A STUDY ON

VULNERABILITY OF WOMEN IN RAJASTHAN TO HIV/AIDS FOR SUGGESTING MEASURES TO REDUCE IT AND AMELIORATING THE CONDITION OF WOMEN ALREADY INFECTED

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Submitted by:

SHANTI DEEP
WE AIM TO INSTIL HOPE, NOT FEAR !!

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RAJASTHAN
N
Ganganagar
Hanumangarh
Bikaner
Churu
Jhunjhunun
Sikar
Alwar
Bharatpur
Nagaur
Jaipur
Dausa
Jaiselmer
Jodhpur
Dhaulp
Ajmer
Tonk
Karauli
Sawai Madhopur
Barmer
Pali
Bhilwara
Bundi
Baran
Jalor
Rajsamand
Kota
Sirohi
Udaipur
Chittaurgarh
Jhalawar
Dungarpur
Banswara
Map not to Scale
State Capital
State Boundary

EXECUTIVE SUMMARY

The vulnerability of women in Rajasthan to HIV/AIDS as expected is on increase. The basic reason behind it is low socio-economic status of women in Rajasthan. The literacy levels, sex ratio, employment position and poor health are predominant factors narrating the story itself. Due to non-availability of seropositivity data, there appears to be a great possibility of more HIV infection amongst women in Rajasthan.

As per NACO, HIV prevalence in women in 2002 is of moderate nature. The predominant factors do support that soon Rajasthan may become a serious concern for the country. The number of cases of HIV infection in women shows an increase of 2.4% from 2002 to 2003. 32.9% women now constitute the full-blown AIDS cases in Rajasthan as against 26.34% at the national level.

In 1998, as part of the response to the growing HIV/AIDS epidemic, SHANTI DEEP established a partnership with Ministry of Youth Affairs and Sports, Govt. of India to train peer leaders amongst student youth, particularly girls in Jaipur. Later it extended its programme in adjoining rural areas with UNICEF support. The evaluation of these was supported by NACO/UNICEF. The purpose of the evaluation was manifold and indicated youth behaviour to be of fragile nature. It also indicated vulnerability of women in Rajasthan to HIV/AIDS.

As a result of it, SHANTI DEEP thought it appropriate to make a detailed study on vulnerability of women in Rajasthan to HIV/AIDS, to suggest measures to reduce it and to ameliorate the condition of women already infected. The findings of study are being forwarded to the National Commission for Women to be used to guide and shape future strategies to combat HIV/AIDS spread in women and to improve condition of women already infected.

Impediments Faced During the Study

The Study was planned with the confidence that all the stakeholders in the fight against HIV/AIDS would be happy to help us in conducting a study that would go a long way in devising a policy for preventing further HIV infection in a state where the status of women was one of the lowest in the country. We were already aware of the confidentiality aspect of the infection and the stigma attached with it, especially to women. The entire study was based on this premise. Unfortunately, Rajasthan State AIDS Control Society, the organization that should have helped us, did not provide any assistance. Dr Dinesh Mathur, Professor of Skin at the SMS Medical College, Jaipur who has been a pioneer in the field of HIV/AIDS in Rajasthan did his best through his personal contacts with the field officers of the Department of Medical and Health but failed to get their support for us. Even the verbal directions by Shri GS Sandhu, Secretary to the Government in the Department of Medical and Health, to RSACS and to the districts was not enough to shake them out of their attitude of indifference. The worst role was of ICHAAP, an Indo-Canadian Collaboration for HIV/AIDS, which has nearly taken over the control of the efforts to fight the epidemic in Rajasthan. It prevented other NGOs also in sharing information with us.

It was also found that it required much more time and patience to make women come out with personal information for fear of publicity. Women did open up ultimately and then were very cooperative.

There were many personal stories of anguish narrated by the HIV+ women. To live with the virus as a widow in a patriarchal society is extremely difficult especially if one is already below the poverty line. Most of the infected women asked for rehabilitation and employment. Till today, there is no scheme for providing employment to such women although the percentage of women infected in India is rising continuously.

A detailed analysis of the survey results has been given in the various Formats made after the Survey and a separate Chapter has been included at the end of the Study with suggestions for further action by the National Commission for Women, the Government of India and the Government of Rajasthan.

COVERAGE STATISTICS

STATE	:	Rajasthan
DISTRICTS	:	Ajmer, Bikaner, Bharatpur, Jaipur, Jalore, Nagaur, Sikar, Udaipur
BLOCKS	:	Bikaner, Pisangan, Nasirabad, Kishangarh, Ajmer, Srinagar, Nokha, Kolayat, Nadbai, Didwana, Jalore, Phulera, Sikar, Nagaur, Thoi, Kesriaji, Rishabhdev
PLACES	:	Napasar, Dherandu, Nandla, Govind Yadav Ki Dhani, Derathu, Jorawarpura, Gajsukhdesar, Rasiar, Uttatmamdesar, Boraj, Srimodhopur, Jurasan, Simarla, Kherwara, Dewas, Badla, Sundra, Kal, Pahada, Karcha, Katewari, Wards of Cities of Ajmer, Bikaner, Bharatpur

Number of villages covered: 100

Number of HIV+ women covered : 106

Chapter I

THE BACKGROUND

It is a matter of some concern that even after 20 years into the HIV/AIDS epidemic, the gravity of the syndrome has not been realized by the women's movement in the world and more so in countries like India which is reportedly going to have the dubious distinction of being the World's AIDS capital. In spite of a mention in the Beijing Declaration, neither women activists nor national machineries have bothered much about it. It has been placed on the back burner of issues of concern to women. In India, political representation seems to be occupying most of the time of the political parties and women's groups. HIV/AIDS has been left, by and large, to be taken up as a health issue and to be tackled by the National AIDS Control Organization with massive World Bank, Global Fund and Bill Gates Foundation funds. How much out of these massive resources is used for women both for prevention and care and support is not known. May be a trifle.

Clinical research on the differential impact of HIV/AIDS has always been limited to a few laboratories in the USA and Europe. It was very clear from the early eighties that HIV/AIDS is not a health issue only. It has huge socio-economic dimensions and women were going to be greater sufferers than men and gender roles were going to play an important part. From Day One, the epidemic had started unfolding its bias against women.

When some women proposed a study to find out whether women could also be infected, the US National Institute of Health rejected it summarily. In 1982, the first diagnosed case of AIDS in women was recorded. Meanwhile, more women were getting sick with AIDS- related diseases and were dying but the

characterization of the epidemic by gender (male) and sexual orientation (homosexual) remained dominant. A few women who were diagnosed were classified under the risk category called "prostitutes". Many states made laws for forcible testing of arrested prostitutes.

Although clinical trials started after a lot of pressure by women's groups, those of childbearing age were excluded from them unless they agreed to use birth control pills or IUD. No childcare, transportation or on site gynecological care was made available to women who wanted to participate. "No pregnant women and no non-pregnant women allowed" were the directions.

In 1988, women became one of the fasted growing populations with HIV, but continued to be neglected from clinical trials of drugs being tested for AIDS.

It was only in 1992 that the US Center for Disease Control expanded the definition of AIDS to include cervical cancer in addition to recurrent bacterial pneumonia, pulmonary TB and the presence of fewer than 200 T-cells. This led to the number of women diagnosed with AIDS to increase manifold.

By 1999, it became clear that there were gender differences in the complications related to antiretroviral drugs. The difference starts from the first step of diagnosis. They are diagnosed later because they do not perceive themselves at risk as well as because they have neither the knowledge about the infection nor access to a facility in the developing world. Also, the drug dosages have to be especially fine-tuned for them because of their lower weight and a lower viral load at the same level of sickness. Lastly, we live in a society where men's health is more important than women's.

A Woman's Vulnerability to HIV: A Situational Analysis

There are different risks to women in different situations-rural and urban, married and unmarried. The important aspects are the caste and the family background, poverty leading to malnutrition, sexual practices which is the main route to vulnerability, multiple partners as a result of traditional commercial sex,

polygamy and the *nata* system. Also to be considered are the medical practices like unsafe deliveries and a general lack of access to good medical facilities leading to the possibilities of infected blood transfusion.

Consider an unmarried rural woman. She has lack of education, low or no income, has to put in hard physical work with poor nutrition and is under constant family and social pressure to get married in childhood and may have to indulge in unprotected sex at puberty with pressure to prove her fertility at the earliest with a son. Her husband would be mostly much older and may have had premarital sex while he was working away from home as a migrant labour, thereby increasing the risk of STD/HIV to his wife. Even unmarried, she faces pressure for sex at work site or has to indulge in tribal prostitution. This could lead to STDs, Reproductive Tract Infections and HIV.

Consider a married rural woman. She is responsible for food, fuel and water for a large joint family and, therefore, has to do hard physical work but remains undernourished and has children early by an untrained *dai*. She is prone to infection and may need blood transfusion, increasing the risk for HIV. She may be married to a migrant worker, a truck driver or a nomad with sheep and cattle, who may be indulging in extra-marital sex and may get infected with STD or HIV passing it on to his wife when he returns home. Owing to early marriage to a much older man or to a child husband who may die in childhood, she may become a widow early and may have to spend the rest of her life either as an easy prey to the male members of her husband's family or selling sex, both increasing her vulnerability to HIV.

Consider an unmarried urban woman who is poor, hardly educated and in need of job for food, shelter and money. She either takes to prostitution and becomes vulnerable to HIV and STD or looks for low paid jobs, gets married and lives a life of malnourishment with an alcoholic husband who indulges in extra-marital sex with the possibility of STD or HIV infection which he promptly passes to his wife. The highest risk of HIV infection is found in this group. Lastly,

consider a rich married urban woman. She is fond of high life style. Both she and her husband may indulge in sexual adventures by choice or under peer pressure risking STD and HIV.

Gender Implications of Prevention Strategies

HIV, as is well known, is not random in its spread and its impact is disproportionately high on those who are socially, sexually and economically vulnerable. A woman is a natural target. The virus strikes her at an age at least five years earlier than in a man. Sexual transmission is the overwhelming way in which women become infected.

The three main prevention strategies being advocated since the beginning of the epidemic in the world are:

1. Reduction of the number of sexual partners;
2. Condom usage;
3. Faithfulness in relationships and celibacy and abstinence outside of them. To these, a fourth has been added recently;
4. Treatment of STDs.

Let now examine how useful these strategies are for women.

Reduction of sexual partners: Data from all over the developing world clearly shows that 60-80% of all infected women have only one sexual partner. Therefore, this strategy has no relevance for them. For those who, owing to economic reasons, are forced to sell or exchange sexual intercourse, it is still more irrelevant. Interviews with commercial sex workers working on the highways in Rajasthan brought out that insistence on using a condom melts away with the offer of a little extra money from the client.

Condom Usage: It is clear the men use condoms and it is a strategy exclusively for them. Most men do not use a condom at home and very few housewives can

successfully negotiate condom usage by their husbands even for family planning. Most rural women in the Women Development Project reported that after their awareness on HIV/AIDS, they started insisting on condom use after their husband's return from temporary migration. They faced angry husbands and some of them were beaten up for this unexpected demand. Women have neither the ability nor the leverage to protect them by this strategy.

Faithfulness, abstinence and celibacy: It is now very clear that most of the women who are getting infected are housewives who have no sexual partners other than their husbands. Faithfulness is, therefore, no protection. Also sexual assault in the form of rape and incest is a grim reality today and is borne out by the epidemiological data.

The strategies for prevention that are being advocated even after 20 years into the epidemic are for men and not women and are not within their control.

Vulnerability to HIV/AIDS of Women in Rajasthan

There are many reasons for vulnerability to HIV/AIDS of women in Rajasthan. Some of them are given below:

1. Poverty
2. Existence of Tribal Prostitution
3. Child Marriages
4. *Nata* system in many, especially poor, castes
5. A massive network of highways resulting in huge truck traffic. Highway prostitution is now seen in areas like Dungarpur, Banswara and Udaipur where it was absent earlier.
6. Heavy male migration to towns in search of work, especially during famines which are very regular
7. Heavy animal migration with males leading the herds and being away from their homes for months

8. Women's status being very low leading to difficult access to health care facilities. There has been a tremendous growth in reproductive tract infections and other sexual health diseases owing to high fertility.

Poverty

There are many geophysical disadvantages that the state faces. Situated in the northwest of India, with most of its terrain arid or semi-arid, Rajasthan is now the largest state in India after Chhatisgarh was formed. Its area of 3.42 lakh sq km is 10.4% of the area of the country but has only 1% of its water resources. There is an excessive dependence on ground water. There is a continuous over drawing because it provides water to 55% of the area under irrigation. More than 60% of the state's area covering 40% of the population and 11 districts lies west of Aravallis and is characterized by deficient and erratic rainfall. Last three years have been severely drought affected. Its women population is 5.46% of the country's women population. The socio-economic impact of the severe geophysical constraints is much more on them than on men.

The size of land holdings is small requiring much more care to survive as may be seen in the Table 1:

Table 1

Category	**% Total Holdings**	**Size**
Marginal	30	0.48 ha
Small	20	1.44 ha
Semi-medium	21	2.84 ha
Medium	20	6.22 ha
Large	9	18.69 ha
Total	100	3.96 ha

Source: Tenth Plan Document 2002-07. Government of Rajasthan

Owing to famines, out of the total reporting area of around 34250 thousand hectares, only 15509 to 17075 thousand hectares is sown on an overage.

Rajasthan ranks at 8th in population size among the States and Union Territories in the country. There has been only a marginal change in the Decadal Growth Rate from 28.44% in 1981-91 to 28.33% in 1991-2001. It ranks 24th in the population density because of its size but 29th in literacy in spite of a jump in literacy from 38.55% in 1991 to 61.03% in 2001 among the States in the country. For female literacy it is 30th in a list of 35 States and Union Territories. The States that are worse in female literacy are Bihar, Dadra and Nagar Haveli, J & K, Jharkhand and Uttar Pradesh.

Table 2

State	Literacy Rare (2001 Census) (in %)			Literacy Rate (1991 Census)	Change in Literacy Rate (1991-2001)
	Persons	Males	Females	Persons	
Rajasthan	61.03	76.46	44.34	38.55	22.48

Source: Provisional Population Totals India: Census of India 2001. Paper 1 of 2001

Rajasthan's rural population has been declining very gradually from 78.95% in 1981 to 76.62%. The largest percentages of rural population are in Jalore (92.41%), Barmer (92.60%), Dungarpur (92.76%) and Banswara (92.85%). Except for Banswara which is ranked at 18 among the districts of Rajasthan under the Gender Development Index, the first three are ranked at 30, 29 and 31 respectively. The first two are desert districts that are under famine conditions almost every year and the last two are tribal districts.

Rajasthan has a large livestock population of 54.4 million heads of cattle, sheep, camels and goats with women and girls spending a major share of their time in grazing them and tending to them at home.

The following Table 3 gives a comparative picture of the State's net domestic product at current prices in 1999-2000 and per capita income at current prices in 2000-01.

Table 3

State	**Per capita Income (In Rupees)**
Andhra Pradesh	16562
Bihar	5108
Gujarat	18922
Haryana	23057
Karnataka	18041
Kerala	19463
Madhya Pradesh	10666
Maharashtra	22179
Orissa	9273
Punjab	24111
Rajasthan	11986
Tamil Nadu	20367
Uttar Pradesh	9721
West Bengal	16115

Source: Provided by various State Directorates of Economics & Statistics

From the figures it is seen that Rajasthan is better than only Bihar, Orissa, Uttar Pradesh and Madhya Pradesh in per capita income.

Deprivation Levels

From the House listing Data collected for rural households by the Census of India in 2001 it is seen that

31.3% rural households depend on hand pumps, 30% on wells, 7.6% on tube wells and 9.4% on tanks, ponds and other unclean sources of water for drinking purposes.

Only for 6.5% households, these sources are within their premises, for 92.9% they are far away.

56% households are still without electricity compared to 64% in 1991. 54.7% still use kerosene for lighting.

85.4% rural households have no latrines. The figure has gone up from 80% in 1991. 79.5% have no privacy for taking a bath.

For 29.7% there is no separate kitchen inside the house and 20.5% cook in the open.

94.4% still use firewood, crop residue and cow dung cake for cooking purposes. Only 1.2% use kerosene.

18.9% houses have thatched roofs, 27.6% mud walls and 57.9% mud floors. They all need constant maintenance mostly by the women of the household.

34.2% houses have only one room for the entire family, an increase from 33.8% in 1991. It is seen that 14.6% houses having nine or more members also had only one room. There is no privacy for sex.

With only 31.7% households owning a transistor and 16.6% a television, information dissemination through audio-visual media is very difficult.

The growth in female literacy has not played a catalytic role in other spheres. As we have seen the decadal growth rate has not shown a significant downtrend. The 0-6 sex ratio of 909, far worse than the sex ratio of 922, proves that girls are still considered a burden which should be unloaded as quickly as possible by either marrying them off early or by killing them in their infancy. The age at marriage is still lower than the prescribed legal age. About 60% women have to depend on their husbands or families for approval if they have to seek medical attention. More than 50% are still beaten by their husbands.

Tribal Prostitution

In Rajasthan almost all women in prostitution are either *dalits* or tribals. A survey by the Central Social Welfare Board in 1996 pointed out the 36.7% belonged to the S.C./S.T., 24.24% to backward classes and 39.19 to other castes. Most of these tribes are concentrated in south-east Rajasthan. The commercial sex workers in Sirohi district are in the proximity of Jaipur-Mumbai highway and Jodhpur-Mumbai road. All over Rajasthan, truck drivers constitute the largest segment of customers catered to by these commercial sex workers. The concentration of these tribes along the U.P. and M.P. borders could be owing to these areas being infested with dacoits under whose protection prostitution flourished. Some concentrations are found on the Jaipur – Agra highway because of growing tourism, especially at Bharatpur. The settlements in Alwar are on the Alwar –Delhi highway and there is a huge clientele from Delhi. Similar reasons are for the growth of settlements of these tribes in Dholpur, Baran and Karauli.

