Marathi words used by them were:

Uterus = *Anga*

Anemia = *Raktapandhary*

P/V discharge = *Angawarun jane*

Uterine prolapse = *Anga baher yene.*

- Was there any problem in learning?

Initially we were afraid whether we will understand all this or not. But once we started there was no problem as everything was in Marathi, so problem of language was solved. Also every lesson was in practical form and the atmosphere was very good. (*Khelimelechya watawaranat.*)

Then we thought, *people pay so much for learning, we are getting this opportunity free of cost and we will be able to help people with this, so why not to take the advantage!*

- Were there any problems in attending the training?

-2: *I used to come for the training for initial four months, without telling my family members, as I was sure that they wouldn't allow me. But we somehow did it, with all our family problems, by finding one or the other solution.*

-4: *My youngest child is 4 year old. My mother in law had started living separately. My husband knew nothing of household work. So I had to prepare everything for 4 days. Then he gradually started cooking a few things. But he used to drink lot of liquor some times and came home late. Children used to sleep without eating anything. After coming back and learning the situation I used to get very upset. Once my younger son had a bone fracture at 2pm. and I went for the training at 4pm.*

- Didn't family members oppose you?

-1: *I will like to tell you about how I joined this training. Initially I had refused to join the training because I am not educated much and there were few young girls, who were educated till 10th Std, so I told to take them instead of me. But these people came to my home and said that I should also join. Then I was afraid whether I will able to do it or not. Then during the training it was discovered that I had a uterine tumor. My menses had stopped eight years back and I had no symptoms but as I saw the tumor myself I was convinced for the operation which I had refused to do earlier. It was done in SGH. I went to SGH and told the doctor that I have uterine fibroid /tumor. He asked me how did*

I know that? So I demonstrated self per speculum examination. He was really surprised, he said that you are the real doctor. (Laughs merrily.)

-2: I will tell about myself. My daughter during her pregnancy was very ill and so the pregnancy was terminated. Second time there was a spontaneous abortion. After that she was not conceiving for long time so I took her to a Baba (quack), he told that she would conceive after her coming menses, and she really did! This was 7-8 years back. Now I feel like laughing at it. The doctor had told to take lot of care during that pregnancy, which I did. Then after delivery when first time we cut baby's hair (jawal) I was told to kill a goat for god and invite people to eat that meat. After that for her next pregnancy I did nothing and the baby is healthy. There was no problem throughout. After that I stopped believing in all such things. Now I get angry with people when they do something like this.

- Are there any superstitions that lead to unhygienic conditions during menses?

-4: women are supposed to sit outside the house during menses. They don't change pads for a long time. They don't take bath for four days. They are not allowed to keep those cloths used as pads in house. Those clothes are kept hidden in some dark, dirty corner. They do not wash it before using it for the next time. These may be the reasons for complaints like p/v white discharge, rash, itching, etc.

- Tell us about PHC/ Govt. hospital in your area.

-1,2: In our village there is a sub-center.

-2: But the female health worker/ nurse appointed there is never available on time. It is as good as not having a center.

** What are the services provided there?*

-2: They give vaccinations. They treat simple illnesses like loose motions or nausea, vomiting. Also, ANC is done. They give us the medicines, like, Iron tabs, anti-diarrhea drugs, ORS etc.

-4: There is PHC, there are medicines but doctor is not available on time. Nurse doesn't give medicines in doctor's absence. Doctors do practice privately instead of giving free service, so villagers complain about it. Doctors are not available full time. Their timings don't match with the people's timings.

- Is condom distribution done?

No. We also try to tell people about condom use but men don't agree. They say that they don't get satisfaction with condoms. Women tell us that it's of no use telling the women about it, instead of that take meeting for men and tell them about it.

- Do government people give information?

Government has never arranged any information program. They conduct health camps for women. But they don't do any examination, don't even touch them and just give medicines, but what's the use?

- What are the misconceptions about HIV/AIDS?
 - 4: People don't talk to or touch or go near a patient of HIV/AIDS.
 - 3: After the death of such a person, they don't go near/give bath to the body (which is a ritual). They take the dead body for cremation without performing the rituals.

- What are the other problems of women?
 - 1: Family problem (*sasurvas*), mother in law treating badly, sending her back to her parent's home (*takun dene*).
 - 4: 'Vinaybhang' (harming the modesty of women)
 - 3: 'Chedchad' (eve-teasing).

- Are family members concerned about the women in family?
 - :The family members are not at all concerned. According to them she should work like and servant always even when she is ill. 'Payataly wahan payatach pahije.' (Footwear should always be kept in its position.)

- What about addiction?
 - 3: In our village use and selling of liquor are prohibited 100%. Women fought for it.

- What should be the ways/methods of giving information to people according to you?

Information should be given separately for men and women, so that they will talk openly. It should be given in small groups of 20 to 25 people at the most. In a large meeting people are not attentive. It's of no use telling once. They have to be told again and again so that they will not forget the information.

There were two groups out of Pune district. One of them was from Konkan area and other one was a mixed group from Thane, Sangli, Kolhapur areas. Both the groups mentioned that there was little awareness about HIV in their areas. The area was apparently very badly hit as many of them knew about many cases in the community. People were dying. But few came out and sought treatment. There was a lot of stigma to this disease of the 'promiscuous' people. In Konkan the problem was complicated further because of many men staying in Mumbai or travelling to the middle-east. They were forced to stay away from their families. The arrival of Konkan Railway had further worsened the situation. The sexual behaviour patterns in Konkan also were probably different and needed further investigation. Rates of abortions in young women were unusually high, as suggested by some. So, they felt, Konkan was an area, which demands urgent attention. Other problems like alcoholism, and violence against women due to their inferior position in the society increased their vulnerability to HIV. "Whenever drunk, men went to prostitutes, and fell prey to HIV." These women also shared similar problems with the government system. They said, "these people were unable to understand and also did not have the initiative to learn new things. They work not to help people but to complete their paperwork." The other health problems of women enlisted by them were more or less similar to the list from other groups. These women had just completed an intensive training in HIV/AIDS and wanted to work in the fields. They were happy that the training NGO promised them of all the back up support.

XIII. The Health Care Providers

When we look at HIV from different angles we do see a kaleidoscopic picture of the problem. From one perspective it is definitely a socio-political and economic issue affecting the development. Another perspective is that the virus fuels the disease but the epidemic is fuelled by the gender inequalities. For those who are suffering from the symptoms it primarily remains a health issue. Unlike many other diseases it has very high prevalence, very high morbidity and mortality, a prolonged course, definite modes of transmission- some of which are not socially acceptable, has no definitive cure or preventive vaccine. That it affects youth is experienced by most PLWHA but the societal implications remain a virtual reality. When one gets sick the first thing one does is to seek medical care. This is done in several ways. With so much of stigma associated with the disease there are home remedies tried, quacks are approached, traditional treatments sought, public health care facilities accessed, private medical professionals visited, consultations with HIV specialists arranged and when needed hospitalizations are done. The overall outcome in an individual case may depend upon the clinical status of the patient and the appropriateness of the treatment, but the social outcome certainly depends upon the availability, quality and attitudinal appropriateness of the care and support provided. So we tried to gather data from the health care providers in the field area. We interviewed 10 doctors from public health facilities and 13 doctors from the private sector. We used a semi-structured guideline for conducting these interviews.

