CHAPTER I
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CHAPTER I
THEORETICAL FRAMEWORK AND SITUATION ANALYSIS

1.1: Introduction:

Human beings since the beginning, apply their minds to create a better world, and live a comfortable life. With communication media, inventions in science, medicine, technology, social sciences have made life richer, , as if the world has become very small. Overall, there is a development in agriculture, industry, infrastructure, quality of life, health and explosion of knowledge and information. Despite incredible improvements there are number of challenges before us. If we look at global issues, there is poverty, inequality, in the era of globalization the disparity between rich and poor has widened. There are other problems of global warming like insufficient water supply, deforestation, biodiversity and ecosystem losses. On the health front, there are issues about communicable diseases, one billion people lack access to health care, 36 million deaths are caused each year due to life style diseases. Over 7.5 million children under the age of five die from malnutrition and mostly preventable diseases. Vaccines are not yet affordable to many people. There are problems of Tuberculosis (TB), Malaria and measles. Tuberculosis kills 1.7 million people every year with 9.4 million new cases a year, HIV has spread rapidly. Five million people are living with HIV and are receiving Anti Retroviral Therapy (ART) but an additional 10 million are in need of treatment.

Since last 50 years India has made significant progress in various fields. Health, education, agriculture, employment, science and technology are some of the frontline fields where we have achieved self sufficiency and self-reliance. Since 1990, India is emerging as one of the superpowers in the world. We have succeeded to reduce Infant Mortality Rate (IMR) from 70 to 40 per 1000 live births, we have succeeded to increase our life expectancy from 62 to 75. We are self sufficient in food grains, number of jobs opportunities are available in the I.T. sector, in industrial sectors and in the field of science and technology. We are much more ahead than any other country in the third world. Along with this, we are marching ahead significantly in other fields too. Government of India is making hard and sincere efforts through various strategies to achieve the optimum growth rate in these fields. In spite of these efforts, Indian society is still facing some of the problems which are becoming

chronic and complex in nature along with newly emerging problems. It is not so, that efforts are not made to solve chronic problems, but these efforts fail to show expected results. There are two reasons to explain the underachievement, one, despite the fact that the development programmes have reached to millions of people, a few millions of the people are yet to be reached, therefore more resources are required and the second reason is whatever the social problems we have, these are mainly due to the overpopulation or rapid population growth, widespread malnutrition, poor quality of health services, deforestation and soil erosion. Environmental problems are created by rapid urbanization and industrialization, over exploitation of natural resources and high rate of migration for employment. These are some of the examples of social problems from which we are creating hurdles in the overall development. Migration from rural to urban, urban to urban and rural to semi-urban areas itself has invited several social problems like slum, over population density, poor quality of living etc.

Currently we have health problems like malnutrition, 42% of India's children below 3 years are malnourished, we have poor sanitation, people don't wish to construct and use latrines. We do not have sufficient safe drinking water supply. Though some of our public health programmes have controlled few infections, epidemic diseases and life style diseases. In spite of the National Rural and Urban Health Mission strategy, we still have inadequate infrastructure and health personnel, apart from the above problems.

The consequence of prime age adult ill health and death for families and households are dramatic and devastating. The most severe and immediate economic impact emanates from treatment and travel cost incurred by the individual affected. We do not have adequate health insurance in our country. As HIV allows a number of fairly healthy years, careful financial planning is necessary which could start early to reduce hardships of the person. Services are made affordable and accessible, for poorer sections of the society.

1.2. HIV/AIDS

Global and National Scenario:

AIDS, which is one of the most dreaded diseases of humanity, has spread to every part of the world, threatening people from all spheres of life. The first case of HIV infection was reported in 1981 among the homosexuals in U.S. of America.

- More than 2.5 million people have died of AIDS worldwide and another 33 million are currently living with HIV/AIDS (NACO).
- While cases have been reported in all regions of the world, almost all those living with HIV (96%) reside in low and middle income countries, particularly in sub Saharan Africa.
- Most people living with HIV or at risk for HIV do not have access to prevention, care and treatment.
- HIV primarily affects those in their most productive years, more than half of new infections are among those under age twenty five.
- The HIV epidemic not only affects the health of individuals, it impacts households, communities and the development and economic growth of nations.
- Two million people died of AIDS in 2007 up from 1.7 million in 2001, but deaths are now declining due in part to Anti-Retroviral Treatment. (ART). HIV is a leading cause of death worldwide and the number one cause of death in Africa.
- Most new infections are transmitted heterosexually, although risk factors vary.
- Women represent half of all people living with HIV worldwide and more than half (59%) in sub-Saharan Africa. Gender inequalities, differential access to services, and sexual violence increase women's vulnerability to HIV and women especially, younger women are biologically more susceptible to HIV.
- In Latin America-nearly 2 million people are living with HIV.
- Eastern Europe and Central Asia have an estimated 1.5 million people are living with HIV in this region. The epidemic is driven primarily by injecting drug use although heterosexual transmission also plays an important role.
- Asia – Nearly 5 million people are living with HIV across South/South East Asia and East Asia.

India : As per the available statistics in India currently 2.5 million people are living with HIV(NACO). India's HIV prevalence level is equal to roughly 0.36% of its population of more than one billion people. HIV prevalence shows signs of slight decline among the general population. However it continues to be high among vulnerable groups. Those are sex workers, injectable drug users, street children, mobile population or migrants.

India was relatively quick as compared to other countries to device a nation strategy to prevent HIV. NACO was established in 1990, since 1986, HIV/AIDS emerged as most serious public health problems in the country. Government established National AIDS Committee within the Ministry of Health and Family Welfare. This body collected data from testing centres and Sexually Transmitted Infections Clinics (STI). In following five states mainly Tamilnadu, Karnataka, Andhra Pradesh, Maharashtra and Manipur more number of HIV cases were seen. In Maharashtra, five districts report high number of cases those are Sangli, Kolhapur, Pune, Mumbai and Thane.

1.3. Modes of Transmission

Human Immunodeficiency Virus (HIV) is the virus that causes AIDS. HIV belongs to the family of retroviruses. A person infected with HIV is infectious for life. Most people living with HIV remain asymptomatic (without signs and symptoms of disease) for long periods of time and may not know that they are infected. HIV is transmitted by sexual contact, through blood and from mother to child during pregnancy, delivery or breast feeding.

Sexual Mode : Heterosexual transmission is the prominent route of transmission around the world. Sexual transmission occurs during heterosexual and homosexual intercourse. Sexual intercourse refers to the penetrative, vaginal and anal intercourse with infected individuals of highest risk is unprotected penetrative vaginal or anal intercourse with an infected individual.

Exposure to infected blood, blood products : Exposure to contaminated blood may occur as a result of the transfusion of blood not screened for HIV-antibodies, the reuse of contaminated syringes and needles, or contaminated medical equipments. This situation can occur in health care settings, traditional healing rituals like scarification and through intravenous drug use.

Mother to child transmission: The majority of HIV infection in children occurs from the HIV infected mother passing the virus to her infant before, during or after birth. The vast majority of children with HIV are infected from their mothers in-utero, at the time of labour and delivery and after birth through breast feeding. However, now since 1994 there is prophylaxis available to prevent mother to child transmission of HIV, and it is now adopted as a standard care of HIV infected pregnant women during ante-natal (ANC) care.

High risk group: High risk groups are the people who can get HIV infection much faster. The first such group is sex workers. Sex workers encompass a diverse group of people (male, female, transgender).

Sex Workers and HIV risk: Sex workers are especially vulnerable to HIV transmission due to their large numbers of sexual partners and often high rates of other sexually transmitted diseases. Sex workers often feel disempowered to negotiate safe sex practices with clients on whom they rely for income.

Injectable drug users (IDUs), inject drugs into veins, under the skin. Drug injecting is often conducted as a group activity among drug users. A common practice is to use the same injecting paraphernalia syringe, needle, filter for all the members of the group. Sharing is also common among regular sexual partners. If one member of the group or a partner in a sexual relationship with a member of the group has HIV infection, and sharing of paraphernalia occurs, the chances of infection through the injecting route are much higher than sexual route of transmission. Thus, once HIV enters into a social network of IDUs, the spread with the IDU community can be very high.

HIV and Mobile population: Migration and mobility have increased over the past several years and are likely to continue to increase as:

- Means of transport are easily available
- Economic imbalance which pushes people to move in search of better lives.
- Job opportunities available at international, national, interstate level.
- War, riots continue to displace people.
- Organized migration and trafficking continue to flourish.

HIV and migration are two crucial social issues in today's world. Understanding the poverty and economic transition often associated with migration and mobility helps us realize, why migrant populations are at high risk than the overall population for poor health in general and HIV infection in particular.

Origin of HIV:

The first recognized cases of AIDS occurred in the USA in 1980s, a number of gay men in New York suddenly developed rare opportunistic infections and cancers that seemed resistant to any treatment. HIV causes AIDS, it is a lent virus it attacks the immune system. The name lentivirus means 'slow virus', it takes long time to

produce any adverse effects in the body. It is accepted that HIV is a descendent of simian Immunodeficiency virus because certain strains of SIV bear a very close resemblance to HIV 1 and HIV 2.

How could HIV have crossed species ? It has been known for a long time that certain viruses can pass between species. The very fact that chimpanzees obtained SIV from two other species of primate shows just how easily this crossover can occur. As animals ourselves, we are just as susceptible when a viral transfer between animals and human takes place, it is known as zoonosis. There are some theories about this zoonosis and how SIV became HIV in humans.

1) **Hunter Theory:** the most commonly accepted theory is that of the 'hunter'. In this scenario, SIV CPZ was transferred to humans as a result of chimps being killed and eater or their blood getting into cuts or wounds on the hunter. Normally the hunter's body would have fought of SIV, but on a few occasions it adapted itself within its new human host and became HIV-1. In 2004, it was discovered, that this infections were believed to have been acquired through the butchering and consumption of monkey and ape meat. Such discoveries led to outright ban on bush meat hunting to prevent HIV.
2) **The Oral Polio Vaccine Theory (OPV):** Another theory is HIV was transferred estrogenically i.e. via medical interventions particularly polio vaccine. But it could not be proved during researches in 2001. The fact that the OPV theory accounts for just one of several different groups of HIV also suggests that transferred must have happened in other ways too, as does the fact that HIV seems to have existed in humans before the vaccine trials were ever carried out.
3) **The Contaminated Needle Theory:** This is an extension of the original 'hunter' theory. In the 1950s, the use of disposable plastic syringes became commonplace around the world as a cheap sterile way to administer medicines. However, at the places where huge quantities of syringes needed, were costly, so it was likely that one single syringe would have been used to inject multiple patients without any sterilization in between. This has raised chances of transfer of viral particles from one person to another creating huge potential for the virus to mutate and replicate.
4) **The Colonialism Theory:** In 2000, Jim Moore American specialist in primate behavior published his findings in journal AIDS Research and Human

Retrovirus. During 19-20th century much of Africa was ruled by colonial forces. This rule was harsh, there were poor health conditions, due to which immune system weakened to have HIV. There were labourers who were inoculated with unsterile needles and many of the camps actively employed prostitutes to keep the workers happy. SIV could easily have infiltrated the labor force and taken advantage of their weakened immune system.

5) **The Conspiracy Theory:** Some people believe that HIV is a 'conspiracy' or it is 'man-made'. It is believed, that the virus was spread to thousands of people all over the world through the small inoculation program or to gay men through Hepatitis B vaccine trials. While none of these theories can be definitively disproved, the evidence given to back them up is usually, based upon supposition and speculation, and ignores the clear link between SIV and HIV or the fact that the virus has been identified in people as far back as 1959. Given the evidence, we have already looked as, it seems that Africa was indeed the continent where the transfer of HIV to human first occurred. The AIDS epidemic in Haiti first came to light in the early 1980, at around the same time that cases in the USA were being uncovered. Following the discovery of number of Haitians with kaposi's sarcoma and other AIDS related conditions, medical books and journals claimed that AIDS had come from Haita and Haitians were responsible for AIDS epidemic in the U.S. Further there are number of factors that have contributed to the sudden spread of HIV which occurred in latter half of the twentieth century factors are travel, the blood industry and drug use.

1.4: Tests for HIV:

Immediately after infection, some people may develop mild, temporary, flu-like symptoms or persistently swollen glands. Even if one feels healthy, he may be infected. The only way to know one's HIV status for sure is to be tested for HIV antibodies – proteins the body produces an effort to fight off infection. This requires a blood sample. If a person's blood has HIV antibodies that means the person is infected.

HIV Tests:

A variety of HIV antibody assays are available. These assays can be broadly classified into three groups. Enzyme Linked Immuno Sorbent Assay (ELISA), Western blot

assay, and rapid tests. These assays use different methodologies. Most current HIV antibody tests are capable of detecting antibodies to HIV 1 & HIV 2.

ELISA:

HIV antibodies in the test serum are detected using an antibody sandwich capture technique. If HIV antibodies are present in the test serum are sandwiched between HIV antigen, which is fixed to the test well and to 'enzymes' that are added to the test well following addition of the test serum. The test well is washed thoroughly to remove any unbound enzyme. A colour reagent is then added to the well. Any bound enzyme will catalyze a change in colour in this reagent. The presence of HIV antibodies is thus inferred from the change of colour.

Western Blot:

HIV antibodies in the test serum are detected by reacting to a variety of viral proteins. These proteins are initially separated into bands according to their molecular weight on an electrophoresis gel. These proteins are then transferred or 'blotted' to nitrocellulose paper. The paper is then incubated with the patient's serum. HIV antibodies to specific HIV proteins bind to the nitrocellulose paper at precisely the point to which the target protein migrated. Bound antibodies are detected by colorimetric techniques. This test is done to confirm the HIV diagnosis.

Rapid Tests:

A variety of rapid tests are available, those are appropriate for the smaller health institutions, where only a few samples are processed every day. Rapid tests are quicker and do not require specialized equipment. Most are dot-blot immunoassays or agglutination assays requiring no instrumentation or specialized training and takes little time. The major advantage of the rapid HIV test is that, it allows results to be given on the same day, which reduces the number of visits of the clients at the clinic. Another advantage is that client can receive results from the same health care worker who performed pretest counseling (VCTC Training manual 2004).

1.5: Treatment for HIV/AIDS :

There is still no cure for AIDS. While new drugs are helping some people who have HIV live longer, healthier lives, there are many problems associated with them.

- Anti-HIV drugs are highly toxic and can cause serious side effects, including heart damage, kidney failure, and osteoporosis. Many patients cannot tolerate long term Highly Active Anti Retroviral Therapy (HAART).

- HIV mutates quickly, roughly half of patients experience treatment failure within a year or two, because the virus develops resistance to drugs.
- Treatment regimens are unpleasant and complex, many patients miss doses of their medication, which leads to development of new drug resistant viral strains.
- Even when patient responds well to treatment, HAART does not eradicate HIV.

Alternative Medicine for HIV/AIDS :

Alternative medicine has been variously called natural, complementary, 'holistic and other numerous terms, which' refer to elements of a particular modality or tradition. The traditional ethno medicinal systems are by nature holistic which aims to treat the whole individual, rather than a specific disease or symptom, and they not only address the physical aspect of the patient but also the mind and spirit. It is assumed that each individual possesses an innate healing capacity, and the goal generally is to reinforce this capacity and restore strength and balance the weakened systems using a variety of natural modalities: body work, detoxification, foods, herbs and botanicals, tailored as much as to the individual's specific constitution and condition. The use of alternative therapies for AIDS grew out of this same eclectic mix. At the beginning of the epidemic, there was no treatment available for people with HIV. Although, as yet there is no cure, over the decade's researchers have identified a number of drugs that slow progression of the virus as well as therapies to treat the many opportunistic infections that attack people with HIV disease. The treatment aim at strengthening the immune system, help patients reduce stress and maintain good nutritional practices and appropriate exercise regimens.

Traditional Chinese Medicine:

The use of acupuncture and Chinese herbal medications has philosophy of life and is based on a holistic of view of supporting the mind – body's innate ability to maintain health. This Chinese medicine was first popularized as a treatment for AIDS in San Francisco by Misha Cohen, a doctor of oriental medicine in 1984. Many of the herbs have been found to inhibit HIV and other virus in laboratory experiments. Other herbs have been shown to act as biological response modifiers, enhancing certain immune responses. In addition, a small strictly controlled study, using acupuncture to treat HIV infected persons was conducted at Lincoln Hospital in Bronx, New York. It was

reported that persons receiving correctly applied acupuncture needling had notable increase in their CD4 counts after only a brief course of theory.

Homeopathy:

Prior to the emergence of AIDS, few people were familiar with or cared about the immune system. Homeopathy is beginning to develop a reputation for helping people at varying stages of this disease. It includes minerals, vitamins, and animal products. Homeopathy is highly individualized to a patient's symptoms. The treatments of people with HIV or AIDS require professional health care, even when their ailments are seemingly minor. One of the advantages of homeopathy in treating AIDS patients is that they tend to get various unusual symptoms, diseases and syndromes which evade immediate diagnosis. Homeopathic medicines are prescribed on the basis of a person's unique pattern of symptoms. Numerous homeopaths find that select patients with advanced stages of AIDS experience dramatic improvement in their quality of life. The experiment by Dr. Issac Mathai in India – Bangalore, there were 20 cases handled by him with positive changes.

Acupuncture:

This modality of treatment involves the painless insertion of extremely thin needles into the skin at specific points to help balance the body's flow of energy, when needles are inserted into the appropriate points, it is thought that energy is unblocked and symptoms can be relieved. Acupuncture can significantly add to an overall improvement in the sense of well-being of HIV infected patients. More and more people with HIV are using acupuncture to reduce stress, pain, tension.

Ayurveda:

Dr. Shanthakumar in Mumbai, India claims that Ayurveda identified AIDS over 2000 years ago. The same treatment used for (Rajaykshama – AIDS) can be applied fruitfully in the war against HIV. Initially the patient is given tonics and rejuvenators to boost immunity levels. Subsequently select medicines to counter the virus are administered.

Body Work and Massage Treatment:

There is much evidence that suggests many complementary and alternative therapies have a therapeutic effect on body, relieving stress, anxiety and depression in HIV patients. The stigma surrounding AIDS has many negative effects on the mind and body. The hands on intimacy of aromatherapy have a great psychological benefit on body and mind. Many of the today's health problems arise from stress, it upsets the

delicate integral balance of the body's functions, so regaining this balance requires a holistic approach. Massage can help people with HIV to relieve chronic muscle tension and ease the mental and emotional stresses that accompany the illness.

Yoga:

It takes a great deal of courage to face a disease that seems to have no cure. Many people with HIV experience intense feelings of fear, hopelessness, anxiety, loneliness and depression. Yoga technique can help to reduce excessive fear, anxiety, acquire stress coping skills and build inner strength through the relaxation and self awareness training of meditation. Yoga is the practice of ancient system of breathing exercises, postures, stretching exercises and meditation based on Ayurvedic medicine and Indian philosophy and religion. The aim of Yoga is to help the individual to balance the body's energy centres. Yoga can help in detoxification, strengthen particular organs, improve stamina and alleviate chronic fatigue. Yoga is quickly gaining ground as an important complementary therapy in the treatment of HIV because of its adaptability and its physiological and psychological benefits. Though there are alternative systems of medicine are being tried out for HIV, Anti-Retroviral Therapy (ART) has been very effective.

Impact of HIV on health system:

1. Managing waste disposal in hospitals.
2. The adoption of universal precautions in hospitals.
3. Managing blood in and outside hospitals.
4. Training of health care provider not only for HIV, but for other related illnesses.
5. Availability of drug, medicines other safety gadgets.
6. Provision of counseling services.
7. Providing terminal care.
8. Overloading of communicable disease care at primary care level.

1.6: Psycho-social stages of HIV disease:

- Pre HIV antibody testing.
- Post HIV antibody testing, knowledge of being positive.
- Falling CD4 count.
- Severe medical illness.
- Restore feeling of well being with attitude change (aids etc.org).

In the pre HIV antibody testing stage the individual involved in the high risk behavior i.e. multipartner unsafe sexual behavior, suspects whether, he has contracted HIV and experiences fear about it. He is not sure about his status but due to the HIV information, person knows the modes of transmission and if it gets confirmed, 'death' is sure. There is a feeling of grief and loss. Even though, there is effective treatment it is for life time, and depending on the marital status, person also fears about the decision of marriage and having children. Some people also experience denial and shock in this stage.

In the post HIV antibody positive test, individual reacts with anger, loss of trust from the partner. In this stage, he is told about meaning of positive HIV test and the importance of treatment and care. This requires, sharing this diagnosis with the family members, which requires courage on the part of individual. He is expected to share diagnosis immediately with partner but in the absence of proper communication and trust, he does not share it. There is a fear of shattering the marital relations. The care which is expected in this stage cannot be provided in the absence of sharing of diagnosis. Individual continues to have unprotected sex with marital partner, woman gets pregnant in this period, depending on the overall health of the infected person, and he develops opportunistic infections. Subsequently person gets angry and asks 'why me'? He experiences shame, guilt, feelings of hopelessness, depression and suicidal ideas. If he accepts diagnosis, shares with dear ones, he receives care, but if not, family members especially wife feels being deceived, it is at this stage, she is expected to care for the husband. HIV as a crisis is seen as there is a fall in the CD4 count, and person develops opportunistic infections. He requires repeated hospitalization, due to loss of weight, other complications and experiences feeling of dependency, repentance over his risk behavior. Few patients even after developing severe symptoms receive care and treatment at family and at hospital level and still they can restore their wellbeing. Here, both husband and wife are counseled for attitudinal change about health, nutrition and safer sex practices. Those who follow, nutritional guidance, seek medical advice and care for health, can maintain their health with the help of Anti-Retroviral-Therapy (ART). Those who do not care for themselves unfortunately cannot survive. In this entire effort of caring for patient, he has to accept the diagnosis, treatment with positive attitude. If not, family has to take care of the patient; in addition they have to manage material and social resources. At this crisis situation family, relatives, friends and neighbours reveal the HIV status of

the person and they react with ‘stigma’ with the patient and family. Woman loses support from her in-laws, due to HIV diagnosis of the husband. Children suffer due to HIV of parents, while getting admissions in school and among friends they are isolated and discriminated. Woman experiences fear, insecurity and uncertainty about health condition of husband. Intervention can be done in this situation through individual counseling and group counseling.