The Kanjaras and Rajnats are mainly involved in the sex trade in Jaipur. The girls have been found to be as young as 11-12 years old. They are controlled by the elder women of the family who teach the basics of the trade to them. Every girl attends to 5-6 clients every day. The average income of a girl is only Rs. 1500-2000 p.m. Condom use is quite negligible and only some educated clients use them. They bring their own condoms. They are not available in the vicinity. Nearly all the girls are addicted to liquor, smoking and chewing tobacco. Knowledge of HIV/AIDS is very low.

Almost all the sex centers are situated in the remote areas for away from the highways and general village communities and are deprived of essential services like safe drinking water, medical facilities, education, etc. The sex workers are not allowed to drink from the public taps. Males in the family work as pimps.

In Ajmer district, sex workers are spread along the highways and not in the remote areas. They are also *rajnats* and *kanjars*. The older members of the families work as pimps.

In Tonk district mainly *rajnats* are involved in the sex trade. Male members sell liquor.

In Bundi, mainly *kanjars* are involved in the sex trade. Condoms are not available.

In Udaipur, *Bheels* and *Meenas* are the main tribes involved in sex trade. The trade prospers along the national highway. The main cause of adopting prostitution is poverty and not tradition like in the *kanjars* and *rajnats*. The trade flourishes throughout the night because of the truckers who mainly pass by at night. There is no condom use. The girls drink and smoke. They are oblivious of the HIV/AIDS pandemic. The males of family have small cultivable lands.

In Dungarpur and Banswara *Bheels, Meenas and Bheel Meenas* are involved in this trade. It is poverty which has led them into prostitution. The girls sit along the highways at night to attract truckers. There are no medical facilities. They have no knowledge of HIV. Males work as agricultural labour during the sowing season.

In Bharatpur, *Bedias, Kanjars and Rajnats* work in the sex trade. The sex centers are situated in remote areas far away from highways and general habitations. Girls have also been brought from Bihar, West Bengal. Nepal, Bangladesh, etc. Sex is sold around the clock. Those who have information on HIV are not willing to pass it to others. Males are involved in trafficking of liquor and girls.

In Dholpur, mainly the *Bedias* are involved in the trade. They are protected by armed touts. The girls look after their households during the morning and attend the clients the rest of the day and night. Most of the clients want to avoid condoms.

At many places situated in the interior, jeeps are used to bring the clients from the main roads.

Amongst the *Bedias*, women sell sex only till they are married. A number of these girls go to Mumbai to learn new sex practices. The *Rajnats* are women-headed. They took to prostitution after the feudal system, which supported their gymnastic activities, collapsed and left them penniless. These women are more free to talk to outsiders.

In the *Bheels* the practice of free sex at the monthly *ghotuls* puts the partners at great risk of HIV/AIDS.

The *Kanjars* are nomadic. They used to live in forests but after the forests were cut and as they did not own land they were forced into prostitution. The men of the tribe are engaged in criminal acts.

Surveys have shown that the clients are willing to pay more to avoid a condom if the sex workers insist on them. Condoms are not available in and around the sex centers.

Age wise involvement of girls in sex trade reveals that a substantial number of girls are in the 10-16 age group as shown in the Table 4 below:

Table 4

Total	Above 17	10-16 years
4088	2891	1197

Child Marriages

Women in Rajasthan still marry early. 49% in age group 15-19 are already married, including 11% who are married but the *gauna* has not been performed. Rural-urban break up in this age group shows that 57% rural girls are already married compared to 27% in urban areas.

It may be seen that the mean age at marriage for rural girls is still below 18 years. Also girls between the ages 6 to 14 are getting married but are waiting at

their parents' place because they have not reached menarche' to start their reproductive role.

Child marriage is an established social custom in Rajasthan. It is a common sight to find little children, even infants, getting married on an auspicious day called *aakha teej*. The custom is still so widely prevalent that in the local language it is said that the infant is being married in *peelay potre*. It is, therefore, not an uncommon sight to see either the parents or an uncle or aunt carry the child in arms or have the child put in a *thali* in order to perform the traditional *phere* of the wedding. The most common tradition is to marry off all the girls in the family at the time the older girl reaches a marriageable age of 10-12 years.

If a girl is married young, she is not sent to her husband's place immediately. She may go for a few days after marriage but then she comes back to her parents and goes to start her marital life after she attains puberty and parents have performed a ceremony called *muklava, sava or ano*. This may be an elaborate affair with the groom coming with two or three persons to the bride's house and after spending a day or two, taking her back along with him. Among the backward scheduled castes and scheduled tribes exists the custom of bride price in economically backward families. This bride price custom is now gradually losing its hold. On the other hand the custom of dowry is prevalent in all the casters. Among the forward castes, dowry is even demanded from the groom's side.

Reasons for Child Marriages

Both boys and girls start working in the rural areas much before their counterparts in the urban areas do. Similarly, children of SC/ST and other poorer castes start working earlier than their counterparts from the higher castes. The girls start much earlier than boys and, therefore, their sexual security is at risk much earlier.

Child marriage is a common practice among scheduled castes as well as some muslim communities and some scheduled tribes. The practice does not exist in *Brahmins, banias, mahajans and rajputs*. The practice is wide spread in *Yadavs, lohars, kumhars, nais, rawats*, S.C. groups like *bagaria, berwa, regar, chamar, balai, khatik, sansi, dhobi, dhanak, bhand, kolis,* etc. In some sub-castes, the practice started catching up later only to emulate other castes.

Some of the salient reasons given for child marriages are given below:

1. Early marriages are less expensive
2. It is an age old social custom
3. It is a practice to marry all the girls in the family when an older one at the age of 11-12 years is getting married to save money
4. Sometimes, if a number of boys are available for marriage is a single family, all the daughters of the house are married together
5. Pressure of grandparents to see their grand children get married during their life time to see their progeny grow
6. To avoid involvement with the opposite sex because girls are constantly in the fields or forests for grazing their cattle.
7. As most of the marriages take place in childhood, if the marriage is delayed it becomes difficult to find a suitable match
8. There is a custom that if the proposal of a girl is refused, parents of other girls refuse to send proposals for their daughters to that house.
9. In order to avoid expenditure on a marriage, a child is married when a *mausar* (death feast) is held on the death of an old person. Similarly, whenever an occasion arises when a feast has to be given to the community, the occasion is used for the marriage of the children. This happens in poverty-ridden castes and tribes.
10. *Akha teej* is a very popular day for mass marriages, especially in the districts of Ajmer, Bhilwara, Tonk, Chittorgarh, Jodhpur and Jaisalmer.

The Child Marriage Restraint Act has not been effective to curb the practice. The State Government is not in favour of amending the Act to make the offence cognizable. Both the Woman and Child Development and the Medical and Health Departments have launched vigorous drives for awareness generation. As registration of marriages will go a long way in curbing the practice, there is an urgent need to expedite the Marriage Registration Bill which is still pending.

The *Nata* Custom

The *Nata* Custom interestingly, the castes in which child marriages take place also have the custom of *nata* or remarriage. A boy can be married more than once but if a girl has to be remarried, only *nata* is possible. This is a simple ceremony that varies from caste to caste but never includes the traditional *pheras* of the Hindu marriage. Sometimes, the boy can just come and stay in the girl's house and with the permission of the parents, take the girl to his home. Thus, they become man and wife. In some castes the girl has to carry a pot of water on her head, from the well to the house of the man she wants to marry. The man takes the pot from her head and puts it aside. This simple ceremony makes them man and wife. The custom of *nata* is prevalent among *regars, gujars, meenas, berwas, khatiks* and other scheduled and backward castes. It is not prevalent among the *brahmins, banias, rajputs, mahajans and jains.*

Nata generally takes place when either of the spouse dies, or there are mutual disagreements or when one of the spouses leaves the other. Generally, it is the woman who leaves the man. This could be related to the fact that matches are readily available for girls but not for boys. It could also be due to adverse sex ratio. *Nata* is also possible when no child is born, or the girl is unhappy in the in-law's house or due to physical incompatibility of the partners. In some cases it happens because the girls father wants to make some money. For the custom is

that the man who takes the girl in *nata* has to give money to the former husband. Sometimes he has to give to both the husband and the father.

Animal Migration

In addition to the human migration, there is annual migration of cattle and sheep from an area owing to lack of fodder. It is estimated that every year one to two lakh cattle and sheep breeders migrate with 30 lakhs of animal heads from their villages.

Nomadism is a traditional practice in Rajasthan.

There are three types of nomadic groups : Pastoral Nomads, *Khanabadosh* or the wandering tribes and the semi-nomadic tribes. The pastoral nomads travel because of the need for fodder for their herds of cattle, sheep, goats and camel. The *khanabadosh* also do it to make a living as food gatherers, musicians, quack doctors, traders or artisans. They are homeless and herd less. The semi-nomads have their own homes and agriculture lands but travel around from time to time to make a living. The geographical nature of the land, continuous famines, lack of carrying capacity of the land, shrinking land for pastures, absence of any policy by the government to improve pasture lands, shortage of drinking water for men and animals are factors that have contributed over the years to make these nomads resist any changes in their way of living. Pastoral nomads do have their village homes but as their economy depends entirely on animals they are constantly on the move for grazing purposes but they return home once a year when the rains come. Most of these pastoral nomads belong to the *rsika* community. In Rajasthan they are also known as *Rebaris*. They take not only their own herds of animals for grazing but also of other villagers. In addition to the *raikas*, non-pastoral nomads like *banjaras, jogis, nats, kalbeliyas, gadoliya luhars,* etc are also on the move to entertain people or to perform small tasks like iron smithy.

In Rajasthan the districts from where pastoral migration usually takes place are Barmer, Jaisalmer, Nagaur, Jodhpur, Pali, Sirohi and Ajmer. The migration destinations are Haryana, Uttar Pradesh, Madhya Pradesh and Gujarat.

Raikas are the largest group of pastoral nomads. Each year hundred of thousands embark on their migratory journeys that can cover distances as far as 1200 kms and that last till the next rains. Every day they camp at a new location. Each herd of animals is looked after by men and boys of various age groups. Although no authentic figures are available, nearly one lakh *raikas* are on the move every year in addition to other nomadic groups.

Earlier there was a very healthy relationship between the pastoral nomads and agriculturists. The animals will eat away the unnecessary grass and foliage from the fields so that the new crop could be sown without much labour. In return the animals would leave their droppings that would be very good manure. But with growing pressures on land and production of up to three crops in fields, very little grazing land is now available for the migrating animals and frequent violence is now seen in the rural areas during animal movements. Therefore, traditional routes are now being replaced by carefully laid down paths to avoid skirmishes.

In addition to the above-mentioned kind of migration which is considered to be temporary because these herds return to their homes at least once in a year, there is another kind of pastoral migration which is called permanent migration in which return to home may be delayed for years.

During these migrations, the nomads may or may not carry their wives. Older women and young children are invariably left behind. Most of them have no assets and therefore live a miserable life especially during famine years when they do not get employment even as an agriculture labourer.

The nomadic groups consist of many families of the village and several times families of adjoining villages also join them. So there is plenty of inter-

action that could be sexual also. There is no study of the sexual behaviour of those men who do not take their wives and stay away from homes for months and sometimes years. Wives do report that when their husbands return home there is excessive unsafe sex.

POOR HEALTH STATUS OF WOMEN IN RAJASTHAN

Health Care System in Rajasthan

It is also known that women's access to health care is as difficult as their access to other spheres like education and employment. During a study made by the author of this report, most of the women interviewed complained about it. Other major reasons are:

1. Reluctance of the family to take a woman/girl child to the health facility unless she is in a precarious condition. There is no sympathy shown by any one in the family about her ill health.
2. Distance of the facility coupled with the lack of transport and money to go there. In Jaisalmer, the nearest health center is at an overage distance of 35 km from a village.
3. Shortage of women staff at rural health centers.

A sub center is the lowest unit of health care. In Rajasthan, a recent survey showed that most of them have no electricity or water supply. Thirty percent did not have sufficient space for even a check up, 57% for delivery and 32% for IUD insertion.

There is also a big tilt in favour of urban facilities. The Table 5 below gives the number of facilities in Rajasthan in 2000-2001:

Table 5

Item	Number
Hospitals	
Urban	205
Rural	14
Dispensaries	
Urban	268
Health Centers	
PHCs	1674
Sub Centers	9926
Community Health Centers	263
MCW Centers	
Urban	92
Rural	26
In patient Beds	
Urban	21116
Rural	16802

Source: Tenth Five-Year Plan Document. Govt. of Rajasthan

That women are far less served by the health system is proved amply by the large gap between the general health index which is 0.6060 and the gender-related health index which is 0.4399 in Rajasthan. It is an indicator of gross discrimination against women.

Poor Sex Ratio and Poorer 0-6 Sex Ratio

The following Table 6 shows the Sex Ratio and 0-6 Sex Ratio in various districts of Rajasthan.

Table 6

District	Total Sex Ratio		0-6 Years Sex Ratio	
	Rural	Urban	Rural	Urban
Ganganagar	881	848	863	815
Hanumangarh	895	899	875	862
Bikaner	896	878	917	909
Churu	953	936	915	905
Jhanjhunu	958	902	871	850
Alwar	896	838	895	838
Bharatpur	854	867	878	861
Dholpur	821	857	863	840
Karauli	855	876	873	894
S. Madhopur	890	886	901	895
Dausa	900	888	903	872
Jaipur	915	878	908	881
Sikar	959	924	880	891
Nagaur	958	920	920	919
Jodhpur	922	883	925	906
Jaisalmer	832	764	869	847
Barmer	899	858	924	892
Jalore	975	890	925	908
Sirohi	962	868	930	844
Pali	1003	914	930	916
Ajmer	952	902	930	907
Tonk	933	945	926	906
Bundi	909	905	914	874
Bhilwara	982	899	960	912
Rajsamand	1013	927	937	916
Udaipur	988	903	954	877
Dungarpur	1035	935	967	885
Banswara	982	930	978	852
Chittorgarg	974	923	934	890
Kota	909	884	904	899
Baran	907	915	921	901
Jhalwar	931	906	935	996

Source: Provisional Population Totals Rajasthan: Papa 2 of 2001. Rural-Urban Distribution of Population

High Total Fertility Rate

The figures below in Table 7 show the total fertility rates in Rajasthan.

Table 7

Urban	3.0
Rural	4.1

Source: National Family Health Survey-2 1996-99. Rates are for 1996-98.

Some women become mothers of three children by the time they are 19.

Crude Birth Rates

Crude Birth Rates in Rajasthan as compared to the National figures in various years are given below in Table 8.

Table 8

Year	Rajasthan	India
1985	39.7	32.9
1991	35.0	29.5
1995	33.3	28.3
1997	32.1	27.2

Source: Sample Registration Bulletin 1998.

Crude Death Rates in various years in Rajasthan and India are given below in Table 9 and Infant and Child Mortality Rates in Table 10

Table 9

Year	Rajasthan	India
1985	13.2	11.8
1991	10.1	9.8
1995	9.1	9.0
1997	8.9	8.9

Source: Sample Registration Bulletin 1998.

Table 10

Infant and Child Mortality in Rajasthan

	Urban	**Rural**	**Total**
Neonatal Mortality	45.2	50.6	49.5
Postneonatal Mortality	24.5	32.5	30.9
Infant Mortality	69.7	83.0	80.4
Child mortality	24.2	41.0	37.6
Under-five Mortality	92.3	120.6	114.9

There has been an overall decline in infant and child mortality. However, one in every 12 children born is dying within the first year of life and one in every 9 children before reaching five years.

Other Vulnerability Factors

Current Contraceptive Use	
Condom	3.1%
Female Sterilization	30.8%
Safe Motherhood and Women's Reproductive Health	
Percent of births whose mothers were assisted at delivery by a:	
Doctor	19.5
ANM/nurse/midwife/LHV	16.1
Traditional birth attendant	40.8
Percent reporting at least one reproductive Health problem	43.2
Awareness of AIDS	
Percent of women who have heard of AIDS	20.8
Nutrition	
Percent of women with anaemia	48.5
Percent of women with moderate/severe anaemia	16.2

Chapter II

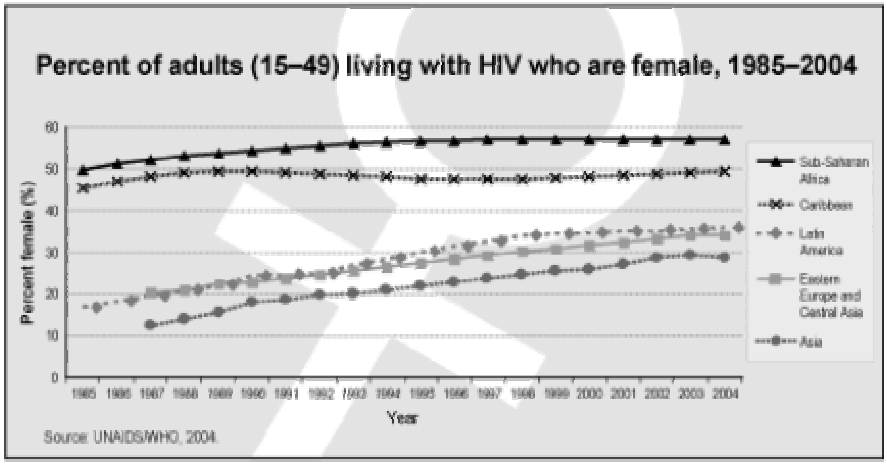
THE HIV/AIDS SCENARIO

Table 11
HIV/AIDS - THE GLOBAL PICTURE
WORLD AIDS SCENARIO

	1998	1999	2000	2001	2003	2004
People infected in						
Total	5.8m	5.6m	5.3m	5m	5m(4.2-5.8m)	4.9m(4.3-6.4m)
Adults	5.2m	5m	4.7m	4.3m	4.2m (3.6-4.8m)	4.3m(3.7-5.7m)
Women	2.1m	2.3m	2.2m	1.8		
Children <15 yr	59000	570000	60000	800000	700000 (59000-810000)	640000(570000-750000
People living with HIV/AIDS						
Total	33.4m	33.6m	36.1m	40m	40m (34m-46m)	39.4m(35.9-44.3m)
Adults	32.2m	32.4m	34.7m	37.2m	37m (31-43m)	37.2m(33.8-41.7m)
Women	13.8m	14.8m	16.4m	17.6m		17.6m(16.3-19.5m)
Children <15 yr	1.2m	1.2m	1.4m	2.7m	2.5m(2.1-2.9m)	2.2m(2.0-2.6m)
AIDS Deaths						
Total	2.5m	2.6m	3.0m	3m	3m(2.5-3.5m)	3.1m(2.8-3.5m)
Adults	2.0m	2.1m	2.5m	2.4m	2.5m(2.1-2.9m)	2.6m(2.3-2.9m)
Women	900000	1.1m	1.3m	1.1m		
Children <15 yr	510000	470000	4.3m	580000	500000(4200760-580000)	510000(460000-600000)
Total Deaths since the beginning of the epidemic						
Total	13.9m	16.3m	21.8m	24.8m		
Adults	10.7m	12.7m	17.5m	19.9m		
Women	4.7m	6.2m	9.0m	10.1m		
Children <15 yr	3.2m	3.6m	4.3m	4.8m		

The AIDS epidemic is affecting women and girls in increasing numbers. Globally, just under half of all people living with HIV are females. In most regions, an increasing proportion of people living with HIV are women and girls, and that proportion is continuing to grow, particularly in Eastern Europe, Asia and Latin America, as shown in the graph below.