Summary of the interviewees

Public health system:

MBBS, Medical officers, Public Health Center, (4)
MS, Medical officers, Rural Hospital, (2)
MBBS, Medical officers, Rural hospital, (2)
MBBS, Intern,
MD (PSM), In-charge RTC,

Private medical system:

MD, (Chest), (2)
BHMS (2)
BAMS
MD, (Gynecology)(4)
MBBS, (3)
MD, (Dermatology)

We tried to understand about:

- Their perceptions about the problem of HIV in their community,
- Their ways of dealing with it,
- Their attitudes towards PLWHA,
- Their knowledge and their perception about the level of knowledge in the medical fraternity,
- Their perceptions of level of awareness in the society,
- Their perception about the stigma and other social issues thrown up by HIV epidemic,
- Their views about the treatment seeking patterns of the PLWHA,
- Their suggestions regarding improvement in the system as well as in controlling the epidemic.

Observations:

All the private practitioners unanimously felt that it was already a major problem. *" Two years back we used to see a suspected case in 2-3 months but now I see at least a case every 15 days."* The opinion was however divided in the public health doctors. Seven felt that it was a problem but three said it was not at all a problem. One felt it was not a major problem. *" I have not seen a single case neither already tested nor suspected."* The in-charge of the RTC asked the interviewer in return, *" Here you are asking a doctor whether I feel it is a major problem, when in the community we have already reached the stage of mother to child transmission?"*

How do they diagnose HIV infection?

Most of the patients are being tested without their consent and without any counselling. Three doctors said they did provide counselling and generally did not do any testing without informing the patient. Many others felt that counselling was not at all essential. *" Don't we test our patients for so many other tests without consent? I tell them to get certain tests, if someone denies then I tell that I will not treat you."* On the other hand one of the practitioners said, *" I agree that HIV is a different disease, but all diseases which have a fearful impact on peoples' mind need more counselling. Why only deadly diseases, even a patient of diabetes needs counselling regarding exercise, diet and importance of regular treatment. Only difference is that in diabetes we may wait till next visit but not in case of TB or HIV."* All the ANC cases are being screened. Even unregistered obstetric cases landing for delivery are also screened. Some of them mentioned that they tested all patients even if the procedure was minor. One of them said she tested all women who said their husband was a driver. All patients with sexually transmitted infections were tested. The chest physician said that he tested all tuberculosis patients, and he found that about 10% were positive. It was a general observation that more men were being tested positive than women. This was because less number of women came for the treatment of STIs. *" I directly do not get any woman who is positive. I get male patients first, then when we ask for the test of the spouse we know about the woman. It is exactly opposite with the gynecologists."*

" One of my regular women patients tells on her own that I test her husband. Somewhere in her mind she has that doubt about her husband's behaviour. She does not want to suffer because of him. She also suggests that I test her , but without telling her husband."

There are also many people (especially men) who keep on requesting, and even if advised not to do so go for the test repeatedly. They have tremendous phobia about HIV and these kinds of people are very difficult to be convinced that they are not infected. It is not always that these men have had multiple exposures, some have had only one and that too absolutely minimally risky behaviour, and still the fear of HIV, mainly instilled by the media creates this phobia. These men are mostly educated, uneducated people usually believed in the doctor. They have read some anecdotal reports of HIV test remaining negative for many years, or they confuse the window period with long asymptomatic period, or they are mis-informed by doctors about their risk. We had one patient who was very confidently and assertively told by his doctor that he was definitely in the window period. This man then spent thousands of rupees, and many days and nights in mental agony. He came to our clinic with a heap of negative reports still not convinced that he was not infected.

What about STI cases ?

Private as well as public doctors said that they did treat STI cases. Generally in OPD practice women were less. Even the field workers said that very few women came forward for treatment, men generally preferred private doctors.

Very few knew about the syndromic management, especially in the private sector. There is hardly any investigation facilities. So not all patients get investigated. There being no system of regular follow up most are lost to follow up. Very few people brought their partners for treatment. When suggested only a few really got them. Many a times doctors just asked the question whether the partner had any symptoms and only occasionally treated both the partners simultaneously.

One doctor said, "As patients do not come for treatment of STIs we organized a camp for diagnosis and treatment we had organized a camp. Twenty per cent of the village population attended the camp, of which 20% had some STI. It was seen that most were female patients."

How did they deal with HIV cases?

Most of the doctors in public sector said they rarely came across cases, but whatever cases they saw, were always in the advanced stage, therefore we can hardly do anything than disposing off the patient to Sassoon hospital. Though all of the private practitioners felt that it was a major problem and they came across HIV patients 6 of them did not treat but refer them to Sassoon general hospitals, KEM hospital or HIV consultants. Of the remaining, six said that they managed many patients but as most patients were non-affording they just provided treatment for opportunistic infections. In case of complications they asked for special opinion. They also admitted patients in their hospitals, but none provided obstetric care. Only two gynecologists attached to a large trust hospital provided all the care without discrimination.

Another gynecologist said, " I generally avoid treating these women. I prefer sending them to KEM or Sassoon. It is mainly a problem because the paramedical staff. They do not care for the patients willingly. They are under tension. Even if you train them they are always under tension. Also we do not have separate room facilities, if two women land up simultaneously. "

Interviewer: " Do you get tensed?"

"Yes, I do get tensed and some times I feel that I should not be doing these procedures, but because of the pressure from the patient we have to do it."

What type of health care facility do the people prefer?

Most doctors from both groups felt that people preferred private care to public health facilities.

The causes cited were:

Inadequate facilities,

Unavailability of drugs,

Lack of privacy,

Lack of confidentiality,

Money required any way,

Complicated structure where people have to wait in four different queues to get medicines. In contrast private clinics were more time efficient.

There were two different observations worth mention. Some of them said people preferred private practitioners, as anyway they had to pay money at PHCs. One said, "*as patients demanded injections and operations, doctors in public facilities do not satisfy the desires of patients. In private clinics the doctor would gladly give an injection or perform a hysterectomy if the patient demanded.*" Some medicines like injections of penicillin were used only in public facilities, private practitioners avoided using them due to the fear of reactions. Only one doctor said that, especially STI patients preferred public facilities as one could maintain his/her anonymity in the crowds at PHCs. Public facilities were accessed mainly by the very poor. Sterilization and immunizations were done at public health facilities very efficiently. One said, "*People preferred public hospitals only if they knew some one there.*"

HIV patients had to go to public facilities as private practitioners refused to treat them in their hospitals. However one of the chest physicians said we needed more co-operation between the two sectors. Even DOTS program could be effectively managed if there is co-operation. In such a situation private doctors should not be afraid of his patients being 'snatched away.'

Were there any differences in the attitudes of the health care providers from private and public sector?

As already mentioned private practitioners felt that HIV was a major problem as against the doctors in the public sector. This obviously had a bearing on their attitudes. Those from the public sector said they had no facilities to manage the cases so they referred the cases to the general hospital. It was also seen that these doctors were provided training in

STI, RCH and HIV/AIDS. The overall awareness about the technical aspects of HIV was relatively better in these doctors as compared to those in private sector. They also knew about the 'syndromic approach' for management of STIs. They were also talked to about counselling in their training programs, However, few seemed to understand the difference between providing information and counselling. Many seemed to be confused regarding several delicate issues like maintenance of confidentiality, right to have a child, right to marry, etc.

The private sector doctors were treating a lot of patients. Their overall level of even the technical knowledge was on the lower side. There was a lot of fear of occupational exposure but the systems to prevent the risk (universal precautions) were not in place. A few of them were however extremely well informed. Trying to correlate the attitudes and knowledge we found that it was the training, especially in the medical colleges, that made the difference. It is not only the technical information but also the sensitivity and desire to care that also gets translated into the day to day practice of many a doctor. Some classical examples of attitudes are:

"In Sassoon we could demand history of exposure from a patient, and could tell 'no history-no treatment' but not in private practice."