HIV has a large psychological, physical and social impact on infected individuals and their families. Stigmatization worsens this impact; it hinders the prevention and the treatment of HIV and hampers social support and HIV disclosure. The risk of transmitting HIV, which includes mother to child transmission increases when people are unaware of their HIV infection and do not disclose their status and in the absence of access to treatment and care, they face side effects of medicines.

1.7: Psycho-social implications

HIV / AIDS is a medical condition, but the person who gets affected, it is a study of psychological aspect. Anyone of us would always like to live normal and problem free life. Especially we wish that our body should have stamina and strength and should never suffer any health problem. However, as we live in the environment, there is a constant interaction between individual’s body and physical environment, comprising heat, cold, light, pollution of air, water and noise and our body does gets affected by these environmental factors. Our body itself also is prone to have certain infections. Since 1986, we see HIV/AIDS as one of the incurable and dreadful diseases. It affects on individual, family and community.

Impact of HIV on families

Family is the basic unit of society when families are healthy; societies remain healthy and can make progress. There are many factors, which are influencing changes in families, it affects on solidarity and integration of families. In family, when a breadwinner is diagnosed HIV positive, there is a shattering of relationship. The partner feels the end of everything. There is a distrust experienced by one of the spouses, disclosing HIV status means, as if accepting risk behavior which is very difficult, especially talking to an intimate person like spouse/partner. This results into conflicts in family; sometimes the other spouse reacts harshly and deserts the infected person. Eventually the person falls sick and needs extra care. He experiences pain, fear of death, guilt, and due to opportunistic infection and repeated hospitalization,

further it is seen lowering self esteem, there is a burden on family's resources for paying for treatment and other related expenses. There is a strain on relationship between spouses. In such a situation, if children are small, they suffer most. Little older children wonder, as to why there is non-communication between parents or hatred, hostility between the two. There is a role reversal as the sole breadwinner is sick; the woman has to take the role to support family financially. As seen earlier, families from lower socio-economic strata live in poor living conditions, having low access to health care facilities and face stigma and discrimination; sometimes they find the partner had taken loan that is to be repaid. In addition, husband has some addiction also. On these background women find it difficult to cope with the situation, as they are the sole caretakers. Apart from this, after the death of husband woman also has to arrange for cost of funeral. They experience stigma by the community people in this process due to HIV status of the husband. In all the above situations, if in-laws are supportive, even after knowing the diagnosis of their son and daughter in law, and especially after the death of the son, the woman is not accepted in the house and she is left without any financial resources like house, land, ornaments etc. Hence, the woman has to restart the life by redistributing the existing resources and the time to perform multiple roles. She requires strength to cope up these additional responsibilities including the responsibility of the child.

Statistics do not actually explain critical matters of concern such as psychological manifesto of HIV, fear, loss, guilt, shame not everyone will experience same emotional response **(**Van Empelen WHO 2005) but self image and self esteem gets affected (Watstein and Chandler 1998). They become aggressive, withdrawn feel being victimized, self confidence is lost, and they feel the end of everything. It is due to the dreadfulness, stigma attached to HIV. It affects their well-being; coping with being infected involves confronting fear and denial while maintaining hope. Infected persons are normally in fear because they have to adjust to a new life style, thus shock and disbelief leading to denial is an initial response. Persons with HIV are looked down upon, due to their risk behavior this may lead to social isolation and emotional breakdown. They experience loss of support by family and friends. Additional feeling of loss, isolation is due to need to change their sexual practices and take more precautions to protect themselves. Watstein and Chandler explain another destructive stressor is feeling of dependence. It is due to infections, deteriorating health condition, inadequacy of resources and emotional dependency uncertainty, anxiety about future

is experienced. To handle the emotional reactions prior to the test and after the test, counseling is needed. It is important to seek testing at a place that provides confidential sharing of test results with person. Pre test and post test counseling has to be done by trained counselors.

Pre-test and Post-test Counseling

Most people are tested by private physicians, at local health department facilities or in hospitals. In addition many states now offer anonymous Integrated Confidentiality counseling and Testing Centre's ICTC at every district hospitals. It is mandatory to take consent of the person before testing.

Pre test counseling has following aspects. (WHO guidelines)

- Understanding knowledge about HIV, of the person being tested.
- Explaining consent, quantity of blood required for testing.
- Exploring person's socio-economic data.
- Explaining test implications on marriage and child bearing.
- Ensure test results will be shared to the person tested for HIV.

Explain test results could be positive or negative.

Post test counseling has following aspects.

- After the test, explore person's comprehension about pretest counseling.
- Explain, and share test results.
- Wait for patient's reactions.
- Explain importance of partner notification.
- Use of safer sex practices.
- Watch opportunistic infections and take treatment.
- Refer HIV/AIDS related resources.
- Explain negative test result and maintain the same.

It is due to the nature of modes of transmission, gradual deterioration of immunity and threat to the survival of the person he reacts with fear, anxiety and depression hence counseling is necessary to help the person live with positive status.

HIV/AIDS is a subject matter of medical science while coping with it is a behavior science, which has following facets like behavior, adjustment, personality, motivation and quality of life.

1.8: Efforts at combating with HIV/AIDS

Table 1.1: Milestones of HIV/AIDS epidemic in India

1985-86	ICMR initiated HIV surveillance at specified sites. First report of HIV infections in sex workers in Chennai and first report of AIDS in India
1989	HIV infection reported among ID users in Manipur state.
1990-91	– ICMR established National AIDS Research Institute (NARI) in Pune city
1998-99	Majority of intravenous drug users investigated in Manipur were found to be HIV infected, sexual transmission to partners of HIV infected drug users documented.
1991	The Supreme Court ruling made HIV testing of all blood bottles mandatory. NACO estimated 3.87 million HIV infections in 1998 in India.
2000-2001	Feasibility studies for PPTCT by NACO
2001	Indian pharmaceutical companies marketed anti-retroviral (ARV) drugs with considerable price reduction.
2002-03	NACO-ICMR and International AIDS (IAVI) Vaccine Initiative signed to facilitate HIV vaccine development and testing in India.
2003	The central government announced anti-retroviral therapy (HAART) to those who suffer from AIDS.
2004	Programmed implementation begins for phased scale-up programme of anti-retroviral therapy by NACO
2005	First AIDS vaccine trial was initiated.

(Source: Indian Journal of Medical Research 2005, Dr. Sheela Godbole, Dr. Sanjay Mehendale)

1.9: Phases of HIV AIDS Control Programme (NACP)

Phase I (1992-1999) was implemented across the country with the objective to slow the spread of HIV to reduce future morbidity, mortality and the impact of AIDS by initiating a major effort in the prevention of HIV transmission.

Phase II (1999-2006) aimed at reducing spread of HIV infection in India and strengthen nations capacity to respond to HIV epidemic on long term basis.

Some of the significant achievements of NACP I, II

- Increased access to free ARV. (Anti – retroviral)
- Providing Community Care and Support Services
- Condom Promotion Programme to Prevent HIV and STI
- Initiating the process for developing draft legislation on HIV and AIDS

With the growing complexity of the epidemic, there have been changes in policy framework of the NACP. Focus has shifted from raising awareness to behavior change, from a national response to a decentralized response and an increasing involvement of NGOs and network of People Leaving with HIV/AIDS (PLWHA).

Phase III (2007-2012) This is based on experience from NACP I and II. Its priority areas are as follows :

- Considering that more than 99 percent of the population in the county is free from infection, NACP III places highest priority on preventive efforts and seeks to integrate prevention with care, support and treatment.
- High risk group population is given the highest propriety in the intervention programme, which covers long distance truckers, migrants and street children.
- In the general population those who have the greater need for accessing preventive services such as treatment of STIs, voluntary counselling and testing and condoms distribution is the next in the line of priority.
- The number of integrated counselling and testing centres ICTCs increased.
- In 2007, pregnant women accessed PPTCT services at ICTCs across the country.
- The number of STI clinics being supported by NACO has increased.
- There was an increase in the reported and treated cases of STI.
- Anti Retroviral Treatment centers are providing treatment.
- The Targeted Intervention (TI) projects aim to interrupt HIV transmission among highly vulnerable populations.
- NACP III further is committed to address the needs of persons infected and affected by HIV, especially children. This is ensured with the help of NGOs for supportive services which includes community care centres, psycho-social support, outreach services, referrals and palliative care.

Objectives of NACP III:

- Prevent infections through saturation of coverage of high-risk groups with targeted interventions

- Provide better care, support and treatment to more people living with HIV/AIDS
- Strengthen the infra-structure systems and human resources in prevention, care, support and treatment programmes at district, state and national levels by reducing the rate of incidence by 60 percent in high prevalence states and by 40 percent in vulnerable states.

The HIV situation in the country is assessed and monitored through regular sentinel surveillance mechanism established since 1992. The overall HIV prevalence among different population groups continues to portray the concentrated epidemic in India, with a very high prevalence among high risk groups.

Five years plan (2012-17) The draft strategy paper for NACP IV has been prepared in consultation with experts from field, positive networks, civil society, communities and technical experts, the representatives from state and central government.

NACP IV planning process:

Programme reviews indicate most of the targets are likely to be achieved by mid 2012. NACP IV will continue to provide care, support and treatment to all eligible population along with focused prevention services for the high risk groups and vulnerable populations. The policy is based on principles of human rights, aims at reducing and managing the impact of the epidemic in the world of work.

It emphasizes on :

- Prevent transmission of HIV infection amongst workers and their families;
- Protect rights of those who are infected and provide access to available care, support and treatment.
- Protect workers from stigma and discrimination related to HIV/AIDS by assuring them equity and dignity at the workplace
- Ensure safe migration and mobility with access to information services on HIV/AID.

Policy constraints –

- Policy makers still consider HIV related issues taboo. These attitudes reinforce the stigma and discrimination.
- NACP III does not have mechanism for implementing and sustaining many policy initiatives.

- Issues of social stratification – caste, gender class make it difficult to overcome practices.
- Data authenticity for accuracy of India's HIV statistics to assess impact of HIV policies.
- India still depends on international funding for HIV work.
- Disparities in states in prevention, treatment and care.
- HIV not understood purely as a health issue but as development issue.

Seven major areas of discrimination against women in India:

Carol S. Coonrod (1998) specifies seven major of discrimination against women in India.

- Malnutrition:

  India has exceptionally high rates of child malnutrition, because tradition in India requires that women eat last and least throughout their lives, even when pregnant and lactating. Malnourished women give birth to malnourished children, perpetuating the cycle.

- Poor Health:

  Females receive less health care than males. Many women die during child birth of easily preventable complications. Working conditions and environmental pollution further impairs women's health.

- Lack of education:

  Families are far less likely to educate girls than boys, and far more likely to pull them out of school, either to help out at home or from fear of violence.

- Over-work:

  Women work longer hours and their work is more arduous than men's, yet their work is unrecognized. Technological progress in agriculture has had a negative impact on women.

- Unskilled:

  In women's primary employment sector agriculture extension services overlook women.

- Mistreatment:

In recent years, there has been an alarming rise in the atrocities against women in India in terms of rapes, assaults and dowry related murders. Fear of violence suppresses the aspirations of all women. Female infanticide and sex selective abortions are additional forms of violence that reflect the devaluing of females in Indian society.

- Powerlessness:

  While women are guaranteed equality under the constitution, legal protection has little effect in the face of prevailing patriarchal traditions. Women lack power to decide who they will marry and are often married off as children. Legal loopholes are used to deny women of their inheritance rights. Another area of discrimination is health and family planning (Dr. Shobhana Nelasco 2010).

1.10: Women and HIV:

Since the study is about coping mechanisms of women infected with HIV it will be appropriate to see condition of women in general and with HIV in particular. We understand by status, social and legal position of women. It has been low in Indian Society, since last 60 years, reformers, social workers have worked very hard to change women status and give them equal rights. In reality we observed that since last few decades' women are joining the mainstream of development in the country, however they still experience inequality. They are working in every field, several of them have become economically independent but it has not enhanced their status and not in all strata of society on the contrary, crime heard against women are on the increase ever before. Women are taking education, making choice of career, yet the perception that women are second to men has not been erased. There are women's issues like gender discrimination in health, nutrition, education and the opportunities for development. One of the major health problems women presently are facing is HIV/AIDS.

Women and HIV/AIDS: The major route of transmission of HIV is through heterosexual intercourse. As in the case with all STDs women are vulnerable than men, there are following reasons:

- Semen, which has high concentration of virus remain in the vaginal canal for a longer time

- It is physically and culturally more difficult for women to clean the vagina after intercourse.
- Transmission of HIV is facilitated by the presence of other STDs. Women may have these infections without realizing it.
- Women are less likely to seek timely treatment for STDs. Stigma attached to STDs, inaccessibility of the clinics, non-availability of female gynecologist, lack of money, less priority given to women's health in the families further prevent them from care for STIs.
- Young women are at a greater risk than mature women. A teenager's vagina is not as well lined with protective cells; her cervix may be more easily eroded. Potential bleeding at the time of first intercourse could be a risk factor. In our country, very young girls are married to men much older their age.
- Young women are also vulnerable, as their negotiating and economic power is the least. This makes them easier targets for sexual coercion and exploitation. The situation is worst when men start feeling younger girls are safer for sex.
- In India, women have little control over the sexual behavior of their sexual partners. A society which holds monogamy and mutual fidelity in high esteem however condones multi-partner sex by males but stigmatizes the same by women. So women are more likely to be monogamous, yet they can get infected from their steady partners.
- Males do not wish to use condom and women are unable to negotiate safe sex and put themselves at a greater risk of HIV infection.
- Lack of education, awareness and economic self sufficiency make women more dependent on males for support. This leads to inability to take important decisions in life about choice of career, choice of mate and reproductive rights.

International experience everywhere has demonstrated that women are generally denied the access and opportunity to protect themselves from HIV infection, due to gender discrimination women's sexual vulnerability. In one of the studies reported in Indian Journal of Medical Research (Dr. Godbole, Dr. Mehendale 2005), women attending STI clinics in Pune from 1993 to 96 prevalence of HIV infection was observed to be 49.9 percent in female sex workers and 13.6 percent in those who were not sex workers with majority reporting single sexual partner. This was the first evidence of high HIV prevalence in married monogamous women in India with a

strong suggestion of risk from their husbands. Women's child-bearing and child-rearing roles also affect the care and support they receive for their HIV infection. The infection may prevent them from having children, not only because of physical factors, but also because pressure is exerted on HIV positive women to terminate pregnancies. However now there are effective medicines to prevent transmission of HIV to child. Many women come for HIV testing and medical care, late in their HIV disease often at a stage of acute illness. They are afraid of diagnosis revealing past secrets to family leading to re-emergence of conflicts and disagreements and the risk of being stigmatized, rejected and isolated when they most need support. The conditions are better now due to access to testing, counseling and anti-retroviral treatment.

Women as Care takers:

Most care provided to people with chronic illnesses is provided by female family members. This is true with HIV patients also. Richardson (1989) concluded that, 'while women do get AIDS themselves, it is as care takers of people with AIDS that the disease has, so far, had its biggest impact on women's lives. Women act as care takers for partners as well as children. HIV infection affects women's careers and roles as mothers. This means they put their own health needs after the needs of others in the family (Butler and Woods 1992). Women are an important community resource and community support (Delhi Network of Positive People 2003).

The changing definition of family and its implications for the organization of care in the context of HIV/AIDS in (Heaphy et al 1999, Levine 1994) developing countries, family caregivers in HIV are mainly women (Ankrah 1994, D'Cruz 2003). As society's traditional caregivers, women carry the main psychosocial and physical burdens of AIDS care; even though they have the least control over and access to, the resources they need to cope effectively. In providing care process, women may feel pain and anger after finding out the sexual orientation or lifestyle of their partner or child. Caring for HIV infected child is further painful. Emotional strain relating to uncertainty, isolation, lack of support, fear of infection, implications of the diagnosis and impending death is common. Women also have to take role as a breadwinner in the absence of partner or during his hospitalization and treatment process. This brings tremendous strain and they cope, in already disadvantaged situation of poverty poor housing, poor educational and health facilities. The situation becomes further complicated when women caregivers are themselves positive and need care.

1.11: Legal Issues:

It comprise of confidentiality, stigma and discrimination. Person with HIV faces segregation in schools and in hospitals, denial of shelter in matrimonial home, arbitrary testing, violence and discrimination at work place. Other legal issues are consent and testing. It is related in the context of respect, human dignity and bodily integrity. Consent has three important aspects: person's competence, consent should be informed and it should be voluntary. The issue is of confidentiality is very crucial i.e. the HIV diagnosis has to be shared only with the person concerned.

Right to know: It is a duty of HIV positive person to disclose his HIV status to his sexual partner.

Guiding Principles:

The policy adopts the key principles of the ILO Code of Practice on HIV/AIDS and the World of Work that is in line with the Government of India's National HIV/AIDS policy. The ten principles are:

1. HIV/AIDS, a workplace issue: HIV/AIDS is a workplace issue because it affects workers and enterprises, increases labour costs and reduces productivity. The workplace can play a vital role in limiting the spread and effects of the epidemic,
2. Non-discrimination: There should be no discrimination or stigmatization of workers o the basis of real or perceived HIV status. Discrimination and stigmatization of people living with HIV/AIDS inhibits efforts aimed at promoting HIV/AIDS prevention.
3. Gender Equality : Women are more likely to become infected and adversely affected by the HIV/AIDS epidemic than men due to biological, socio-cultural and economic reasons. Equal gender relations and the empowerment of women are vital to successfully preventing the spread of HIV infection and enabling women to cope with HIV/AIDS.
4. Healthy Work Environment: The work environment should be healthy and safe, and adapted to the physical and mental state of health and capability of workers (National Policy on HIV/AIDS and the World of Work).
5. Social Dialogue: A successful development and implementation of HIV/AIDS policy and programme requires full cooperation and trust between employers, workers and government.

6. No Screening for purpose of Employment: HIV/AIDS screening should not be required of job applicants or persons in employment or for purposes of exclusion from employment or worker benefits. In order to assess the impact of HIV, employers may wish to do anonymous, unlinked HIV prevalence studies in their workplace. These studies may occur provided it is undertaken in accordance with the ethical principles of scientific research, professional ethics and the protection of individual and confidentiality. Where such research is done, workers should be consulted and informed that it is occurring. Testing will not be considered anonymous if there is a reasonable possibility that a person's HIV status can be deducted from the result.
7. Confidentiality: There is no justification for asking job applicants or workers to disclose HIV related personal information. Nor should co-workers be obliged to reveal personal information about fellow workers. Personal data covered by medical confidentiality should be stored only by personnel bound by rules on medical secrecy and should be maintained apart from all other personal data.

   In case of medical examination, the employer should be informed only of the conclusion relevant to the particular employment decision. The conclusions should contain no information of a medical nature. They might as appropriate, indicate fitness for the proposed assignment or specify the kinds of jobs and the conditions of work which are medically contra-indicated, either temporarily or permanently.
8. Continuation of Employment Relationship: HIV infection is not a cause for termination of employment. Persons with HIV related illnesses should be able to work for as long as medically fit in appropriate conditions.
9. Prevention: HIV infection is preventable. The social partners are in a unique position to promote prevention efforts through information and education, and support change in attitudes and behavior.
10. Care and Support: Solidarity, care and support should guide the response to HIV/AIDS at the workplace. Care and support includes the provision of voluntary testing and counseling, workplace accommodation, employee and family assistance programmes, and access to benefits from health insurance and occupational schemes. All employees are entitled to affordable health services including access to counseling and testing, ART and treatment for

STI and opportunistic infections and to benefits from statutory and occupational schemes. The availability of treatment encourages confidential voluntary HIV testing, making it easier to provide care and support and encourages prevention. While the HIV is from the medical science coping with it involves social sciences i.e. psychological concepts like coping, motivation, personality, behavior and quality of life.

1.12: Coping:

Coping has been defined by Susan Folkman and Richard Lazarus as "Constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing" or "exceeding the resources of the person". Coping is thus expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict. Psychological coping mechanisms are commonly termed coping strategies or coping skills. Unconscious or non conscious strategies (e.g. defense mechanisms) are generally excluded. Coping refers to adaptive or constructive coping strategies i.e. the strategies reduce stress levels. However, some coping strategies can be considered maladaptive i.e. stress levels increases. Coping responses are partly controlled by personality (habitual traits) and partly by the social context, particularly the nature of the stressful environment. Coping mechanisms can save lives but they have human and social costs. Coping mechanisms are a spectrum of activities : one end of the spectrum represents the best example of solidarity. The concept of coping mechanisms and strategies is closely related to the idea of survival and threat. Coping is a capacity to respond and recover from something, which is a complex process, it has following factors – infrastructural (i.e. biological, demographics and environmental), structural (i.e. social and economic), super-structural (i.e. cultural and political). Coping strategies vary by region, community, social group, household, gender, age, season and time in history. They are deeply influenced by the people's previous experiences.

Components of Coping:

1. Biological and physiological: The body has its own way of coping with stress. Any threat to an individual in environment triggers a chain of neuroendocrine events (Frankanhauser 1986). There is fight or flight response that we have a reaction of increase heart rate or rise in blood pressure.

2. Cognitive Component : This is a mental process of how individual appraises the situation, where the level of appraisal determines the level of stress and the unique coping strategies individual partakes (Lazarus 1984). There are primary strategies, it is a conscious evaluation of the matter at hand of whether it is a harm or loss, threat or challenge, and secondary strategy is 'What can I do', it is evaluating one's resources in terms of physical–health, social resource in terms of family and friends, personal resource as self esteem and self-efficacy and material resource.
3. Learned Component : It includes everything from social learning theories which assumes that, much of human motivation and behavior is a result of what is learned through experiential reinforcement, learning from society and culture and one's behavior during stressful situation.

Towards a new theory of coping : The researchers have come to an agreement that coping is a complex process influenced by both personality characteristics and situational demands and social physical characteristics of the setting (Mechanic 1978).

Factors of Coping:

Personal factors, support, religion, faith, stress, motivation, need are the factors of coping.