Graph



AIDS is affecting women most severely in places where heterosexual sex is a dominant mode of HIV transmission, as is the case in sub-Saharan Africa and the Caribbean. Women and girls make up almost 57% of adults living with HIV in sub-Saharan Africa. Overall, three quarters of all women with HIV worldwide live in that region. According to recent population-based household surveys, adult women in sub-Saharan Africa are up to 1.3 times more likely to be infected with HIV than their male counterparts (UNAIDS, 2004). This unevenness is greatest among young women aged 15–24 years, who are about three times more likely to be infected than young men of the same age.

Graph

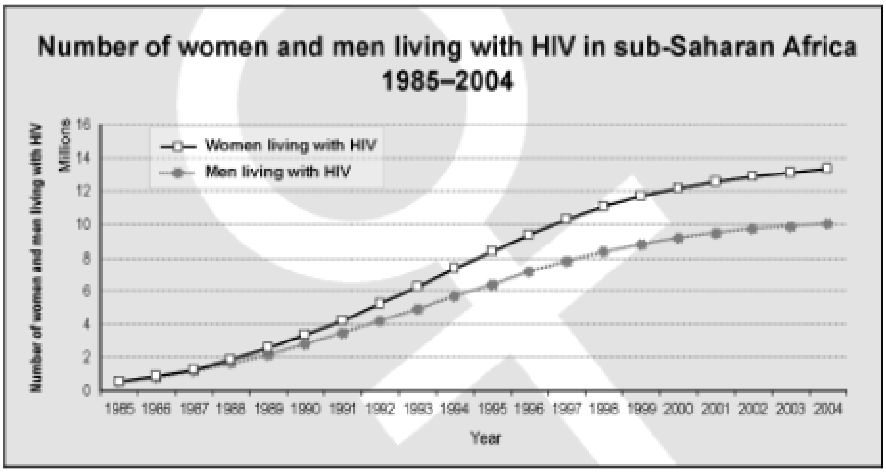


Table 12

HIV and AIDS

End of 2002 and 2004 in Asia

	Adults and children living with HIV	Number of women living with HIV	Adults and children newly infected with HIV	Adult prevalence (%)	Adult and child deaths due to AIDS
2004	8.2 million [5.4–11.8 million]	2.3 million [1.5–3.3 million]	1.2 million [720 000–2.4 million]	0.4 [0.3–0.6]	540 000 [350 000–810 000]
2002	7.2 million [4.6–10.5 million]	1.9 million [1.2–2.8 million]	1.1 million [540 000–2.5 million]	0.4 [0.2–0.5]	470 000 [300 000–690 000]

Table 13

HIV/AIDS- The Indian Scenario

The Growth of Full Blown AIDS Cases in India (Cumulative)

Month & Year	Male	Female	Total	% Female
31/10/04	65828	25252	91080	27.7
31/12/03	44975	16226	61201	26.5
30/11/02	31786	10625	42411	25.05
30/10/01	22023	6984	29007	24.07
1986-01/01	13787	4210	17997	23.4
31/03/00	8850	2401	11251	21.3

The above figures clearly show that the percentage of women infected is rising steadily. Let us examine the percentage of females in various age groups over the same period.

Table 14

Month & Year	**10/04**	**12/03**	**11/02**	**10/01**	**86/01**	**Age Group**
% Female out	**40.4%**	**39.1%**	**38%**	**37.9%**	**37.1%**	**0-14**
of Total	**37.3%**	**35.3%**	**32.3%**	**30.3%**	**27.2%**	**15-29**
	21.9%	**20.9%**	**19.8%**	**18.6%**	**18.6%**	**30-44**

It is clear that a much larger number of AIDS cases among women are found in the 0-29 year age group than above 30 years.

We may also look at the percentages of women in various age groups out of the total women in that year and compare the figures for men in the same age group. The figures for men are given in parenthesis. The Table 15 below gives the comparison.

Table 15

Month & Year	Oct 2004	1986-2001	Age Group
	6% ,(3.4%) 44.3%, (28.5%) 44%, (60%)	6% (3.1%) 49% (39.7%) 36% (48%)	0-14 years 15-29 years 30-44 years

There are more women in the 0-29 year age group than in 30-44 years age group compared to men.

The following Table16 gives the number of AIDS cases up to September 2004.

Table 16

AIDS Cases	Cumulative
Male	65828
Female	25252
Total	**91080**

Table 17

Risk / Transmission Categories

Sexual	78177
Perinatal transmission	3048
Blood and blood products	1923
Injectable Drug users	2583
Others (not specified)	5349
Total	**91080**

Table 18

Age Group Distribution

Age Group	Male	Female	Total
0-14 yrs	2250	1527	3777
15-29 yrs	18803	11182	29985
30-49 yrs	39611	11135	50746
>50 yrs	5164	1408	6572
Total	**65828**	**25252**	**91080**

Table 19

Statewise AIDS Cases in India (Reported to NACO)

(As on 30th September, 2004)

S.No.	State / UT	AIDS Cases
1.	Andhra Pradesh	9549
2.	Assam	225
3.	Arunachal Pradesh	0
4.	A & N Islands	33
5.	Bihar	155
6.	Chandigarh (UT)	964
7.	Delhi	925
8.	Daman & Diu	1
9.	Dadra & Nagar Haveli	0
10.	Goa	440
11.	Gujarat	4667
12.	Haryana	382
13.	Himachal Pradesh	182
14.	Jammu & Kashmir	2
15.	Karnataka	2043
16.	Kerala	1769
17.	Lakshadweep	0
18.	Madhya Pradesh	1202
19.	Maharashtra	12783
20.	Orissa	128
21.	Nagaland	507
22.	Manipur	2866
23.	Mizoram	922
24.	Meghalaya	8
25.	Pondicherry	302
26.	Punjab	292
27.	Rajasthan	1089
28.	Sikkim	8
29.	Tamilnadu	37087
30.	Tripura	5
31.	Uttar Pradesh	1383
32.	West Bengal	2397
33.	A, bad Mun.Corp.	399
34.	Mumbai M.C.	5711
	Total	**87596**

The High Prevalence States in India

As per the National AIDS Control Organisation, high prevalence states are those where the HIV prevalence in antenatal women is 1% or more. Moderate prevalence states are those where it is less than 1% and among STD-infected is 5% or more. Low prevalence states are those where the prevalence is less than 1% in antenatal women and less than 5% in STD clinics. According to it, the status in 2002 was as follows:

Table 20

Rajasthan	Moderate
Maharashtra	High
Andhra Pradesh	High
Karnataka	High
Kerala	Low
Tamilnadu	High

Number of Full Blown AIDS Cases in these States as on 30th September 2004

(as per Govt. of India, NACO Statistics)

Table 21

Rajasthan	1089
Maharashtra	12783
Andhra Pradesh	6134
Karnataka	9549
Kerala	1769
Tamilnadu	40214

Percentage of Women Infected

As per NACO, in high prevalence states, for every infected female there are 1.2 infected males, in moderate prevalence states for every female infected there are two males and in low prevalence states, for every infected female there are three infected males.

Situation in Rajasthan

The number of cases year wise up to October 2004 in Rajasthan is given below in Table 22

Table 22

Year	Total	M	F	F as % of Total
2000	82	54	28	34.1
2001	99	66	33	33.3
2002	281	189	92	32.7
2003	372	242	130	34.9
2004(Oct)	454	313	151	33.2
Total	**1288**	**864**	**434**	**32.9**

The figures show that women now constitute 32.9% of total full-blown cases in the State that is alarming. The following Table gives age wise distribution of AIDS cases

Table 23

Year	Total	M	F	F as % of Total
0-10	79	52	27	34.1
11-20	56	29	27	48.2
21-30	582	344	238	40.9
31-40	451	339	112	24.8
41-above	120	100	20	16.6
Total	**1288**	**864**	**424**	**32. 9**

Source : Department of Medical and Health, Government of Rajasthan

* Cases reported at the Department of Skin, STD, Leprosy and AIDS

It is not surprising that the largest number of women is in the 21-30 year age group. Some of them might have been infected when they were in their teens. More alarming is the fact that out of 56 cases in the age group 11-20, 27 are girls. Women are getting infected far earlier in life than men.

Comparing the infection rate of women in Rajasthan with the country, it is found that out of a total of 91080 cases of full blown AIDS reported in the country till 31st Oct.04, there are 25252 women, which is 27.7%. It is lower than the Rajasthan figure of 32.9%

It is seen that the infection rate in the young adolescents and adult women in Rajasthan is far more than in the country. The major mode of transmission of the virus is hetero sexual in Rajasthan as in the country. The pre-natal transmission in Rajasthan at 2.56% is almost same as of the country at 2.68%.

Chapter III

NEED FOR A STUDY IN RAJASTHAN

It has been very clear all the time that HIV/AIDS is not a health issue only. Even if it were, with the invisibility of women to the health care system, women would have suffered far more than men under the impact of HIV/AIDS. With its socio-economic impact the fall out on women is expected to be far worse than on men. The epidemic is certainly biased against women. Clinically also, it has a far worse impact on women who move more rapidly towards death than men even when the treatment given is the same. With more and more ordinary housewives unwittingly getting infected from their husbands, they may die before knowing what has struck them because their problem may not be diagnosed at all. Even if they come to know about it, they may hide it for fear of strong stigma attached with it. They may be blamed for the infection to their husband. Even anti-retroviral medicines have far more serious side effects on women than on men. Strategies for preventing HIV infection are male- oriented. Women have no control on the number of sexual partners their husbands have had. They cannot negotiate the use of condoms by their husbands. They may be highly faithful to their sexual partner but they cannot be sure about his faithfulness. Most of them cannot even question him. Much before they know the meaning and purpose of menstruation, they start having sex. It is, therefore, important to talk to these women and find out what they want and would be able to do prevent getting infected.

It is a paradox that in states where the HIV prevalence rates are high, the status of women is also better. May be that is one of the reasons why women have been able to get tested for HIV. They have also been able to set up a large

number of NGOs working in the field. They have also been able to negotiate large amounts of funds from multinational funding agencies and have good counseling networks. Rajasthan lacks all these factors. There may be a very large number of women who are suffering in silence and are also be passing the infection to their children in the womb or while feeding.

Objectives

- To study the vulnerability of women to HIV/AIDS in Rajasthan;
- To find ways and means to ameliorate the condition of women already infected;
- To link health and family planning facilities for women with their accessibility;
- To devise a plan of action for developing women based awareness programmes with traditional approaches and modern technology;
- To find ways for women's empowerment to negotiate the use of condoms by their sex partners;
- To make recommendations for the Rajasthan State health Care System to tackle the growing demand for looking after women with HIV/AIDS.

Methodology of Study

Field Survey: As very little is known about the status of female infection in the rural areas of Rajasthan, it was necessary to have a detailed field survey for at least three months. The aim was to

1. Identify the vulnerability issues
2. To look into the social, sexual and cultural practices in different areas
3. To examine the sexual behaviour patterns
4. To hold community meetings in rural areas to help investigations

5. To meet NGOs, if any, working in the area of HIV/AIDS prevention

Sample Size for Study

There are more than 50000 estimated cases of HIV/AIDS. About 20% of them are women. That shows that more than 10000 women in the state are HIV+. More than 300 of them are officially having full-blown AIDS. Owing to the confidentiality about the HIV status, it was difficult to have a large sample size. However, the study could interview about 106 women infected with HIV/AIDS.

The District wise gender disaggregated figures of full-blown cases of AIDS are not known. However the total figures district wise are as follows:

Table 24
District and Year wise reported AIDS Cases in Rajasthan

SN	District	1987-96	1997	1998	1999	2000	2001	2002	2003 (Aug)	2004 (Nov)	Total
1.	Ajmer	10	4	0	6	0	2	10	4	13	49
2.	Alwar	1	0	0	0	4	8	12	6	22	53
3.	Banswara	1	0	0	1	0	1	0	1	1	05
4.	Baran	0	0	0	0	0	1	2	0	0	03
5.	Barmer	0	0	0	0	0	0	0	3	0	03
6.	Bharatpur	0	1	0	0	1	1	5	4	6	18
7.	Bhilwara	1	0	0	0	1	3	9	2	14	30
8.	Bikaner	0	0	0	2	0	5	7	5	9	28
9.	Bundi	1	0	1	0	0	1	2	0	1	06
10.	Chittorgarh	0	0	0	1	2	1	0	2	0	06
11.	Churu	1	1	1	1	2	3	4	8	9	30
12.	Dausa	0	0	0	0	0	0	7	5	3	15
13.	Dholpur	0	3	2	0	0	0	2	1	8	16
14.	Dungarpur	3	0	0	1	2	4	1	2	6	19
15.	Hanumangarh	0	0	0	0	0	2	1	3	3	09
16.	Jaipur	0	0	2	8	43	21	71	44	60	249
17.	Jaisalmer	0	0	0	0	0	0	0	1	0	01
18.	Jalore	1	0	0	0	0	1	0	8	1	11
19.	Jhalawar	0	0	0	0	0	0	0	1	0	01
20.	Jhunjhunu	1	0	0	1	16	3	17	14	15	67
21.	Jodhpur	1	1	0	0	0	3	0	9	0	14
22.	Karauli	0	0	0	1	2	0	6	2	0	11
23.	Kota	2	0	0	0	1	6	10	17	8	44
24.	Nagaur	1	0	0	0	9	7	32	14	27	90
25.	Pali	7	0	0	0	3	3	1	16	2	32
26.	Rajsamand	2	0	0	3	2	3	0	5	0	15
27.	Sawai Madhopur	0	0	0	1	1	2	5	1	1	11
28.	Shriganganagar	0	0	0	0	0	0	0	2	2	04
29.	Sikar	1	3	3	3	28	8	42	33	33	154
30.	Sirohi	6	1	1	2	1	0	0	2	6	19
31.	Tonk	0	1	0	0	0	0	7	7	10	25
32.	Udaipur	11	0	0	1	7	7	15	10	9	60
33.	Other States & Foreigners	3	9	0	3	11	2	22	18	15	86
34.	NA							2	1	0	
	Total	**54**	**24**	**10**	**35**	**136**	**98**	**292**	**251**	**259**	**1184**

It may be seen that full-blown AIDS cases are now found in all the districts in Rajasthan. The concentration is in the desert belt, primarily the *Shekhawati* region and eastern Rajasthan. What is the exact status of each district has to be look into.

It may also be seen from the Table 25 below that the STD cases among women is also increasing.

Table 25

Report of STD Cases Treated at Identified STD Clinics

Year	Male	Female	Total	% of Female
1999	2375	3408	5783	58.9
2000	3689	2676	6365	42.0
2001	5407	4633	10040	46.1
2002	5358	6116	11474	53.3
2003 (Sep.)	5050	6023	11073	54.4
Total	**21879**	**22856**	**44735**	

The Table 26 below shows the rate of growth of full blown cases of AIDS between 2002 and 2004.

Table 26

Year	AIDS cases in Rajasthan
Upto Nov.2002	254
Upto Nov.2003	351
Upto Nov.2004	462

Source : Department of Medical and Health, Government of Rajasthan

* Cases reported at the Department of Skin, STD, Leprosy and AIDS

Chapter IV

FIELD SURVEY

When the initial proposal of the Study was made and submitted to the National Commission for Women, New Delhi, it was envisaged to have a detailed survey of those districts in the State that had a large number of men and women reported to be suffering from HIV/AIDS. However, as the Commission substantially reduced the grant for the Study and did not allow any increase in spite of the request that fieldwork of the nature that required interviews with a category of women suffering from the most stigmatized infection in the world requires much more funding than in the routine investigations, we had to curtail the coverage.

Methodology of the Survey

Rajasthan was divided into zones and districts having the highest number of reported AIDS cases in each zone were selected.

Preference was also given to those districts that had strong community-based NGOs willing to help us in their areas of work.

It was decided to send a team consisting of one man and one woman to each district for the survey.

As it was decided to have a questionnaire-based survey, three types of proformas were prepared:

1. Village profile: semi-structured
2. Family profile: semi-structured
3. Interview with the women respondents: semi- structured.

Copies of the profiles are annexed.

Training Programme

Before the teams were sent to the field, a two-day training programme of the team members, resource persons of Shantideep and various NGOs and women's groups was organized under the auspices of the Women's Resource Center, Rajasthan State Institute of Public Administration, Jaipur.