" A positive patient must tell the doctor before injection or even dressing. If they don't tell how we are to know? And why at all should we risk our lives treating these people with such dirty habits?"

" We maintain no records, so how can we remember each and every patients history. Patients expect so many things from the doctors."

"Approximately 2 months back we conducted a survey of number of HIV positive people from our area looking at the data in the laboratories. We found that we had approximately 5000 HIV positive persons in our area. We then submitted letters to SP, DYSP, CM and even the Prime Minister. We asked for a separate hospital or research center or diagnostic facility. We have lots of prostitution in our area. We asked the police to take a very strict action against the prostitutes. We started screening the girls and if found positive, we feel they should be sent to some institution or isolated."

The most important paradox is that those doctors who are seeing less number of patients are more informed, while those with most patients are lacking even the technical knowledge. So those in the private sector seemed to be very uneasy, uncomfortable, impatient. They also felt that they had to face the brunt, as public sector was not responding adequately. On the other hand those in the public sector seemed to be contented with them. This could also be typical because those in government service always have shown this attitude. Those who do not have to bother about the number of patients coming to them, whether the patients feel better after treatment, etc. A medical officer of a rural hospital who has been trained in HIV, who is conducting awareness programs, is president of local medical association said, *" We have trained all doctors through IMA. The attitude of all doctors is good. What treatment a leprosy patient used*

to get in the past is not the same with HIV patients. All doctors give HIV patients injections and intravenous fluids whenever required. All are using autoclaved needles and syringes. Relatives neglected even in the past patients with maggots in the wound at home but not by the doctors. Now the only difference is that instead of maggots we have very small virus." This is a very contented view of the scenario, not at all echoed by the patients, their relatives, the focus groups or the key informants.

Out of all the doctors only two were not at all interested in HIV related issues. They said it was not at all a problem as they never saw any patients and they were not interested in learning anything about it. All others accepted that it was a problem and most had at least something to say about it. One doctor from private sector, who said it was a major problem in his area, however expressed extremely shocking views.

"You should isolate all the HIV positive patients and lock them up into one compartment and let them do whatever they want to do, so that these people will not spread the disease in the community."

What was the level of knowledge about HIV?

The overall level of technical knowledge about the transmission of HIV was good. There were some misconceptions about the ways it is not spread. Many a times doctors asked the patients to be kept separate, isolated. There were a few who organized workshops for barbers on HIV. Now the question is not whether barbers should be informed or not, but the doctor felt that barbers are a definite source of spread of the infection. This misconception has translated into a funny situation. In a small township the barbers now have a safe-locker system. The clients keep their personalized shaving kits in these lockers and take the keys with them.

There is also quite a bit of misinformation about the treatments available. Few doctors knew about the anti-retroviral treatment. Many also asked this question; *"If there is no cure then what kind of treatment do you give?"* They did not know about chemoprophylaxis and treatment of opportunistic infections. One doctor asked, *"can this be cured in very early stage?"* this ignorance on one side and on the other there are some who are already using anti-retroviral drugs. The doctors hardly know about any pharmacology. It is all the knowledge learnt from the medical representatives of the pharmaceutical companies. We have seen 'horrible' prescriptions. If this kind of prescribing without any discussion about the duration, cost and side effects continues we might be heading for a disaster, especially when the drugs are getting cheaper. We had a patient who was being treated with 600 mgms. of AZT every day as a monotherapy and the treating doctor had not even bothered to monitor her hemogram. When she reached our hospital, severely breathless her hemoglobin was mere 2 gms. per cent. This emphasizes the need for extensive training of the health care providers.

According to the doctors, what are the social implications of HIV?

All of them felt that women would have more problems than men would. They correlated this to the women's lower social status, but more of this was a mere pep talk, as hardly anybody tried to correlate it with other social issues of dowry, domestic violence,

substance use, harassment by the in-laws, etc. Only thing almost everybody said that if only the woman is infected she would be thrown out of house. Presently the women are not being thrown out because they got the infection from their husbands. As soon as he would die the fate would be the same. They also observed that most women were accompanied by and were supported by their parents and not by the in-laws. This confirms our observation from the data of infected women. There is tremendous fear in the minds of the people so they avoid interaction with HIV positive people. This has got reflected in our data from the knowledge and attitudes study of the general population. Some of the doctors said they would like to admit patients with HIV but in hospitals other patients do not like to have AIDS patients next to them. A doctor said that there were people who said that we should let them die. *" We had a patient in our hospital. He came alone; no relatives came to see him for 3 days. We managed his food from other patients' meals. Then he told that his village was 3 Kms. away and a barber knew him. I informed that fellow to inform the relatives. The barber wanted to tell me that this fellow had a very bad character, he had done all sorts of things when he was all right, now it is alright even if he is dying. Why should we care for such a person."*

On the other hand one said that there is no stigma. *"People do care for their relatives. Why would they run here and there for Ayurvedic treatment if they did not want to do anything? They do try their best."*

What should be done?

The suggestions from doctors could be divided into three general categories. Suggestions regarding things to be done in general for the community, things to be done by the doctors for the community, and the changes required in the system.

As far as the first category is concerned the suggestions were more or less general. There should be more awareness programs. These programs should be concentrated in schools and colleges; men should be targeted for HIV information. There should be target specific programs for different age groups; 'good' sex education to reduce misbehavior; promoting functioning of at least one NGO in every area; developing self-help groups; encouraging small savings groups to take up health issues; promoting family life education (and not just sex education) and seeing that the programs are sustainable. *"Two to three years ago I remember to have seen one NGO doing some programs in schools, but since last two years everything has stopped. Then what is the use of spending so much of money?"* and, discouraging or banning quackery.

What should the doctors do? The suggestions were as follows:

Doctors should do counselling or organize good counselling services. Health workers should give correct information to the people.

What are the changes in the system that is needed?

Private practitioners: Establishing diagnostic centers, organizing workshops for doctors, and bringing down the cost of testing.

Public sector doctors: Improving the infra structure facilities, providing facilities for testing, increasing the number of doctors, separate facilities for women, expanding RCH beyond ANC, deliveries and immunization, seeing that the drug stores is well maintained and all the drugs are replenished constantly, including HIV testing in ANC protocol, providing doctors legal protection, etc.

It was surprising that not one doctor talked about the costs of anti-retroviral drugs and improving access to care.

The Health Workers

Apart from these doctors we interviewed 4 auxiliary nurse midwives and a lady health worker.

All of them were unanimous in saying that HIV/AIDS was a major problem. All of them had seen cases of HIV. Some of them treated them. They were afraid of the risk to them. *" We use gloves whenever we know someone is positive."*

Only one felt that awareness in the society was low. One felt that acceptance could be better in educated families, but was not possible in rural areas.

"There are plenty of cases in our area. Not necessarily I have seen the results of tests in all of them but people talk, they talk even taking the name. Whenever anyone is chronically ill people discuss that he has AIDS. People are now aware of the symptoms."

" People know because we celebrate AIDS day to every year."

"The reaction of the society is generally negative. HIV positive people are afraid and worried about this reaction. One of them committed suicide immediately after knowing the report."

One of them did not know what RCH was; others knew about it. Most of them felt that women did not come for STI treatment. But when they organized half-yearly STI diagnostic camps women attended these camps in large numbers. *"During the campaign for these camps we do not discuss STIs openly, we ask women about symptoms of RTIs/STIs. If found positive we refer them to Sassoon general hospitals."*

Asked whether there was any component of sex education in the RCH program that an ANM is supposed to do?

One said, *" Yes, we supposed to take programs related to sex education for girls in schools. We did that 2 years ago, now the program has stopped."*

" People are aware of HIV but they do not ask information HIV. They are more interested in Hepatitis B vaccination. The distribution of oral contraceptive pills is more than condoms."