Theories of Stress: There is a connection between coping and stress. Theories that focus on the specific relationship between external demands (stressors) and bodily processes (stress) can be grouped in two different categories approaches to 'systemic stress' based in physiology and psychobiology (Selye 1976) and approaches to 'physiological stress developed within the field of cognitive psychology (Lazarus 1966. Folkman 1984) Hans Selye, endocrinologist worked on this concept. In series of animal studies he observed that a variety of stimulus event (e.g. heat, cold, etc.) applied intensely and long enough are capable of producing common effects, meaning not specific to either stimulus event. Selye defines stress as a state manifested by a syndrome which consists of all the non specifically induced changes in a biologic system. This stereotypical response pattern, called the 'General Adaptation Syndrome' proceeds in 3 stages.

a) The alarm reaction comprises an initial shock phase; it increases an increased adrenalin discharge and gastro-intestinal ulcerations.

b) If noxious stimulus continues, the organism enters the stage of resistance. In this stage, the symptoms of alarm reaction disappear, which indicates the organism's adaptation to the stressor.
c) If the aversive stimulation persists, resistance gives way to the stage of exhaustion, symptoms of stage (a) reappear, but resistance is no longer possible. However, this theory was criticized, as it became a synonym for diverse terms such as anxiety, threat, conflict or emotional arousal.

Selye fails to specify those mechanisms that may explain the cognitive transformation of 'objective' noxious events into the subjective experience of being distressed. He does not take into account coping mechanisms as important mediators of the stress outcome relationship.

Psychological stress: According to Lazarus theory, two concepts are important to any – psychological stress theory : 'appraisal, i.e. evaluation of the significance of what is happening for their well-being and coping, i.e. individual's efforts in thought and action to manage specific demands (Lazarus 1993) . In the latest versions, stress is regarded as a relational concept, i.e. stress is not defined as a specific kind of external stimulation nor a specific pattern of physiological, behavioral or subjective reactions. Instead, stress is viewed as a relationship (transaction) between individual and their environment. Psychological stress refers to a relationship with the environment that the person appraises as significant for his / her well-being and in which the demands tax or exceed available coping resources (Lazarus Folkman 1986). Study by Arnold (1960) added emotion research in understanding stress relevant transaction. This concept is based on the idea that emotional processes are dependent on actual expectancies that persons manifest with regard to the significance and outcome of a specific encounter.

Stress and Coping:

Table-1.2: Six personal factors of coping.

Health Lifestyle Personality Causal and control beliefs Emotional states Teaching Skill Job Satisfaction	Personal Factors	Appraisal

The first considerations in this model are personal factors which influence the experience of stress (fig). In considering our ability to cope with pressure we will start by looking at (appraising) how we feel about ourselves.

Types of coping strategies : About 400 to 600 coping strategies have been identified, but there is no agreement about it. According to Weiten there are three broad types of coping strategies.

- Appraisal focused (adaptive cognitive)
- Problem focused (adaptive behavioral)
- Emotion focused.

Appraisal focused strategies occur when the person modifies the way he think. People may alter the way they think about a problem by altering their goals and values. Some may use denial or humor as a strategy. People using problem focused strategies try to deal with the cause of their problem. They do this by finding out information on the problem and learning new skills to manage the problem. It aims at changing or eliminating the source of the stress. Emotion focused strategies involve releasing pent-up emotions, distracting oneself, managing hostile feelings, meditating or using systematic relaxation procedures. It is oriented toward managing the emotions that accompany the perception of stress. People use a mixture of all three types of coping strategies and coping skills will usually change over time.

Positive techniques–Constructive coping. One strategy of positive coping is, "anticipating a problem, is known as proactive coping". Two others are "social

coping, such as seeking support from others and focused coping in which the person concentrates on deriving meaning from the stressful experience.

Keeping fit –"When you are well and healthy, when nutrition, exercise and sleep are adequate, it is much easier to cope with stress" and learning "to lower the level of arousal–by relaxing muscles the message is received that all is well are also positive techniques. People use to cope with painful situation humor". While dealing with stress, it is important to deal with one's physical, mental and social well being. Mentally it is important to think positive thoughts, value oneself, demonstrate good time management, plan and think ahead and express emotions, socially one should communicate with people.

Negative techniques – (maladaptive coping) Maladaptive coping technique will just reduce symptoms while maintaining and strengthening the disorder. Maladaptive behavior strategies include: dissociation, sensitization, safety behaviors, anxious, avoidance and escape.

Further examples of coping strategies are :

- Self distraction.
- Denial
- Self blame
- Behavioral disengagement
- Indulgence in drugs or alcohol.
- Substances

In the 1940s, the German Freudian Psychoanalyst Karen Horney developed theory in which individuals cope with anxiety produced by feeling unsafe, unloved, and undervalued by disowning their spontaneous feelings and developing strategies of defense. She developed four coping strategies to define interpersonal relations, one describing psychologically healthy individuals, the others describing neurotic states. The healthy strategy is called as "moving with" is that with which psychologically healthy people develop relationships. It involves compromise. To move with, there must be communication, agreement, disagreement and decisions. The other three strategies are "Moving toward," "Moving against" and "Moving away" represented neurotic unhealthy strategies people utilize to protect themselves.

Models of coping:

There are many models of the coping process. It involves a series of stages. These begin with identifying a threat, for one cannot cope with something that is not

recognized. Most models refer to the process of appraisal, an assessment of the severity of the threat and our resources available to handle it. Antonovsky brought a sociologist's perspective in health, stress and coping (Jossey–Bass,1980). He observed that many people are exposed to pathogens but few get sick. He proposed a model of resistance and susceptibility that depends on 'generalized resistance resources' (GRR) These seek to resolve problems rather than Selye's holding process. GRRs may refer to a person or a group of people. They include physical factors, material resources (wealth) information, (knowledge is power) emotional flexibility, attitudes and interpersonal skills.

Coping Responses :

Each person's style of coping reflects their personality and describes their enduring approach to handling life experiences. No coping strategy seems wholly good or bad. There are active or passive styles one can take to suit different circumstances. There are many possible taxonomies of coping strategies, but a common distinction is between practical strategies which seek to deal with the situation and cognitive strategies that seek to handle the symptoms of emotional distress that arises.

Transactional model of stress and coping :

Coping with stressful Events : Stressors are demands made by internal or external environment that upset balance, thus affecting physical and psychological well-being and requiring action to restore balance (Lazarus and Cohen 1977) In 1970s, stress was considered to be a transactional phenomenon depending on the meaning of the stimulus to the perceiver (Lazarus 1966, Antonovsky 1979). Stress experiences are construed as person- environment transaction. This is mediated by firstly, the person's appraisal of the stressor and secondly on the social and cultural resources at his disposal (Lazarus, Cohen 1977, Antonovsky and Kats 1967, Cohen 1984). When faced with a stressor, a person evaluates the potential threat-primary appraisal.

It is a person's judgment about the significance of an event as stressful, positive, controllable, challenging or irrelevant. Facing a stressor, the second appraisal follows, which is an assessment of peoples' coping resources and options (Cohen 1984).

Secondary appraisals address what one can do about the situation. Actual coping efforts aimed at regulation of the problem give rise to outcomes of the coping process.

Table 1.3 Key constructs of transactional model of stress and coping.

Concept	Definition
Primary Appraisal	Evaluation of the significance of a stressor or threatening event
Secondary Appraisal	Evaluation of the controllability of the stressor and a person's coping resources
Coping efforts	Actual strategies used to mediate primary and secondary appraisals
Problem Management	Strategies directed at changing a stressful situation
Emotional regulation	Strategies aimed at changing the way one thinks or feels about a stressful situation
Meaning – based coping	Coping processes that induce positive emotion, which in turn sustains the coping process by allowing reenactment of problem – or emotion focused coping
Outcome of coping	Emotional well-being, functional status, health behaviors
Dispositional coping styles	Generalized ways of behaving that can affect a person's emotional or functional reaction to a stressor; relatively stable across time and situations.
Optimism	Tendency to have generalized positive expectancies for outcomes
Information seeking	Attention styles that are vigilant (monitoring)versus those that involve avoidance (blunting)

Glanz Et al (2002) use therapeutically techniques as well. Those are biofeedback, relaxation and visual imagery. It helps in reducing stress and tension, relaxation techniques use, a constant mental stimulus, passive attitude and a quiet environment. Techniques are used as hypnosis, relaxation training and Yoga. Visual imagery is used to improve mood and to improve coping skills. This model is useful for health education, health promotion and disease prevention.

Cognitive–Relational Theory of Stress, Coping and Emotions

Cognitive-relational theory defines stress as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his resources and endangering his well-being (Lazarus-Folkman 1984). Stress

experiences and coping results bring along immediate effects, such as affects or physiological changes and long term results concerning psychological well-being, somatic health and social functioning. The individual evaluates his competence, social support and material and other resources in order to readapt to the circumstances, and reestablish equilibrium between person and environment. This theory also emphasizes primary and secondary appraisals. The same is termed as 'demand appraisal' and 'resource appraisal' (Hobfoll 1988, 89),that is the conservation of resources as the main human motive in the struggle with stressful encounters.

Dimensions of Coping :

Different ways of coping have been found to be more or less adaptive. In a meta analysis, Suls and Fletcher (1985) have compiled studies that examined the effects of various coping modes on several measures of adjustment to illness. It is further stated that avoidant coping strategies seem to be more adaptive in the short run where as attentive-confrontative coping is more adaptive in the long run. It remains unclear, however, how the specific coping responses of a patient struggling with a disease can be classified into broader categories. There are many attempts to reduce the total of possible coping responses to a parsimonious set of coping dimensions. Some researchers have propounded dimensions such as instrumental, attentive, vigilant, or confrontative coping on the one hand, in contrast to avoidant, palliative and emotional coping on the other. (Parker, Endler 1996, Schwarzer and Schwarzer, Suls and Flectcher, 1985). A well known approach put forwarded by Lazarus and Folkman who discriminate between problem focused and emotion focused coping. Another conceptual distinction has been suggested between assimilative and accommodative coping (Brandtstadter, 1992). These coping preferences may occur in a certain time order, when individuals first try to alter the demands that are at stake and after failing, turn inward to reinterpret their plight and find subjective meaning in it. Beehr and McGrath (1996) distinguish five situations that create a particular (life) temporal context :

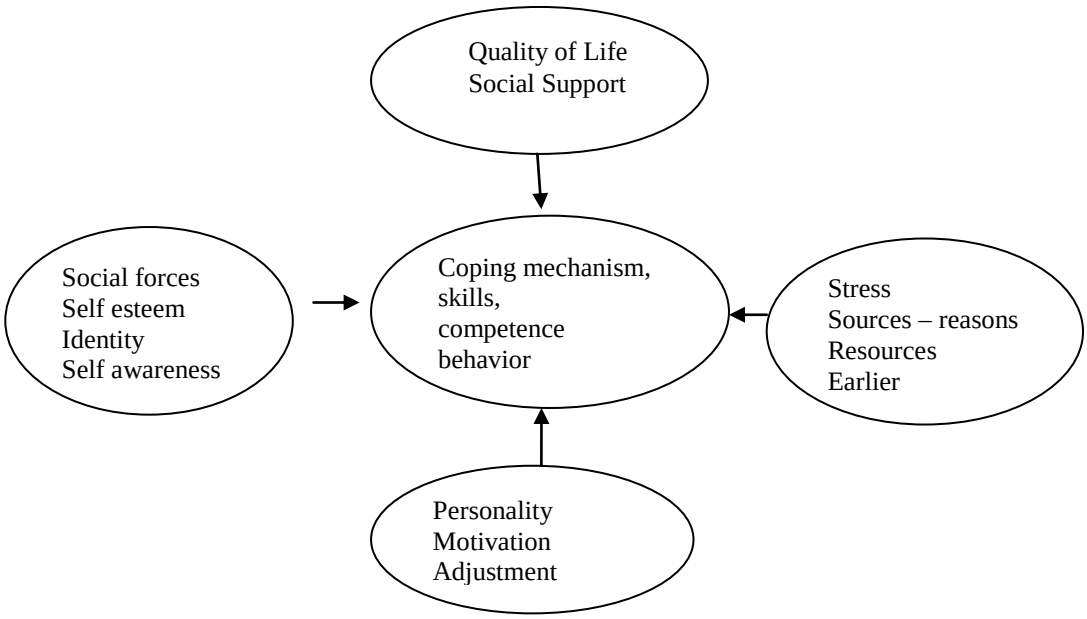
a) Preventive coping – long before the stressful event occurs,
b) Anticipatory coping – when the event is anticipated soon
c) Dynamic coping – while it is ongoing
d) Reactive coping – after event has happened
e) Residual coping – long afterwards –

Personal coping resources :

Individuals who are affluent, healthy, capable and optimistic are seen as resourceful in life. It is very important to be competent to handle a stressful situation. Bandura (1992-95) has labeled 'perceived –self-efficacy' or optimistic 'self beliefs'. If people believe that they can take action to solve a problem, they become more inclined to do so and feel more committed to this decision. This 'can do' cognition mirrors a sense of control over one's environment. It can also be regarded as an optimistic view of one's capacity to deal with stress. Self efficacy makes a difference in how people feel, think and act. In terms of feeling a low sense of self–efficacy is associated with depression, anxiety and helplessness. Such individuals have low self-esteem and harbor pessimistic thoughts about their accomplishments and personal development.

Personal coping resources and the onset, progression and offset of illness. The relationship between self efficacy and specific health outcomes like recovery from surgery or adaptation to chronic disease has been studied. Patients, with high efficacy beliefs are better able to control pain than those with low self efficacy. (Altmaier, Russell, Kao, Lehmann, Weinstein 1993, Litt 1988, Manning and Wright 1983) Self efficacy has been shown to affect blood pressure, heart rate in coping with challenging and threatening situation. (Bandura, Taylor, Williams, Mefford, Barchas 1985) Concept of Coping Mechanism

Figure 1.1 Relationship of factors to coping mechanism.



Approaches to coping – (Donald Oken 1970) one approach is that emphasizes the style, that it treats coping as a personality characteristic, and another emphasizes

coping as a process, i.e. efforts to manage stress that change over time and are shaped by the adaptation context out of which it is generated. Coping mechanism is a very comprehensive term which has many aspects like adjustment, behavior self–esteem, motivation, quality of life, personality and stress (see fig.).

1.13: Adjustment

Adjustment is a harmonious relation with the environment-involving the ability to satisfy most of one's needs and meet most of the demands both physical and social. The variations and changes in the behavior, that is necessary to satisfy needs and meet demands to establish a harmonious relationship with the environment. Adjustment and needs are interrelated. It leads to change in behavior. Behavior is a response to environment by individual which depends on his motivation and personality and the inputs he has received through the process of socialization, quality of life and the availability of resources.

Adjustment is a reaction of a person to (unforeseen) difficult situation like chronic illness, disability. There are different tests developed by Western and Indian Psychologists to measure level of adjustment. It has following aspects, home environment, family relations, health, emotional aspects, and adjustment to old age. There is a 'stage theory' of adjustment, which states for any difficult situation, individual reacts with shock, he cannot believe reality, and gets confused, next stage is denial. This is a reaction that he denies the reality, that whatever has happened cannot happen with him .e.g. the diagnosis of HIV in any woman especially at a younger age; she goes to an extent, that the reports are false or the lab sample must have been misplaced. Next comes 'anger', 'why me'? stage, individual becomes angry for any difficulty, according to persons religious / philosophical orientation, he/she curses 'karma'. This is the stage, where one starts believing on horoscope, religious methods of healing, persuading 'Bhagat', 'black magic' etc. Then after realizing that these reactions are not going to help, depression and isolation is experienced. Some may have suicidal thoughts, they think everything is 'over', this is the end of life. Finally, comes the stage of adjustment that of 'acceptance'. That when we cannot change the reality, we have no alternative than to accept it. This is what we learn through the process of development.

According to Self Determination Theory–(SDT-Deci and Ryan 1985-2000) Adjustment**:** Adjustment is a process of setting right or settling, trial and error

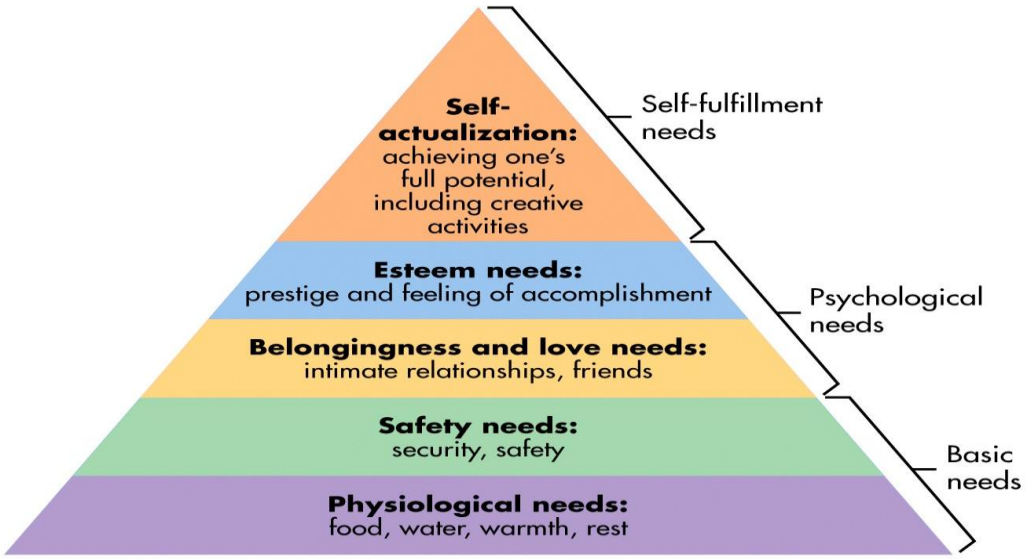
behavior of organism (Theodore R. Sarbin). It is self determined motivation, perception of autonomy. Psychological need of autonomy is crucial for personal development; it energizes a wide variety of adaptive behavior and psychological processes. Autonomy refers to being self- initiative in regulating one's action, to being able to make independent choices that are not constrained by others and having sufficient opportunity for self expression.

Diagnosis and treatment of HIV/AIDS can profoundly and sometimes irrevocably affect people's lives. HIV cannot be cured, though Anti-retroviral therapy is available, it has long term side effects and the treatment is for lifelong period. Yet despite the dreadfulness, discomfort and stigma associated with this disease, some individuals are able to maintain or quickly reestablish their pre-HIV emotional equilibrium. Understanding this adjustment process is a primary goal of psychologists, social workers and health care professionals, who conduct psychological interventions with HIV patients. By doing so, we can design effective interventions (Lepore, Stephen J Ref. 2001). It is with this objective in mind the study is undertaken.

1.14: Motivation Maslow's Theory

Human behavior is motivated because of various needs. Need is inner desire, tension within organism to achieve the set goal, it directs our behavior. Individual has needs, so there is a motivation for need fulfillment, it leads to satisfaction, pleasure and it enhances development. Maslow has given types of needs it is presented in the pyramid form as per hierarchy of need.

Figure 1.2: Hierarchy of Needs



The above triangle shows, the bottom of primary needs. Maslow argued that as primary needs are fulfilled, individual strives for secondary needs like safety, love and affection and esteem needs. Very little portion of the triangle is left for self actualization, it shows, very low percentage of the individuals can really achieve what they want to achieve. This concept also is reflected in Maslow's theory of quality of life.

Henry Garrelt Evrasia Pub. House 1975

Organic needs, attitudes, interests – all these are motives which spur the individual to action and direct activity by making one course of behavior more likely than another. Motives operate from within the individual.

Conflicts among motives :-

For a variety of reasons, motives are frequently unable to find free or adequate expression. Interference or blocking of a motive may come from several sources (1) from competing and antagonistic motives (2) from religious or ethical principles, ideas and contrary habits (3) from stumbling blocks imposed by circumstances : Physical and personal liabilities, restraining laws and customs, social taboos, lack of money or education. When a strong drive is blocked by equally strong motives or circumstances, a sense of frustration often leads to conflict. Individual may react to this frustration by irritability, tension, anxiety.

Ways to meeting conflict –

Adjustment to conflict by direct action or by compromise. A person may attempt to solve a conflict by direct action. He may examine the reasons for his indecision objectively and make a choice between contrary responses or may adopt a compromise to avoid anxiety set up by conflict the decision reached by compromise is better for better mental and physical health of the person involved in the scene. This adjustment depends on one's skills in handling conflicting situations, maturity. The entire effort individual makes to save him to maintain 'face' or 'prestige', persistent efforts to face the situation, comes from personality traits, habits, and behavior. This depends on the inputs during socialization period for personality development and the quality of life one has during this period.

1.15: Quality of life:

Quality of life means, how one lives, his well–being, need fulfillment, status, and enjoyment in life. A good life means living life with a high quality, which includes concepts like well-being, satisfaction and happiness one achieves in life. Motivations as well as quality of life are measured with standardized psychological tests. Quality of life indicators worked upon since 1930s, to measure quality of life. Around 1930's, it was perceived as one's happiness and a sense of joy. In 1948, UN Human Rights and Development Index concept provided another dimension to quality of life. In 1990, UN Human Development report provided a landmark, in the concept of quality of life, which included life expectancy at birth, and standard of living. Then, human poverty index provided another dimension like sustainable economic welfare, gender related development index added empowerment component. In 2009, UN suggested National criteria, i.e. socio-economic condition, environment, nation of well-being quantitative measures of income and production. World Health organization suggests, for quality of life following criteria–physical health, psychological health, level of independence, social relationships of person, and one's spiritual, religious and personal beliefs. From most of the criteria, it is seen, one's physical condition, enjoyment in life, financial resources, social relationship, independence indicate the quality of life.

In the context of motivation, it is stated in one article, daily newspaper (14th February 2012, Sakal) that human being is innately a problem solving person. It is always observed, that he is never satisfied in the condition, in which he lives, and wants to do, perform better. This continuous feeling of enhancing, one's own capability and the feeling of dissatisfaction gives him the motivation to strive for better, comfortable life. This leads to innovative ideas; this is an art and skill of the human beings. The human being defines the problem, sets goals, concentrates on it, and makes persuasive, sincere efforts to search for alternatives, takes challenges and creates better world.

1.16: Behavior

Coping mechanism is a behavioral response : Behavior is defined the totality of intra and extra organismic actions and interactions of an organism with its physical and social environment.

Coping Behavior -Maslow : A behavior pattern which facilitate adjustment to the environment for the purpose of attaining some goal.

Theory of Behavior / Planned Behavior

It is a link between behavior and attitude. It has been applied to studies of relations among beliefs, attitudes and behavior in various fields like advertising, public relations and health care. The theory states that personal attitudes, subjective norms, perceived behavior, control and shapes individual's behavior.

Theory of planned behavior proposed by ICEK Ajzen in 1985. It came from reason action theory propounded by Martin Fishbein, it is grounded in theories of attitude such as learning theories. It also has base of theory of self by Bandura Albert 1977 which came from efficacy social cognitive theory. According to Bandura, expectations such as motivation, performance and feeling of frustration associated with repeated failures determine affect and behavioral reactions.