FORMAT I

City / Village Details (under study)

(100 Villages Profile)

1	Geographical Position			Hilly –26 Plain – 35 Desert – 30 Others – 09		
2	Housing Position of Village / City			Houses in groups – 35 Houses in isolation – 38 Systematic – 15 Others – 12		
3	Number of houses			Max. – 4000 Min. – 145		
4	Total population			Max. – 50,000 Min. – 650		
5	Caste Wise No.'s			(Range) Gen . 30-5000 SC 75-1000 ST 125-3500 OBC 180-5000 Ors 150-600		
6	Caste Occupancy details	Brahmins, Chipa, Lohar, Suthar, Muslims, Rawat, Jat, Raiger, Mali, Gurjar, Harijan, Mahajan, Yadav, Bairwa, Khati, Nut, Bagadia, Meena, Sansi, Migrants from Bihar/Bengal/Gujarat				
7	Religion Wise Categorisation - (Range)					
	Hindu	Muslims	Sikhs	Jains	Christians	Others
	170-40000	350-1500	50-1600	15-1600	200	100

<table>
<tr><td rowspan="4">8</td><td rowspan="4">Literacy Range</td><td></td><td>Nos</td><td>% age</td></tr>
<tr><td>M</td><td>4,06720</td><td>70%</td></tr>
<tr><td>F</td><td>3,69480</td><td>48%</td></tr>
<tr><td>Total</td><td>7,76200</td><td>59%</td></tr>
<tr><td>9</td><td>Population covered language wise</td><td colspan="3">Marwari, Hindi, Rajasthani, Gujrati, Bihari, Bangla, Punjabi</td></tr>
<tr><td>10</td><td>Main Occupations</td><td colspan="3">Farming, Shopkeeper, Animal husbandry, Service, Truck drivers, Labourers, Household work, Domestic servants</td></tr>
<tr><td>12</td><td>Distance from nearby city (in km)</td><td colspan="3">6-48 km(Range)</td></tr>
<tr><td rowspan="2">13</td><td rowspan="2">Is village linked with road</td><td>Yes
No</td><td>85
15</td><td></td></tr>
<tr><td colspan="3">If Yes, type of the road
Kaccha - 06
Pakka - 90
Rodi - 04</td></tr>
<tr><td rowspan="4">14</td><td rowspan="4">Available means of communication</td><td>Yes
No</td><td>95
05</td><td></td></tr>
<tr><td colspan="3">Type</td></tr>
<tr><td>Post Office</td><td>Telephone</td><td>Telegraph Office</td></tr>
<tr><td>78</td><td>85</td><td>35</td></tr>
</table>

15	Is electricity available	Yes No	95 05		
		Percentage of houses with electricity - 95%			
16	Does village have a Hat-bazaar ?	Yes No	55 45		
17	Does village has industries in 12 km radius	Yes No	40 60		
		Type of industries : Woolen industry, Brick making, Crockery, Embroidery, Khadi, Cloth printing, Painting, Stone crushing, Lime, Crackers, Cement			
18	Does the village have a school	Yes No	90 10		
		Type of schools			
		Primary	Middle	Secondary	Sr.Secondary
		95	95	30	32
19	Is there separate school for girls	Yes No	17 83		
		Type of schools			
		Primary	Middle	Secondary	Sr.Secondary
		---	---	10	7
20	Which is the nearby (a) Place for education after schooling	Nasirabad, Kishangarh, Srinagar, Ajmer, Nokha, Bikaner, Jasrasar, Udaipur			
	(b) Distance from village	0-25 km range			

	(c) Means available for going	Jeep, Bus, Taxi			
21	Other available places of education	Literacy centres Adult education centres Angan baris NGO- run centres			
22	Does village have				
	(a) PHC	Yes No	81 19		
		Facilities available			
		ANM	Doctor	Lady Doctor	Maternity facilities
		79	30	22	28
	If not (b) Distance of nearest PHC / Hospital				3-18 km range
	(c) Is private doctor available in village				Yes 79 No 21
	(d) How many of them are RMPs				0-3 available
	(e) How many are having MBBS degrees ?				Not known
	(f) Is lady doctor available in village				Yes 15 No 85
	If yes, what type				
		Govt.			Private Practioner
		12			03
23	Which NGOs are working				
	(a) in village ?	ICHAP, SWRC, Garib Nawaz Mahila Kalyan Samiti, Savera, St. Francis Hospital			

	(b) what type of work is being carried out by them ?	Malaria Control, Education, People's awareness, Health, Eye operations, Small sayings, HIV/AIDS awareness, STD awareness
24	No. of BPL families in the village / place under study	02-960 Range
25	Name Govt. development / assistance plans being run	Mahila Bal Vikas, SHG, Famine relief, BPL Ration, Widow pension
26	(A) Opinion of public reps. / govt. agencies about PLWHAS (Sarpanch, Ward Panch, Angan bari workers, Sathins, school teachers)	
	Points of discussion	
	(a) How many people are infected	M 47 F 64 Children : Not known Not aware of position : 50% of total covered

	(b) What do people think about HIV/PLWHAS ? • A dreadful disease. Its testing and treatment is necessary. People hide it, thus numbers remain unknown. Most of the people reside outside whereas the disease is in the village. • It is a wrong disease, people hate the PLWHAS consider AIDS to be a dangerous disease. • People think that it is a Brahmin dominated village. There is no truck driver, so disease cannot enter the village. (A myth developed from HIV/AIDS awareness) • Serious disease, once virus enters the body, cannot be destroyed. Prevention only cure. • Bad disease, women know that it spreads when males go outside the village and indulge in casual sex. • People keep a vigil on houses having HIV+ and are cautious about their movement. • People know about AIDS, know it from Radio, TV, Angan bari, ANM • Know it by its name and are aware that it kills slowly and internally • People are afraid of the disease. • People are scared. It is required that people should be told about good / bad aspects of it. • There is no problem in village. If someone does a wrong thing, he will get infected. *Nats* are CSWs – they may be having it and they may face its dreadful consequences. Why should we bother ? • People think that it is spread by unprotected sex with males. Such people are not good and we should keep ourselves away from them. • In big cities, awareness is only through media. No agency is working. • People do not want to talk about it because of ill-reputation. • Do not give attention till unaware about it. On knowing, get puzzled / nervous. • Refused to talk about AIDS.	
	(c) Have to contacted them for support	Yes 46 % No 54 %

	(d) If yes, what support has been provided • Keep patience. By taking medicines the disease will be controlled • By taking them to hospital. By care and taking medicines the intensity of disease will become less and you will feel better. • Asked them to contact PHC • Were sent to Nursing home • Contacted ICHAP, but no help given at ground level • TB patients do come, but I do not know if they have AIDS • Contacted ICHAP; but nobody is willing to tell and shed the fear of community. • ICHAP people helped those persons who were sent to Kishangarh. • PLWHAS have been motivated to go to camps organised for the purpose. • Has done lot, but NGO is not active continuously • Had the opinion that some separate hospital is being run for the treatment of PLWHAS.	
	(B) Information from ANMs / Angan bari workers / Sathins	
	(a) Have you discussed HIV/AIDS in women groups?	Yes 71 No 29
	(b) What were the points of discussion Time of MC, UTI, Sex, Use of condom, only one sex partner, health, hygiene, HIV/AIDS, sexual health, women told of preventive measures ; No to unsafe sex, TB is also talked about along with HIV/AIDS, Awareness about Jaundice, Hepatitis, Polio being done along with HIV/AIDS use of condoms is stressed.	
	(c) Have you got proper awareness materials	Yes 73 No 27

	(d) If yes, how you have used it? Hospital, by using stickers on walls Posters, Slogans when women come to hospital for injections etc. – showed them posters on HIV spread by needles / sex, using booklets, folders. Booklets are distributed; condoms also distributed Sanstha Gareeb Navaz works in community on HIV/AIDS. Distribution of booklets without any explanation.	
	(C) Information from school teachers	
	(a) Do HIV+ children / or with PLWHA parents children come to school ?	Yes 20 No 20 Don't know 60
	(b) What is the behaviour of teachers / students with them? - Refused to tell names. Behaviour appears to be vindictive - Unaware - We do not tell it to other children. But if the information gets leaked from other sources / places; then other kids tease such students - Children of PLWHAs do not come to school - No comments	

FORMAT - II

FAMILY WISE DETAILS

100 families investigated

1. Name (of person being interviewed) Disclosed 75 Not disclosed 25

2. Age groups (Range)

15-20	20-35	25-35	35 yrs & above
10	31	44	15

3. Castes / Communities

Rajput	Jat	Brahmins	SC	ST	Others
03	08	22	07	32	28

4. Religions

Hindu	Muslims	Sikhs	Christians	Others
65	21	04	08	02

5. Single / Joint families : Joint 21 Single 79

6. No. of family members

0-5	5-10	10-15	More than 15
88	06	05	01

7. No. of Adults in family : 0-5 Range

8. No. of Children in family

	Range
Boys	0 - 4
Girls	0 - 5

9. Marital Status

Married	184
Unmarried	Rest Unmarried
Widows in families	13

10. Educational Status

Illiterate	Primary	Secondary	Sr. Sec.	College
348	141	20	05	01

11. Has family a tradition of re-marriage : YES 81 NO 19

If yes,

(a) What are the traditions: *Nata 60, Chadder 15, Chura* 25, Others

(b) Is any re-marriage performed in family? YES 11 NO 89

12. Has family land for farming : YES 36 NO 64

(a)

(b) Then, how much land 0-20 bigha range

13. Are they land labourers? YES 37

(a) Do they own any traditional small scale industry? YES 11 NO 89

(b) Are you engaged in some other job relating to industries? YES 26 NO 74

14. Approx. Annual income of family

< 5000	5000-10000	10000-25000	> 25000
45	20	25	10

15. Does family come under BPL? YES 60 NO 40

16. Does the family get any Govt. assistance? YES 10 NO 90

17. Do your family members go away from the village for a long time ?

YES 66 NO 34

If yes,

(a) Period of stay ……..2-7 months range

(b) Where do they go?….Kota, Mumbai, Ahmedabad, Kolkata, Ranchi, Delhi, Nearby places

(c) What work do they perform? Truck driver, Labour work, work on shops

(d) Do other males also go with him or alone: Alone 67, With other males 33

18. Is any member suffering from a serious disease? YES 61 NO 39

(a) Who are they? Husband, Children

(b) Name of disease Fever, TB, AIDS, UTI, Cancer

(c) For how long 2-3 years

(d) Is treatment on NO 63% YES 37%

(e) Where they are being treated?

By Quacks	At Home	Hospital	Ayur. Hos.	Homeo.Hos.	Private Doctor
08	09	35	05	05	06

19. Is there any HIV+ person in the family? YES 58 NO 42

If yes, then

(a) For how much time 6 months 5 years

(b) Are they getting treatment YES 32 NO 23

(c) Where they are being treated? Bikaner, Jaipur, Nasirabad, Kishangarh, Ajmer, Udaipur

FORMAT - III **INFORMATION GATHERED FROM WOMEN**

GENERAL DATA

1. Name (of person being interviewed) Disclosed 72 Not disclosed 34
2. Age groups (Range) 16-45
3. Castes : Brahmin, Jat, Prajapat, Ghumawat, Jain, Kumawat, Balai, Rao, Nut, Rajnut, Rawal, Meena, Bania, Suthar, Damor
4. Religions

Hindu	Muslims	Sikhs	Christians	Others
74	26	03	02	01

5. Education

Illiterate	Primary	Sec.	Sr.Sec.	College
72	22	09	02	01

6. Whom do you live with

Joint family	41
Nuclear family	65

7. Marital Status

Single	Married	Divorcee	Remarried	Widows
18	61	02	01	24

8. If married, place where residing

   Same place as of residence 12

   Other than original 49

9. (a) Age at the time of marriage : 05-25 years (Range)

   (b) Age at the time of *gauna*: 03-25 years (Range)

10. Employment status : Occupation – Labourer, teacher, household, Anganbari workers, CSW, service, farming, beggar
Monthly Income – Rs.500-5000 (Range)

11. Occupation of husband : Farmer, carpenter, shopkeeper, factory worker, labourer, rickshaw puller, truck driver, tailor, teacher, blacksmith
Monthly Income – Rs.1500-8000 (Range)

12. (a) Is husband addicted to YES 41 NO 20

If yes, name the addition

Wine	**Cannabis**	**Tobacco***	**Others**
34	02	36	05

* Common with others

13. Number of children (of married persons)

Sons	94
Daughters	85

14. How many children died :

(a) During pregnancy 05

(b) At the time of birth 05

(c) Sometime after death 18

(d) Sex of the Children 12 Males 24 Females

15. Is your menstrual cycle regular? YES 65 NO 41

16. Is there any family ritual linked with menstrual cycle?

Responses

- Not allowed to touch water utensils 09
- Not allowed to enter kitchen 58
- Considered untouchable 37
- Not allowed to worship 19
- Forced to live in isolation 14

- Forced to sleep on floor 04
- No sex 49
- Considered unclean 68
- Forced to take bath in early morning 03

17. What do you use during menstrual cycle?

Sanitary Napkin	Old Clothes	Under Wear	Anything else
19	76	10	01

18. Do you use the same cloth during menstrual cycle or change it daily?

Same cloth	63
Change it daily	43

19. How do you dispose of the

(a) sanitary napkin / cloth

By throwing	74
By digging	29
By burning	03

(b) Do you use the same cloth during next menstrual cycle?

2 % women responded in affirmative

20. (a) Do you have an STD / UTI : YES 55 NO 15 Don't know 36

(b) If yes, can you name the disease

STD	Cancer	AIDS	UTI	Weakness	Pain in Uterus	NO
18	02	25	29	08	05	19

(c) Are you taking medicines for it?

Allopathic	**Ayurvedic**	**Home Made Med.**	**Going to Quacks**	**Any other**
56	02	37	05	06

21. Do you have any property in your individual name or in the name of your husband along with you? YES 36 NO 70

If yes, give details Responses

- Land ranging from 1-10 bighas 24
- Land and House 05
- House 07

FORMAT - IV **INFORMATION GATHERED FROM WOMEN**

PERSONAL DETAILS

1. When did you come to know that you are HIV+? : 1 month to 8 years (Range)

2. Is HIV/AIDS called by some other name in the village?

AIDS	67
White Discharge	05
Bad disease	10
Dangerous disease	03
Contagious disease	05
Do not know status	16

3. How did you come to know of your disease for the first time?*

Getting tested for long disease	28
At the time of blood donation	06
Some tests during pregnancy	05
Doubt for HIV pregnancy	55
Some one was infected in family, so as a precaution got tested	09
On husband's illness	03

* Remaining did not respond

4. How much money was spent on getting tested?

No expenditure	43
Rs. 30-100	55
More than 100	08

5. How did you manage money for testing?

Own expenditure	35
By taking loan	16
Mortgaging ornaments / material	03
Mortgaging land	03
Selling land	01

6. If taken loan, at what rate …….12% to 60%

7. Did any body explain to you

(a) about disease before testing or after testing?

Before testing	17
After testing	89

(b) Who explained and when

Husband	**Friend**	**Mother**	**Father**	**Sister**	**Nurse / Doctor**	**Others**
09	01	---	---	---	87	09

(c) What was explained?

- An NGO was explaining about AIDS for pretty long period
- Own expenditure is in the range of Rs. 300-400 per month
- When husband got tested for HIV, he was found HIV+. But told me after 2 years. Initially, he told about TB infection. But no medicine was effective during this period.
- After the death of husband, doctor told me about it.
- After testing, I started remaining sick
- When I showed my wounds to doctor
- My husband told me to get tested on long illness of mine
- A close friend told me about it during pregnancy and also cautioned me that even child can be infected
- NGO told me that you are a CSW, it is better to get yourself tested for HIV
- When my fever did not become normal for pretty long time
- ICHAP / World vision / Action AIDS explained but not in effective manner
- After I got infected and got tested for HIV as a precautionary measure

- My husband told me after marriage that he was HIV+
- Spent Rs.60,000/- on the treatment of husband by mortgaging gold articles and by taking loan @ 2%
- On TB check up of my husband, he was found HIV+. Then, I also got HIV tested and my husband made me understand about it
- Till now Rs. 70,000/- spent on self / husband (died) treatment by selling cattle.
- When my husband was being treated, two people were there to give advice to truck drivers. At that instance, they told me to get HIV testing done as truck drivers usually get the virus.
- I was advised for check up when my husband was being treated for TB.
- For not getting cured for cough, got tested
- During camp, I was told about disease
- After my blood test, it was told to me abruptly
- Before testing ANM told that by treatment you will get relief
- This disease is incurable. It is spread thro sex, so you should go for safe sex.
- It is a dangerous disease and keep vigil on your health
- It is a UTI
- Advise by nurse to contact Doctor. Doctor prescribed medicines and asked to consult after some time
- Use condom, Eat nutritious food, don't get worried
- Get testing done from time to time. Continue medicines
- It is an STD, spreads through sex, is incurable
- Is spread through needles, infected blood and unsafe sex
- Does not spread by eating together, sitting, touching, sleeping etc.
- By breast feed (if infected mother feeds)

- Keep special care during menstrual cycle
- Do not become pregnant, use condoms
- Use sanitary napkins during menstrual cycle, otherwise virus spreads faster
- Prevention is better than cure
- Abstain sex
- As you go for sexual contact with so many people, it is necessary for you to go for HIV testing (I am distributing HIV to others, I should use condom)
- Ensure use of condom in future
- Nurse told to be watchful while having sex with husband
- Regular check up and medicines. If I would have used condoms I would not have been infected
- Take medicines immediately on minor sickness even
- Your child can also die of infection
- Nothing can be done after infection
- Use condom to avoid fast spread

8. Were you acquainted with

(a) disease before getting sick? YES 56 NO 50

(b) What was the medium of information?