"All the patients I have seen had tuberculosis."

" We conduct so many programs, but as a part of job given to us, not because we feel the need. Actually community's participation should increase."

" We have more HIV positive cases in our area because most men visit Mumbai very often. They have to stay away from their wives."

"We need testing facilities here, at least the basic ones. Travelling to Pune for the test and then for results is very costly."

Most of these health workers were not aware about the issues like confidentiality. If they had an access to any person's reports they readily shared the information with others without bothering about the consent.

"A truck driver used to come to our OPD and used to tell us that he had some problem but never really told us. After some years he got himself tested in Pune. He showed us the report thinking that we will not understand. Once his mother asked us about the exact problem of her son. We told her that he has AIDS. She did not believe us, said her son can not be like this. But after some days when he became really sick and was admitted to the hospital and ultimately died, did she believe in us."

Most said that PLWHA always preferred private practitioners for treatment. It could be that they are more confident about confidentiality in private clinics than in government hospital. So on one hand they were conscious that HIV positive people would like their status to be kept secret, yet on the other they themselves were not very much bothered about confidentiality.

XIV. Knowledge and attitudes of the general population

Profile of people from whom knowledge and attitudes data were collected (n= 403):

We also carried out a field-based survey to understand the knowledge and attitudes of the community. Trained field workers gathered the data randomly from all the areas of Pune district using a structured; field-tested questionnaire filled in by asking questions. For descriptive purposes we have divided the district into 6 zones. These are the rural and semi-urban areas around the five major highways spreading out from Pune City. The analysis of the data shows that the sample is reasonably well distributed and is probably representative.

Table 5: Distribution according to age

15 - 25	131	32.5%
26 - 35	158	39.2%
36 - 50	89	22.1%
> 50	25	6.2%

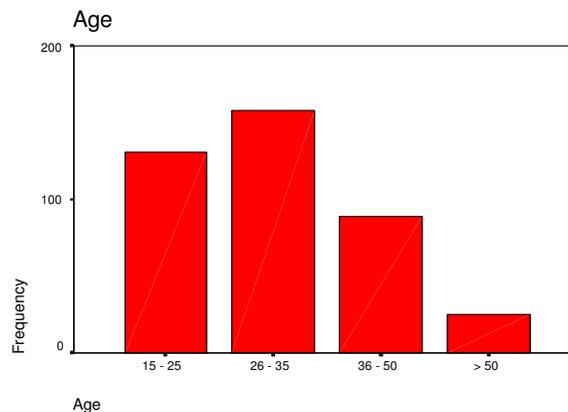


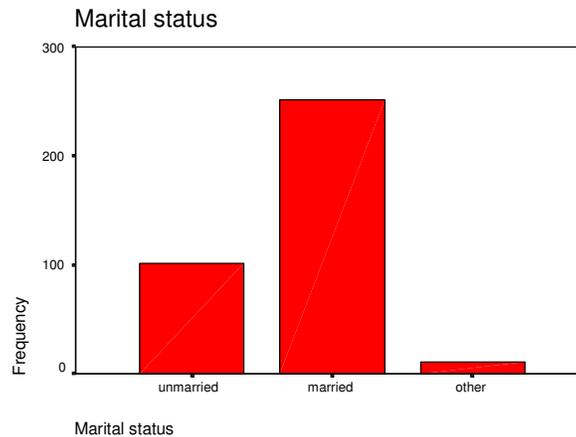
Table 6: Distribution according to sex

female	192	47.6%
male	210	52.1%
other	1	0.2%

Here the category 'other' represents a person belonging to a sexual minority (transsexual) group.

Table 7 : Distribution according to marital status

Unmarried	102	25.3%
married	251	62.3%
other	11	2.7%
missing data	39	9.7%



In these data regarding marital status, the category 'others' represents women once married but now widowed, divorced and deserted.

Table 8: Distribution according to educational background

We wanted representation of all types of subjects, with varied educational backgrounds. We then tried to correlate answers to questions about knowledge about modes of transmission of HIV, about how HIV is not transmitted, attitudes, etc., to the educational background. The data will be presented subsequently.

illiterate	51	12.7%
1st to 4th std.	39	9.7%
5th to 12th std.	257	63.8%
> 12th std.	56	13.9%

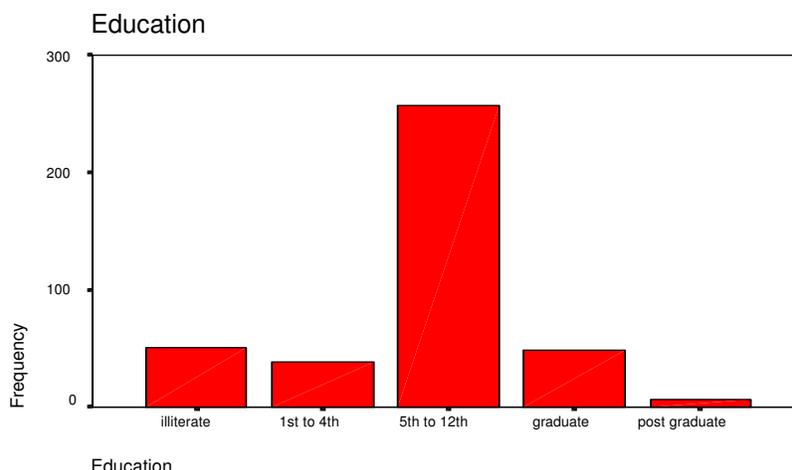


Table 9: Distribution according to area in the Pune district

Bombay highway	49	12.2
Nasik highway	147	36.5
Ahmadnagar highway	22	5.5
Solapur highway	71	17.6
Satara highway	58	14.4
Other places	56	13.8

Just for the sake of convenience we have divided the Pune district area into 5 basic zones depending upon the location around the five major highways going out of the Pune City. The professions, the movement of the people in and out of the major cities varies a lot according to the location. Some areas are famous for vegetable business are connected to Mumbai, some are very drought prone areas from where many men have migrated to Pune or Mumbai for jobs, some are sugar rich belts and some are rice cultivating zones. Except for minor, statistically not significant differences the data present similar picture all over. From such a small sample it is difficult to conclude about relative distribution of HIV positive cases in the district. However from our limited observations we feel that Saswad area in Purandar Taluka; Rajgurunagar, Manchar area along the Nasik highway; the new industrial areas along the Sholapur highway are probably worse affected than other areas. There would be certain locality specific socio-geographic factors contributing to this distribution. These observations need to be validated through analysis of larger data pool and then if found correct these contributory factors investigated further.

As far as the knowledge about routes of transmission is concerned we observed that 93.1% knew about unsafe sex, 93.1% about un-sterile needles, 91.6% about transfusion of HIV infected blood and 85.6% about MTCT. It was a significant observation that the

areas along the Satara highway (Shivapur, Bhor, Welhe areas) had higher percentage giving wrong answers (approximately 15% regarding unsafe sex, 10%, regarding unsterile needles, 15% about MTCT). Overall it suggests that our messages regarding routes of transmission are reaching people.

Looking at their perceptions about the likely cause of HIV disease 11% felt it is a hereditary disease, only 66.7% knew that it was caused by some disease organisms (bacteria/virus), 13.5% felt it is transmitted by polluted water, 24.8 % said it is transmitted by using public toilets, 34.5% by insect bites, 36.7% by sharing utensils used by HIV positive person, 17.6% by donating blood, 24.3% sharing clothes of HIV positive person, 29% through air, 16.4% through touch. So if we call this as 'wrong knowledge' then we have not been able to remove such wrong knowledge from the community. We tried to analyze this further according to locality, age, sex, education, etc. the strongest association noted was with age. Higher the age more the 'wrong knowledge'. Now this 'wrong knowledge' is the most important basis of the treatment meted out to HIV positive persons. This is the root cause of the stigma and discrimination. The most ill informed older persons are the decision-makers in the family. They dictate the way HIV positive people will be treated in the families and as a consequence in the community.