Behavioral beliefs and attitude toward behavior

Behavioral change theories : It explains the reason behind alterations in individual's behavioral patterns. It has application in areas of health, education, criminology (1970-80). More prevalent are the learning theories, social cognitive theory; more common of them is Self–efficacy**.** It is an individual's impression of their own ability to perform a demanding or challenging task such as facing an examination.

Self Efficiency : Self efficiency is thought to be a predictive of the amount of effort an individual will expend in initiating and maintaining a behavioral change is determined by environmental, personal and behavioral elements.

Behavioral change is a 5 steps process :

1. Pre-contemplation
2. Contemplation
3. Preparation
4. Action
5. Maintenance

Behavior Theory :

The behaviorist's theory is an attempt to explain human personality. It is in conflict with the psychoanalytic and humanistic theory in several important ways. These are the ways in which each claims how human personality is formed. The behaviorist believes that cultural and sub-cultural conditioning moulds and shapes behavior and subsequently the personality. Theory in the behaviorist modes based on the principles

of learning with all of learning processes or methods; conditioning, reinforcing, desensitization, aversion therapy, modeling, imitation.

1.17: Personality:

Table 1.4: Theories explaining personality

THEORY OF HUMAN BEHAVIOR	FOCUS OF THEORY	MAIN CONCEPTS RE : HUMAN BEHAVIOR	SOME THEORISTS	SOME PRACTICE APPLICATIONS	SOME PRACTICE INTERVENTIONS
BEHAVIORISM AND SOCIAL LEARNING THEORY : Include : Cognitive theory, Behavioral theory, Social Learning theory (Social Behavioral Perspective)	How individuals develop cognitive functioning and learn through acting or their environment	* Limitation and reaction to stimulation shape behavioral learning. * Knowledge is constructed through children physically and mentally acting or objects. * Intelligence is an evolutionary, biological adaptation to environment". "Cognitive structures enable adaptation and organization.	Pavlov Skinner Watson Piaget Bandura Beck	* Useful for enabling behavioral and symptomatic change *Useful for assessing individual cognitive functioning, group and family interactions.	* Behavioral interventions such as classical or operant conditioning, positive or negative reinforcement. * Time-limited, problem focused interventions. * Cognitive reframing of automatic thoughts about presenting problems to facilitate change.
PSYCHODYNAMIC THEORY Includes : Classical psychodynamic theory, Ego-psychology, Object-relations theory, self-psychology. (Psychodynamic Perspective).	How inner energies and external forces interact to impact emotional development.	* Unconscious and conscious mental activity motivate human behavior. * Ego functions mediate between individual and environment. * Ego defense	S. Freud Adler Jung Horney A.Freud Kernberg Kohut Klein Mahler Bowlby	* Useful for understanding inner meanings and intrapsychic processes * Useful for understanding motivation, adaptation and interpersonal relationships * Useful for assessing	Ego supportive treatment : * Clarification, education and support of adaptive functioning * Empathy and attention to affects and emotions * Understanding of ego defense mechanisms and

		mechanisms protect individuals from becoming overwhelmed by unacceptable impulses and threats. * Internalized experiences shape personality development and functioning * Healing occurs through attention to transferences and the treatment relationship.		strengths and ego functioning.	underscoring of ego strengths * Establishing, building and using the treatment relationship to facilitate change
PSYCHOSOCIAL DEVELOPMENTAL THEORY (Developmental Perspective)	How internal and external forces shape life development, generally by life stages.	* Human development occurs in defined and qualitatively different stages that are sequential and may be universal. * Individual stages of development include specific tasks to be completed and crises to be managed. *Time and social context shape and individualize the meaning of	Erikson	* Useful for understanding individual growth and development across life cycle * Beneficial for assessing individual strengths and deficits.	* General assessment of developmental functioning that can be compared with chronological age of the client

		life stages.			
TRANSPERSONAL THEORY (Developmental Perspective; built upon Humanistic Perspective)	How the spiritual and religious aspects of human existence can be understood. How spiritual development builds upon and goes beyond biopsychosocial development	* Focuses on meaning, connection, and purpose *Some people achieve developmental level beyond the personal (ego-based) level into transpersonal (beyond self or ego) levels of consciousness and functioning. *There is an inherent tendency to express innate potentials for love, creativity and spirituality. * There is a difference between psychopathological phenomena and spiritual growth experiences.	Maslow Jung Fowler Wilber Washburn	*Provides nonsectarian frame for understanding spiritual aspects of human experience *Describes developmental process beyond self actualization * Provides guidelines for clinical discussions of spiritual or transcendent experiences *Stresses the importance of spiritual and religious support systems for life meaning and well-being	*Assess and understand client's spiritual and faith development *Ethically and appropriately utilize spiritually-derived interventions *Understand and support clients' spiritual and religious beliefs, practices, and support systems.

Table 1.5 Erikson's psychosocial theory – summary diagram

Erujsib's psychosocial crisis stages (syntonic v dystonic)	Freudian psychosexual stages	Life stage / relationships / issues	Basic virtue and second named strength (potential positive outcomes from each crisis)	Maladaptation / malignancy (potential negative outcome – one or the other – from unhelpful experience during each crisis)
1. Trust v Mistrust	Oral	Infant / mother / feeding and being comforted, teething, sleeping	Hope and Drive	Sensory Distortion / Withdrawal
2. Autonomy v Shame and Doubt	Anal	Toddler / parents / bodily functions, toilet training, muscular control, walking	Willpower and Self-Control	Impulsivity / Compulsion
3. Initiative v Guilt	Phallic	Preschool / family / exploration and discovery, adventure and play	Purpose and Direction	Ruthlessness / Inhibition
4. Industry v Inferiority	Latency	Schoolchild / school, techers, friends, neighbourhood / achievement and accomplishment	Competence and Method	Narrow Virtuosity / Inertia
5. Identity v Role Confusion	Puberty and Genitality	Adolescent / peers, groups, influences, resolving identity and direction, becoming a grown-up	Fidelity and Devotion	Fanaticism / Repudiation
6. Intimacy v Isolation	(Genitality)	Young adult / lovers, friends, work connections / intimate relationships, work and social life	Love and Affiliation	Promiscuity / Exclusivity
7. Generativity v Stagnation	n/a	Mid-adult / children, community / 'giving back', helping, contributing	Care and Production	Overextension / Rejectivity
8. Integrity v Despair	n/a	Late adult / society, the world, life / meaning and purpose, life achievements	Wisdom and Renunciation	Presumption / Disdain

Erik Erikson's psychosocial theory overview

Erikson's psychosocial theory is widely and highly regarded. As with any concept there are critics, but generally Erikson's theory is considered fundamentally significant. Erikson was a psychoanalyst and also a humanitarian. So his theory is useful far beyond psychoanalysis – it's useful for any application involving personal awareness and development – of oneself or others. There is a strong, but not essential, Freudian element in Erikson's work and mode. It helps in understanding how personality and behavior develops.

Erikson's theory refers to 'psychosocial crisis' (or psychosocial crises, being the plural). This term is an extension of Sigmund Freud's use of the word 'crisis', which represents internal emotional conflict. You might also describe this sort of crisis as an internal struggle or challenge which a person must negotiate and deal with in order to grow and develop.

Bandura Put forwarded theory of personality in 1959. According to this theory, one's environment causes one's behavior. But behavior also causes environment. Bandura labeled it' reciprocal determinism'.

Environment World ⟷ Person Behaviour.

Further he put forwarded personality as interaction between person's environments, behavior psychological processes.

Carl Rogers and Maslow were the founders of humanist theory (1950). It focused basic goodness of human beings, needs hierarchy and self efficacy. Personality theory explains why people behave the way they do. It looks at patterns of thought, feelings and behavior that make a person unique.

Trait theory (Roy Posner www.google.co.in) : Traits of human being – human consciousness.

(1)Attitudes (2) Attributes (3) Social endowment (4) Skills

Gorden Allport (1936) Traits that dominate an individual's whole life, often to the point that the person becomes known for these traits.

Eysenck's 3 dimensions of personality

(1) Introversion / extraversion

(2) Neuroticism / emotional stability. Tendency to become upset or emotional.

(3) Psychoticism – Individuals who are high on this trait tend to have difficulty dealing with reality.

Cattell – Eysenck – Five factor model.

- Extraversion
- Agreeableness
- Conscientiousness
- Neuroticism
- Openness.

Costa – McCrae 1992 Personality

Big five (5) characteristics-factors :

- Openness,
- Conscientiousness,
- Extraversion,
- Agreeableness and
- Neuroticism.

Conscientiousness is being disciplined achievement oriented.

Neuroticism – is degree of emotional stability.

Extraversion is assertiveness and talk activeness impulse control high degree of sociability talkativeness.

Openness – Strong intellectual curiosity preference for novelty and variety.

Agreeableness – being helpful, cooperative, sympathetic.

There is evidence that personality and motivation have close link with individual differences in learning styles.

From all the above discussion, it is clear that coping mechanism has a link with motivation, quality of life, personality, capacity to adjust and resources in hand.

1.18: Stigma Theories

Stigma is one of the reactions shown to people with HIV/AIDS. Erving Goffman defines quality of life has connection with stigma. Stigma and Discrimination is a complex system of beliefs about illness and disease that are often grounded in social inequalities. It depends on people's knowledge and attitudes. This affects help seeking delay, under utilization, denial, non compliance.

Goffman defines stigma as a social force that has profound consequences for stigmatized persons and their status in the world. He conceptualized it as a discrediting attribute that reduces the bearer "from a whole and usual person to be a

tainted, discounted one". Stigma is defined as occurring when human differences are labeled, stereotyping and cognitive separation of 'us' from them occurs, status loss and discrimination result in reduced life opportunities within the context of a power situation that allows these processes to unfold. Emotional reactions to stigma are disgust, shame.

Models of Stigma (Yang L.H. 2007).

1. Maintenance of integrity of self esteem via the cognitive construction of social identities, this affects on psychological health (e.g. lowered self esteem) and impaired role performance.
2. Identity threat model : Threat to identity stress, coping decreases. It affects on self esteem, health and academic performance.

Stigma : abs.sagepub.com/2007

1. Glenn Reader – in the article A Social Psychoanalysis of HIV related stigma – states, if perceivers have enough time, motivation and cognitive resources, they may adjust their initial reactions in a positive direction.
2. In developing countries PLWHA experience strong stigma and discri. and it has a strong enormous negative impact on their social relationships, access to resources and hampers. HIV related health promotion. Stigma can be reduced with intervention strategies. Psychology Health & Medicine / Journal (Arjan E.R. Nos. Herman Schaalma John B. Pryor Vo. 13, Issue 4, 2008).
3. Stigma has been identified as a major barrier to health care and Quality of life in illness management (2006) Harriet Deacon.
4. Decreases interest in HIV care barrier for testing (Arachu castro 2005) www.ncbi.nlm.

Self Perceived Stigma, stigmatization, loss of self-respect-People often experience hostility, rejection, emotional and physical exhaustion, loss of self image and self-esteem. The nature of behavior of sick person with a care giver also determines the quality of care being provided. Patient undergoes a feeling of multiple losses: loss of youth, of confidence, of coping, sexual interest, but looking at the disease progression, one has to also be aware about completing the incomplete tasks. People, who are infected, further have fear of becoming a subject of 'gossip'. Though confidentiality has so much importance while dealing with HIV patient, still it is not being maintained by family members, relatives and neighborhood. Persons also have

fear of losing respect, fear of losing status at workplace and obvious feeling of being rejected and discriminated. This further leads to isolation and self blame, denial, avoiding treatment, restricted health seeking behavior, so all the above-mentioned reactions ultimately affects on physical, psychological and social well-being and makes it difficult to cope with the situation.

People experience differential behavior when there is something abnormal, unacceptable especially in terms of chronic, communicable diseases, mental illness, disability, people don't accept, entertain or feel awkward to interact with people. This 'stigma' is seen in HIV. Stigma – the fear of how people would fear have react if they come to know about the patient's HIV status.

Enacted Stigma:

'The experiences of stigmatisation and discrimination from those who knew about the HIV status', in this study (Dr. Darak-Dr. Kulkarni 2005) people expressed fear about breach of confidentiality and a possibility of gossip. Other fear is of losing respect, families also experience social disapproval. Fear of rejection is very common. This is reason people prefer to keep their HIV status a secret. Isolation was experienced by people, they avoid visiting relatives and friend,s avoid attending social functions. Enacted Stigma – Stigmatisation experiences positive people have from natal family, in-laws, relatives and neighbours, friends, coworks, spouse. Natal families were supportive in the study while in-law were criticals harsh. Reactions were severe and they were blamed aftr the death of husband. They are looked as 'burden'. Other relatives made the positive person feel ashamed of, used to hurt them. From friends and co-workers, there was no discrimination as people did not disclose their status. Stigma from spouse, people were not willing to share their reactions. However, by and large, husbands and wives had same relationship before diagnosis of HIV.

1.19: Social Work Intervention :

Individuals have basic needs as food, shelter, clothing, oxygen, his secondary needs are love, care, recognition, self esteem, appreciation. All these needs are fulfilled by family as a social unit. In the family child gets all his basic primary needs fulfilled and also the secondary needs of appreciation, love, care, recognition. As the child grows in his development process, parents socialize the child and child learns to adjust, adapt, cope with the surroundings. We receive few characteristics of our personality from heredity (through genes) and many characteristics we develop on our

own from the surrounding environment. As we grow from childhood to adult hood, our needs change, and parents school, peer group, other hobby classes and other inputs help us in developing our personality. But in this process, there are times, when our needs cannot be fulfilled, for example, our financial condition, our socio-cultural position, absence of one of the parents, alcoholism of parents, being an orphan, being disabled etc. At such times, we need help from someone, it may be a support, help from family member, from society, but many times, we need professional help, like from doctors, nurses, counselors, psychologist, social workers, dietician, physiotherapist, lawyers etc. Social work as a profession has come into existence since early 19th century in USA and in U.K. earlier; this was done by religions leaders, well withers from society. Gradually it was observed in few hospitals in Massachusetts and in London, that patients feel better get well Soon, more due to the visits by Lady Almoners in addition to medicine.

Those were the women, who had some time and desire to work for the people who need help. These almoners used to talk to patients and relatives, enquire about patient's condition, and provide emotional and material support. This was observed by the heads of the hospitals and they helped to develop essential training components in social work. Because this developed in health, care (MPSW) settings, the clients were called 'cases', their problem was defined as 'diagnosis' and the intervention was called 'treatment'. This was around 1940's. In India, we had a practice of visiting sick people, people who had lost the dear one, but exact social work origin cannot be traced. AS we were under the British Rule, we had then, the social scenario, like we were not independent.

- Education was for particular castes
- Caste system was strong
- Women's status was very low
- Family norms, values and its impact was very strong
- Gender equality was not there
- Thinking was not rational/impact of superstitions was seen

- Economic Front : We were agriculture based economy, our needs were limited. Family was the unit of production, consumption and exchange.
- Division of work was gender based
- Many occupations were followed from one generation to another

- Communication and infrastructure was not very progressed

- On the Health Front :

- Maternal mortality, infant mortality was high
- Epidemics and its impact
- Longevity of life was low
- Institutional deliveries were very few
- Birth rate was high
- Knowledge and use of contraceptive was low
- Overall knowledge about hygiene and cleanliness was low

On this background, we experienced war for independence, social reforms, social service, social welfare. India was undergoing changes in this period (1936) changes were in value system, laws, family structure and function, in occupations, we could see changes due to industrialization, migration, war, partition, the fabric of society was changing and we found, that the existing system could not answer/respond to these social situations. There came, the realization to establish social work training Institute at Bombay, the Tata Institute of social sciences. It provided education, training, research in social sciences and offered for the first time social work training. Social work intervention is "to help the person to help himself".

There are six social work methods :

- Social Case Work – working with Individuals
- Social Group Work – Working with Groups
- Community Organization – Working with Community
- Research Methodology : By doing research reaching out to people, analyze problems and working on them
- Social Welfare Administration : This is by few administrative programmes and services working with minorities, disadvantaged groups. E.g. working with women, disabled, children, etc.
- Social Action and Advocacy : Few issues and problems cannot be dealt with by above mentioned methods, so sometimes to provide justice to people, one has to start creating awareness, by organizing campaigns against any issues like water, environment, violence etc to work with masses, and to bring about changes, this method is used. Overall, social work aims at giving justice to the

people. I have passed through phases like welfare to rehabilitation to development.

In one of the methods, case work, a technique of ‘counseling’ is used. Counseling is an interaction between two individual with mutual understating, carried out in a confidential manner and it aims at changing the behavior, thinking, perception and attitude of a person. Counseling is a process which takes place between counselor and the counselee. Counselor is a trained person having knowledge and skills to help the person to take decision take the desirable alternative to come out of the difficult situation. As stated earlier, the mode of transmission of HIV, the non-availability of cure and the stigma attached to it, makes it a difficult situation, and a person diagnosed as HIV, experiences fear, guilt, uncertainty, depression. To help him to come out of this situation and to have better ability for ‘coping’ he needs to be counseled. Coping is a continuous process. But if one works consciously on it, coping can improve. Similarly if inputs are given in counseling about raising the quality of life, it can be improved. Adjustment and motivation also are such concepts, that counselor constantly talks to counselee, about adapting, adjusting with the circumstances. During the counselling process, morale boosting is done, as well as motivation level of counselee is raised by which, his mood changes, his desire to live is increased and he learns how to ‘cope’ with situation with better motivation, and all these things are dependent on our personality. Our socialization and the kind of personality development of a person determine his opinions attitudes, thinking, perception and behavior and accordingly develop coping mechanisms. In the present study effort was made to provide intervention about improving coping mechanisms, motivation, adjustment and improving quality of life and study make up of personality also was assessed.

Social work intervention has six methods out of which in the context of study working with individual, working with groups and group counseling were used.

Group Therapy

During the last 30 years, studies have shown the growing benefits of group psycho therapy in a number of areas of life challenges. Through groups, individuals find a forum of peer support, gaining strength as they share their feelings and experiences with those facing the same obstacles. Some gain strength in seeing the resourcefulness of those in the same situation, they gain self worth and confidence. During the group process members develop a support network, feel no longer isolated, lonely with

group in certain medical conditions, group psychotherapy can help in improving one's psychosocial functioning. Research has demonstrated positive results across the variety of disorders, it is cost-effective also. (www.agpa.org / efficacy – 23.2.12)

Supportive – Expressive group therapy for people with HIV infection.

Jose Maldonade, Cheryl Gore – Felton Ron Duran, Susan Diamond Cheryl Koopman, David Spiegel, 1996.

1.20: Social Support in Treatment :

Even with the recent advances HIV research our technology can provide us only with treatment that slow viral replication, promote health and prevent opportunistic infections among HIV positive person.

Psycho social interventions, such as support group, have been shown to play an important role in enhancing the quality of life for patients. This has been seen in cancer patients. So support helps in dealing with stressful life events, provides opportunity to express emotions and buffer from stress. Groups have the potential to impact positively on both adjustment to illness and course of disease. It improves coping. (Study of breast cancer). The group focused on problems of nature of illness, including improving relationship with family, friends and physicians and living as fully as possible in the face of death. The treatment group was found to have lower levels of mood disturbances and maladaptive coping responses. The most significant finding of supportive expressive therapy group studied by Spiegel was that (50) treatment patients lived significantly longer than (36) control patients from the time of study entry. So it is clear from the study that expression of relevant emotions and direct discussion of difficult subject matter enhances quality of life and increase the life expectancy of people with terminal illness such as HIV. Group experience provides the members platform to express, sense of belonging sense of acceptance. It provides social network. The group becomes a powerful medium for restoring the patient's home stasis in that very critical situation. They learn to mobilize their existing resources, develop new coping strategies and support. Effective coping has been associated with a decrease in high risk behavior among HIV positive individuals. Support groups provide an opportunity for sharing of experience, listening to and accepting others' experiences, provides sympathetic understanding and social networks (e.wikipedia.org). It may engage in advocacy and create public awareness.

They maintain contacts through telephone, news letter, and internet forums. Support groups are managed by members those who have same personal experiences. (eg. AA, PLWHA) several studies have shown importance of support group with chronic health problems (Henry Potts. 1982). Support group provides (Baym 2010) a great outlet where one can feel comfortable in expressing feelings, courage, removes embarrassment, increases confidence level. Support groups are important (Walther and Boyd 2000 www.ehow.com) : They provide emotional support for people facing similar tough situations. It allows people to share information and openly discuss their problems without judgment, to process their feelings and to hear, talk about their situation. It provides the feelings that you are not alone in difficulties.

1.21: Gestalt Therapy (www.elementsuk.com)

Gestalt therapy focuses on (What is actually happening) as well as on content (What is being talked about). The emphasis is on what is being done, and felt at that moment, rather than on what was, might be, could be or should have been. It is a method of awareness practice, by which perceiving, feeling and acting are understood to be conducive to interpreting, explaining and conceptualizing. This distinction between direct experiences versus indirect interpretation is developed in the process of therapy. The client becomes aware about what he / she is doing that triggers the ability to risk a shift or change. Its objective is to enable the client to become fully aware about blocks and unfinished business that may diminish satisfaction, fulfillment and growth and to experiment with new ways of being. So it is also called as cognitive approach. This model is less centred on leader, more interactive and more oriented to group development.

Gestalt Work – 1940s, Feder & Frew's doctoral thesis in 1961 dealt with the effect of group therapy on the therapeutic readiness of institutionalized delinquent adolescent boys. Worked on interactive group, to develop something new. It is intense and demanding, it requires extra care in selecting members. Avoid taking rigid persons in groups should not create conflict. Avoid taking too many passive people. There should be group which promoter's growth, intimacy, openness promotes relations and conflict resolution. Person should abide by ground rules of group.

1) Agree to devote attention.
2) Contact among members outside group.

3) Confidentiality
4) Informing about not attending group has cohesion in group.
5) No violence is allowed in group.

In Gestalt theory it is considered that the individual and the environment as a unified field or system, in which all parts are interdependent, so as a unified field or system, so that a change in one part of the total affects all other parts. Gestalt therapy and group dynamics are developed from psychology and philosophy. Laura Perls (1976) describes contact as a boundary – phenomenon between organism and environment. Perls further expressed group workshops be encouraged instead of individual therapy. It was in 1950s and 1960s, to train mental health professionals. Since 1958, three distinct forms of group processes have been used; the individually oriented psychotherapeutic model, the personal growth model and group process oriented model. These models have something in common but certain methods and techniques have emerged from the practice of Gestalt therapy.