Poster	Leaflets	TV	Radio	Friends	Others
03	08	39	39	05	15

9. How did you get the disease?

By getting infected blood	Infected Needles	Sexual Contact	Do not know	Others
03	04	54	42	03

10. How did you feel when you came to know for the first time that you have been infected by HIV?

- As a sex worker, infection was inevitable
- I got infected, but felt no symptoms. I never thought I would ever be infected. Now, how does it matter?
- In camp, there were so many more women, I feel relieved from fear of infection in their presence
- I have taken many unwanted / unavoidable risks in my life, so why care for it!
- Bad shape of mind
- Got afraid
- Nervous
- No feeling as there is no thrill involved
- Suicidal mentality
- Revengeful attitude towards community men
- Felt uncomfortable
- My world has ended
- Started fighting with doctors, can't be me
- Not feeling guilty
- Felt much disturbed
- Felt bad
- It was a set back
- It was shocking
- Started hating myself
- My family is destroyed
- How will I earn now?
- Who will care for my child / family?
- Felt pain in my limbs / started shivering

- Became useless for society
- The will of long life has ended

11. After knowing that you are HIV+ when did you start getting treatment?

Immediately	57
1-3 months	03
3-6 months	08
Not started	15*
Can't manage medicines	23

* Treatment not started as told that disease is incurable
* I go to a saint for treatment
*As my husband has died, I do not want to live, so not getting the treatment
* Afraid of injections, pricks scare me

12. Do you go to hospital as soon as disease is increased? YES 88 NO 18

13. Whom did you consult before going to PHC/ hospital?

Doctor	**Nurse**	**Father**	**Friend**	**Brother**	**Husband**	**No body**	**Parents**
73	05	02	03	02	05	12	04

14. Do you have any

(a) other serious disease? YES 38 NO 52 Don't know 16

(b) Name the disease

Jaundice	**UTI**	**TB**	**Prolonged Fever**	**Chronic Dysentery**	**Cancer**	**Weakness**
01	03	19	08	02	03	02

(c) Since how long you are suffering from it? 6 months-7 years (Range)

(d) Are you getting some treatment for it? YES 28 NO 10

(e) From where you are getting the treatment

(i) Nasirabad, Kishangarh, Ajmer, Bikaner, Mumbai, Khandela, Jaipur

(ii) One response for going to quacks

15. Is there any other person

(a) HIV+ in your family? YES 38 NO 43 Don't know 25

(b) If yes,

Relationship with sufferer (No. of responses)	**From when sick + how long (range)**	**Age of infected person (range)**
Husband (31)	8 months-10 years	28-50 years
Daughter (01)	2-3 years	17-21 years
Son (01)	From birth	1-1½ years
Co-workers (05)	2-4 years	18-24 years

16. How was the first person getting the infection?

(a) Who he / she was

Husband	**Self**	**Fellow workers**	**Not known**
52	20	08	26

(b) When Not known (26) Otherwise : 1-8 years (range)

(c) From where Ajmer/ Makrana/ Surat/ Assam/ Mumbai/ Not known

(d) How infected By sex / Truck drivers/ Injections/ Multi sex partners

(e) Is he getting treatment YES 26 Not known: Remaining i.e. 26

(f) Did they tell you about infection YES 25 NO 27

(g) If not, then when did they tell?

- Came to know, when they got sick seriously;
- On testing;
- In my pregnancy days;
- After three years;

- On death bed;
- Not at all.

17. Has anybody in

(a) Your family died of AIDS? YES 30 NO 76

(b) What was your relationship with the dead persons?

Husband 13

CSWs (fellow workers) 16

Son / daughter 01

18. What symptoms did you observe or feel on knowing your HIV+ status?

Body Pain	**Fever**	**Serious cough-cold**	**Less Appetite**	**Itching**	**Others***
58	74	45	54	80	06

* Including Jaundice

19. What precautions do you take after knowing that you are HIV+?

A. Towards children (specially in case of breast feeding)

- My sister breast feeds the baby;
- Children are grown up, we do not allow them to share food with us;
- Initially I was breast feeding my child. But after knowing that I am positive, I am feeding on other milk
- Breast feeding being done in 06 cases (no precaution status)

B. For sexual contact with husband (use of condoms specially)

Using 18 Not using 06

- Left husband and established sexual contact with brother in law

C. During pregnancy

- Using condoms during sexual contact

D. Daily routine*

Using condoms	24
Not using condoms	58
Sometimes using	04

* Rest no response

FORMAT - V **INFORMATION GATHERED FROM WOMEN**

SOCIAL ATTITUDES

AND DISCRIMINATIONS

1. Have you told about your

(a) HIV infection to someone? YES 73 NO 33

(b) If yes, with whom you shared the information?

Husband	Parents	Children	Close friends	Relatives	Fellow workers	Neighbours	Others	To no one
28	12	09	06	02	08	02	06	NIL

(c) If not, why?**

Getting defamed	Fear of discrimination	Fear of boycott	Others*
51	35	21	06

* For children sake

* For family reasons

* Fear of loss of job / trade

** Responses multiple in nature

2. What was the reaction of your family members when they came to know of your infection?**

(i) Reaction of Husband*

Abused	Unhappy	Beating	Didn't talk	Starting abstaining	Threw way from house
03	06	04	03	05	02

(ii) Children's reaction*

Abused	Unhappy	Beating	Didn't talk	Starting abstaining	Threw way from house
---	---	---	02	03	---

(iii) Other family members*

Abused	Unhappy	Beating	Didn't talk	Starting abstaining	Threw way from house
03	06	---	02	08	---

(iv) Reaction of Relatives*

Abused	Unhappy	Beating	Didn't talk	Starting abstaining	Threw way from house
04	02	---	06	14	---

* Rest non-committal ** All responses multiple in nature

(v) What was the reaction of society / community?

- Good behaviour;
- Don't want to go back to village because of ill behaviour;
- Indifferent;
- Full of hatred;
- Don't want to talk, living in father's house;
- People consider us bad and call us names;
- Discriminated and stigmatised;
- Because of fear, people remain silent;
- Started keeping a distance;
- Neighbours talk about us in our absence;
- Have lip sympathy, but murmur at common places;
- Think that we are criminals;
- We are isolated from society.

3. Does your husband / relatives / family members consider you to be the guilty? YES 30 NO 76

4. What type of discrimination you had to face after you acquired HIV+ status?

(i) From whom : hospital staff; neighbours, fellow workers, women in village, family members, Panchayat, Govt., Police, Community

(ii) When : Going to hospital, market, Panchayat meetings, while eating together, while at work, while fetching water from well / hand pump / pond ; during distribution of medicines

(iii) Various reactions expressed by women :

- People talk in groups and pretend;
- As yet, nobody knows; I am hiding it;
- Start criticizing; can not explain to anyone;
- Considered as persons from hell;
- Every time touched by someone for sex, I feel that all of them are seeing me;
- They ask me why I am losing weight at common places like farm, well / hand pump;
- After awareness, our job is affected;
- People defame us for spreading AIDS. They do not have a good impression about us;
- Pressure to leave the living place;
- As if I am not required. Taunting at eating place / coming-going / dressing up way in bazaar / school / vegetable market;
- Pass comments;
- People blame me, not my husband, who in fact infected me
- In laws started building distance while cooking, eating etc.;
- Husband keeps a distance when at home;
- Mother in law says that her son died because of me;
- Father in law now talks / cares as before infection.

(iv) In what way :

In Hospital

- Asked me to sit outside for consultation / blood testing;
- Asked me to deposit blood sample, put it there and open it for testing;
- Asked others to break relations

Customer

- The beauty bazaar is ruined;
- Started from Calcutta, after infection : was stigmatised and thrown away. I ran away and came to Ajmer for earning livelihood;
- Being identified and told me in particular that I am HIV+. After getting raped without a shelter and protection, it is bound to happen to road dwelling women;
- NGOs disturb us. We have become an instrument of entertainment. Everybody wants to locate us, but what far?
- We were turned out of the hospital when we (wife and husband) went for testing as if we are not a part of society and are untouchable, rebuked us. We know what happens to a person who has the virus;
- When I go to hand pump to get water, women keep away from me and murmur;
- After knowing from hospital, I did not go to my village / in laws / parents;
- My family members have stopped eating food cooked by me;
- I belong to higher caste. After infection, I feel that I am low caste person as per community behaviour / women in particular;
- I was traveling in bus. On next stop, a person boarded and then left the bus by saying that I have seen her. Seeing an HIV +person, will spoil my day;
- Clients have developed a sense of terror;

- I went to a shop for purchasing ration. People start staring at me, start talking, call me a sinner. These things disturb me;
- Public servants use us, also misbehave and force us to leave the place or stop our flesh trade;
- On one hand, we are told how HIV is not spread. In hospitals doctors behave just opposite to it. They talk from a distance, behave with us as if we are sinners. Then, what is the use of telling the ways of how HIV is not spread?
- So many people visit us, we are not able to distinguish who is real helping hand. They do not sit, do not drink water, keep hanky on their noses, hid their faces and what not;
- People comment that I am of no use now. On saying that I am HIV+, use condom, people go away. It destroys my earning prospects. Fellow CSWs say that because of me, they are also earning less;
- I have suffered a lot. My stepmother in Mumbai forced me to be a CSW for money. I ran away, came to Ajmer. Started begging as I did not get any work to do. It was not sufficient. I was beautiful; I got into flesh trade again to quench my hunger both of stomach and sex. Now, I am in it, I am HIV+ and have only regrets that my end is near. Rest you know better;
- On hand pump, while I am filling water, no one comes near. After I have filled up my utensil, they will wash hand pump and then fill water. Also, villagers have stopped coming to our place. In schools also, children are stigmatised and discriminated by teachers / students. Children started weeping, when they came back from school. We had no respect and had no alternative but to keep silent.

5. Has it created any difference in behaviour of your family society towards you due to your long illness?

A. Towards me

- Bad behaviour;
- Feel isolated;
- Neighbours don't sit; they taunt and laugh at us;
- Sickness has caused less attraction;
- Say that my sickness is due to the death of my husband;
- No one gives job to my brother / sister now;
- Consider me to be unwanted burden;
- I am treated as untouchable;
- Loss of self respect in family;
- Family wishes that I should die at an earliest;
- Expenditure on medicines has increased, daughter cannot go to school

B. Towards husband

- See him with discrimination;
- Consider him to be a sinner;
- Husband has multi sex partners, so no change in his behaviour;
- Husband remains away;
- No change

C. Towards children

- The children of beggars are unidentifiable – so no change;
- Started worrying about children because of affection;
- Being looked upon as orphans and with pity;
- On the contrary, daughters care more for me

6. Did your family accept you in spite of being HIV+?* YES 434 NO 166

* In no time only 20 responses;

* Husband feels that he infected me, so immediate acceptance;

* After testing.

7. When you know now that you are HIV+, what thoughts come to your mind?

- Terror has entered us. We cannot explain but it can be read from our faces;
- Because of ailments / fear, my disease appears to be double;
- Where should I go;
- Earlier considered cancer as deadly disease, but after HIV infection the fear has become multi fold;
- Finished, God may give me death immediately;
- Broken, waiting to die;
- Pretty certain about early death;
- No words to explain my fate;
- We won't survive for a long time;
- I should pass remaining part of my life in hospital;
- Living for the welfare of children till alive;
- Have no wish to live;
- I cannot survive;
- Felt scared;
- Now, nothing can be done, all is over;
- I am broken, no desire to live;
- Was scared / sad, now I have learnt to live like it / in fear;
- As I have to die, why should I take medicines? Developed confidence and now I am happy;

- There is darkness around me. Nothing comes to mind;
- What will happen to our children? What will people think about us?

8. Do you feel guilty of getting the disease by doing a wrong thing?
   YES 32 NO 74
9. Do you think that it is due to some curse or due to the doings of previous births? YES 55 NO 51
10. Did you came to know of the disease when doctor saw you in the hospital? YES 91 NO 15
11. Did doctor ask you to go for HIV / AIDS test?
    YES 93 NO 13
12. Did you get the test in Govt. or private hospital?
    Govt. 84 Private 22
13. What was the distance of place where you got tested? 1-60 km (Range)
14. Did somebody accompany you during testing?

Husband	**Doctor**	**Alone**	**Nurse**	**Sister**	**Brother**	**Father**	**Social Worker**	**NGO People**
40	04	17	06	03	08	05	14	09

15. What was the behaviour of doctor towards you?

Good	**Cooperative**	**Not good**	**As if you are born criminal**
54	15	31	06

16.(a) Did hospital have a lady doctor? YES 80 NO 26

(b) What was the behaviour of lady doctor towards you?

Good	**Bad**	**Cooperative**	**Non-committal**
58	25	16	07

(c) How did nurse / compounder behave with you?

Good	Bad	Cooperative	Non-committal
62	30	10	04

17. Now, when you go to hospital, how do employees behave?

Sympathetic	Show pity	Discriminating	Helpful	As with other patients
15	15	30	28	18

18. Have you used costly medicines for AIDS? YES 61 NO 45

19. Have doctor told you some other medicines also? YES 63 NO 43

20. Are you taking medicines?

All told medicines	Some of them	Not at all
36	49	21

21. Do you know some other women, who have undergone

(a) HIV testing

YES	NO
36	51

(b) If yes, how many in numbers?

Many	Did not tell	Not known	01-05	06-10
15	10	02	08	03

FORMAT - VI **INFORMATION GATHERED FROM WOMEN**

IMPACT ON OWN LIFE

AND FAMILY

1. When you fall sick, who cares for you?

Children	Relatives	Self	Husband	Friends	Mother	Daughter
15	26	16	15	06	20	08

2. What losses you / your husband has suffered after infection?

Job loss	Loss of House	Economic loss	Husband's job loss	Land loss	Nothing
31	02	14	46	01	12

3. What is the quantum

(a) of impact on your income? Rs.500-5000 per month (Range)

(b) Did infection affect your income? YES 74 NO 32

4. Did you have to leave your village / dwelling place? YES 22 NO 84

5. How do you compensate the increased expenditure due to you because of your illness?

- Selling clay pots / pitchers;
- More indulgence in sex;
- Mother bears it;
- Family support;
- Begging;
- Turned CSW;
- Took loan;
- Started peon's job;
- Doing agriculture and animal husbandry

6. In order to compensate additional expenditure of family, what steps were taken by you / your husband to compensate expenditure due to HIV infection?

More work was done	Finding alternate income sources	Nothing
15	10	81

FORMAT - VII **INFORMATION GATHERED FROM WOMEN**

YOUR EXPERIENCES

1. How much do you spend on medicines for treatment of disease per month?*

(a) On husband's illness Rs.200-5000 (Range)

(b) On children Rs.100-400 (Range)

(c) On self Rs.300-500 (Range)

* A few of them stopped taking medicines because of money constraints

2. If husband, children and you are all infected, how will care the most with regards to food / facilities (in order of preference)*

S.No.	Order	Responses
1.	Children, Husband, Self	36
2.	Husband, Children, Self	24
3.	Self only	27
4.	Self, Husband, Children	01
5.	Husband, Self, Children	11
6.	Children, Self, Husband	02
7.	Self, Children, Husband	05

3. Where do you go for regular checkup and for taking medicines?

Govt. Hospital	Private Hospital (Charity)	Medicine Shop	Social Worker	No Where
48	01	01	03	53

4. What was your expenditure quantum when you went for regular check up last time?

(i) On Commuting Rs.10-100 (Range)

(ii) Fee to Doctor Rs. 0-100 (Range)

(iii) On Medicines Rs.400-500 (Range)

5. What is your annual expenditure on treatment? Rs.5000-30000 (Range)

6. Do you get financial assistance from some place for treatment?

   YES 63 NO 43

7. Does any NGO come

(a) to you for any type of support? YES 57 NO 49

(b) If ye, what type of support is being provided?

- Medicines
- Testing
- Awareness
- Condoms
- Booklets
- Medicines (to some extent)
- Advise
- Free travel
- Moral support
- Film shows

8. What are your views for Govt. / NGO support to PLWHA women?

- Employment
- Free education
- Free food
- Free medicines
- Doctor's responsibility be fixed to test people in area for identification purpose
- Rehabilitation
- Complete care
- Ban on CSWs
- Work on truck drivers as target group
- Distribution of condoms

- AIDS houses for PLWHAs
- Education of children
- Free travel in Rail / Buses
- Should find its cure
- Open dialogue through media
- Camps (rural based) be organized
- Orphan homes be constructed + their care + support system be developed right now

9. In your view, what should be done as preventive measures and for checking spread of the virus?
    - Awareness amongst illiterates in remote places
    - Awareness – target women as a specific group
    - More awareness drives in villages through NGOs
    - Strengthening of care of support system at all levels of administration
    - Timely and regular check ups of PLWHAs
    - Free distribution of condoms
    - Ban on CSWs
    - Agenda point for political parties manifesto
    - Development of films / VCDs for mass distribution and exhibition, after making such films with positive attitude
10. What type of work

(a) Can be done by you while sitting at home for earning additionally to support your self for combating disease?
    - STD booth
    - Dhaba
    - Grocery Shop
    - Animal husbandry

- Garland making
- Tailoring
- Papad making
- Embroidery work
- Vegetable shop
- Running of school
- Sewing work
- Mehndi work

(b) Are you really willing to do something for this purpose? YES 48 NO 58

(c) How much finances are required for this purpose?

Initial investment of Rs.2000 – 50000 (Range)

11. In your village, where women go for getting treatment for their sex-related diseases / maternity related problems?

Type	Responses*
Advise of elders	15
Quacks	23
Desi treatment	31
MCH	04
PHC	35
District Hospital	41
Homeopathic Hospital	12
Ayurvedic Hospital	13
Private Doctor	33

* Responses are multiple in nature

12.(a) Where your children were born?

In house	Number	In hospital	Number
30 responses	105	03 responses	10

(b) What is the distance of hospital from your residence? 4-15 km (Range)

(c) Is lady doctor available in the hospital? YES 64 NO 42

(d) If lady doctor is not available, you hesitate to go to a male doctor?

YES 76 NO 30

13. Where do you go for getting treatment for other ailments? (other than HIV/AIDS)*

Advise of Elders	Quacks	District Hospital	Homeopathic	Ayurvedic Hospital	Private Doctor	No where
29	15	66	07	03	22	18

* Responses are multiple in nature?