As far as treatment is concerned 11.7% felt it is totally curable by giving medicines, 23.6% felt it is totally curable in initial phase, only 71.5% said it is totally incurable and 40.2% said it can be controlled by medicines. Only 13% said that there is no curative treatment. Why so much of confusion? Lack of proper information, effect of wrong messages given through the media (advertisements of claims made about cure), wrong beliefs and rumors. Of the sample 21.4% believed that there is remedy in traditional medicine. The good thing was that despite all this confusion about 85% said we should treat HIV positive persons as far as one can. Knowledge about prevention was also good (use of condoms during unsafe sex, sterilizing needles and syringes properly, transfusing only tested blood, etc.) However people also suggested that HIV transmission can be prevented by avoiding touching HIV infected person (34.6%) not mixing with HIV positive people (35.5%), by avoiding use of public toilets (36.5%), by avoiding organ donation by HIV positive people (19.4%), by avoiding sharing of swimming areas (42.8%).

What about the safer sex options? As already said 74.4% said one should use condoms during unsafe sex. Approximately 85% had heard about Nirodh. Only 5.2% had ever seen a Nirodh (or a condom), 54.1% of these said they knew how to use a condom, however our observation was that only about 40% had proper knowledge about the proper use of condoms.

What about the attitudes regarding PLWHA?

Should they be allowed to stay at home or be thrown out? 18.4% said they should be thrown out, 39% said that they may be allowed to stay at home but should be kept separate, 29.6% said these people should be thrown out of their jobs, 40.7% said they will not offer an HIV positive person a job with them. When the attitudes regarding non-intimate contacts were so severe, it was obvious that there would be even harsher

judgements regarding more intimate contacts like getting married or having children. 94% said HIV positive persons should not be allowed to marry, 93.1% said they should not be allowed to have children.

Why so much of negative attitudes? Either we have not reached the masses through our awareness campaigns and/or we are spreading wrong messages. The latter seems to be most likely as, as already discussed, the information regarding transmission has been well widespread. The attitudes of the campaigners, built on improper training could be the reason behind this problem.

We tried to understand the sources of information. Were there any awareness programs conducted in their areas? Only 25.1% recalled in the affirmative. What types of programs were these? Government organized 8.8%, NGO initiatives 6.5%, individual efforts 1.8%, mixed efforts 1.8%. How many of the respondents had actually been at these programs? Only about 11% people had attended. This shows that the source of information is not the awareness programs but the other mass media, like radio, television, newspapers, magazines, etc. These media, unfortunately, are playing a dual role. While spreading right kind of information they are also sensationalizing the issue of HIV/AIDS. They are spreading wrong attitudes and unnecessary fears. They are misinforming by publishing advertisements of unproven medicines. They are creating unwarranted discussions like "Is there something like HIV?" They are reporting disasters more than the best practices studies. They are grossly violating the human rights, especially of the most persecuted groups like women in prostitution, men and women with alternative sexual orientations, PLWHA, etc.

Contrast this with the following data. Of these approximately 400 persons interviewed, 60.4% had heard about a person from their area suffering from HIV disease (or AIDS, as they put it). Of these 33.8% had something to say about it. So many of them said they were their friends or relatives.

"One of our relatives and two neighbors have died of AIDS. When our relative died his wife was pregnant, 5 months. Doctor advised to get an abortion done, but she said, come what may she would continue the pregnancy. They tested her blood, she was negative."

"Son-in-law of my cousin died of AIDS. We have not allowed his wife to use our toilets."

"The elderly people in the family do not know, so they keep on doing things like Bhagat (local quack or godman)."

"In the hospital doctors did not go near him. The person who served food tied a cloth around his nose and mouth and pushed the dish with a stick."

"In Karnataka, all the hens in a village were killed because a rumor spread that hens that eat spitting of HIV positive persons pass the virus to the eggs. If one ate these eggs he would get AIDS."

"One of neighbor died of AIDS. Another boy in the family is chronically ill. Everybody says that he has AIDS. He was married just for 2 months. His wife left him and went away."

"In our village there are so many people have died due to AIDS. There is no proper guidance. They don't take treatment. Everybody is only afraid."

"After the death they burnt him in a hurry. They also burnt his belongings."

"Two AIDS patients came to the dispensary. The doctor did not allow them to come in."

"My brother died of AIDS. His wife was had loose morals. I kicked her out of the house."

"I know so many people. We do not drink tea or water with them. They are always ill, just go on shrinking. They always ask money for alcohol. I tell, take these 2 rupees but don't come near me."

"He was driver of my tractor. He died more of the harassment. He died like an abandoned dog. His wife is HIV negative, but she is also going to have the same fate as no one accepts her."

"My friend committed suicide."

"He was truck driver, was our relative. I hated him. After death we put his body into a gunny bag and disposed it off."

"In our village there are my affairs, all the time. Girls are taken to the fields, or to the school and everyone does it, even the women from rich families. I had relations with 13 girls before marriage, my wife is the 14th."

"When his wife came to know she left and came back only to see him on the pyre."

"The proportion of HIV in police is very high. They have to investigate matters related to prostitutes. As it is many police go to prostitutes."

"We should ban prostitution. We should test prostitutes, and positive should be executed with bullets."

With all this background it was not surprising to see that only 43.8% peoples said that they would continue friendship with HIV positive persons, and only 32.1% said they would make new friends who are HIV positive. Here again it was again very significantly seen that older the age more the negative attitude. It was possibly a positive sign that, though not in very high proportions, young persons, whose problem HIV/AIDS mainly is, are changing their attitudes.

Figure **

XV. Summary of Observations

We wanted to understand the issues that affect the HIV epidemic and the societal response to it. We started our journey at the interviews of 42 infected women. We then travelled backward in time trying to understand the circumstances that brought them here.

Almost exclusively their stories begin at a very young age. At this age they are not mature enough to understand the complexity of the various issues. They are getting married very young, that too before 18 years of age (in spite of the fact that the law demands so). They get married to men who are comparatively much older. There is always a possibility that these men have had sexual experience, that too unprotected high-risk exposure, before marriage and are infected with HIV. The younger women have immature genital mucosal lining, more prone to get damaged during sexual intercourse and therefore making them more prone to get infected.

Most of these marriages are arranged marriages. Given the secondary status of the women in the society, in an arranged marriage a woman always is in a "did not know" and "did not question" situation. She knows nothing about her partner, especially nothing about his sexual life. She neither has the liberty nor the space to discuss these issues. In fact many a times she is not aware that she should know these things. Most things are taken for granted. There were a few love marriages in our sample. There too, discussing sexual lives of would be life partners is never the agenda.

What are the possible outcomes of such a marriage?

Most often he is already infected or acquires it somewhere along this journey. He gets sick, she becomes the caregiver, he dies, she becomes a widow and is also HIV infected. After his death she is thrown out of the family.

Or neither of them know, she gets pregnant, she is tested positive during ANC, then he is tested and detected positive. During the testing the doctor has not informed her. After the reports he may inform her, or her husband, or her in-laws, or her parents. If the doctor provides good counselling and support she may be able to bear it. But more often than not the doctors' use testing as a criterion for exclusion of these women from care. Whichever way, for the woman this is a great shock. A newly married young woman, pleasantly pregnant is just declared to be having a disease that has tremendous stigma. She has hardly any windows of opportunity. All her relations are suddenly at stake. There is a lot of psychological pressure to cope with. There are decisions to be made. To continue the pregnancy or not? With whom she can share and discuss? What would be the reactions? What about her fate? What about her husband's? What about her child? Issues of illness, death of spouse, death of child needs to be dealt with. Also there is the imminent fear of her illness and death. How long will she survive?