Experiential form of psychotherapy.

Group therapy is a humanistic therapy that focuses on gaining self awareness of emotion and behavior in the present than the past. This emphasizes on experiencing the present situation than talking about past. Patients are made aware of their immediate needs, meet them and then let them recede into the background. The well-adjusted person is seen someone who has a constant flow of needs and is able to satisfy them. Emphasizes personal response self regulating adjustment people make as a result of their overall situation (www.google.co.in).

Gestalt therapy from German word meaning form, the major goal is self awareness. Patients work on uncovering and resolving interpersonal issues during therapy. This can resolve the issues. Gestalt therapy is useful for patients to work with openness. (Fritz Perls Laura Perls Paul Goodman 1940-50).

Group therapy including Gestalt group work is deeply rooted in group development theories as a principal way of orienting to group. Group therapy emphasies personal responsibility, self regulating adjustment as a result of their overall situation.

Psychological support (David Hass) is provided through support group companionship, less depression and anxiety resulted in “better relation, better management of illness, and comparatively better survival, and more comfortable and enjoyable experience. When medicine and support group come together coping is

better. The study has aimed at assessing the coping mechanisms and strengthening them by providing required intervention.

1.22: *Summary*

The chapter presents the overall situation of HIV / AIDS globally and nationally. The brief description is presented about source of infection and 4 modes of transmission. There is a mention of specific high risk groups of people susceptible to receive infection those are sex workers, drug addicts and mobile population. Theories of HIV discuss origin and interpretation of etiology of infection. Since last 25 years there were consistent efforts made to fight with HIV in the form of early diagnosis, prompt treatment and prevention. Presently emphasis is on providing Anti-retroviral therapy to the poorest of the poor and promotes condom usage. Efforts were also made to invent (NACP I to III) vaccination against HIV. Every alternative system of medicine is trying its best to provide relief for patients. Every illness has implications on sufferer. Similarly nature of HIV has special psychological implications that are stigma and discrimination and uncertainty of life and gradual deterioration of health. Therefore living with HIV needs intervention. It is being provided presently in the form of pretest, post test and adherence counseling. The patient suffers multiple problems being HIV positive. Women in our society suffer many health problems due to their low social status, especially they are vulnerable to receive HIV infection.. They receive infection from spouse, they realize it very late and then live longer with the intervention of Anti-retroviral therapy. While women suffer HIV, they have to face multiple problems and find it difficult to cope. Coping is a very complex concept. Chapter provides detailed conceptual understanding about ‘coping’, its components, factors, dimensions and relationship between stress and coping. Further concept of adjustment and motivation are discussed in detail. There is a relationship between quality of life and coping, hence meaning and concept has been explained. Coping has a dimension of behavior and personality those concepts are also described. One of the important aspects of study were stigma and support, those are given in detail and last concept of social work intervention gives details about individual and group intervention, importance of social support is also being discussed.

CHAPTER II

REVIEW OF LITERATURE

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REVIEW OF LITERATURE

2.1: Introduction :

The dimensions of the pandemic of HIV / AIDS are well known. The gravity of the situation, in India has also been acknowledged with more than 2.5 million people estimated to be living with HIV in the country (NACO) and with an addition of a minimum of 30,0000 new infections per year. The task necessary to contain this wild fire spread of the disease are also more or less clear. The global and the national estimates of HIV / AIDS prevalence clearly suggest that it is a major public health problem. In India, in the initial phase of the epidemic, the focus was on the prevention of transmission through public awareness and behavior change. Since 1986, efforts were being made for prevention, testing, treatment and care. Both prevention and care intricately related to each other. HIV / AIDS effects on 'immunity' and its modes of transmission is heterosexual multi partner unsafe sexual behavior. This creates fear and stigma in the mind of an infected person. Therefore, his first reaction for testing is denial. In India, health care system, its accessibility, availability and affordability is very difficult. To maintain health, one has to have proper nutrition, hygienic habits, adequate housing and germ free water supply. In the absence of one of the above, there are chances of health deterioration leading to opportunistic infections resulting into repeated hospitalizations. HIV infected person experiences denial, shock, guilt, threat to life and shattering of marital relationship. Although there is a tremendous importance given to confidentiality in HIV/AIDS cases, once the person's HIV status is known to his family, neighborhood and friends, it results into discrimination and stigma. Repeated hospitalization affects on efficiency of a person, eventually he cannot work and naturally responsibility of family rests on spouse i.e. women. By this time, women already have received infection from their partners. In such situation, they have to take a prime role as caretaker and breadwinner to care and rear children and to look after sick husband. If children are also infected, they face multifaceted crisis situation. This requires strong ability to 'cope'.

2.2 Women and HIV: Present study is conducted on women infected with HIV; let us see how women suffer from HIV. Women constitute about 50 % of the population. The number of women living with HIV is 38%. They realize their

infection much later. Since last 7-8 years, due to availability of ART, longevity of their life has increased. Women have very little control over the sexual behavior of their partners and in the absence of any communication from partner, they develop infection of HIV. Women receive infection in their reproductive years. HIV is the leading cause of disease and death worldwide. Women are twice more likely to acquire HIV from men during sex than vice versa (UNAIDS 2010). The AIDS epidemic has had a unique impact on women which has been exacerbated by their role within society and their biological vulnerability to HIV infection. Biologically chances of infection are more through unprotected intercourse than men. In many countries, women are less likely to be able to negotiate for condom use and are more likely to be subjected to non consensual sex. Therefore millions of women have more chances for acquiring infection. The study conducted by Dr. Leena Sumaraj (1991) stated that the women's child rearing role means they have to contend with issues such as mother to child transmission of HIV. The responsibility of caring of AIDS patient and orphans is also an issue, which grossly affects on women. Medical problems of women are a result of several issues like women's status, role, decision making capacity, control on family resources along with the minimum health care. Due to large variations observed between individuals some take immediate medical aid, while others may ignore the symptoms and leisurely take treatment.

The International Encyclopedia of AIDS (2000) recorded that the women are increasingly becoming infected with HIV. The infection of HIV/AIDS in third world countries the proportion of women is more than men. These women are getting infected at a significantly younger age, i.e. in their teens and early twenties than men and the biological or virological susceptibility among women gets changed with age. Anna Chao's (2005) data from Rwanda shows that younger the age of the first pregnancy or sexual intercourse, the higher the incidence of HIV infection. Over 20% of young women pregnant at the age of 17 or younger are infected and about 17 % of those 17 or younger at first sexual intercourse were infected. Other than the age factor, there is high incidence of STIS, nutritional status, presence of lesions; inflammation in the female genital tract is one of the causes, other than STIs, women's socio-economic status is also important to give them infection.

In a study (Colvin 2000) in Uganda, adverse effects of HIV on menstruation and fertility were reported and reproductive tract infections were found more. The study stated that, often the first sign of infection is when the youngest child (infected in

vitro) fails to thrive and dies. The mother is likely to have been infected by her partner. It is estimated that 60 to 80 percent of African women with HIV have had only one partner but were infected because they were not in a position to negotiate safe sex or prevent their partners from having multiple sexual contacts.

Women's percentage (Kristin L. et al 1997) (American) with AIDS had continued to increase; more than 18 percent of all AIDS cases diagnosed in the U.S. are women (CDC, 1995). AIDS is now the fourth leading cause of death among American women between the ages of 25 and 44. This increase has been especially pronounced among impoverished women of color (MC Cray, Onorato, Qwinn, Grose Close, Spence 1992). Women of color living in urban areas have been particularly affected by the HIV epidemic. Women faced socio-economic stressors that exacerbate the negative consequences of HIV for physical and mental well being (Cochran, 1989).

Women also faced multidimensional responsibilities of family's primary care giver. Women with HIV infection usually live in high crime areas, can obtain only low wage jobs with few benefits, are under educated, have rarely an access to health care facilities (Che, Buehler, Berkleman, 1990, Ickovics and Rodin 1992, Liftshitz, 1990, Wofsy 1987). Recently diagnosed mothers are faced with difficult issues of disclosure, role identity, and personal responsibilities.

In some societies women have few rights within sexual relationship and in the family; often men make the majority of decisions, such as, choice of mate, career, and number of children to be born to them. This power imbalances makes it difficult for women to protect themselves from getting infected with HIV (Marge Berer 2007).

The major route of transmission of HIV in our country is through heterosexual intercourse. It is due to the physical structure of female genital organs, transmission of HIV is facilitated by the presence of STIS. Women are less likely to seek prompt treatment of STIS, due to inaccessibility to clinics, lack of money, less priority given to women's health problems in the families. Young women are at a greater risk than mature women. Young women are most vulnerable when their negotiating and economic power is least. This makes them easier targets for sexual coercion and exploitation. In India women have very little control over the sexual behavior of their sexual partners. Males resist condom use and women are unable to negotiate safe sex putting them at a greater risk of HIV infection. Lack of education leads to lack of

awareness as well as lack of economic self-sufficiency. This makes women more dependent on males for support.

Various studies in the late 1990's have revealed that HIV/AIDS is increasingly affecting the poor and women who by reasons of their socio-economic dependency are unable to take steps to protect themselves against the risk of infection. Socio-economic factor is the driving force behind transmission. Poverty leads to a breakdown in rural communities and migration of labour. In addition, the lack of alternate economic opportunities forces women into prostitution as the only available means of economic support. Women's risk factors include poor healthcare, inadequate treatment of STDs, lack of awareness, inaccessibility of preventive measures like condoms, lack of power to insist on the use of condom and other measures that are exclusively within the control of the women. Women are considered to be the reservoir of the disease as they are vectors of transmission to their children and male sexual partners rather than individuals, who are themselves, infected or are at high risk of HIV infection.

Due to the peculiarity of the transmission of the virus through sexual contact and the moral stigma attached to 'promiscuous' behavior, many women are unwilling to be tested for the fear of being branded as loose character woman. They remain unidentified, suffering silently without any care and treatment. Women's vulnerability to HIV is enhanced by the inequalities and discrimination they face in society. Women are subordinate sex, relegated to second class status, kept uneducated, dependent, isolated and confined within the four walls of the house. They are denied access to education, health, income and property rights. There is a necessity to understand the interaction between HIV infection and cultural values, the rights and needs of women and socio-economic patterns in the society which render women vulnerable to HIV infection. It is difficult to provide protection to women in a society where discussion about sex is a taboo; it is difficult to educate women to have safe sex practices, so one needs to address broader social structure. We have practices like dowry, fidelity and problems in condom usage. Sexual inequality and the spirit of patriarchy still pervade our personal laws which confer lower status of women.

Majority of women (Samiran Panda et al 2002) don't have any risk factor other than being married to their husbands. The vulnerability of women is due to male migration, adverse gender norms and weak infrastructure. Double standards of morality and

gender norms leading to conditions where women are denied the same rights as men are important factors in spread of HIV. Women have little or no control over decision regarding their sexuality over the sexual behavior of their male partners or use of condom for prevention of pregnancy or STI and HIV (Dr. Vinay Kulkarni 1999).

An effort was made to assess the relationship between experiencing Intimate Partner Violence (IPV) and the occurrence of HIV infection in a nationally representative sample of married Indian women tested for HIV (Jay Silverman et al 2007). Prevalence estimates of lifetime IPV and HIV infection were calculated and demographic differences assessed. Intimate partner violence was conceptualized as physical violence with or without sexual violence. Study revealed, one third of the married Indian women (35 – 49%) reported experiencing physical IPV with or without sexual violence from their husband. Approximately 1 in 450 women, (0.22%) tested positive for HIV. It was concluded that married Indian women, physical violence combined with sexual violence from husbands was associated with an increased prevalence of HIV infection. Prevention of IPV may augment efforts to reduce the spread of HIV.

2.3 Poverty and HIV :

There are several studies to test the association of poverty and HIV. However, one of the important studies state (UNICEF 2002), AIDS is a very long wave event, the true death toll cannot be estimated until the full wave form of the epidemic has been seen. If we look at the social and economic impacts, in particular HIV/AIDS related impoverishments, then HIV impact related death have already reached very large numbers indeed. The epidemic is a development crisis, which depends on poverty and increases inequality at every level from household to global. AIDS has reversed progress towards international development goals. It needs social as well as medical and technical responses. There is very little information available about relation between infectious disease and poverty. With regard to HIV and poverty, very little is known at analytical level. Response to the epidemic seems to chase rather than lead it. Apart from persistent fear, denial and stigma, there is still lack of clarity on biological, social, economic and development relationship and HIV and what is known may be poorly implemented. While prevention must remain a priority, the reality is the impact of the disease must be mitigated. The study conducted

(Stillwagon 2001) argued that HIV prevalence is highly correlated with falling calorie consumption, falling protein consumption, unequal distribution of income and other variables conventionally associated with susceptibility to infectious disease. Poverty contributes to epidemic and epidemics contribute to poverty. HIV leads to financial, income impoverishment. Households become poorer as a result of the illness and death of members and in many cases, it is the income earning adults who are lost. Illness and death leads to an erosion of social capital and socially reproductive labour. Among the various types of the poverty following poverty is very crucial, for the HIV patients, which makes adverse impact on almost all dimensions of the social life.

- Income Poverty – when a household takes in less than one US dollar per day. This means that people cannot even have access to satisfaction of basic needs, due to lack of money and assets.
- Service Poverty – Where people are unable to access or are not provided with services such as health and education.
- Physical Poverty – This indicates poverty of physical health.
- Financial Poverty – This indicates there poverty of finance, which automatically leads to lack of resources.
- Intellectual Poverty – People have such low living conditions, which hinder application of knowledge.
- Poverty of Solidarity – There is integration among people but no institutional support, this leads to Poverty of Stability (Adam Grahan 2006).
- Resource Poverty, where income may be sufficient, but people are unable to access resources, in terms of availing their rights, representation or governance.

Impact of AIDS on Poverty – In the late 1980s and in 1990s, a number of studies looked at macro economic impact of AIDS and it was observed that the scale and the speed of the epidemic has been worse than expected, there are known demographic effects, are now such that recognition of economic consequences is unavoidable. The complexities of disease impact and scope of its consequences are better understood, impact on development also are realized (Bonnel 2000). World Bank estimates AIDS reduced Africa's Economic growth by 0.8 percent in the 1990s. In South Africa also (2001 Quattek) study concludes that AIDS will cause the economies to grow more

slowly. Household income and expenditure will decrease, as will government revenue and domestic savings. Another South African study (Arndt and Lewis 2000) suggests, that the main reasons are, the shift in government spending towards health, which increases the budget deficit and reduces total investment and slower growth in the productivity.

The illness has the effects on household resources and income. No matter who is ill, they will need care, medicines, treatment and possibly a special diet. All this costs extra money, when the person dies, the funeral will be a further drain, on resources. Illness and eventual death affects on household labour. In addition to this, the cost of medical care is also another burden (Kangera 1997). Households 'cope', however, that coping in other words is desperate poverty, social exclusion and marginalization. Further it is said deaths cause the dissolution of households (Mutangdura 2000). Households with adult female infections experiences lower birth rates and higher infant and child mortality rates. People leave households, children are sent to stay with relative or adults move in search of employment. Deaths in individual households have implications for other households because of interdependence. Regalema (1999) showed how coping mechanisms became increasingly weakened as more households in a community are affected and communal support networks are less and less able to cope. From the above studies it is clear, that there is close association between poverty, economic development and HIV/AIDs.

2.4 Coping :

Coping means problem solving action. Stress in a negative emotional experience accompanied by predictable biochemical, physiological, cognitive and behavioral changes that are directed either toward altering the stressful event or accommodating to its effects (Baum 1990). Definition emphasizes relationship between individual and environment, when person's resources are more than adequate to deal with a difficult situation he / she may feel little stress if not suffice to meet stress person experiences stress.

Coping is explained as the way of dealing with stress or an effort to master conditions of harm, threat or challenge when a routine or automatic response is not readily available (Lazarus 1974) . Coping is an effort to master conditions that tax or exceed adaptive resources. (Monar & Lazarus 1977). Lazarus and Folkman 1984 define

coping as cognitive and behavioral efforts to manage specific external and internal demands appraised as taxing or exceeding the resources of individual.

Coping:

Coping is acknowledged as key factor in the relationship between the experience of stress and outcome (Aldwon and Revenson 1987, Billings and Moos 1981, Pearlin and Schooler 1978). Study was on effect of intervention on coping mechanism it was found that coping was largely context specific, coping strategies varied across scenarios, although problem focused strategies were predominant. In most vignettes, specific problem solving was the most common strategy such as information seeking and help seeking were the model strategies. Results in several areas provide support for the effect of intervention on coping strategies. Coping styles are relatively stable dispositions reflecting general preferences in choosing amongst specific competing coping responses in a given situation (Carver, Scheier, Weinstraub 1989). In this sense, they can be personal recourses, to face stressful encounter.

2.5 Coping Mechanisms

Coping has been widely studied as a possible mediator between stressful circumstances and health and mental health related outcomes (Carver etal 1989, Taylor and Assinwall 1996). Lazaurs and Folkman defined coping as behavioral strategies used to manage demands that are perceived to exceed existing resources. They further described coping strategies as either problem focused or emotion focused (Folkman – Lazarus 1988). Understanding, how people cope with distress is particularly important among HIV infected persons, as coping deficits have been related to sexual risk behavior, psychological distress and poor physical health outcomes with this group. Improvement in coping and use of positive coping strategies have been associated with decrease in mood disturbances, (Cruess et al 2002) lower distress and slower disease progression (Ironson et al 1994, Antoni et al 1995, Leserman etal 2000). Within the coping literature, relatively few studies have examined the relation between race and coping strategies. Findings from studies of non HIV infected persons suggest that African Americans use a number of coping strategies at higher rates than whites. It is reported that less is known about coping strategies used by racial minority individuals living with HIV (Domanico and Crawford 2000). African American with HIV often face different socio-economic,

cultural and psychological constraints that may compromise their adjustment. While examining the relationship between races and coping strategies, it is important to consider social support, as it has been linked to coping in theoretically and empirically meaningful ways. First, both coping and social support perform similar functions and have been studied as mediators between stressors and health (Folkman et al 1991) social support has been studied as a buffer against stress that exerts a positive influence on health in general and on mental health in particular (Gottlied 1983, Cohen and Willis 1985, Cohen 1988). Among HIV positive men and women negative associations were found between perceived supports and avoidant coping responses such as isolation, anger and wishful thinking, results were consistent with the idea that coping mediated the relation between perceived support and mood (Fleishman et al 2000). There is an evidence that social support is related to coping strategies. Further research is necessary to clarify the relation between social support and different kinds of coping responses.

2.6 Coping Mechanism and HIV

In 1940, German Freudian psycho analyst Karen Horney, developed her mature theory in which individuals cope with the anxiety produced by feeling unsafe, unloved and undervalued by disowning their spontaneous feelings and developing elaborate strategies of defense. She defined coping strategies to define interpersonal relations, one describing psychologically healthy individuals and the others describing neurotic states. The healthy strategy is moving with, the three other strategies are 'moving toward', moving against' and moving away. Coping is thus, conscious efforts to solve personal and interpersonal problems and seeking to master, minimize or tolerate stress or conflict (S.Folkman and R.Lazarus). Two studies of coping among community dwelling adults (N-255, 151) were used to examine the influence of coping responses, the perceived effectiveness of coping mechanisms and the effects of coping and personality on wellbeing. (Robert R. MC Crae, Paul T Costa 2006). In both studies, a wide range of potential stressors were examined, categories were losses, threats and challenges. There was general agreement across types of stressors on the use and perceived effectiveness of the 27 coping mechanisms and individuals who used more effective ways of coping, generally reported higher subsequent happiness and life satisfaction. However, personality variables also are known to be determinants of well being and the associations between coping and well being were

reduced when personality measures were parted out (MCcrae, Robert R. 1984). Two studies conducted to assess the influence of losses, threats and challenges on the choice of coping mechanisms. In the study 1,255 men and women (age 24-91 years) completed a questionnaire concerning their coping responses to a recent life event categorized by the investigator as either a loss, a threat or a challenge. In the second study, 151 respondents (aged 21-90 years) completed a shortened version of the questionnaire in response to 3 separate stressors that they selected as a loss, a threat and a challenge. Analysis of the use of 28 coping mechanisms showed that across both studies, type of stressor had a consistent and significant effect on the choices of coping mechanisms. Faith, fatalism and expression of feelings were used especially when respondents had experienced a loss, wishful thinking; faith and fatalism were used by them facing a threat. A number of mechanisms were used under conditions of challenge including rational action, perseverance, positive thinking, denial, restraint, self adaptation, drawing strength from adversity and humour. The efficacies of a number of concrete coping behaviors representing the three functions were evaluated. Result indicate, that individual's coping interventions are most effective when dealing with problems within the close interpersonal role areas of marriage and child bearing and least effective when dealing with the more impersonal problems found in occupation. The effective coping modes are unequally distributed in society, with men, the educated and the affluent, making greater use of the efficacious mechanisms. In another paper 'adaptive coping mechanisms in adult acute Leukemia patients in remission' by Judith Sanders and Carl Kardinal it is stated, that the adaptive coping mechanisms most frequently identified were, denial of being sick, identification with fellow patients to form a "hospital family" and anticipatory grief of one's own losses by participation in grieving another patient's death. The means of adjustment was, to adapt to the 'hospital family' and benefit from the therapeutic milieu established on the ward. The patient's total response to remission in acute leukemia can be influenced positively by appropriate intervention based on an assessment of his previous and present patterns of coping.

The things that create stress are called stressors; it can be internal, external. For something to be stressful, the event must be threatening to the individual in some way. (Bird & Harms, 1990). It is theorized that it only takes one stressor to lead to depression (Carver and Sheire, 1994). They argue that depression can result from a number of losses and worries that occur in an individual's life. The ability to cope is

seen as a crucial factor in determining whether someone adapts to life's stressors. Successful behavioral and or cognitive reactions to stressors are known to lead to heightened feelings of worth and value and a decreased amount of stress and anxiety (Mearns 2000, West 1994). It is argued that coping strategies such as cognitive decision making and problem solving are connected with minor levels of symptoms. The ability of an individual to effectively cope has been traditionally classified into two types – problem focused coping, where the individual aims to modify the situation or environment and emotion focused coping, where an individual may try to control or reduce the emotional distress being experienced (Folkman Lazarus 1984). Lazarus argued that problem focused strategies have a two part component known as 'inner directed coping and outer directed coping'. Inner directed coping means modifying one's attitude and way of thinking and try to utilize new skills and responses that could be applied to current situations, outer directed coping aims at changing the current situation (Rippetoe et al 1987).