14. Is lady doctor posted in the hospital?

YES 71 NO 13 Do not know 22

15(a) Additional information on position of women vis-a-vis HIV/AIDS in Rajasthan as per present study

- Single; husband has died, no treatment being taken.
- People aware of HIV. Consider the necessity of camp for HIV testing because most of males are truck drivers. Then, if found positive their care / support / medicines be arranged by Govt. /some NGO. HIV – be asked to take precautions. No control of women on men!
- Husband / wife both are HIV+ for last 5 years. Are taking medicines and are alive. Children not tested. But what will happen to them? When they become orphans. No family support otherwise available.
- One women (HIV+) did not give any information about her family and was asked questions on HIV, she lives with her old father and none else. She looked nervous dejected and was giving a stunned look.
- No awareness. People profess that as no one is HIV+ and we are religious, there is no need to discuss such things here.
- People say that awareness amongst women others be done by adopting open approach.

- A women named X is found to be HIV+, her husband is HIV– and the couple have no children. But they are ignorant about HIV.
- Policy frame work is missing; Much money is being spent but programme is not reaching the affected person.
- CSWs take medicines, but still spread it.
- A women got the treatment once, but now it is stopped for want of funds / employment.
- Road-dwellers – Establish sexual contact for money easily; go on changing partners even after marriage. It is a matter of pride to have 3-4 sexual contacts.
- Katan Bawri (under Koat) Ajmer 43F, 15M HIV+ out of a population of 500

15(b) Some suggestions from women suffering from HIV/AIDS

- PLWHAs should be identified and policy of their rehabilitation must be framed for education, health, employment, living space etc. along with activities so as to enable them to live a respectable life.
- PLWHAs / families must be supported
- Basic education facilities be provided
- Free health facilities
- Some scale industries be set up for them
- Family conferences for such people be organized

All women were briefed about questionnaire before filling it by NGO / Others.

16. Impact / position of women and AIDS / Some important observations

- CSWs are neglected lot and they are taking society to a dangerous corridor
- CSWs are tested. But later they are not cared for. On one hand, the information is kept secret, while on the other hand no treatment is

provided. They are not able to buy costlier medicines. They get partial treatment, change place and then it is difficult to locate them. Govt. / NGOs should go to adopt them / construct shelter houses with complete care and support with avenues of employment. SFS be encouraged.

- Asha (name changed) ,17, took medicines for six days after counseling and then left taking medicines.
- Commuting of CSWs is a grey area / an area of real concern.
- Jyoti (22) complains that NGOs do not provide medicines on regular basis and she does not have money to buy. She says that NGOs work for their own benefit. She has no alternative but to do flesh trading.
- Bijli (19) – What else to do but to sell her body?
- Meena (25) and her husband both are PLWHAs. She had UTI and was very serious. Got HIV tested and has relief after taking medicines.
- Noorjahan (30) had multi sex partners, is PLWHA, but does not go for regular check up / counseling.
- Jaitoon (40) has a family of 4 daughters and 2 sons. The family believed in establishing sexual relations at very early age. For bread and better, all daughters are in trade now. Have no respect and all probably have acquired virus because of urge for sex as well as money.
- Manju (35) and husband are PLWHAs and are suffering from TB. One son has died after birth. The position of family is critical. They are taking medicines for TB but not for AIDS. Are not getting any support from any NGO / Govt. They complain that they are getting very shabby treatment in hospital.
- Chameli (25) says what is the fun of filling these papers. You cannot save me. I am the sufferer. Govt. does not bother.
- Sita Devi (25) – In laws family died in an accident. Husband died of AIDS. She has two daughters. For her treatment sold her buffallos. But, what to do next? Economically, or verge of collapse.

- Derathun (Nasirabad) is a village having so many truck drivers. Many people have died, including women. There is a need for counseling truck drivers', as a target group.
- 'A' saw her mother as CSW from childhood. Her father married another women and had four issues from that woman. She started as CSW at the age of 12, she never felt bad as she got much money, good food. She married a boy in temple, got a son and a daughter by caesarian operation. One child died during pregnancy. She suffers from jaundice. Her husband comes only when he has a desire for sex. She is a PLWHA and says there are many more like her in near by villages.
- Women are not telling about disease as they think that they will be given a poisonous injection. Also, they say that trade will be ruined.
- There is a feeling that PLWHAs can get a place in hospital easily. But they can't be accepted by society / village / family. The govt. does not have a realistic policy.
- Family / society / husband / children have accepted PLWHAs status but Sarpanch etc defame them and want to throw away Jamuna (38) from village.
- Hemlata (25) is PLWHA. Her husband is HIV– but knows that she is HIV+. She does not tell it to others. She feels that people should be bold enough to talk about AIDS as they talk of malaria. Awareness will provide such patients with an opportunity to live with self respect. She does not have children and is healthy, needs counseling.

SUMMARY OF KEY COMPONENTS AS PER USED FORMATS

Keeping these factors/constraints in consideration, it was considered worthwhile to take up a study which could evaluate ground level reality. For this purpose, districts of Ajmer, Bikaner, Bharatpur, Jaipur, Jalore, Nagaur, Sikar and Udaipur were selected and places/villages were so selected so as to make the study really meaningful. For making benchmark surveys, various formats were used.

The city/village profile in Format I indicates that literacy rates in females is 48% as compared to 70% for males. The population has to commute 6-48 km rage for earning livelihood of petty nature pointing to poverty indicators. School education facilities for girls are a bare minimum. The health facilities deprive women even, as only 15 places have a lady doctor out of 100 under study. NGOs are doing work in patches while Government involvement for women's health is far below the prescribed standards.

The opinion of public representatives/govt. agencies about PLWHAS depicts that they are least bothered and in fact are instrumental in developing more myths. The study indicates that their role has led vulnerability of women in Rajasthan to HIV/AIDS to a point of no return perhaps.

The care and support system has many constraints e.g. irregular supply of HIV/AIDS medicines, incomplete information spreading techniques, casual attitude of PLWHAS, distribution of materials without any explanation, increase in vindictive behaviour towards wards of PLWHA, drop out of children from schools with PLWHA parent/parents.

Format II which analyses the family wise details is no different from position of women in Rajasthan. The factors of concern/interest are traditions of re-marriage, *Nata, Chadder, Chura* etc. The families under study were labourers and were below poverty line (60%). Males members are commuting to W.B., Mumbai, Delhi, Gujrat, Jharkhand, nearby places for a period of 2-7 months rage.

Out of the people covered under study 61% are suffering from some serious diseases like fever, TB, UTI, Cancer, AIDS. Out of these 63 % are virtually not getting treatment. Those getting treatment are not in safe hands. HIV has also made inroads into families.

These are all indicators of vulnerability of more women to HIV infection as poverty and no medical facilities compound to problem.

Format III speaks of information gathered from women. It is surprising that a majority did not want to disclose their identity, indicating traditionalism in thinking for any open dialogue. The 05-25 years age marriage range speaks itself of child marriages and earlier sexual contact. Out of the interviewed females, 49% say that their husbands are addicts. Out of the children born to these women, 36% died at one stage or another. It is alarming to note that a large number of females interviewed did not have regular menstrual cycle. The common rituals like not to touch water utensils, not to enter kitchen, not allowed to worship, forced to sleep on floor, forced to take bath in early morning, forced to live in isolation etc. are linked with menstrual cycle in one way or the other. Out of the interviewed females, 68% narrated that they were considered unclean during menstrual cycle. More than 70% females use old dirty clothes during menstrual cycle which 63% females use the same one cloth. The way of disposing sanitary napkins/cloth was 71% by throwing, 26.5% by putting in a dug pit and rest by other means. 55% were suffering from STD/UTIs while 36% did not know what STD/UTI means. Those suffering from STD/UTI, 37% take homemade medicines which majority of them consume allopathic medicines. The plight of women is miserable as 64% women don't have any property what so ever in their own name or husband's name.

Information gathered from women revealed that more the income was, more was the addiction to alcohol, tobacco and drugs in case of men. It was interesting to find that restrictions in Muslims were much less in comparison to Hindus during menstrual cycle. The prevalence of irregular menstrual cycle in

CSWs was an interesting feature and needs further exploration. The information with regards to use of cloth/napkin during menstrual cycle percolates through traditional ways. In one case, the mother advised the daughter to use one cloth only during period which was subsequently being thrown away after menstrual cycle was over. CSWs don't indulge in sex during menstrual cycle. Out of them uses napkins only when has money otherwise used old clothes. Such cases indicate that hygiene is being scarified due to poverty. Respondents to reside in joint families, ever divorced/separated/widows. Some hints were given for sex exploitation in these cases.

Format IV was designed to gather information from women who were suspected to be HIV+ / were HIV+. Out of the gathered information, 63% knew AIDS by same name, 5% thought it to be leukoria, 19% called it a bad/dangerous/contagious disease and the rest did not know about it. More than 53% came to know about their infection, when got testing done for having doubt in mind. The incurred expenditure on testing was met by taking loan, mortgaging ornaments/materials, mortgaging land, selling land, own resources. Those found positive were explained about HIV after testing (74% respondents). The HIV status was explained by a doctor/nurse in most of the cases (87%)

Other interesting facts with regards to who explained, what was explained, when was explained, other reactions/comments are summarized in Annexure 1 and 2. These remarks have been kept as such so as to reflect that actual state of affairs in the minds of women and to enable us to assess vulnerability of women about HIV/AIDS in Rajasthan.

The access to treatment for HIV + persons reveals that immediate treatment is available but in a discontinued fashion due to financial constraints. In many cases, it was not known haw these people got infected. Even now, the use of condoms has not made inroads in the minds of infected persons.

Format V was designed to extract information with regards to social attitudes and discrimination. It was found that most of the women did not tell it

to others for fear of boycott, discrimination, getting defamed, loss of job etc. It is found that attitude of people change overnight towards HIV+ and discrimination ultimately results. The whole scenario changes and ultimately a woman is put to the sword. The behaviour of medical staff also indicates discrimination towards HIV + persons.

The impact on one's own life and family is reflected in Format VI and narrates that story of poverty in combating AIDS. There are no alternate sources for income generation available with these women. Only 9.7% women have shown willingness to find alternate income sources.

Format VII accounts for their experiences with the disease. A lot of money is being spent on medicines by them. The family is now focused on bare survival. The access to medical facilities is meager and takes a heavy toll of earned money. No govt./NGO support is available at remote places. The support is in the form of advice, camps, partial awareness, booklets, moral preaching, film shows etc. The experiences shared by them emphasizes on free education of children, free food, free medicines, employment opportunities, free travel in rail/buses, rehabilitation, care and support in form of some policy frame work to ameliorate the condition of women already infected. Policy framework on timely and regular check ups of PLWHAs, free distribution of condoms, development of films/VCDs projecting positive attitude appear to be the need of the hour.

It was interesting to find that PLWHAs also wished to contribute to country's progress for combating AIDS by running STD booths, dhabas, grocery shops, garland making, tailoring, *papad*, small scale industry, vegetable shop, embroidery work, running of school, *mehndi* work. Initial investment in these works was proposed to be between Rs.2,000-50,000/-.

Lessons Learnt

- Time has come to ameliorate the condition of women already infected by giving them opportunities to **"Speaking their bit of truth";**
- Time has come for "**Mapping the invisible";**
- Time has come for face life of infected women by giving the slogans like

"Love they self";

- Time has come to restore their dignity not by words but by knowledge and action.

Policy frame work should now include / accept

- Vulnerability of women to HIV/AIDS on issues like
    - Inadequate, insufficient access to HIV prevention services;
    - Inability to negotiate safe sex for HIV prevention;
    - Lack of access to microbiocides;
    - Biological reasons;
    - Majority of HIV infections are inside marriage;
    - Violence, sex abuse at an early age.

POLICY INITIATIVES SHOULD HAVE

- Investments on women's health;
- Liberal care / support for women living with HIV/AIDS;
- Effective Surveillance Management;
- Sustained pressure for Govt. support on the basis of human rights;
- Inclusion of women's status vs HIV/AIDS in mandates of political parties for elections.

Chapter V

NEED FOR A WOMAN- CENTRIC APPROACH TO HIV/AIDS

Apart from the impact of HIV/AIDS on the body of infected women there is going to be a much more serious impact on their socio-economic lives. Their low status parameters are going to be a very difficult obstacle in their fight against HIV/AIDS. We may look into some of the areas of concern for women.

Education: - As women will be more and more involved in the care and support of their HIV-infected husbands, it will have a fallout on the literacy rate of girls because their female children will have to help them at home in their daily chores and will not able to attend their schools.

Health: - In the field of health a woman is already suffering from lack of access to medical care facilities. If she herself is HIV-infected along with her husband, this access will get reduced further because the primary attention will be given to her husband. Whatever little money they have kept for medicines will be utilized by her husband.

Employment: - With more and more of their time devoted to the care and support of their husbands, women are likely to be thrown out of whatever petty jobs they are employed in. Women in the organized sector will also have to look for low paid unorganized sector jobs because they will not get enough time for a full-time organised sector employment. HIV infected women in Rajasthan are facing a far greater stigma and discrimination in their families in their society than women in the southern states as has been seen during the survey. After their husbands' deaths, they are finding it extremely difficult to support themselves and their children.

STERILIZATION AND INCREASE IN HIV VULNERABILITY

In whatever garb and however holistic in approach it has been presented, the population policy in India has basically been a coercive population control programme dependent on terminal methods of family planning. The other methods included have proved to be merely suggestive, without any serious efforts for their implementation. Patriarchal forces in the form of Don't- Touch-the- Male have made women an easier target for government agencies because they themselves are keen to adopt contraceptive methods to get out of multiple pregnancies. Although the population policies offered them a basket of contraceptive choices and also promised to increase the age of marriage and reduction in maternal mortality ratio and infant mortality rate and better MCH facilities, their ground level implementation agencies provided almost nothing but sterilization and women, heartily supported by their men, went all out to get sterilized. Those in the more literate states, with a higher status in the society from the point of IMR, MMR, TRR, etc, and more anxious for a small family were in greater numbers as may be seen from the Table 27 below:

Table 27
Female Sterilizations (1995-96 to 2000-01)

S. No.	State	Total
1	Maharashtra	2851543
2	Andhra Pradesh	2584580
3	Karnataka	1962364
4	Madhya Pradesh	1946433
5	Uttar Pradesh	1905185
6	Tamil Nadu	1708675
7	West Bengal	1423239
8	Gujarat	1287506
9	Rajasthan	1090513
10	Bihar	744090
11	Kerala	672206
12	Orissa	595981
13	Punjab	576173
14	Haryana	485735
15	Himachal Pradesh	164406

Source: Deptt of Family Welfare , Ministry of Health & Family Welfare, Govt of India

Although the female-focused population programme impacted on the TRR favourably, it might have inadvertently led to an accelerated growth of the epidemic in these states.

State wise figures of AIDS cases from NACO for July 2004 given below show that the number of AIDS cases in the southern states is far higher than in the northern states. The only exception is Kerala where the number of female sterilizations is also lower than even Rajasthan.

Table 28

S. No.	State / UT	AIDS Cases
1	Tamilnadu	31996
2	Maharashtra including Mumbai	17749
3	Andhra Pradesh	8355
4	Gujarat	4306
5	West Bengal	2397
6	Karnataka	2001
7	Kerala	1769
8	Uttar Pradesh	1389
9	Madhya Pradesh	1174
10	Rajasthan	1089
11	Haryana	371
12	Punjab	292
13	Assam	225
14	Bihar	155
15	Himachal Pradesh	149
16	Orissa	128

Could there be other reasons for this huge difference? A more permissive society? Much greater migration and far longer periods of stay outside Rajasthan

or Bihar in the North? The answer is No. One of the reasons could be that a large number of AIDS cases may not have surfaced owing to lack of awareness about HIV/AIDS in the north and a greater awareness in the south may have led to detection of more cases. But it does not explain the big difference.

Let us examine the fact that there has been a big time gap between awareness about the need of a small family and the nature of HIV transmission. Sterilization, oral pills and IUD do not prevent HIV transmission either from men to women or vice versa in the absence of a condom or a strong unbroken vaginal wall. Unaware of the virus but the fear of pregnancy gone, it is possible that any form of protected sex was given the go by in the southern states.

Today, population control measures cannot ignore the HIV/AIDS epidemic and the only methods to be propagated should prevent both pregnancy and HIV/AIDS. They include condoms- both male and female- diaphragms and microbiocides and not sterilization, oral pills, IUDs, etc. They will also prevent STDs. But these methods are seldom publicised. Female condoms are not seen or heard about in most of the country. Their cost is prohibitive and they are inconvenient to wear. There is no research to improve their design or make them cheaper. Microbiocides are not known in India. Researchers say that it would take another 5-6 years for them to be marketed. There seems to be no hurry in expediting research on them. With more and more northern states getting restless about the growth of their population and preferring female sterilization as the easiest control measure to adopt, the HIV/AIDS volcano on which India is sitting today may erupt earlier than expected.

A similar pattern emerges in Rajasthan where districts with a higher number of sterilizations have also reported a larger number of AIDS cases. Although the figures are not gender disaggregated , it cannot be ruled out that the number of women with HIV must be higher in these districts than the others.

Table 29

Rajasthan

Female Sterilization				Total AIDS Cases	
1	Jaipur	204310		Jaipur	217
2	Alwar	117088		Sikar	134
3	Ganganagar	110739		Nagaur	77
4	Sikar	101522		Jhunjhunu	60
5	Nagaur	98462		Udaipur	54
6	Jhunjhunu	79901		Ajmer	46
7	Ajmer	72422		Kota	42
8	Jodhpur	70797		Alwar	43
9	Churu	68877		Pali	32
10	Pali	65014		Bikaner	25

RAPE AND THE THREAT OF HIV INFECTION: NEED FOR POST-EXPOSURE PROPHYLAXIS

There is a growing number of rape cases that are being reported in Rajasthan. Internationally, there has been a rising concern for providing anti-retroviral therapy to reduce the risk of HIV transmission following sexual assault. Such therapy is being widely used as safe and effective in cases of occupational exposures like needle prick injuries to healthcare workers. Studies have shown that in such cases the viral replication may stop. The efficacy of prophylactic treatment in preventing mother to child infection is now accepted worldwide. Although there is no scientific evidence so far to conclusively prove that this may also happen in cases of sexual assault where the viral load could be very high, the doctors can assess individual cases and initiate these prophylactic measures if they find it necessary.