She may be divorced or deserted. What kind of supports would she get?

As a woman she is generally a dependent member of the family. With HIV and with a host of such problems her dependency increases.

What are her prime needs? She needs support, she does not want to be stigmatized. She wants her secret to be kept a secret and at the same time needs psychological and economic support. That most women prefer to disclose their status to parents and not to the in-laws speaks a lot about our social structure.

There are other factors that fuel these problems. These are domestic violence, alcoholism of the husband, and his sexual relations. She has almost zero control over the situation. She has to cope up with this with the help of her failing body and dispirited mind.

Woman in discordant couples could be infected or not infected. The situations throw up different possibilities. If she is infected there are chances that she would be abandoned. If he is infected it is her moral duty to care for him, knowing fully well that she would be thrown out immediately after his death. If she is infected she would carry the guilt that she may infect him. If she is not infected she would be required to have sex, despite all the tension about getting infected.

It is not only the infected individuals but also the families go through a lot of stress. They have to deal with issues of confidentiality, discrimination, stigma, and the need to provide support within the limitations of their resources.

There are issues of rapid urbanization and migration of rural men to the cities that are making them, and in turn their spouses, more vulnerable.

All these issues were authenticated and supported by our FGDs and KIIs.

Stigma and discrimination related issues were confirmed by the knowledge and attitudes study in the general population.

The infected individuals need medical care and therefore health care providers are important actors in the story. They are not primarily affected, have access to information and also generally have the sources to deal with the situation. Yet it comes out very starkly that the health care providers carry a lot of attitudinal baggage on this journey. At times it seems that it is their knowledge that has made them blind to the real life situations and they do not have the inclination or the motivation to deal with this problem. The problems start looking even more glaring when we see that most people prefer private medical care to the public sector facilities. The public sector facilities and health care providers are going to be the ones implementing RCH programs. There needs to be a massive revamping of the capacities of these providers.

On top of this there is the problem of unproven medicines. These are nothing but exploitation ploys.

There is hardly any political will to address the issue of HIV/AIDS comprehensively. In fact as mentioned by one of the KI, even the locations of PHCs are determined politically, but the issues of access to care is not dealt with adequately.

The observations in the present study are from a limited sample, however the FGDs from different areas and KIIs; as also the interviews of health care providers have given us a comprehensive picture of the situation. Apart from the size and selection of the sample there are some other limitations, e.g. groups of women with special needs like women in prostitution have not been represented. However we feel that their issues deserve definite separate attention and investigation. In fact quite a few studies are already available. We can at the most say that RCH programs should include care of these women as an integral part of the system. There should be no discrimination, no stigma.

It also needs to be mentioned that no reproductive health program will be complete unless we include men's sexual behaviour and genitourinary tract illnesses in the package. We must keep it in mind that in almost all sexual transmissions of HIV there is at least one male involved. Therefore participation of men is absolutely crucial for any HIV prevention program. Men with HIV are not the 'culprits' who need to be demonized. We also need to research their concerns and problems in dealing with HIV. An ideal RCH program should have this as an integral component. However it is a limitation of this study that we have concentrated only on women's issues. The goal of present RCH programs is to increase male involvement in reproductive health, including family planning and sexual health. We feel that our idea of male involvement is not just to improve women's health but to improve the overall quality of sexual lives in order to achieve the ultimate goal of "sexual health for all". It is quite ironical to call the program reproductive health program and concentrate only on women. In fact the name also needs to be changed to sexual health program.

XVI. Discussion

Some facts:

- HIV epidemic is spreading rapidly in the Indian population.
- Women are increasingly becoming infected with HIV.
- The global score board (UNAIDS: Gender and HIV) tells us about the story of how women are increasingly being affected with HIV all over the world. The national score board does not paint a different picture.
- Just promoting awareness campaigns can not control the epidemic. We have to supplement the prevention campaigns by developing good systems for initial support and then good health care of HIV infected individuals.
- Women infected with HIV or affected by HIV in the family have specific and special needs which need to be addressed in totality and not in isolation.
- The contributing factors, which affect women's vulnerability to HIV, include biological, social and economic factors. These factors interact, making it difficult for women to effectively control the conditions in which they are sexually active and limit their ability to protect themselves from HIV infection. Men are often the decision-makers and women have little negotiating or bargaining power. The men's interest in women's health should not only be for safeguarding their own interests but for promotion of a more just society.
- The strategies for prevention of HIV in women should address their specific needs in terms of these factors increasing their vulnerability.
- New caring strategies need to be developed to meet the needs of women both infected and affected by HIV/AIDS. The current burden of care currently falling on women needs to be redistributed equally between men and women, between the private and public sectors, between communities and the voluntary sector.

India was the first developing country in the world to launch a state-sponsored National Family Planning Program in 1952. The goal was of lowering fertility and slowing the population growth rate. Since that time fertility levels have declined throughout the country albeit at varying rates in different parts. Still the reproductive health situation in India remains poor. Although the infant mortality rates have declined from 86 deaths per 1,000 live births during 1984-88 to 68 deaths per 1,000 live births during 1994-98, an average rate of decline of nearly 2 infant deaths per 1,000 live births per year (NFHS-2) the maternal mortality ratios (540 deaths per 100,000 live births in the two years preceding NFHS-2) are in fact considerably higher than the value of 424 deaths per 100,000 live births in two years preceding NFHS-1. Although a finer statistical analysis tells that the increase is not statistically significant it still means that there is no decline in the maternal mortality rates. These are one of the highest in the world. Moreover only forty-two per cent of births in the 3 years before NFHS-2 were attended by a health professional. More than one-third of births (35%) were attended by a traditional birth attendant and almost one-quarter (22%) by only friends, relatives, and other persons. Obstetric and gynecologic disorders are widely prevalent and remain largely untreated and silently borne. (Visaria L., Jejeebhoy S. and Merrick T. 1999. "From Family

Planning to Reproductive Health: Challenges Facing India". Family Planning Perspectives, Vol.25.,ppS44-S49.) The AIDS pandemic has added a new dimension to the poor reproductive health scenario. The reasons for this failure to improve reproductive health status were:

- The program as implemented was insensitive to the needs of clients and discouraged community involvement.
- Both initial and on-the-job training of service providers had been poor.
- Information and education efforts had been ineffective.
- Family planning was presented as a means of population control rather than as a way to improve family's economic and social status by limiting births.
- The infrastructure for extension services was lacking in many, especially most populous, areas.
- The program had few resources for new initiatives or for strengthening health care services.
- The government program allowed for little active involvement of the community.

The new approach of RCH was borne out of such critique of the earlier versions of the program. In addition there were the issues of violations of human rights in the mid-seventies. More and more women's groups had also started challenging the government propaganda about various contraceptives, which they claimed to be violating ethical principals of any clinical human subject based research. The goals of the new RCH program launched in 1997 were:

- Removing all targets.
- Phasing out payments to both providers and acceptors of family planning methods.
- Increasing utilization of present facilities rather than creating new structures; and using the voluntary and private sectors to increase access to services.
- To fill gaps left by public sector providers.

There are not many examples of such models being successfully implemented, but some of them which are, are emphasizing on:

- Comprehensive services for women and children.
- Focus on women's rights and choice.
- Attention to counseling and clinical services.
- Focus on health promotion.
- Expansion of services to unmarried women, men, adolescent girls and boys and post-menopausal women.
- Reliance on local women as community health workers.
- Innovative and repeated training of workers using different media. And
- Nominal fees for service.