In a study, effects of information about a health threat and two aspects of coping ability, self – efficacy on two adaptive and five maladaptive coping strategies, showed that high threat condition energized all forms of coping, it did not differtially cue specific coping strategies. The critical factor in determining the specific strategies used were the coping information. The high response efficacy and high self conditions strengthened adaptive coping and did not foster any maladaptive coping. Further path analysis revealed an intriguing pattern of relations, including the finding that the most maladaptive strategy was avoidant thinking, which simultaneously reduced fear of the threat and weakened intentions to the adaptive response (PSYCINFO 2010). It is also suggested that humour and laughter could be used as a coping mechanism (Doug Dvorak 2006).

Coping Mechanism : It is defined as an internal, physical or mental action initiated in response to the consequence of one's HIV status, which is directed towards external circumstances or on internal state. The process of emotional healing especially, in the aftermath of major life stressors often takes a long time. Healing has its own natural course. One experiences emotional distress and a lot of psychological stress and related physical symptoms. If individual has a balance between the demands of life and ability to cope with it, one does not feel overwhelmed by this situation, though life may feel stressful to some extent, but individual is confident, it

may be a difficult time. It helps in growth enhancing for individual. In the absence of coping, individual experiences powerlessness, helplessness. Negative self talk is one the reasons behind it. Cognitive psychologists studied self talk and found, it plays a crucial role in determining how people feel and how well they cope during difficult times. It is necessary to maintain self-confidence; it is basically the ability to trust in coping resources. The term 'coping' has been used to deal with stress with some strategy or the effort to master conditions of harm, threat or challenge when a routine or automatic response is not readily available (Lazarus 1974). Coping traits are stable characteristics of persons that transcend classes of situation. Coping style implies a broader more encompassing disposition. Trait and style refer to a characteristic way of handling situations. They are stable tendencies on the basis of which inferences are drawn about individual's coping in stressful situations. Psychologists have identified two major ways in which people cope with stress. In the first approach, person may decide to suffer or deny the experienced stress, this is passive approach or person may decide to face the realities or experience stress and clarify the problem through negotiations with other members, this is the active approach. Coping can have an effect on three kinds of outcomes : Psychological, social and physiological. From a psychological perspective, coping can have an effect on morale (that is the way one feels about oneself and one's life). From a social perspective, one can measure its impact on functioning effectiveness. From a physiological perspective, outcome includes short term consequences such as progression of a particular disease. Pareck (1983) has proposed two types of coping strategies which people generally use in order to handle stress i.e. dysfunctional and functional coping styles. Coping may either take the form of avoiding the situation i.e. dysfunctional or confronting and approaching the problem (proactive strategy) i.e. functional style. The dysfunctional styles are impunitives, impropunitive, extra-punitive, defensive. Functional style : impersistive, intro-persistive, extra-persistive, inter-persistive. Hence there are two coping strategies avoidance and approach. In one of the studies conducted by Gupta and Murthy (1984) about coping strategies among Indian women, the coping strategy that was the most popular among the respondents was : personal role re-definition. The data indicated that adjustment and compromise were the most commonly used and successful methods of coping.

In another study by Ahmed (1990), a difference was observed in the coping styles of male and female technocrats. While men used the defensive style of coping, women

used the approach style for coping. Some people find it useful to think of coping in terms of system, composed of accurate perceptions, a memory bank of relevant experiences and behavior strategies programmed for efficiency. When coping is manifested as a homeostatic strategy, emotions are managed, problems are solved and life returns to normal. The coping process is dynamic and changes overtime are not reflected in a typical 'snapshots' obtained by asking people how they did or might cope with a specific event (Fleming Baum and Singer, 1984).

2.7 Coping strategies used by HIV infected Women : A study conducted by (Allice Demi Linda Money ham et al 1997) , with the purpose to know the coping strategies used by women to deal with the experience of being infected with HIV and to develop a typology of coping strategies for the same group. There were 264 HIV infected women from urban and non-urban areas of US. Coping strategies were assessed through two open ended questions as to how have women been dealing with being HIV positive and what has been most helpful to them being positive. Coping strategies were found to be seeking / using support, spirituality, avoidance, denial, focusing on the here and now, managing the illness / promoting health, positive thinking, focusing on others and information seeking. Another study about ways of coping among HIV infected individuals by Mary Kay Dege nova et al 1994, a sample of 85 HIV infected Americans completed a questionnaire that assessed coping styles, depression and physical illness. An effort was made to examine the relationship of emotion focused coping and problem focused coping to depression and physical illness. Analysis revealed significant effect for emotion focused coping on depression. Those who used more emotion focused coping also experienced more depression. No interaction effect or main effects for problem focused coping were found.

Another study of coping mechanisms of HIV infected women (Alice Demi et al 1997) revealed, that support, spirituality, denial, promoting health and positive thinking. Effect of death of HIV infected family member was studied (K.I. Sikkima et al 2010) and respondents had experienced loss and it was suggested to study effect of intervention for coping with AIDS related bereavement. In majority of the studies, women's role as a primary care giver has been emphasized; relationship of stress and coping also is underlined at several places. One of the studies has shown interrelation of stigma, support system and coping. HIV infected mothers faced difficulties in disclosure, role identity and parental responsibilities. Women also have experienced

discrimination from families, friends and even professionals. They also experienced fear of losing custody of children being infected mother. Women's problems are seen as stigma, multiple roles, disclosure, parenting and quality of life are discussed. Researcher felt the need to understand, if intervention can help in strengthening coping mechanisms, Can researcher suggest module for intervention with the HIV infected women, and can this effort provide an insight into further research about developing coping mechanisms.

Further it is stated that, women particularly housewives, (Srimp et al 2007) have entered the fourth wave of HIV infection and will lead to fifth wave. They contract infection from their partners and as a consequence there is a possibility that they will transmit it to their babies. Discrimination and stigma to PLWHA – People living with HIV/AIDS have given them psychological burden especially for women who never predict will get a long life present for their marriage in form of HIV infection. Possibly, all of those will make to see coping mechanism of women and factors which influence coping mechanism, how long women can accept their condition and the support they receive. Results showed, no one respondent wanted to be diagnosed as HIV. The source of distress in respondents came from diagnosis problem as well as from big family and parent in laws. The death of the husband and children almost loss of guardian right, endorse their child to be infected, loss of income, loss of residence, forced to work and their unstable health status, compulsory health control and take a medicine, care giver duty for their husband, child and themselves are the source of very complex distress for HIV infected women. Most of women who got HIV from their husband are not ready to face those problems. Coping mechanisms vary between one and another. It is caused by their difference in using support and internal capability as a basic characteristic of personality. It is concluded, that only one respondent who is able to practice adaptive coping mechanism. It indicates that for PLWHA's women who are infected from their husband, those conditions are very hard and very difficult to be accepted.

Coping mechanisms on behavioral health **(Roger C Mcintosh Monica Rosselli)** outcomes a meta-analysis was conducted using forty empirical articles which sampled 7602 adult women living with HIV in the U.S. It was observed, significant effects on functional impairment. Coping by avoidance and social isolation predicted more severe mental health outcomes. Spirituality and positive reappraisal predicted greater

psychological adaptation than did social support seeking. Despite advancement in anti-retroviral treatment for women, HIV/AIDS symptoms and acute and / or chronic psychosocial stress pose the same threat to behavioral and mental health. In this situation, positive reframing appears to promote psychological adaptation in a way which may lead to positive health outcomes in women living with HIV. Several studies (Kristin L et al 1995) bring out socio-economic stressors and its negative consequences of HIV infected women on their physical and mental well-being (Cochran 1989, Osmond et al). The stressors of HIV infected women with few financial resources are often compounded by the multidimensional responsibilities of being the family's primary care giver. Women with HIV infection live in high crime areas, can obtain only low-wage jobs with few benefits are undereducated and rarely have access to health care facilities (Chu, Buehler et al 1990, 92, 1987).

Recently diagnosed mothers are faced with difficult issues of disclosure, role identity and parental responsibilities. Women who share their HIV status with family or friends risk stigmatization, isolation and potential loss of self-esteem. Keeping the HIV diagnosis a secret may hinder a woman's ability to develop effective coping strategies and leave her vulnerable to fear, anger and depression.

The need for better understanding of the psychosocial needs of women with HIV infection is widely recognized. Women living with HIV often report a desire for support groups or individual therapy to deal with the depression, hopelessness, and anxiety surrounding the unpredictability of disease progression. Development of effective support services is particularly challenging with impoverished women, for whom HIV infection is but one of many life stressors (Cates, Graham, Boeglin and Tielker, 1990; Chung and Magraw, 1992; Kelly, 1992; Kelly, Murphy, Sikkema and Kalichman, 1993; Murphy, Bahr, Kelly, Bernstein and Morgan, 1992; Reidy, Taggart and Asselein, 1991; Tiblier, Walker and Rolland, 1989; Wofsy, 1987; Zuckerman and Gorden, 1988).

AIDS influences the psychological coping not only of the person with the disease but also those close to that individual. Following the death from AIDS, family members and friends may experience atypical bereavement (Sikkema et al 2010). Bereavement coping challenges can be especially difficult and pronounced for persons who are themselves HIV positive. The prevalence of AIDS related bereavement and psychosocial predictors of grief severity were examined in an ethnically diverse sample of 199 HIV infected men and women. Eighty percent of HIV positive

respondents had experienced the loss of someone close who died of AIDS, the majority of whom had sustained multiple and repetitive losses. Hierarchical regression analyses revealed that grief was most closely associated with emotional suppression and avoiding coping strategies, with residual variance related to depression. Interventions for AIDS related bereavement that reduces distress and maladaptive ways of coping needed in order to meet the secondary prevention needs of bereaved people living with HIV/AIDS.

Illness related factors, stress and coping strategies in relation to psychological distress in HIV infected persons in Hongkong. Study examined the relationships (CHAN et al 2006) among illness related factors, stress, coping strategies and psychological distress in HIV infected person in Hongkong. Multiple regression analyses were used to examine the models of psychological distress as a function of demographic factors, illness related factors, psychosocial stressors and coping. Results showed that positive thinking was inversely related to psychological distress and avoidance was associated with higher level of anxiety. However, problem solving was found to be inversely related to anxiety. The study was in the context of Chinese culture and findings suggested directions for future research with the local population.

The study on adaptive and maladaptive coping strategies in relation to depression and perceived stress in individuals living with HIV (Martin, Luci. Vosvick, M. & Smith, Nathan) examined association between HIV related ways of coping with depression and perceived stress in a gender balanced sample of seropositive adults. It further aimed at examining adaptive and maladaptive coping mechanisms related to perceived stress and depression associated with living with HIV, to identity the specific coping mechanisms used by individuals living with HIV and to determine, how each is associated with stress and depression. Data was collected from questionnaires, consisting of HIV related questions, stress scale, depression scale and coping with HIV scale. Participants were recruited from AIDS service organization. Results indicate significant relationship between HIV related coping and depression in addition to HIV related coping and stress for people living with HIV. It suggests those who use maladaptive coping strategies such as anger, self isolation to deal with stressors of living with HIV, report a higher level of depression, those who use fantasy to cope with living with HIV, report higher level of stress and depression. Further research should focus on these psychosocial variables in order to provide

insight into the role that they play in wellness for people living with HIV. The clinical application of these findings is that attention to styles of coping may improve interventions aimed at increasing overall quality of life in this population.

In a longitudinal community survey of 291 adults, the relationship between coping strategies and psychological symptoms was explored. Respondents completed the revised ways of coping scale (Folkman and Lazarus 1985) for a self named stressful episode. Factor analysis produced eight coping factors, three problem focused, four emotion focused and one that contained elements of both. Multiple regression analyses indicted bidirectionality in the relation between coping and psychological symptoms. Those in poorer mental health and under greater stress used less adaptive coping strategies, such as escapism, but coping efforts still affected mental health independent of prior symptom levels and degree of stress. Main effects were primarily confined to the emotion focused coping scales and showed little or negative impacts of coping on mental health, interactive effects, though small, were found with problem focused scales. The direction (PSYC INFO 2010) of the relation between problem focused scales and symptoms may depend in part on perceived efficacy or how the respondent thought he or she handled the problem. The continuum of coping mechanism styles with regard to HIV infection (INT Conf. AIDS 1990) **(**Earlw et al 1990). With an objective to describe elements associated with denial as an adaptive style in HIV infected individuals to provide more useful counseling, study was conducted. Three styles of denial have been identified using subjects from a variety of sites. Psychosocial inventories were administered within the context of a structured interview. Study showed Fifty eight randomly selected seropositive clients from HIV counselling programme presented characteristic difference between knowledge and behavior that were identified as primary denial (PD), secondary denial 9SD) and Denial with NO Benefits (DNB). Three stages of denial appear to be experienced as a continuum in response to HIV infection. Some patients are able to shift to better adaptive styles of defense.

Coping and HIV infection : Much of the research on coping with a life threatening illness has examined the impact of coping or psychological distress. The most consistent finding is that, there is an emotion focused behavior such as ‘denial’ associated with increased distress (Revenson –Felton 1989, Spiegel and Bloom 1983, Vitaliano, Katon, Maiuro and Russo, 1989). Research with HIV positive individuals

also supports this finding, in one of the first HIV studies on the impact of coping on psychological distress (Namir, Walcott, Fawzy and Alumbaugh 1987), discovered that avoidance was positively correlated with depression in HIV infected gay men recently diagnosed with AIDS. Other research (Nicholson and Lon 1990, Reed, Kemery, Taylor 1990, Wolf 1991) supports a positive relationship between avoidance coping and worsened the mood poor adjustment in individuals with HIV. Similarly, DeGenova, Patton, Jurich and MacDemid (1994) found that HIV infected individuals who used more emotion focused coping, also experienced more depression.

In the paper by Dr. Bimal kanta Nayak (2007) author states HIV/AIDS presents major challenges to human survival, human rights and Human development with implication for beyond the health sector. AIDS is dramatically reducing life expectancy, increasing the vulnerability of future generations by creating millions of orphans and diminishing the capacity of private and public sector. An HIV/AIDS patient loses four important aspects of life (4Hs):

- Health- (medically ill)
- Hope- prolonged illness leads a patient to world of darkness and confusion.
- Happiness: (Happiness of a patient is taken away by the disease)
- Home (ostracized by the family and community due to social stgma like discrimination, prejudice and isolation)

Author has emphasized importance of counseling for people living with HIV/AIDS to cope with different situations. It helps the infected persons to discover ways to reduce stress. Counseling and guidance in HIV is a process that can help people understand better as well as deal with their problems and communicate better with people they are emotionally involved. Further she states that coping responses that after immediate and tangible outcomes have significant benefits to people who view their time as limited. In her study of 50 patients in care giving centre in Mangalore reported to have hight intensity feeling of fear , guilt, shame , sorrow and anger. As a result of their stay in the care giving centre, 74 percent of the inmates were able to overcome the negative feelings. Even she has made reference about holistic care to help HIV patients to cope with the situation. The holistic care included stress management, personal care , medical care, spiritual care , education of children, yoga, relaxation, food and nutrition, prayer, support and awareness.

Mallory O. Johnson and Torsten B. Neilands in their article on coping with HIV treatment side effects state (2007), side effects from HIV treatment impacts quality of life and adherence to care and influence decisions about health care. The purposes of their study were to describe the development of a measure of coping with HIV treatment side effects and to provide support for the reliability and validity of the measure. Based in stress and coping theory, the 20 item measure assesses strategies for coping with HIV treatment side effects and included scales of positive emotion focused coping, social support seeking non adherence, information seeking and taking side effects medications. The factor structure was supported by exploratory and confirmatory factor analysis with two samples of HIV + individual on treatment (NS + 173 & 233). The scope has demonstrated reliability and validity is supported through construct and criterion referred analyses. Non adherence as a strategy for coping with side effects was associated with poorer provider relationships, lower treatment knowledge and higher beliefs of treatment effectiveness. Findings have the potential to inform investigations and interventions in the context of treatment of HIV disease and other medical conditions.

Coping efforts in daily life :

Appraisals of stressor severity and individual difference in personality and important determinants of coping strategy used at the daily level, wishful thinking, seeking support, positive thinking, religious faith, planning, accepting responsibility.

In a qualitative study of the adaptive tasks associated with coping with HIV, (Weitz 1989) found that uncertainty was a major problem for 23 male participants with AIDS. The participants employed denial in failing to get test for HIV but once diagnosed, they searched for meaning as a way to reduce anxiety and cope with their positive status. Siegel and Krauss (1991) also explored the adaptive tasks of 55 seropositive gay men and found that they were dealing with the three major challenges, the possibility of a curtailed lifespan, reactions to a stigmatizing illness and a need to develop strategies for maintaining physical and emotional health. McCain and Gramling 1992 in a study designed to identify stress and coping themes in 36 individuals and discovered that the experience of coping with HIV from the point of diagnosis until death involves three processes living with dying, fighting the sickness and getting worn out.

In one study conducted, at Atlanta, Georgia, the data showed participants in research employed different coping strategies immediately after diagnosis from those currently used to live with HIV. Immediately after diagnosis strategies used were of 2 kinds : affective and behavioral. The scope of affective responses was broad, ranging from complete denial to intense anger. Coping strategies used immediately after include, numerous behavioral responses including excessive use of drugs, alcohol, sexual acting out some just did few activities got information to cope better. Coping strategies adopted by the HIV positive individuals in Pune. A study conducted (Rewa Kohli et al 2005) to examine coping strategies and its relationship with the quality of life and future concerns of HIV positive individuals. Out of the 97 individual's studied, immediate reaction to diagnosis was elicited at later date; only 57 individuals could recall their reaction which was being suicidal (6) and other stressful emotions. Wives of affected individuals had mentally prepared themselves for report. Passive coping like denial and worry (10) Active coping like taking care of health, seeking information, starting medicine following advice and developing positive attitudes (52), counselling information from medical professionals (24) social support by friends and family (11) Univariate analysis of the active coping was significant only for the domain of work and earnings (P=0.030) Educating children (34), Family (11) and health concerns (8) fear of discrimination and troubling others when ill was their main concern. Securing future through saving money (25) and through insurance policy (15) was reported while other indicated inability to save money. Acquiring scientific information, counselling and social support helped many persons to adjust to their disease. They needed efforts for their children's rehabilitation.

2.8 Coping mechanism and intervention:

In a study about predialysis psycho educational intervention and coping style influence time to dialysis in chronic kidney disease, it was revealed, time to dialysis therapy was significantly longer, coping mechanisms were acquisition of illness related knowledge, and routine follow up was another coping mechanism (Gerald M. Devins 2003). There is a close association between coping mechanisms, personality, well-being and satisfaction (Robert McCrace, Paul T Costa 1986). In another study on coping and intervention by Jiro Takaki et al 2004, states education helps in reducing stress and patients have better coping mechanisms, there is a decrease in

depression and anxiety. Age also makes a difference in coping, as the age advances coping decreases. In another study (Holaday, Margot 1995) maintaining contact with others was seen as coping mechanism while negative coping mechanisms were seen as drinking, smoking, suicidal tendency and addictions.

There is a close association between stress, physical health, psychosocial resources and coping (John Peterson 1996). In another study by (Olley, B.O. Gxamza et al 2003) it was found that, psychiatric disorders and mood disorders are common in recently diagnosed HIV patients. Depression and anxiety exists commonly among HIV/AIDS people, these negative emotions are particularly related to the severity of their disease, substance abuse, and lack of social support. The quality of life of HIV/AIDS people is significantly lower than that of the general population and this is related to their severity of disease, lack of support and low level of quality of life (Kuang W.H. et al 2005). Quality of life of persons with HIV was markedly affected in the domains of physical health, work, earnings, routine activities, and appetite and food intake. Women reported significantly low quality of life than men. The quality of life scores were significantly lower among persons with lower CD4 count mainly in different domains of physical health. From the above discussion, it is clear, that coping has association between quality of life, personality, stress, adjustment and motivation. Person finds it difficult to absorb diagnosis of HIV and to cope with it.

Coping has a very close linkage with stress. Stress is all about perception. Stress can mean different things to different people, a situation that causes significant stress. Stress affects on one's health. There is no direct correlation between stress and worsening HIV, but stress can weaken the immune system. One's nervous system gets activated and he becomes more sensitive to pain and to emotional stimuli and more easily distressed. Stress increases the risk of depression, a risk that is already created in people with HIV. Stress and depression can trigger poor HIV self care, not adhering to treatment and medication (Glenn Treisman 2010). Individuals differ with regard to the rate of progression through the successive phases of HIV infection. Some remain asymptomatic for extended periods and respond well to medical treatment, where as others progress rapidly to AIDS onset, develop numerous complications and opportunistic infections. Stress may account for some of this variability in HIV progression (Cohen et al 2007). People with HIV diagnosis undergo stress; they have unhealthy behaviors and problems about psychological

adjustments. Study found stressors in the areas of relationships and financial management (S.C. Thomson et al 1996). Study of 147 HIV persons showed that HIV infected people from low income group experience less intimate relationships and experience anxiety (C. Koopman et al 2000). After the diagnosis of HIV, client undergoes a feeling of denial, shock, guilt (Telephone counseling for HIV/AIDS. vinita chitale et.al. TISS-2000). Frustration may built up in individual / client. Client needs guidance in decision making about, which hospital to go to, whom to share the HIV status, how to manage money in additional health care, and lowered physical strength due to HIV infection. Many such decisions are painful and threatening. The client needs information. Throughout this process, the counselor needs to be very supportive. Then assessment of coping is done, this can be done by asking the client about previous life crisis and his / her style of dealing / coping with it. Is the client capable of confronting the problem? Does he / she has a habit of making positive efforts to resolve the problems or avoiding them. If client has maladaptive pattern to resolve the crisis, it could be changed with intervention.