A comprehensive line of action which can take care of the possibility of STD and HIV infection, pregnancy, other injuries and which also provides counseling should become mandatory to be followed by the police and the doctors immediately after a victim reports to them.

It is necessary for the government to frame a policy in this regard and come out with a protocol. Availability of rapid HIV tests should be ensured. The victim should be counseled to take the test. PEP should start if the possibility of the rapist being HIV positive is high.

Are There Any Options For Women?

With most of the strategies being advocated not under the control of women, it is necessary to look for an option within the power of a woman to use. She has to have a means to protect herself from HIV infection.

One way is to take protective measures to decrease the efficacy of transmission when sexual contact takes place.

Women need to keep the surface of their genital tract intact as a defense against heterosexual transmission of HIV. If the vaginal epithelial mucosa, a female's normal barrier against infection is not intact when infected semen enters her, susceptibility to HIV transmission may be significantly increased. As is well known, it is because of this reason that a female is more likely to be infected than a male from a single act of intercourse with a partner who has an STI. Maintaining cleanliness of the genital area goes a long way in meeting this objective. Before the re-use of a cloth during menstruation, it should be properly cleaned.

During each delivery, women risk damage to their genital tract. Child marriages or marriages below the age of 18 years are more vulnerable to damage. Owing to less developed vaginal and cervical walls, childhood or mid-teen sex could make HIV virus pass through them more easily than through genital tracts of adult women. Risk increases if childhood nutrition has been poor. This is the

case with most of the rural girls and a large number of urban girls in India. There is also risk of damage if intercourse takes place with a dry vagina. Rape and other modes of violent penetration cause immense damage to the vaginal walls.

Women are also reluctant for a pelvic examination and even lady doctors, if present in the PHC, are indifferent and seldom insist on it. This leads to overlooking vaginitis and cevicitis and vaginal discharges never attract attention. Cervical cancers are discovered when they are at the last stage. These conditions remain unnoticed but at the same time go on damaging the vaginal walls.

It is well known that access to health care is unequal for men and women. Whereas men go straight to a healthcare facility if they notice any symptoms of an STI, women find it nearly impossible and remain untreated.

Recognizing the major role played by the integrity of female genitalia in reducing heterosexual transmission of HIV can be an important method of self defense used by women.

Spermicides and diaphragms are also means under the control of women. So are female condoms. Spermicidal contraceptives, which place a chemical barrier between the infected fluid and the mucous membrane, are useful. Nonoxynol-9 has been tested as an HIV virucide and offers some protection.

It may be mentioned that all these methods are within reach, may be not within easy reach. But with the support of the women's action groups, the tasks can be achieved and situations which may lead to broken genital skin can be avoided. The infections are also treatable, only if access to health care is available;

NATIONAL AIDS CONTROL ORGANISATION PHASE II- 1999 TO 2005
WHAT IS THERE FOR WOMEN?

The National AIDS Control Project Phase II has suddenly shifted its focus from raising awareness for changing behavior to targeted interventions for the so- called high risk groups like sex workers, truck drivers and men having sex with men. This has resulted in a total neglect of women like housewives who get infected without being a high risk group because their husbands, who may not be in the high risk category of truck drivers, may be indulging in casual extra-marital sex and may infect them. The target intervention programmes have not covered all the sex workers, especially the mobile sex workers or sex workers who do not live in clusters. They have also not covered all the truck drivers. The migrant construction labourer is still not a primary target.

The Voluntary Counseling and Testing Centers which have been opened in each district in Rajasthan are quiet inaccessible to women for whom even the general health care facilities, like the primary health centers, are beyond reach. In spite of an alarming number of women getting infected, Rajasthan does not have a specific programme for containing the epidemic in women. It is time that a separate programme is launched for women in a state where their status is low to reduce the spread of HIV infection in the general population.

The National AIDS Control Programme has failed to tie itself with the Family Welfare Programme to achieve a high level of condom use in the general population.

The programme has also failed to provide sufficient number of trained doctors, para- medical staff and counselers to meet the special needs of women whose husbands are HIV + or those who themselves have been infected. Pregnant HIV+ mothers also have any one to counsel. The efforts of the State government in this sphere have been pathetic. The Table 30 below gives the number of trained manpower:

Table 30

TRAINING REPORT Quarter ending June 2003

A	Doctors B			Nurses C			Lab. Technicians D			Field Health Workers E			NGOs F	Others G	Total
	MH	DH	PHC	MH	DH	PHC	MH	DH	PHC	MH	DH	PHC			
1.Number of health personnel trained during the quarter Q.E.1.4.2003 to 30.6.2003	--	--	79	--	12	17	--	--	11	--	5	244	--	--	368
2. Cumulative during current financial year w.e.f. 1.4.2003 to 30.6.2003	--	--	79	--	12	17	--	--	11	--	5	244	--	--	368
3. Cumulative w.e.f.April 99 to 30.6.2003	1128	1342	1091	2350	2179	1845	359	120	201	27	251	2008	--	585	13486

MH : Major Hospital DH : District Hospital PHC : Primary Health Centres

It is also seen that Rajasthan's State Policy for Women has mentioned HIV/AIDS in passing only and has not given it enough emphases. There has been no linkage between the Rajasthan AIDS Control Society and the department of Woman and Child Development. There are many districts in Rajasthan where there are many more cases of HIV/AIDS than other districts. It is necessary that preventive efforts, Voluntary Counseling and Testing Centers and the care and support programmes should be strengthened in such districts and should be easily accessible to women. It is time to take care of the growing number of orphans in the area and we must start building creches for them so that they are taken care of.

THE FOLLOWING ISSUES EMERGE OUT OF THE STUDY

1. HIV / AIDS has now assumed a woman's face' with more than 60% cases in south of Sahara
2. More young women are becoming infected by husbands and long term partners
3 Because of their lack of social and economic power, they are unable to negotiate relationships based on abstinence, faithfulness and use of condoms.
4 Vulnerability is primarily because of inadequate, insufficient access to HIV prevention services, inability to negotiate safer sex for HIV prevention, not pregnancy.
5 Lack of access to spermicides and microbiocides.
6 Women are also biologically more vulnerable to infection. Male to female infection is twice as likely as female to male
7 90% HIV infections to women are inside marriage or relationship which wives **believe** are monogamous
8 Very few women have a right to ask their husbands/ partners to use a condom

9 Violence increases the risk – first sexual encounters are forced ones for many girls

10 Microbiocides , although only 60 % effective against HIV/AIDS, need a lot of research in India.

11 Increase the use of female condoms. India should provide more funds

12 Small investments in women's health can pay large social dividends

13 HIV infected women in the age group 15-24 are 2.5 times more in number than men in this age group

14 Whatever little women know is rendered useless by the discrimination and violence their face.

15 Women's right to sexual contraceptive choice is a must. Where is the choice?

REHABILITATION OF WOMEN

It is now becoming more and more necessary to provide livelihoods to women whose husbands have either died or are incapacitated by HIV/AIDS and are unable to work. Rehabilitation of women who themselves are infected is also necessary because of the stigma attached with the infection.

If women have to fight the epidemic the government will have to develop a fresh policy for them. This policy will have to take care of the illiteracy and ignorance of women about the epidemic and how to deal with it. Most do not know that they are infected. Most of them do not even want to know because infected or otherwise they must continue with their daily lives as they cannot have a replacement. The policy also has to deal with the fact that the women who know that they are infected have no accessibility to health care, no money to get treatment, no privacy or confidentiality to consult and to keep their HIV status confidential. The government will have to provide free treatment including the A.R.T. It will have to provide specially trained counselors for women. Most women come to know about their infection when they are pregnant and when

their newborn child is diagnosed as HIV+. A number of women during our survey have reported that it is they who are blamed for the infection of their husbands. The policy will also have to include care for the children of such women. A massive legal support system also needs to be developed to fight the cases of women thrown out of their jobs owing to discriminatory attitude of the employers.

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शांतिदीप, जयपुर

क्रमांक

डी-82/II पवन पथ, हनुमान नगर, जयपुर-302 021

एवम्

'राष्ट्रीय महिला आयोग', नई दिल्ली

राजस्थान में HIV/AIDS एवम् महिलाओं की स्थिति

प्रश्नावली

- स्थान (गांव/ढाणी/कस्बा/नगर) का नाम : .....
- ब्लॉक या विकास खण्ड : .....
- जिला : .....
- अध्ययन की तिथि : .....
- शोधकर्ता का नाम : .....

गांव का विवरण

1. भौगोलिक स्थिति :

पठारी	पहाड़ी	मैदानी	रेगिस्तानी	अन्य

2. गाँव की बसावट :

समूहों में	छितरी	व्यवस्थित	अन्य

3. कुल घरों की संख्या :

4. कुल आबादी :

5. जातिवार संख्या :

सामान्य	अ.जा.	अ.ज.जा.	अ.पि. वर्ग	अन्य

6. क्या जाति के आधार पर बसावट है ? यदि हाँ तो विवरण दें।.....

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7. धर्म के आधार पर संख्या

हिन्दू	मुस्लिम	सिख	जैन	बौद्ध	ईसाई	अन्य

8. पढ़े-लिखे लोगों की संख्या : पुरुष | महिला | कुल

9. अधिकांश लोगों की भाषा क्या है ? :

10. लोगों का मुख्य व्यवसाय/धन्धा :

11. निकटतम कस्बे या शहर की दूरी (किमी.) :

12. कस्बे या शहर तक आने-जाने का मुख्य साधन :

13. क्या गाँव सड़क से जुड़ा हुआ है ? : हाँ | नहीं

यदि हाँ तो सड़क किस प्रकार की है ? : कच्ची | पक्की | रोड़ी की सड़क

14. क्या गाँव में संचार सुविधा उपलब्ध है ? : हाँ | नहीं

यदि हाँ तो तो कौनसी ? : डाकघर | टेलीफोन | तारघर | अन्य

15. क्या गाँव में बिजली है ? : हाँ | नहीं

यदि हाँ तो कितने घरों में है ? :

16. क्या गाँव में कोई हाट-बाजार लगता है ? : हाँ | नहीं

यदि हाँ तो गाँव से उसकी दूरी ? :

17. क्या गाँव की 25 किलोमीटर की परिधि में

कोई उद्योग-धन्धे हैं ? : हाँ | नहीं

यदि हाँ तो कौन-कौन से ? :

18. क्या गाँव में स्कूल है ? : हाँ | नहीं

यदि हाँ तो किस स्तर का है ? : प्राथमिक | मिडिल | सैकण्डरी | सी. सैकण्डरी

19. क्या लड़कियों के लिए अलग से स्कूल है ? : | हाँ | नहीं |

यदि हाँ तो किस स्तर तक :

20. गाँव के स्कूल से आगे की पढ़ाई के लिए

निकटतम स्कूल कौनसा है ? :

21. उसकी गाँव से दूरी कितनी है ? :

22. उस स्कूल तक जाने का साधन क्या है ? :

23. गाँव में स्कूल के अलावा शिक्षा के अन्य साधन क्या हैं ?

(जैसे : साक्षरता केन्द्र, स्वयंसेवी संस्थाओं द्वारा चलाए जाने वाले केन्द्र आदि)

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24. क्या गाँव में प्राथमिक चिकित्सा केन्द्र है ? : | हाँ | नहीं |

यदि हाँ तो उसमें क्या-क्या सुविधाएं हैं : | एएनएम | डॉक्टर | महिला डॉक्टर | प्रसव कराने की सुविधा | अन्य |

यदि नहीं तो-

25. निकटतम प्राथमिक चिकित्सा केन्द्र की गाँव से दूरी :

26. क्या गाँव में निजी चिकित्सक हैं ? : | हाँ | नहीं |

27. उनमें कितने आरएमपी या प्राइवेट प्रेक्टिशनर हैं ? :

28. एमबीबीएस या उच्च योग्यता वाले कितने हैं ? :

29. क्या गाँव में महिला डॉक्टर है ? : | हाँ | नहीं |

यदि हाँ तो कौनसी ? : | सरकारी | निजी प्रेक्टिशनर |

30. क्या गाँव में कोई स्वयंसेवी संस्था काम कर रही है, यदि हाँ तो क्या काम करती है ?.....

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31. गाँव में बीपीएल परिवार कितने हैं ? :

32. गाँव में कौन-कौन सी सरकारी विकास/सहायता योजनाएं चल रही हैं ?

(उदाहरण : बचत समूह, महिला बाल-विकास कार्यक्रम, स्वयं सहायता समूह, अकाल राहत या इसी प्रकार के अन्य सरकारी कार्यक्रम)

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33. **पंचायत जनप्रतिनिधियों और सरकारी एजेन्सियों की एचआईवी रोग व पीड़ितों के बारे में राय**

(सरपंच, वार्ड पंच, आंगनबाड़ी कार्यकर्ता ए.एन.एम., साथिन, शिक्षक से चर्चा करें)

चर्चा के बिन्दु :

(अ) आपके गाँव में कितने व्यक्ति एचआईवी/एड्स से पीड़ित हैं ?

महिला	पुरुष	बच्चे

(ब) आपके गाँव में लोग इस बीमारी के बारे में क्या सोचते हैं ?

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(स) क्या उनमें से किसी ने सहयोग के लिए आपसे संपर्क किया है ?

हाँ	नहीं

(द) यदि हाँ तो आपने उन्हें किस प्रकार का सहयोग किया है ?

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निम्न प्रश्न ए.एन.एम. और आँगनबाड़ी कार्यकर्ता से पूछें -

(अ) क्या आपने इस बीमारी के बारे में महिला समूहों की बैठक में चर्चा की है ?

हाँ	नहीं

(ब) यदि हाँ तो चर्चा के क्या बिन्दु रहे ?

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(स) क्या आपके पास इस बीमारी के प्रति जागरूक करने के लिए पोस्टर एवं अन्य प्रचार सामग्री उपलब्ध है ?

हाँ	नहीं

(द) यदि हाँ तो आपने इस सामग्री का किस प्रकार उपयोग किया ?

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स्कूल के शिक्षक से पूछें-

(अ) क्या आपके स्कूल में एचआईवी/एड्स पीड़ित अथवा पीड़ितों के बच्चे पढ़ने आते हैं ?

हाँ	नहीं

(ब) यदि हाँ तो स्कूल में अध्यापकों व अन्य बच्चों का उनके प्रति क्या व्यवहार रहता है ?

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शांतिदीप, जयपुर

क्रमांक

डी-82/II पवन पथ, हनुमान नगर, जयपुर-302 021

एवम्

'राष्ट्रीय महिला आयोग', नई दिल्ली

राजस्थान में HIV/AIDS एवम् महिलाओं की स्थिति

प्रश्नावली

- स्थान (गांव/ढाणी/कस्बा/नगर) का नाम : .....
- ब्लॉक या विकास खण्ड : .....
- जिला : .....
- अध्ययन की तिथि : .....
- शोधकर्ता का नाम : .....

पारिवारिक विवरण

1. नाम (अगर बताना चाहें) : .....
2. उम्र : 15-20 वर्ष | 20-25 वर्ष | 25-35 वर्ष | 35 वर्ष से ऊपर
3. जाति/समुदाय : राजपूत | जाट | ब्राह्मण | अ.जा. | अ.ज.जा. | अन्य |
4. धर्म : हिन्दू | मुसलमान | सिख | ईसाई | अन्य |
5. संयुक्त परिवार है या एकल : संयुक्त | एकल
6. परिवार की कुल सदस्य संख्या : 0-5 | 5-10 | 10-15 | 15 से अधिक
7. परिवार में वयस्क सदस्यों की संख्या :
8. परिवार में बच्चों की संख्या : लड़कों की संख्या | | लड़कियों की संख्या |
9. परिवार के सदस्यों का विवरण :

क्रमांक	सदस्य का नाम	संबंध	आयु	वैवाहिक स्थिति	व्यवसाय	शिक्षा

10. क्या परिवार में पुनर्विवाह की परम्परा है ? | हाँ | ना |

यदि हाँ तो –

(अ) कौनसी परंपरा है ? | नाता | चादर | चूड़ा | अन्य |

(ब) क्या इस परिवार में कोई पुनर्विवाह हुआ है ? | हाँ | ना |

11. क्या परिवार के पास खेती की अपनी जमीन है ? | हाँ | नहीं |

है तो कितनी ? |

12. क्या खेतिहर श्रमिक हैं ? | हाँ | ना |

13. (अ) क्या किसी परंपरागत घरेलू उद्योग में लगे हैं ? | हाँ | ना |

(ब) क्या आप किसी अन्य धन्धे में लगे हैं ? | हाँ | ना |

14. परिवार की अनुमानित कुल वार्षिक आय :

5,000 रु. से कम	5,000 - 10,000	10,000 - 25,000	25,000 रु. से अधिक

15. क्या परिवार बीपीएल (गरीबी की रेखा से नीचे) में आता है ? | हाँ | ना |

16. क्या परिवार को किसी प्रकार की सरकारी सहायता मिलती है ? | हाँ | ना |

यदि हाँ तो किस प्रकार की सरकारी सहायता मिलती है ? .....