However there are limitations to the success of programs run by NGOs as they heavily depend on external and continuous funding. So the programs need to be run, albeit efficiently, in the public sector set up.

What should be the components of an ideal comprehensive RCH program?

- Must include access to safe, effective and affordable methods of family planning for both men and women..
- Informed choice in contraception and high quality supplies.
- Must promote safe motherhood.
- Must promote prevention of STDs.
- Must make efforts to reduce violence against women.
- Must provide access to safe and affordable abortion services as well as services for the infertile couples.
- Must have well-trained service providers with good interpersonal communication and counselling skills.
- Must offer appropriate follow-up care, monitoring and evaluation.
- Should also cater to unmarried women, adolescent girls and boys, and post-menopausal women.
- Must address men, both in terms of their own health needs and in terms of their role in ensuring health of the women.

Now putting this theoretical discussion as backdrops how do we see the reality of women with HIV? What is needed to solve these problems?

- The overall awareness needs to increase.
- The stigma needs to reduce.
- The issues of violence and substance abuse need to be tackled.
- The women need to be empowered socially, legally, emotionally, psychologically, economically, and in every other way.
- The counselling facilities need to be made widely available and need to be of good quality.
- Facilities for diagnosis and treatment at affordable price, with humane attitudes need to be evolved.
- Continuous clinical, behavioral and social research should continue hand in hand with the service provision so that the systems can be monitored, evaluated and modified from time to time.

XVII. Suggestions

- For a proper implementation of the program the government set up, the NGOs and the private health care sector will work hand in hand. The co-operation will be extended in all areas of volunteering, software development, training, resource sharing. As far as the women's issues are concerned the women's organizations will be encouraged to become a part of the process.
- All the structures will be open to modifications suggested by participating stakeholders.
- We recognize that recognition of women's sexual and reproductive health and rights are core issues in HIV/AIDS interventions.
- There are three basic and integral components of the model: Awareness, Counselling and Care. The model is structured on the firm belief that control of the epidemic is not possible if any one of the 3 links remains weak or is absent.

Awareness

1. Gender sensitive awareness programs will be conducted on a regular and continuous basis to cover maximum population.
2. Gender sensitive materials will be developed and utilized for conducting such awareness programs. A good example is the slide set prepared by PRAYAS, which discusses HIV/AIDS in a non-judgmental, gender sensitive manner.
3. Extensive training will be given to the people doing such awareness programs, so that they provide the information in a clear, simple manner and in the regional language. In these training workshops there will not be only lectures by experts as was experienced in many a workshop experienced earlier. The workshops will be voluntary, participatory, and interactive.
4. Preferably the workshops will be organized in the areas of activity of the workers and not in the cities. The resource persons will go there so that they also learn about the ground realities. Local residents will be given an opportunity to share their concern with the trainees. So then the training will be in a real life situation.
5. As seen from our data the HIV epidemic in India has gone beyond the third stage (where children start getting infected from mothers). The targeted approaches are unlikely to work any more. We should realize that the whole community is the audience. Within which there are sub-groups like girls and boys, women, males-having-sex with males, women in prostitution, etc. The approach may change from group to group but the core would remain the same. While telling about the don'ts we will highlight the do's, and will not attribute blame and stigma.
6. Special programs will be conducted for the young boys and girls. These would be age appropriate. The messages will be absolutely positive. The sex education will be gender sensitive. The issue of construction of sexuality and sexual identities will be taken up. Special camps will be organized for young boys and girls to discuss body literacy, health and HIV/AIDS literacy. The training will be in a workshop format, will be participatory, interactive, and in fact the boys and girls will be encouraged to evolve their own program.

7. These programs will not be one time. There will be follow-up programs. As the aim is not to 'pour' knowledge but to understand and empower people to identify and solve their problems on their own.
8. Ideally both parents but at least the girls' mothers will be invited to take part in such training.
9. The programs will be aimed to be qualitatively and quantitatively extensive but quality will never be compromised at the cost of quantity. The messages will not be based on fear. In fact there will be an effort to remove myths and create awareness about care of HIV positive persons. Our analysis shows that there are a lot of misconceptions and the stigma and fear arises mainly out of fear. Fear is based on ignorance. And, as one of the posters published by the Lawyer's Collective, Mumbai very rightly proclaims,

***"HIV positive persons are discriminated against because of fear.
One good thing about fear is that it can be overcome!"***

10. The training, performance and feedback will be monitored on a very regular basis; and necessary modifications done accordingly. Stakeholders' participation will be mandatory at each step.
11. The animators will be volunteers from the community as well as from the government setup. As one of the KI has mentioned one need not always have specific educational background. The example of a FG is quite glaring. These, not very highly educated women, were trained extensively (for 18 months) and are doing an excellent work.
12. The issues of health, violence, addiction, and empowerment are all very closely inter-linked and any awareness campaign will have to all of them simultaneously.
13. The key issues are motivation and empowerment. To empower the field workers we must provide them with appropriate software in the form of booklets, brochures, posters, slides, etc. If the field workers are made a part of the process of developing such materials they will have a sense of ownership and will be more motivated to use the materials effectively. The urge of the large-scale programs to create materials in bulk (thousands) at times is not cost effective.
14. Use of folk media and innovative concepts would always be encouraged. Of course the content of the programs will be definitely and closely scrutinized.
15. We encourage participation of groups of PLWHA in these programs, training and other activities. This would encourage others to develop self-help groups, reduce stigma and increased visibility of PLWHA living positively.
16. Alternative methods of service provision like telephone information and help-lines will be encouraged. The people handling these services will be trained extensively. It is our experience that although computer based voice simulated services are accessed by many they are costlier, not-person friendly and in most cases not very useful.
17. It is not just sufficient to talk of safe sex. We will make condoms of good quality freely available. We would also like to make alternatives like female condoms available.
18. To re-emphasize: Challenging gender stereotypes and attitudes, as well as gender inequalities in relation to HIV will be discussed extensively and incorporated in all the components of the program.

19. We will try to develop, design and institute measures that will enable men to undertake responsible actions and decisions on health, reproductive and sexual matters.
20. There will have to be very strong counter propaganda against myths, misconceptions, and quackery, which exploits vulnerable people.

Counseling

This is the second important component of the epidemic control.

1. We will develop and provide gender sensitive, women friendly, easily accessible good counseling services.
2. The services will have to take care of pre-test and post-test situations, crisis management, group counseling. These should be sensitive and responsive to issues of domestic violence, substance use and addictions, etc.
3. Counselors will be capable to provide skills in negotiations, communication and discussions about healthy sexual life.
4. Creating such a network of counseling support is not easy. Yet it has been seen that people with good motivation and appropriate training can do excellent job. This training is thus an important component of the program.
5. In the mean time we should prepare and develop good support material in the form of books, pamphlets, etc. One such excellent effort is the book "*Pudhe Kay?*" published by PRAYAS. The publication may have to be revisited in view of various different audiences.
6. The curriculum for training will be designed with the help of experienced counselors with vast experience.
7. We will also develop books based on the local experience to be used as resource material during the training.
8. The counselors will regularly attend refresher courses. This will give them the opportunity to share as well as will reduce their chances of possible burn out.
9. The counselors and the health care providers will meet regularly to discuss issues about ethical dilemmas, human rights violations, etc. this will help in evolving consensus based strategies.
10. No counseling facility will be helpful unless there is a strong back up of support services. Voluntary testing facilities, availability of care providers, assurance of confidentiality, support systems like women's organizations, legal help, provision for gynecologic and obstetric care are all absolutely essential before we venture into establishing testing centers and counseling facilities. Here again we may reiterate that if the public sector, the private sector and the NGO sector establish good co-operation this should be possible. If the existing facilities are utilized then these are seen as 'best practice' examples and will gradually replicate.
11. Self-help groups and other PLWHA will be included in the process of the implementation of this component.