2.9 Quality of Life :

The relationship between psychosocial factors and health related quality of life among 287 HIV positive women using items from the medical outcomes study HIV health Survey to measure physical functioning, mental health and overall quality of life. Women were in the average age 33 years and had known they were positive for 41 months, 39% had been hospitalized at least once due to their HIV, 83% had children, 19% had a main sex partner who was also HIV positive. More than half of the women, 56% had a history of injection drug use and 63% reported having been physically and sexually assaulted at least once as an adult. A history of childhood sexual abuse reported by 41% of the sample was significantly related to mental health after controlling for socio demographic and HIV related characteristics. Women with larger social support networks reported better mental health and overall quality of life. Women who practiced more self care behaviors reported better physical and mental health and overall quality of life (A.C. Giclen, K.A. Donnell, Compo, Faden 2000)**.**

Another study with a purpose of evaluating a quality of life of HIV infected people receiving ART and its association with Body mass index (BMI) and CD4 count was performed at Orissa, India. Study Design : An observational study was performed on PLHIV receiving ART in Orissa, India. Materials and Methods : Data on socio

demographic profile, BMI, and CD4 were gathered from 153 HIV positive subjects. QOL was assessed using WHOQOL-HIV BREF scale. Results: The overall QOL score of the subjects was moderate; PLHIV with lower BMI also had poorer QOL ($P<0.05$). Employment affected only the social health domain of the subjects. Men reported poorer level of independence and physical health while women reported poorer social relationships and environment. All the six domains correlated significantly with the overall QOL indicated by the G-facet. Conclusion: Attention toward improving the nutritional status of PLHIV should be accorded high priority to ensure improvement in the overall QOL of PLHIV (Deepika Anand et.al. 2012).

2.10 People with HIV and Stigma : The conceptual framework for the study on stigma (Darak, Kulkarni 2005) was based on review of literature on stigma and coping and support system. Many of the studies were not focused on HIV/AIDS are seen in recent past number of studies on stigma globally and in India, there was hardly any study on interrelation of stigma, support system and coping. The history of stigma research suggests that this concept gained currency in social science research first through the work of Erving Goffman. He defined it as "an attribute that is deeply discrediting" and reduces the bearer from a whole and usual person to a tainted, discounted one" (Goffman 1963). Goffman applied the (negative) term 'Stigma' to any condition, attribute, trait or behavior that symbolically marked off the bearer as "culturally unacceptable" or inferior with consequent feelings of shame, guilt, and disgrace. In the study related to stigma HIV/AIDS, social scientists have differentiated the types of reactions to people with HIV viz. instrumental stigma and symbolic stigma. This indicates fear and hostility in the mind of the people (Herek 2001). Another dimension of studies on 'stigma' is the conceptualization of stigma and discrimination as a stressor in the life of a stigmatized person. People with HIV/AIDS have a vast array of responses to different stressors affecting them due to their HIV infection and consequent devalued social status (Allison 1998, Anderson, Clark and Williams 1999, Millers and Major 2000). They are not simply the victims of passive recipients of people's prejudices and discrimination. Rather, they actively respond to the stresses by using their personal and social resources. In other words, they try to cope with the situation. 'Coping' as defined by Catherine et al 2000, is the act of taking specific efforts both behavioral and psychological, to master, tolerate, reduce or minimize a stressful event. It is described as engagement coping and

disengagement coping, positive or negative feedback from one response may alter the next response and a person may use multiple coping strategies simultaneously to cope with the stressful situation (Miller and Kaiser 2001). An effort was made to explore support systems for PLWHA, under the broad heading professional support system and relational support system. Patients at clinic who sought treatment and counselling during 2001 to 2003 were selected by purposive sampling method, all ethical considerations were observed. Three interviews with each respondent were conducted. Total sample was 79 (PLWHA 50 Men and 29 Women). It was found that while coping with HIV, patients expressed fears, fear of stigma, fear of partner and children having the infection, fear of death, fear of facing spouse and relatives after disclosing the HIV status coping strategies used by PLWHA. Disengagement implies the ways in which individuals try to avoid facing up to their personal crisis through denial, avoidance and chasing after 'magical solutions' and with wishful thinking. Engagement strategies are, seeking information and treatment, selective disclosure and communication, modifying the way of looking at the problem cognitive restructuring, adopting activities for maintaining good health and change in sexual behavior. Respondents are not just the passive recipients of stigmatization and discrimination but rather actively attempt to find a comfortable space for themselves by utilizing available resources. Stigma tremendously affects their efforts to cope with the disease and this remains a harsh reality. There are very few experiences of blatant and overt acts of stigmatization from their immediate family and other relatives, in most situations, the expressions are subtle. Some women do experience overt and extreme stigmatization and discrimination from their in-laws and their husbands in the form of blame, rejection, acts of defaming and verbal and physical abuse. Stigmatization in the workplace did not emerge as a major issue, as the PLWHA maintained secrecy about their status at their workplace. In this study also such experiences and fears of stigmatization affect PLWHA's physical, psychological and social dimensions of health. This affects on their help seeking behavior. There is tremendous fear and anxiety at disclosing the status to a spouse, it is directly disclosure of immoral behavior. PLWHA have to cope with the stress of being diagnosed with a serious and incurable disease, which is regarded as shameful by society.

It is further stated :

- Coping is a complex process
- The mode of acquiring the infection does affect the process of coping. Coping is difficult where the infection is perceived to be caused by the 'mistake' of another person.
- There are gender differences in the coping process because of the differences in mode of infection and availability of resources.
- Availability of support and resources affects the process of coping
- Multiple coping strategies are adopted for coping with different stressors.
- Stigma affects the coping strategies not only by affecting the process of mobilization of support but it is a stress in itself with which PLWHA have to cope.
- Knowledge about availability of ART and improvement in health because of ART is very helpful in coping with disease and with stigma.

Two studies found stigma and shame to be prominent themes in determining women's HIV disclosure to medical professionals, family and friends (Chung and Magraw, 1992; Florence, Lutzen, and Alexius 1994). Women in these studies frequently reported health care professionals to be hostile, fearful, and lacking in knowledge; HIV-related gynecological complications often had to be explained by the patient to their physician. The women reported that in spite of their HIV infection, family members expected them to remain in the role of primary child and family caregiver. In addition, the women often feared a more rapid disease progression, no longer viewed themselves as attractive or desirable, felt that their reproductive rights were socially disapproved, and feared they could lose custody of their children if others became aware of their HIV status.

Study by Vosvick (2003) examined the relationship between coping and physical quality of life in a diverse, gender – balanced group of people living with HIV/AIDS. Hypothesis was, that individuals who experienced greater pain and who made greater use of maladaptive coping strategies would report poorer functional quality of life in the four domains of physical functioning, energy, fatigue social functioning and role functioning.. Men and women over the age of 18 years and who provided documentation of their HIV diagnosis were recruited from 1996 to 1999 as part of an ongoing randomized clinical trial evaluating the effects of group psychotherapy for

HIV positive people. Participants ranged from asymptomatic sero-positive patients to those with clinical complications associated with AIDS. This study had a cross-sectional design and examined data from the baseline questionnaires completed before random assignment of 142 HIV positive men (N-81) and women (N-61) to study groups in the evaluation of group psychotherapy. Coping strategies used by participants in the previous 3 months were assessed with the Brief Cope. The Brief scale includes 24 items measured on a 4 point Linkert – type scales with responses ranging from 1, "I have not done this at all" to "I have been doing this a lot". Five of the 12 Brief Cope scales were used to test the hypotheses of this study.

The scales were as follows :

1. Self distraction (e.g. I have been turning to work or other activities to take mind away).
2. Behavioral (e.g. I have been giving up trying to deal with it.)
3. Substance Use (e.g. I have been using alcohol or drugs to make myself feel better)
4. Denial (e.g. I have been saying to myself this is not real)
5. Venting (e.g. I have been saying things to let my unpleasant feelings and escape) (Cronbach's as alpha)

Internal consistency reliability coefficients for the five scales were 0/40, 0.70, 0.9, 0.50 and 0.60 respectively. These values were consistent with previous research, except for the coefficient for self-distraction, which differed from the Cronbach's alpha of 0.71 found in Carver's study.

2.11 Social Support :

Social support was one of the concepts used in the study. It is a multi-dimensional construct. Social integration refers to the presence of social ties such as marriage, friendship – structural aspects of social network such as size and density whereas perceived social support refers to subjective appraisal of satisfaction with support, feeling that others can and are willing to help when needed that appears most strongly to relate to good adjustment and emotional balance (Turner and turner 1999). Social interactions are not always supportive in their nature and thus may also have negative consequences on psychological wellbeing. Social support resource (SSR) measure (Vaux and Harrison 1985) includes five models of social support – emotional practical, financial, advice and socializing. The study on role of coping strategies and

social support in perceived illness consequences and controllability among diabetic women (*Purnima Awasthi et al. 2007) was carried out with 100 women suffering from diabetes who belonged to middle and upper-middle class families in the age-group of 30 to 65 years. Findings suggest approach coping strategies reduced severity of illness consequences. The patients who used approach coping strategies held a stronger belief in disease control by themselves and doctors than those patients who used avoidance coping strategies. Social support tended to reduce physiological, psychological and inter-personal consequences of diabetes.

The literature review has a linkage between poverty, HIV and migration. Similarly, references were seen about stress due to HIV infection and its relationship between coping and social support. Some studies have shown relationship between personality and coping, and the coping strategies were used as positive thinking, spirituality, seeking information about the disease and managing illness by caring for oneself. There was a reference about mal-adaptation with the circumstances and effect on mental health. In one of the studies, issue about the disclosure of HIV infection to partner and parental responsibilities has been discussed. References were also seen about having larger support network and better quality of life inspite of contracting HIV. There was a linkage observed between stigma experience by infected women and the important of social support.

2.12 Summary

The chapter on review of literature throws light on various aspects of living with HIV/AIDS, several papers of Government and academic institutions, net surfing scientific journals, articles and discussions with experts from the field has helped the researcher to do the review. Prominent among these are NACO, WHO, USAID, NFHS I, II,III, NACP, reports.

Information was sought on coping mechanisms and poverty, women, motivation, association of personality, coping mechanism and social work intervention and stigma and social support.

From the review of literature, it is clear that women receive infection from their male partners in the absence of negotiating skills for use of condoms. Women are exposed to infection at a younger age, due to younger age of marriage. A part from HIV, they

also are at risk of suffering from STI's Literature also throws light on association between poverty, unemployment, migration disruption of family and HIV infection. Women suffer more due to gender inequality and inability to express due to control of patriarchal head of the family. It is stated in few studies, that it is difficult to protect women to have safe sex practices due to absence of sex education.

The other aspect of the literature was coping. Definition of coping and elements of coping are given. Everyone of us experience stress and demands from environment. Those who can fulfill those, can cope well. Within the coping literature, few studies have examined association between race and coping strategies and have reported that African Americans use number of coping strategies at higher rates than whites. It further states coping and social support also are connected. Support acts as a buffer against stress. In another study, personality variable also found to be important for well being and coping.

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CHAPTER III

RESEARCH METHODOLOGY

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3.1 Introduction:

Research is an art of scientific investigation. It is one of the methods of social work, through which one can find the solution to the problems and issues to a certain extent. The enquiry into the problems can give us better understanding to deal with issues in an authentic and reliable manner. It also helps to generate theory which would be helpful in further studies. The aim of research is to find out the hidden facts that are operating on particular phenomenon. In this view the present study explores the various dimensions of coping mechanisms of women infected with HIV/AIDS.

The dimension of the worldwide pandemic of HIV/AIDS is now well-known. In India more than 2.4 million people are already estimated to be living with HIV (NFHS-2007). The urgent task to control this wildfire spread of the disease needs more efforts with financial support. It is also been realized that resources should be spent more on prevention and on the caring of the infected persons. Advanced technology in Medical sciences such as Antiretroviral therapy is found to be effective in controlling HIV but the challenge to make the quality of their life better remained as it is. Among HIV/AIDS patients about half the people living with HIV, are women. Women play a significant role in caring of the spouse, themselves and children.

3.2 Origin of the research problem:

Researcher has been working in the field of HIV since last 15 to 20 years. During this period, she got an opportunity to observe the different phases of the work related to HIV such as awareness about HIV, training of health care professionals at different levels, condom promotion programmes, research activities, trials for vaccination against HIV etc. Since last decade the longevity of life of HIV patients has been substantially increased, due to ART. Naturally more people are living with HIV. Being a trainer of counsellors, researcher had an opportunity to observe the kind of efforts counsellors were making to help the patients to live with HIV/AIDS. Around 2005, while addressing a group of HIV infected women, researcher interacted with those women and the kind of motivation, concern, and women had towards their family, struck her to investigate as to what are the women's strong innate qualities that helps them to live with HIV, and to care for dying partner. As a social work

professional, she felt it is necessary to assess their potentialities, which provides strength. Over the years in this field she frequently came across with the psychological condition of the women with HIV, and realized that inner strength is more important than the medication, as medication can control the further physical deterioration but it could not prevent social deterioration. Therefore to strengthen the inner strength is equally important as medication but the reality is, it's beyond the medication. This situation needs intervention which would help to strengthen their capabilities. The women who seek medical help from general hospital mostly belong to lower socio-economic strata, with less support. These women can sustain their strength to fight with disease and to the adverse social condition if they are in state of good health i.e. their weight and CD4 could remain within the range of acceptable norms.

They hardly have adequate financial and material resources. They experience repeated hospitalisation of partners and eventual death, which grossly affects not only their physical condition but the psychological condition and social status too and after revealing the HIV status, they have to face the stigma and discrimination. In such a situation, women are directed by doctors to NGOs, where they get counseling services, nutritional supplement and other necessary services needed to live with positive status through individual and group counselling. Anti-Retroviral Therapy is now available at all district hospitals and at ICTC centers. The counsellors are appointed at these centres. However, the quality of care and counseling services substantially differs from place to place. The network of NGOs is not so well to provide resources to patients; on this background an attempt is made to study relationship between various dimensions of health and the factors affecting on coping mechanisms.

3.3 Scope of the study:

Coping mechanism is a psychological process which depends on social support, financial condition, health status, the genetic entities of the women and the prevailing environmental conditions. Thus, it is a complex process with multi factor and multi dimensions. Naturally there are very few intervention studies available in scientific literature.

The study is conducted in Pune city. There are about 21 ICTC centers, in all centers around 150 women daily attend the outpatient services. Initially it was thought to

conduct the study in the three ICTC's and the women who were willing to participate in the three phases of study. However, due to confidentiality reasons, sampling from ICTCs was not possible and it was decided to study 200 women respondents from different NGOs in Pune city. There are about 90 NGOs working for the HIV patients in Pune city. Out of 90 NGOs, 9 NGOs who gave permission for data collection were selected and the women were approached with the help of counselors through group meetings. Those who were willing to give one hour for interview, intervention and post intervention interview were selected. Coping mechanism is a complex phenomenon, among the various factors which includes adjustment, coping, quality of life, motivation and personality were considered along with the socio-economic background and women's health status.

3.4 Universe of the study:

As stated earlier, every month about 100 to 150 women approach NGOs for different services like nutrition, counseling, sponsorship for children etc. Hence, those women who had approached NGOs between June 2011 to March 2011 were selected for the study.

Western part (Sangli, Satara, Kolhapur, Pune and Mumbai) of Maharashtra has the highest prevalence of HIV infection in the state. Pune city is one of the cities located in western part of Maharashtra. There are several NGOs working for various issues of HIV/AIDS prevention and treatment. Medical, paramedical and social services such as counselling, group therapy, support group and group counseling are the core areas of intervention. Pune city has a special characteristic that the Anti-Retroviral Therapy was started by State Government at Sassoon General Hospital. Trials of medication were taken in Pune, several training programmes had been conducted in Pune for medical personnel as well as for NGO's. As an impact of such activities general awareness is observed to be considerably high along with the number of NGOs working for HIV and the infrastructure needed for HIV prevention treatment and rehabilitation. As compared to any other town or city, the overall infrastructure needed to deal with the problem is considerably high and patients' response to intervention is also better. In this view Pune city was selected for the study purpose. National AIDS Research Institute one of the leading organization was initiated in Pune in 1992, hence Pune has been selected for this study. Considering the population growth of Pune city in the last two decades, the percentage of population in slums has

reached up 35% of the total population. This indicates tremendous migration from various parts of the country. Due to increase in the educational institutes and the opportunities for employment, the proportion of young age groups is also very high. Thus the possibility of high risk behavior has increased. In a natural course, when men migrate for employment, they necessarily do not take their spouse/partners with them, this is one of the possible reasons of high risk behavior.

3.5 Criteria for sample selection:

Married women in the age group of 22 to 45 were selected those who were willing to give one hour for interview in pre intervention, during intervention and post intervention period. They were assured the confidentiality of the information they were giving to the researcher. Their written consent was sought, they were explained the reasons for conducting the study and the benefits they are going to receive in future.

3.6 Tools of data collection:

Interview schedule consisting of identification data, information about family, information on health, about HIV – tests, treatment, anti-retroviral therapy, partner infection, children's health, stigma and support was used. Along with the interview schedule to assess the coping mechanisms following psychological tests were used (1) Adjustment, (2) Coping (3) Personality (4) Quality of Life (5) Motivation. (See Chapter VII).

3.6 a): Aspects covered in the tool:

Under Environmental circumstances : Following aspects were investigated.

- Major developments in family in last 3 years
- Thought of getting remarried
- Experience of Sexual Harassment
- Major differences in family
- Difficulties in life
- Experience of funeral of husband
- Psychological, Social Aspects, Biological

Biological Aspects	Social Aspects	Psychological Aspects
Reaction after diagnosis Insecurities felt Pretest Counselling received Partner notification Tensions Anxieties Supportive services Pressure of pregnancy Coping mechanism Actual behavior and expected behavior	Realization of infection HIV test of spouse Status of spouse Reaction of Family members Experience of stigma Change of roles Self Care	Health Status Past and Present infection Duration of infection Symptoms Duration of diagnosis of HIV ART, side effects Decision about child bearing Use of Condom Special Care

3.7 Hypothesis:

Based on the theoretical framework and review of literature following hypotheses are put forward to test.

1. The strong coping mechanism has less implication of HIV among infected women.
2. Secondary status of women leads vulnerability to infection and it further aggravates the problem related to HIV.
3. There is a negative relationship between the support system and coping mechanism i.e. stronger the support, weaker the coping mechanism visa-vi weaker the social support stronger the coping mechanism.
4. There is close association of health status and coping mechanism.
5. There is large deficit in services required and services available.

6. Social work intervention at individual and group level can strengthen coping mechanisms leading to overcome various prevalent social problems.

3.8 Objectives:

1. To study the social and psychological implications of HIV infection among the women.
2. To assess the factors associated with coping mechanisms
3. To study prevailing social support system to women infected by HIV.
4. To assess coping mechanisms of HIV infected women.
5. To assess the impact of intervention on development of coping mechanism.
6. Critically analyze the requirement of supportive services and presently available services.

3.9 Operational definitions:

1. **Coping**: An ability to face the situation. Human beings are living in the environment. There are different demands on them about their roles and responsibilities. Coping mechanism or skill is an ability of an individual to face the environmental demands, be responsible and to do the best/ideal in his/her own way.
2. **Coping Skill** is a special quality in a person by which he/she does any activity, fulfills responsibility in a desired manner.
3. **Coping Mechanism**: It is a system developed over a period of time in the process of development to face the critical situation.
4. **Adjustment:** Adjustment is a readiness or preparedness to change as per the demand of the time.
5. **Personality:** Personality means person's perception, point of views, nature, attitude and its impact on the life of a person.
6. **Motivation :** It is an 'inner wish' that pushes a person to do any activity, to initiate any effort in the context of study motivation to live happy life,in spite of being diagnosed as HIV and making efforts to look after family, children and one's own health problems.
7. **High risk behavior:** This is person's multi partner unprotected sexual behavior which is one of the reasons of contracting HIV.

8. **CD4 Count: It** is a level of immunity of a person after a person is diagnosed as HIV, the CD 4 count i.e. level of immunity deteriorates. Normal CD 4 count is between 1000 to 1500 cells /cumm.
9. **Quality of Life** Quality of life means the level at which individual is living his basic needs fulfillment (livelihood) and the level of health and the kind of social, cultural life he is living.
10. **Pretest Counselling :** Pretest counselling is done prior to the blood test for diagnosis of HIV. It includes person's knowledge about HIV, consent, explaining modes of transmission and communicating the result of test and its implication, especially on decision of marriage and on child bearing.
11. **Post Test Counselling:** The counselling that is provided to disclose the test result to individual is called posttestcounselling. This deals with emotional reaction of individual and providing support to live with HIV.
12. **Adherence Counseling:** This counseling is provided to the individual, when his CD4 goes down below 350. To maintain the immunity, antiretroviral therapy is prescribed for individual. This therapy has side effects and once it is started it has to be continued till death. Individual has a tendency to give up treatment in between; hence adherence counseling focuses on importance of treatment, side effects, risk reduction behavior and living positively with HIV.

3.10 Research design :

Research design is a systematic plan of work, which includes universe, sampling size, procedure of selection, tools and methods of data collections, method of data analysis strategy of intervention and presentation.

From among the 90 NGOs working for the HIV infected persons 9 NGOs (Approximately 10 % on the non-governmental organizations) who gave permission for data collection and intervention were selected.

3.10a) Sampling design:

The total sample size was 200 women who approached NGOs for help during 2010-11. As stated earlier, there are about 90 NGO's working in the field of HIV in Pune city. A directory of NGOs working in the field of HIV prepared by Pune Municipal Corporation was sought and the description of organization was procured to know the

kind of services they provide to patients, out of 90, those who provide counseling, nutrition, institutionalization of children, financial support were approached by researcher. Proposal of the study was explained to the heads of the NGOs. This was an exploratory intervention study. It needed a pre-intervention study. Later two interventions viz. individual and group sessions were conducted after which, post intervention study was carried out.

Criteria of selection of NGO's for study

- Written permission and willingness of heads of NGO's
- Permission to attend group meetings wherever to develop rapport with staff and patients
- NGO's which were providing some or the other service to their clients
- NGO's which generally organize meetings of patients once in a month.

Willingness of heads of institutions was sought through proper official permission letter. Researcher attended few support group meetings, at few institutions to understand the possibility of conducting the study as per the decisions and after seeking official permission, prepared consent letter and those respondents who were suitable as per criteria and willing to come 3-4 times for study were selected. Respondents belonged to different rural areas and urban slums. They had a tendency to approach NGO which is very far from their residence; it is to keep their HIV status confidential. Respondents used to come for meetings at NGOs. The researcher made it a point to meet the respondents, get acquainted with them, explained them the purpose of the study and requested them to participate in the same.