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17. क्या परिवार के कोई सदस्य काम करने लम्बे समय के लिए गाँव से बाहर जाते हैं ? | हाँ | ना |

यदि हाँ, तो –

(अ) कितने समय के लिए बाहर जाते हैं ? | महीने के लिए | वर्ष के लिए |

(ब) कहां जाते हैं और वहां क्या काम करते हैं ? | | |

(स) क्या वे अकेले या अन्य पुरुषों के साथ बाहर जाते हैं ? | अकेले | अन्य पुरुषों के साथ |

18. क्या परिवार के किसी सदस्य को कोई भी लम्बी बीमारी है ? (जैसे टी.बी. इत्यादि) | हाँ | ना |

(अ) यदि हाँ, तो किसको (पति/बच्चे) : .....

(ब) बीमारी का नाम : .....

(स) कितने समय से है : .....

(द) क्या इलाज चल रहा है ? : .....

(य) हाँ, तो कहां इलाज चल रहा है ? : .....

झाड़फूक	घरेलू	जिला अस्पताल में	आयुर्वेदिक अस्पताल में	होम्योपैथिक अस्पताल में	प्राइवेट डॉक्टर

19. क्या परिवार में कोई एचआईवी पॉजिटिव है ? | हाँ | ना |

यदि हाँ तो –

(अ) कितने समय से है ? |

(ब) क्या इलाज चल रहा है ? : .....

(स) हाँ, तो कहां इलाज चल रहा है ? : .....

शोधकर्ता की टिप्पणी

शांतिदीप, जयपुर

क्रमांक

डी-82/II पवन पथ, हनुमान नगर, जयपुर-302 021

एवम्

'राष्ट्रीय महिला आयोग', नई दिल्ली

राजस्थान में HIV/AIDS एवम् महिलाओं की स्थिति

प्रश्नावली

- स्थान (गांव/ढाणी/कस्बा/नगर) का नाम : .....
- ब्लॉक या विकास खण्ड : .....
- जिला : .....
- अध्ययन की तिथि : .....
- शोधकर्ता का नाम : .....

महिला से साक्षात्कार

सामान्य विवरण :

1. नाम (अगर बताना चाहें) : .....
2. उम्र : | | वर्ष |
3. जाति/समुदाय : .....
4. धर्म : | हिन्दू | मुसलमान | सिख | ईसाई | अन्य |
5. शिक्षा : | अशिक्षित | प्राथमिक | माध्यमिक | उच्च माध्यमिक | कॉलेज |
6. आप किसके साथ रहती हैं ? : | संयुक्त परिवार में | एकल परिवार में |
7. वैवाहिक स्थिति : | अकेले | विवाहित | तलाकशुदा | पुनर्विवाहित | विधवा |
8. यदि विवाहित हैं तो पीहर-गांव का नाम : .....
9. (अ) विवाह कब हुआ ? .....(ब) गौना कब हुआ ?.....
10. स्वयं का व्यवसाय एवम् मासिक आय : | व्यवसाय | | मासिक आय | |

11. पति का व्यवसाय एवम् मासिक आय :

व्यवसाय		मासिक आय	

12. क्या पति नशा करता है ? :

हाँ	ना

यदि हाँ तो किस प्रकार का, नाम दें

शराब	डुग्स	भांग	चरस	गांजा	अन्य	

13. आपके कितने बच्चे हैं ?

पुत्रों की संख्या	पुत्रियों की संख्या

14. क्या आपकी किसी संतान की मृत्यु हुई है ?

हाँ	नहीं

(अ) क्या गर्भ में ही मृत्यु हो गई थी ?

हाँ	नहीं

(ब) क्या जन्म होते समय मृत्यु हो गई ?

हाँ	नहीं

(स) क्या कुछ समय बाद मृत्यु हो गई ?

हाँ	नहीं

(द) कितने बच्चों की मृत्यु हो चुकी है ?

लड़कों की संख्या	लड़कियों की संख्या

15. क्या माहवारी नियमित है ?

हाँ	नहीं

16. क्या माहवारी से जुड़ा कोई पारिवारिक रीति-रिवाज है ? .....

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17. माहवारी के समय क्या तरीका अपनाते हैं ?

सेनेटरी नैपकिन	पुराने कपड़े	अंडरविमर	अन्य	

18. क्या आप माहवारी में एक ही कपड़ा इस्तेमाल करती हैं या हर दिन नया कपड़ा काम में लेती है ?

एक ही कपड़ा	नया कपड़ा

19. माहवारी के समय काम में लिये सेनेटरी नेपकिन या कपड़े आदि का आप क्या करती हैं ? कहां फेंकती अथवा गाड़ देती हैं ? क्या जला देते है ? क्या उसी को अगले माह भी प्रयोग में लेती है ? .....

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20. क्या आपको कोई यौन सम्बन्धी या पेशाब सम्बन्धी रोग है ?

हाँ	नहीं

(अ) यदि है तो क्या रोग का नाम बता सकती हैं ? .....

(ब) क्या आप कोई दवा ले रही हैं ?

एलोपैथिक	आयुर्वेदिक	घरेलू	झाड़फूक आदि	अन्य

21. क्या आपके व्यक्तिगत या पति के साथ संयुक्त नाम पर कोई सम्पत्ति है ?

हाँ	नहीं

यदि हाँ, तो विवरण दें .....

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वैयक्तिक विवरण

1. आपको पहली बार कब पता चला कि आप एचआईवी पॉजिटिव हैं :

माह पूर्व	वर्ष पूर्व

2. क्या **HIV/AIDS** को गाँव में किसी और नाम से पुकारते हैं ? .....

3. आपको पहले-पहल अपनी इस बीमारी के बारे में कैसे पता लगा ?

किसी लंबी बीमारी के लिए जाँच कराने पर	रक्तदान करने पर जाँच हुई	गर्भावस्था में किसी जाँच के दौरान	इस रोग का संदेह होने पर जाँच कराई

घर में किसी और को यह रोग था इसलिए सावधानीवश जाँच कराई	अन्य	

4. इस जाँच पर कितना खर्च हुआ ? .....

5. इस जाँच हेतु धन कैसे जुटाया ?

अपने धन से	कर्जा लेकर	सामान / गहना गिरवी रखकर	जमीन गिरवी रखकर	जमीन बेचकर	अन्य

6. यदि कर्जा लिया तो किस ब्याज दर से : .....

7. क्या जाँच से पहले या जाँच के बाद आपको किसी ने इस बीमारी के बारे में समझाया था ?

जाँच के पहले	जाँच के बाद में

यदि हाँ तो-

(अ) किसने समझाया ?

पति	मित्र	माता	पिता	बहिन	डॉक्टर/नर्स	अन्य

(ब) कब समझाया ? .....

.....

(स) क्या समझाया ? .....

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8. आपको यह बीमारी होने से पहले क्या आप इस बीमारी के बारे में परिचित थी ?

हाँ	नहीं

यदि हाँ तो-

किस माध्यम से जानकारी थी

पोस्टर	परचा	टीची	रेडिया	मित्रों से	अन्य

9. आपको यह बीमारी कैसे हुई ?

संक्रमित रक्त चढ़ाने से	संक्रमित इंजेक्शन से	यौन संबंधों से	पता नहीं	अन्य

10. जब आप को पहली बार मालूम हुआ कि यह घातक/जान लेवा बीमारी है तो आपने क्या महसूस किया -

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11. जाँच में पॉजिटिव पाये जाने के कितने समय बाद आपने इलाज शुरू करवाया ? .....

.....

.....

12. क्या आप बीमारी बढ़ते ही अस्पताल जाती हैं ?

हाँ	नहीं

13. अस्पताल (PHC/जिला अस्पताल) जाने पर आप ने किस से राय ली ? .....

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.....

14. आपको कोई अन्य गंभीर बीमारी है ? | हाँ | नहीं |

यदि हाँ तो बीमारी का नाम बतायें .....

यह बीमारी कब से है ? .....

क्या उस बीमारी का इलाज चल रहा है ? .....

इलाज चल रहा है तो कहाँ ? .....

15. क्या आपके परिवार में और भी कोई एचआईवी पॉजिटिव हैं ? | हाँ | नहीं |

यदि हाँ तो–

पीड़ित का आप से सम्बन्ध	कब से पीड़ित हैं	पीड़ित व्यक्ति की उम्र

16. परिवार में सबसे पहले यह बीमारी –

किसे लगी ? .....

कब ? .....

कहाँ से ? .....

कैसे लगी ? .....

क्या इलाज चल रहा है ? .....

क्या उन्होंने बीमारी का पता चलते ही आपको बताया ? | हाँ | नहीं |

नहीं बताया तो फिर कब बताया ? .....

17. क्या आपके परिवार में किसी की **AIDS** से मृत्यु हो चुकी है ? | हाँ | नहीं |

यदि हाँ तो उसका आपसे क्या रिश्ता था ? .....

18. एचआईवी पॉजिटिव का पता चलने के दिनों में इस बीमारी के क्या-क्या लक्षण दिखाई दिए या महसूस हुए ?

शरीर टूटना	बुखार	तेज खांसी-जुकाम	भूख कम हो जाना	खुजली	अन्य

19. एचआईवी पॉजिटिव का पता चलने के बाद आपने क्या कोई सावधानी बरती हैं ? यदि हाँ तो क्या-क्या सावधानियाँ ?

बच्चों के प्रति (विशेषकर अपना दूध पिलाने पर) .....

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पति के साथ संबंधों में (विशेषकर यौन संबंधों में / कंडोम का इस्तेमाल आदि) .....

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गर्भावस्था के दौरान .....

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सामान्य दिनचर्या में .....

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सामाजिक धारणा-भेदभाव

1. क्या आपने अपनी इस बीमारी के बारे में किसी को बताया है ?

हाँ	नहीं

यदि हाँ तो-

किस-किस को बताया ?

पति	मां-बाप	बच्चों को	करीबी दोस्तों को	किसी रिश्तेदार को

साथ काम करने वाले किसी साथी को	पड़ोसी को	अन्य किसी को	किसी को नहीं

यदि नहीं तो क्यों ?

बदनामी का डर	भेदभाव किए जाने का डर	बहिष्कार किए जाने का भय	अन्य कारण	

2. जब आपके परिवार को आपकी इस बीमारी के बारे में पता चला तो उनकी क्या प्रतिक्रिया थी ?

	भलाबुरा कहा	नाराज हुए	मारपीट की	बात नहीं की	दूर रहने लगे	घर से बाहर निकाल दिया	जमीन जायदाद से भी बेदखल कर दिया
(अ) पति की							
(ब) बच्चों की							
(स) परिवार के अन्य सदस्यों की							
(द) रिश्तेदारों की							

(य) आपके समाज-बिरादरी की क्या प्रतिक्रिया थी ? .....

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3. क्या आपके पति/रिश्तेदार/पारिवारिक सदस्य/समाज के सदस्य आपको दोषी मानते हैं ?

हाँ	नहीं

पहले दोषी मानते थे	अब दोषी नहीं मानते

4. एचआईवी पॉजिटिव होने के बाद आपको किसी प्रकार से भेदभाव का सामना करना पड़ा ?

यदि हाँ तो- किससे ? .....

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कब-कब ? .....

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कहाँ ? .....

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किस प्रकार से ? (कोई तीन घटनाएं उदाहरण के लिए बताएं)

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5. क्या आपकी लम्बी बीमारी की वजह से परिवार एवम् समाज के बर्ताव में अब कोई फर्क आया ?

आपके प्रति क्या फर्क आया ? .....

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आपके पति के प्रति क्या फर्क आया ? .....

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आपके बच्चों के प्रति क्या फर्क आया ? .....

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6. क्या आपके परिवार ने आपको एचआईवी पॉजिटिव होने के बावजूद स्वीकार किया ?

हाँ	नहीं

यदि हाँ तो उन्हें ऐसा करने में कितना वक्त लगा ? .....

7. यह पता लगने के बाद आप एचआईवी पॉजिटिव हैं, आपके मन में क्या विचार आते हैं ?

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8. क्या आप मानते हैं कि आपने कुछ गलत काम किया जिसकी वजह से यह बीमारी हुई ?

हाँ	नहीं

9. क्या आप मानते हैं कि यह पूर्वजन्म के पापों का फल है या कि कोई श्राप है ?

हाँ	नहीं

10. क्या आपको अपनी बीमारी का पता अस्पताल के डॉक्टर के देखने के बाद चला ?

हाँ	नहीं

11. क्या डॉक्टर ने आपको **HIV/AIDS** टैस्ट कराने को कहा ?

हाँ	नहीं

12. आपका टैस्ट सरकारी अस्पताल में हुआ या प्राइवेट में ?

सरकारी	प्राइवेट

13. टैस्ट जहाँ कराया वहाँ की दूरी आपके घर से कितनी थी ? .....

14. आप किस के साथ जाँच कराने गईं ? .....

15. डॉक्टर का व्यवहार आपके प्रति कैसा था ? .....

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16. क्या वहाँ कोई महिला डॉक्टर तैनात है ?

है	नहीं है

17. महिला डॉक्टर का व्यवहार आपके प्रति कैसा था ?

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18. वहाँ तैनात कम्पाउन्डर या नर्स का व्यवहार कैसा था ?

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19. अब, जब आप अस्पताल जाती हैं तो कर्मचारियों का व्यवहार कैसा होता है ?

सहानुभूतिपूर्ण	दयामय	भेदभावपूर्ण	सहायतापूर्ण	अन्य मरीजों के समान

20. क्या आप ने एड्स की महँगी वाली खास दवा ली है ?

हाँ	नहीं

21. क्या डॉक्टर ने और कोई दवाएं बताई हैं ?

हाँ	नहीं

22. क्या आप उन्हें ले रही हैं ?

बताई सब दवा	उनमें से कुछ दवा	कोई नहीं

23. क्या आप ऐसी और भी महिलाओं को जानती हैं जिन्हें **HIV/AIDS** होने का सन्देह है पर उन्होंने टैस्ट नहीं कराया है?

हाँ	नहीं	कोई नहीं

यदि हाँ तो ऐसी कितनी महिलाएं हैं ? .....

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परिवार एवम् स्वयं की जिन्दगी पर बीमारी का असर

1. जब आप बीमार पड़ जाती हैं तो कौन देखभाल करता है ?

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2. इस बीमारी की वजह से आपके अथवा आपके पति के काम का क्या नुकसान हुआ ?

(नौकरी या काम धन्धा छूट जाना आदि स्पष्ट रूप से पूछें)

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3. क्या आमदनी पर कोई असर पड़ा ?

हाँ	नहीं

यदि हाँ तो कितना ? .....

4. क्या गाँव कुछ समय के लिए छोड़ना पड़ा ?

हाँ	नहीं

5. इस बीमारी की वजह से बढ़े खर्च को पूरा करने के लिए आप क्या करती हैं ?

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6. इस बीमारी की वजह से आपके अथवा आपके पति के काम का क्या नुकसान हुआ ?

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7. बढ़े खर्च में परिवार के गुजारे के लिए आपको या आपके पति को और क्या जिम्मेदारी उठानी पड़ी ?

ज्यादा काम करना पड़ा	अन्य आय स्रोत ढूंढना

आपके अनुभव

1. इस बीमारी के इलाज के लिए दवाओं पर हर महीने कितना खर्च होता है ?

   पति की बीमारी पर .....

   .....

   बच्चों पर .....

   .....

   आप पर .....

   .....

2. यदि पति, बच्चे एवम् आप इस बीमारी से पीड़ित हैं, तो किसके खाने-पीने एवम् सुविधा का सबसे ज्यादा ध्यान रखा जाता है ?

   (प्राथमिकता क्रम अनुसार बताएं)

   सबसे ज्यादा .....

   उससे कम .....

   सबसे कम .....

3. आप नियमित जाँच कराने और दवा लेने के लिए कहाँ जाती हैं ?

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4. पिछली बार जब आप जाँच कराने गईं तो कितना खर्च हुआ ?

   (अ) आने-जाने में .....

   (ब) डॉक्टर की फीस में .....

   (स) दवाओं पर .....

5. साल भर में जाँच पर कितना खर्च होता है ? .....

6. क्या आपको इसके लिए कहीं से कोई मदद मिलती है ?

हाँ	नहीं

7. क्या कोई स्वयंसेवी संस्था आपकी किसी प्रकार से सहायता करती है ?

हाँ	नहीं

यदि हाँ तो किस प्रकार की सहायता अब तक मिली है ?

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8. आप क्या सोचती हैं कि इस बीमारी से पीड़ित महिलाओं के लिए सरकार या संस्थाएं किस प्रकार मदद कर सकती हैं ?

(किस प्रकार की मदद की अपेक्षाएं हैं)

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9. आपकी नजर में इस बीमारी से बचाव और इसे फैलने से रोकने के लिए क्या-क्या कदम उठाए जाने चाहिएं ?

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10. (अ) क्या आप घर बैठे पैसा कमाने के लिए कोई काम कर सकती हैं ?

हाँ	नहीं

(ब) क्या काम कर सकती है ? .....

(स) इस काम में कितना पैसा लगेगा ? .....

11. आप के ग्राम की महिलाएं अपने यौन संबंधी या गर्भ संबंधी इलाज के लिए कहाँ जाती हैं ?

बुजुर्गों से सलाह	झाड़फूंक	देशी इलाज
MCH	PHC	जिला अस्पताल
होम्योपैथिक अस्पताल	आयुर्वेदिक अस्पताल	प्राइवेट डॉक्टर

12. (अ) आपके बच्चे कहाँ हुए ?

घर में कितने		अस्पताल में कितने	

(ब) यदि अस्पताल में तो वह आपके निवास से कितना दूर है ? .....

(स) क्या वहां महिला चिकित्सक मिलती हैं ?

हाँ	नहीं

(द) यदि महिला चिकित्सक नहीं हों तो, क्या आपको पुरुष चिकित्सक से इलाज कराने में हिचक होती है ?

हाँ	नहीं

13. अन्य बीमारी के इलाज के लिए आप कहाँ जाती हैं ?

बुजुर्गों से सलाह	झाड़फूंक	जिला अस्पताल	होम्योपैथिक अस्पताल	आयुर्वेदिक अस्पताल	प्राइवेट डॉक्टर

14. क्या अस्पताल में महिला चिकित्सक तैनात हैं ?

हाँ	नहीं

शोधकर्ता की टिप्पणी