Care and Treatment

This completes the triad of a good program.

We will have to take care of asymptomatic HIV persons, persons with tuberculosis, with other opportunistic infections and also those terminally ill with HIV disease. The services needed are out patient care, home care, community based care and hospital based care. Hospice like services for the terminally ill will be an additional requirement as the days pass by and the epidemic unfolds further.

We will be required to have:

1. Voluntary testing facilities. In no situations will there be mandatory, compulsory screening without counseling.
2. Training of health care providers. The training will be not just technical but also will take care of gender issues, human rights issues, the problems regarding attitudes. There will be practical exposure so that the health care providers learn best practices, This will also help alleviating the fear and thus the discrimination.
3. The training will be followed up with continuing updating through follow up visits or newsletter or through meetings.
4. A good STI/RTI management program will be set up.
5. A good set of software in the form of books, videos, slides will be prepared. PRAYAS already has published a book " HIV/AIDS Diagnosis and Management: A Physician's Handbook."
6. There are specific issues related to testing during ANC, problems with MTCT and strategies to prevent the same.
7. Access to medicines and obstetric care should be a part of continuum of care and not an isolated program once again looking at women only as birth-givers.
8. Hospitalization needs will be optimized through judicious co-operation between the public and private facilities.
9. We will evolve our own models appropriate to our local needs and available resources. There will be continuum between home care, community based care and hospital based care.
10. Health issues of children with HIV will be dealt with appropriately. These include testing, treatment, social support and care of orphans.
11. The terminally ill will be taken care of in a humane atmosphere and with full dignity.

For long-term, sustainable change certain structural changes are also essential. E.g.

1. Education will have to become more gender sensitive.
2. Awareness and concern about Human Rights will have to increase. Their violations will need to be investigated, reported and corrected.
3. Legal literacy will have to increase. The legal structures will be required to be gender sensitive.
4. Capacities of the civil society will have to be built on.

5. There will have to be upscaled political will and initiative to address all the issues of development in general and of HIV/AIDS in particular.
6. Policies will have to be prioritized in such a way they are more pro-people. People are made a part of the decision making process and there will have to be efficient and sustained advocacy effort to achieve this.

XVIII. SUMMARY

Our observations show and confirm that the epidemic is less about infection and more about social factors. The epidemic is really spreading very fast. **There is an urgent need of paradigm shift from emphasis on primary prevention through IEC to secondary and tertiary prevention with broad-basing our targeted interventions, increasing availability of testing and promoting early diagnosis of HIV, providing adequate counselling support and medical care to the already infected individuals and modify our awareness campaign so as to address the broader social issues in the context of prevention and control of HIV.** Here we have tried to look at the issues faced by women.

Early marriages, marriages to relatively much older men, unsafe abortions, increased violence, insufficient access to decision making and health care increases women's vulnerability. This is in addition to the physiological vulnerability, which puts them to more risk of unprotected sex as compared to men. Early age of marriage is exposing adolescent girls with immature genital tracts to even greater risks. Although women acquire STDs at an earlier age as compared to men most of them go undetected or unattended to.

With HIV there is the added issue also of mother to child transmission. As the risk of MTCT is higher if the HIV infection is recently acquired, which usually is the case with most women, the problem is becoming very serious. The trends in maternal mortality and child mortality rates are certainly not showing positive directions.

Little, if any, knowledge about their own bodies, reproductive system, sexuality, and sexually transmitted diseases including HIV is making them even more vulnerable. The societal norms, cultural beliefs make the women keep silent about their sufferings. This leads to myriad psychological pressures and illnesses.

There is almost ubiquitous domestic violence. It may take different forms like dowry-related harassment, physical violence, and mental torture. Early widowhood, abandonment, desertion, divorce may force the women to have no other alternative but to use their sexuality to survive. These situations are extremely difficult as far as negotiations in sexual acts and safe sex behaviors are concerned. India's record about domestic violence is at best dismal. Though the issues of women in prostitution have not been dealt with in the present study they are extremely important. At least one point emerges very starkly, and that is that separating women into two groups (mutually exclusive) with women in prostitution being 'aimed' at for the targeted interventions, stigmatizing them as the vectors or the cause of spread of the infection in the community on one side and the 'household' women on the other saying that they are 'innocent victims' is wrong. All women are extremely vulnerable and all need to be empowered.

Alcohol and its effects on the relationship, risk taking, violence, sexual abuse, economic crises are well documented. Alcohol is the chief mover of HIV traffic in the community.

Lack of social support systems make HIV positive women even more vulnerable. Inadequate laws regarding divorce, property rights, right to marry or have children, to seek employment, etc. in addition to lack of adequate health care, access to treatment simply forces them suffer silently.

Apart from these issues there are other observations that good counselling and support helps the women lead life with better quality and probably with better quantity too. There is urgent need for such facilities.

Misconceptions, fear, ignorance, lead to secrecy, which proves counterproductive as the treatment is delayed and chain of infection not interrupted.

There is a differential response to the infection of both the married partners. After the death of the husband the woman is generally thrown out or sent back to the parents.

Psychological needs of these women need to be understood very specifically. There needs to be a especially well trained work force to deal with the issues.

To summarize our suggestions:

- There is a need for sexuality education at a very early age and such that will reach maximum number of our youth, especially women. The programs will need to be evolved with active participation of the youth itself. The content, the simple language, the context and the instruments used will have to be very carefully designed and used extensively. Alternative media will be used but the materials again will have to be very carefully chosen. Quite a few programmes have demonstrated the example of impact of extensive participatory training and its utility in the field areas. At the same time we have seen the failure of top down mass campaigns based on inadequate training which did not evoke discussions on the issues of ethics, confidentiality, best practices, etc.
- It was also seen that the messages being spread right now are generally negative. There is a lot of ignorance about how HIV is not spread. The fear arises out of this ignorance, hence we now need to redefine our strategies. The campaign will have to be sustained, with reinforcing messages reaching people continuously.
- We need adequate testing facilities, but only after we have enough work force to handle the delicate issues of counselling. Once we establish this then we may think of promoting testing before marriage (voluntary, with enough care taken to ensure confidentiality). Community preparedness to deal with this epidemic also needs to be advanced. For this we will require individual and community counselors who are sensitive to the hidden and overt gender issues.
- We will have to build up social support networks along with the counselling services.
- There is an urgent need to train health care providers, not only about the technical aspects of HIV and its management but also about the gender issues, about violence, discrimination, violation of basic human rights and related issues.

- We must increase access to health care, access to medicines and optimum health services for all HIV infected individuals. This would increase their visibility, reduce, stigma and fear and help promote positive living.
- The importance of men's involvement in all these areas cannot be overemphasized. The role now will have to be pro-active. The training for that will have to be extensive, repeated, reinforcing, and participatory. We have been taught by the HIV epidemic that behaviour change is a difficult task and can not be taken lightly or casually.
- Last but not the least the whole patriarchal system needs to be challenged and changed. Not through protests but through constructive awareness that the existing unequal system is detrimental for both men and women though men may find that in the short term it seems beneficial for them.

Annexure I : Consent form.

Annexure II: Issues to be discussed with KIs.

Annexure III: Issues for discussion during FG Interviews.

Annexure IV: Issues for discussions with Health Care Providers (HCPs)

Annexure V: Questionnaire for general population awareness and attitudes survey