3.10 b) Selection of the sample:

Purposive sampling method was used with the following inclusion criteria:

1. HIV infected female patients who were associated with the selected 10 NGOs for the study (Percentage selected justification).
2. It is observed that about 80% of the transmission of HIV is through heterosexual multi partner unprotected sexual behavior. Married women receive infection from their spouse so those who were married and living with spouse or widows were selected for the study.
3. Those who were diagnosed within 3 to 5 years was the other criteria for selection. It is observed, that generally after the HIV is diagnosed, 1st year women/patients experience phases of denial, shock and then they accept

diagnosis. Immediately after the diagnosis it is a difficult period, very hard to cope with the situation including deterioration of physical condition and experiencing social stigma.

4. Those women willing to participate in the 3 phases of study, i.e. pre intervention, intervention phase and post intervention phase and were willing to give about 1 hour for interview and meeting were selected for the study.
5. Age group of respondents was 18 to 45, this is a reproductive age group, most of the women either realize their diagnosis at their pregnancy and child birth or at repeated hospitalization of husband for opportunistic infections.
6. Areas of investigation: Researcher has studied socio-economic aspects, health condition of HIV, care of HIV, infections, psycho- social implications and stigma, support.
7. Socio-economic aspects covered identification- age, education, income, occupation marital status, BPL card, age at marriage, close relatives, number of years of residence in pune.

   In economic aspects, share in property, support from parents, in-laws was covered.
8. Health aspects covered weight, cd4 counts, opportunistic infections, admission to hospitals, number of children, normal and born with HIV infection, use of contraceptives etc.
9. Stigma covered respondent's experience with family, relatives, neighbors, at workplace.
10. Support included, support from family, friends, parents and relatives.

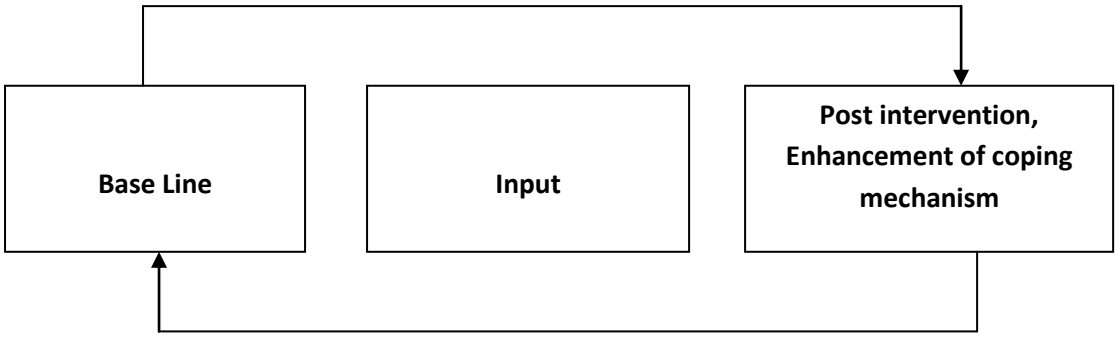
The study was conducted in 3 phases i.e. baseline study, intervention and post intervention study. In the intervention, counseling guidance and moral support was provided for improving coping, mechanisms.

It is presented in figure 3.1 :

3.11: Phases of study

Phase I - Baseline	Phase II - Inputs	Phase III - Post Intervention Study
I : Identification data a. Health b. Nutrition c. HIV diagnosis d. Age at diagnosis e. Infection to partner f.Reaction to test result g.Nature of relation	1.Guidance on health – Self Care, Personal hygiene 2.Coping with depression, anxiety, social adjustment 3.Counselling on social support i.e. Mobilizing resources, income, generating activity 4.Guidance on legal aspects 5.Disclosure of diagnosis to children 6.Parenting 7.Social Skills 8.Time Management 9.Developing Positive Attitude 10.Anger Management 11.Stress Management	I. Test of Coping II. Test of Adjustment III. Test of Quality of Life IV. Test of Motivation V. Test of Personality
II : Tests 1.Coping 2.Adjustment 3.Quality of Life 4.Motivation 5.Personality		

Figure 3.1: Diagram showing nature of study



3.12 Method of data collection:

Two types of data were collected.

a) Primary data was collected directly from respondents selected for the study. As stated earlier, out of 90 NGOs working in the field of HIV in Pune city, 10 NGOs were selected with the criteria of cooperation throughout the 3 phases of study, i.e. pre intervention, intervention and post intervention phase. Initially it was thought to collect data from ICTCS in Pune city, accordingly correspondence was made with concerned authorities. However due to some technical reasons, researcher could not get permission. To overcome this difficulties researcher approached to NGOs and studied the female respondents suitable as per criteria of sample selection. Discussions were held with the heads of NGOs, they were explained purpose of the study and were assured confidentiality and then officially permission to carry out the study, was sought.

b) The other method of data collection was observation of respondents in group meetings, while interviewing them and during intervention and in the post intervention phase. Researcher made reference work at different libraries at Pune, Mumbai and has searched material on internet.

3.13 Tools of data collection:

The required data has been collected with the help of :

1. Structured questionnaire, it consisted questions on :
    a) Identification Data
    b) Information about health
    c) Nutrition
    d) About HIV diagnosis
    e) Age at diagnosis
    f) Infection to partner
    g) Reaction to test results
    h) Nature of relationship between spouse
    i) Psycho-social information consisted of support system
    j) Sharing of feelings
    k) Close relations

l) Questions about coping mechanisms

m) Reference to NGO and benefits (Appendix 1)

Apart from the interview schedule – observation was another tool, investigator attended support group meetings and out patients service at NGO's through which she could get a feel of respondent's concerns and needs.

Medical reports of the respondents also were another tool, which showed weight and CD4 count and referral of the respondents for Anti -retroviral therapy. This provided an insight about the living conditions of respondents, particularly after being diagnosed HIV.

2. Apart from this questionnaire, there were five other psychological tests used to seek information from the respondents.

   A) The first test was Adjustment Inventory prepared by Dr. M. N. Palsane. Originally it had 370 questions, it was in Marathi. The test had sections on:

      a) Family relationships
      b) Emotional aspects
      c) Educational aspects
      d) Health aspects

      It was adapted as per the requirement of the study and 81 questions were finalized. These were shown to a professional psychologist. She was explained the study proposal and it's requirement of questions. All these questions were translated into English.

   B) The other tool was 'coping checklist', prepared by Dr. Kiran Rao, from Department of Mental Health and Social Psychology NIMHANS, Bangalore. The purpose of the checklist was to find out how people deal with or handle difficult situations. The coping checklist has 7 subscales developed on an 'Apriori' basis and validated in a normal, adult community sample. There is one problem focused scale (Problem Solving). 5 emotion focused scale (Distraction Positive Methods, Distraction Negative Methods, Acceptance/Redefinition, Religion/Faith and Denial /Blame). .

   C) Third is social support, which is a combination of both problem and emotion focused coping. This test had 70 questions in English; those were translated into local –Marathi language for the convenience of the

respondents and to make it easier to understand technical words (Appendix2).

The tool 3 was on understanding 'Quality of Life' test; this was taken up from internet. It had 100 questions on the following aspects: Test was developed by Thomas J. Leonare.

Researcher wanted to understand relationship between quality of life and coping mechanism. This tool had questions on :

a) Family relationships
b) Career / Business
c) Money / Finance
d) Joy / Delight
e) Effectiveness / Efficiency
f) Personal Foundation – Self Responsibility
g) Personal Development
h) Self-Care and Wellbeing
i) Happiness
j) Pleasure (Appendix 3)

The other tool was to understand the personality of the respondent as to whether coping mechanisms has any relationship with individual's personality factors. This test is developed by Ramanath Kundu, from Department of Psychology, Calcutta University. Test had five subsections having total of 70 questions. It is found that people differ in their likes, dislikes, personality and habits. Booklet on test consisted questions on these aspects. They indicate type of personality which helps us in facing life situations. As per the requirement of the study, this test also was adapted and used after translation into local language. The last tool was Achievement /Motivation Test developed by V. P. Bhargava, from Agra. Test consisted of 50 questions. It had some incomplete sentences, which were to be completed meaningfully by linking up any of the three alternatives given against them. Each of the alternative was equally good to make the sentence complete. This test also did not have any right or wrong answer. It was to select alternative which showed the respondent's preference of linking it with the incomplete sentence under consideration.

3.14 Pretesting of the tool :

All the tools were translated, adapted and then printed with questionnaire. Simultaneously permission letters to MSACS and NACO along with tools, copy of consent was sent. Pretesting was done at Pune, with one of the ICTCS at Chinchwad area. Nowadays all research permission and formalities are to be followed as per guidelines of Ethics Committee. Accordingly proposals and tools were shown and approved from the Chairman of Ethics Committee, where the pretesting was to be done. After seeking approval, researcher did pretesting of the tools with 10 respondents. It took preliminary discussions with staff at ICTC Centre, they used to read schedule, consent and then gave appointments to their clients for responding the schedule. It took about 60 minutes for one interview, to simplify questions and to seek very personal, confidential information from respondents. The data of 10 respondent's study was analysed and presented before Ethics Committee and then tools were finalized.

3.15 Strategy for intervention:

Pre-intervention assessment was carried out in phase one. In which respondent's identification data gave clear picture about respondent's.

1) Socio-economic condition
2) Share in property
3) Length of residence in Pune city
4) Health and nutrition
5) Experience of stigma of and social support and
6) Services rendered from NGO'S

While interviewing, the respondents were given idea about attending intervention session. This was based on researcher's observations about problems, difficulties faced by respondents, as well as respondents gave suggestions on which aspects they require inputs during meetings. The 2nd phase of study that of intervention was decided as per convenience of NGO and the respondents and on following aspects intervention was provided.

1) Guidance on health and Nutrition
2) Tips on nutritious diet and recipes to preserve nutritional contents of vegetables and cereals, pulses

3) Self-care
4) Coping with depression and anxiety
5) Counseling on social support
6) Mobilizing resources for income generation, financial management and care of children
7) Guidance on legal aspects
8) Remarriage - safer sex practice
9) Disclosure of HIV status to children
10) Parenting
11) Social skills
12) Time Management
13) Developing Positive Attitude
14) Anger Management
15) Stress Management

During the consecutive group counseling sessions, women gave feedback that they experienced ventilation of feelings, sharing of emotions during baseline interview and in the subsequent sessions, they reported better emotional strength, change in the thinking, and alternative ways of problem solving. At post intervention, stage again schedule was filled up and results are shown.

3.16 Types of tests and scoring methods:

Types of Adjustment:

Normal adjustment :- When a relationship between individual and his environment is according to norms, then it is normal adjustment, e.g. child obeying parents, who is not stubborn, studies regularly and has neat habits is a well-adjusted child.

Abnormal adjustment: - Problem behavior or maladjustment – this means, there is not desirable relationship between individual and environment – e.g. a delinquent child is a maladjusted one because he has violated moral codes. Adjustment is a popular expression used by people in everyday life maintaining peace and harmony; it is coping with new situations.

Adjustment in psychology is the behavioral process by which humans and other animals maintain equilibrium among their various needs or between their needs and the obstacles of their environment. A sequence of adjustment begins when a need is

felt and ends when it is satisfied e.g. hungry people are stimulated by their psychological state to seek food. When they eat, they reduce the stimulating condition that impelled them to activity and they are adjusted to this need. Defined as a process of altering behavior to reach a harmonious relation with the environment (www.britannica.com).

Quality of Life

This term is used to evaluate the general well being of individuals and societies. It is used in the context of international development, health and policies. It is different from standard of living. Quality of Life indicators include wealth and employment, infrastructure, physical, mental health, education, recreation, leisure time and social belonging. It also indicates concepts like freedom, human rights. However, happiness is a subjective term and hard to measure, happiness does not necessarily come from comfort and income.

Quantitative measures – Presently researchers distinguish two aspects of personal well being : Emotional well-being, in which the quality of peoples' every day emotional experiences the frequency and intensity of the experience – e.g. joy, stress, sadness, anger and affection and life evaluation in which think about life in general and evaluate it against a scale.

Such measurements are :- Human development Index – This combines measures of life expectancy, education and standard of living in an attempt to quantify options available to individual within a given society.

The physical Quality of Life Index is a measure developed by sociologist Morris. David Morris in 1970, based on literacy, infant mortality and life expectancy. The Happy Plant Index introduced in 2006, is unique among quality of life in addition to standard determinants of well-being, it uses each country's ecological foot print as an indicator.

Motivation

Motivation is a term that referrers to a process that elicits, controls and sustains certain behaviors, e.g. if an individual is hungry, as a response, he or she eats and diminishes feeling of hunger. Adjustment to various theories, motivation may be rooted in a basic need to minimize physical pain and maximize pleasure, motivation is related to, but distinct from emotion. Motivation is a basic psychological process.

Along with perception, personality, attitudes and learning, motivation is a very important element of behavior. Nevertheless, motivation is not the only explanation of behavior. It interacts with and acts in conjunction with other cognitive process. Motivating is the management process of influencing behavior based on the knowledge of what makes people think (Luthans, 1998). Motivation and motivating both deal with the range of conscious human behavior somewhere between two extremes:

- Reflex actions such as a sneeze or flutter of the eyelids and
- Learned habits such as one's teeth or handwriting style (Wallace & Szlag 1982)

Luthans (1998) asserts, that motivation is the process that arouses, energizes, directs and sustains behavior and performance. It is the process of stimulating people to action and to achieve a desired task. There is a self-concept model of motivation, it has four interrelated self perceptions : the perceived self, the ideal self, one's self esteem and a set of social identities. Each of these elements play a crucial role in understanding how the self concept relates to energizing, directing and sustaining organizational behavior.

1) Motivation is the process of boosting the morale of person to encourage him to willingly give the best in assigned task.
2) The difference or gap between what needs to be done and what is not being done can be closed during motivation. Motivation is defined as communicating to an internal force that actuates a behavioral pattern, thought process, action or reaction.

Theories for motivational behavior have been given vast number of researches have appeared in print. Various motives like hunger, sex, power, dependency, affiliation. Achievement motive, power motive have been studied. Majority of the studies have been done following the techniques involving free association and projective technique which were pioneered by Frend, Murray, etc. Few studies have been done by other psychologists like Elizabeth G Frech and Elliot Aronson. They make use of the verbal cues instead of picture cues. The fourth component of coping is motivation. The respondents were given the achievement motivation test developed by V.P. Bhargava consists of 50 items of incomplete sentence completion test. The other

feature of the test is that items are repeated more than once to know the level of consistency with which the subject is, answering the test.

Personality Tests : Personality Traits : Components – Personality is made up of the characteristic patterns of thoughts, feelings and behaviors that makes a person unique.

1) Consistency: There is generally a recognizable order and regularity to behaviors. Essentially, people act in the same way or similar ways in a variety of situations.
2) Personality impacts behavior and actions : It does not just influence how we move and respond in our environment, it also causes us to act in certain way.
3) Multiple expression: Personality is displayed in behavior, thoughts, feelings and it is closely related to social interaction..

   Kundu Introversion Extroversions Inventory

The inventory developed by Dr. Ramnath Kundu, (1976) was used to assess the personality of the respondents. Purpose of the inventory is to obtain a reliable measure of introversion, extroversion dimension of adult behavior or to use it for diagnosis, selection and career guidance. It is developed according to Indian socio-cultural pattern. The test consists of 70 items with uneven number of response choices divided into 5 blocks – A, B, C, D, E. It is found that people are different in their likes, dislikes, personality and hobbies. Within this test, there are questions on these aspects, questions indicate the personality type of the subject / respondent. There are no rights or wrong answers to any questions. There are several options given from among which subject can pick up the most appropriate answer for them. This test also was adapted, the scoring method is as under. Personality has biological factors, environmental and social factors and psychological factors.

Method of Scoring –The general order of scoring is such that high score indicates introversion i.e. negative response is indicative of introversion. But some of the items have been framed in such a way that negative response in these items would indicate extraversion. The different categories of responses are given different weights depending on the degree of introversion extroversion they measure.No scoring key is required. Count the tick (√) in each row in each block and enter the figure under the column T against the respective row.

2.17: Score calculations: All the tests were cross tabled to see if there was any correlation, but it was not feasible therefore, the questions were clubbed into '5' categories and the scores were calculated. Those scores were given below in separate tables.

1. Socio Economic (Table No. 3.1)
2. Health (Table No. 3.2)
3. Family Support (Table No. 3.3)
4. HIV background helping coping (Table No. 3.4)
5. Counseling and NGO support. (Table No. 3.5)

These score were calculated to know if there was any effect on respondents' coping. Each score had '5' questions. Each question had '3' scores. The total of these scores was then divided into 3 main categories. The score includes mean score of all the test was compared with those scores.

Table 3.1 Socio-economic score calculation

Sr.	Variable considered	Categories	Score
1.	Education	Illiterate and primary	1
		Upto 10^{th}	2
		Above 10^{th}	3
2.	Occupation	Unemployed	1
		Skilled + semiskilled labour	2
		Profession (business + service)	3
3.	Family income	Less than 5000	1
		5001 to 10000	2
		10001 and above	3
4.	No. of dependents	0 – 1	3
		2 – 4	2
		5 and more	1
5.	Family Assets	No Assets	1
		Assets – 1 to 2	2
		Three or more assets	3

Total score and categories

1. 5 to 7 Poor
2. 8 to 11 Middle class
3. 12 to 15 Higher class

Table 3.2 Present health condition score calculation:

Sr.	Variable considered	Categories	Score
1.	Major and prolonged illness during last year +	Neither reported prolonged nor reported major illness last year	3
		Reported Major OR prolonged illness	2
		Reported Major AND prolonged illness	1
2.	Need to visit a doctor regularly + suffering from opportunistic infection	No need to visit doctor neither opportunistic infection	3
		No need to visit doctor OR opportunistic injection	2
		No need to visit doctor AND opportunistic infection	1
3.	Morbidity	No morbid conditions reported	3
		Reported 1-2 morbid conditions	2
		Reported 3 and more morbid conditions	1
4.	Menstrual complaints	No menstrual complains reported	3
		Reported 1-2 menstrual complains	2
		Reported 3 and more menstrual complains	1
5.	Side effects of ART	No side effects / No ART	3
		Reported 1-2 side effects	2
		Reported 3 and more side effects	1

Total score and categories

1. 5 to 7 Poor health condition
2. 8 to 11 Moderate health condition
3. 12 to 15 Normal health condition

Table 3.3 Family Support score :

Sr.	Variable considered	Categories	Score
1.	With whom you are residing with	Elders from maternal family and in laws	3
		Elders from maternal family or In laws	2
		No family members others than own nuclear family	1
2.	Major differences in the family	No conflicts	3
		Major conflicts – recovered / stable	2
		Major conflicts – still going on	1
3.	Reaction of family member	Positive reaction / acceptance	3
		Mixed reaction by different family members	2
		Not disclosed / negative reactions	1
4.	Feeling of rejection by the family	No	3
		Not disclosed the status	2
		Yes	1
5.	Reported support by family members :	6 to 7 times – good support	3
	3.19 + 3.20 + 3.31 + 3.32 + 3.33 + 3.34 + 3.35	3 to 5 times – Moderate support	2
	7 questions	0 to 2 times – Poor support	1

Total score and categories

1. 5 to 7 Poor family support
2. 8 to 11 Moderate family support
3. 12 to 15 Good family support

Table 3.4 HIV infection background helping coping :

Sr.	Variable considered	Categories	Score
1.	Duration of diagnosis	More than 5 years/ could not specify	3
		3 to 5 years	2
		Less than 3 years	1
2.	Age at the time of detection	35 and more	3
		25 to < 35	2
		Below 25	1
3.	Partner's duration of infection	More than 5 years	3
		3 to 5 years	2
		Don't know / partner is not infected / less than 3 years	1
4.	Partner talked about his infection	Immediately / partner is not infected	3
		After opportunistic infection / severe symptoms	2
		At the time of death / never told	1
5.	Precaution taken during this period	Safe sex practices / no contacts	3
		Did not take any precaution	2
		Forced not to take any precaution	1

Total score and categories

1. 5 to 7 Poor background of HIV infection helping coping
2. 8 to 11 Moderate background of HIV infection helping coping
3. 12 to 15 Positive background of HIV infection helping coping

Table 3.5 Counseling and NGO Support score :

Sr.	Variable considered	Categories	Score
1.	Did you receive counseling (2.15)	All 3 – Pre test + post test + adherence	3
		Any two	2
		Any one or No	1
2.	Coping has improved after counseling	Very positively	3
		Moderately	2
		Not much	1
3.	Member of a support group / help of support group	Financial support + moral boosting	3
		Other support	2
		Not a member	1
4.	How often visit NGO	Stays there / daily	3
		Less than a month / as and when required	2
		Monthly / bimonthly	1
5.	Services received by the NGO	Counseling + financial help	3
		Other help	2
		Nothing	1

Total score and categories

1. 5 to 7 Poor counseling and NGO support
2. 8 to 11 Moderate counseling and NGO support
3. 12 to 15 Good counseling and NGO support

3.18 Plan of data analysis: Broadly data has been analyzed in the following ways :

1. Simple tables, bi-variate tables and multi-variate tables had been prepared on various aspects.
2. Goodness of the data or association of data has been assessed by deploying chi-square test.
3. Simple measures of central tendencies along with dispersion have been computed.
4. Correlation has been computed on coping mechanism and social psychological and physiological aspects.
5. If possible regression analysis has been computed as per the need of the study.
6. Paired T test has been used.
7. Scores on family support, health condition, HIV infection background, counseling and NGO support, were prepared to understand pre and post intervention effect.

3.19 Limitations of the Study :

The selected topic for research has a base from psychology and social work methods. There were number of factors which proved as a limitation.

1) As HIV/AIDS is a very sensitive topic, everywhere while seeking permission to conduct study, there were problems of confidentiality due to which, permission from ICTC could not be sought
2) For State and Central level, all tools were translated into English and Marathi language, consent was prepared with the help of professionals from field that was also translated and was sent for permission. However it took 4 months to receive any answer and finally permission was rejected. It was a waste of time and delayed further decision.
3) Women respondents were not ready initially for participating in the study. They had difficulties about losing daily wages to come to NGOS, in addition to that transport cost, was another hurdle in participation.
4) Researcher was not financially supported, due to which, she could not assure any respondent any transport cost, which reduced the motivation of participants.

5) Listing women who were diagnosed HIV within last 1 to 3 years and tracing them was difficult task due to change in their telephone numbers and addresses.
6) Completing schedule within 60 minutes was a bit burden for respondents. Many details from the psychological tests, they had not even thought of in the life.
7) For group counseling session's meetings used to be arranged by NGOs but there was no guarantee about attendance of respondents.
8) While interviewing the respondents, there was no privacy due to space availability in NGO. It made further difficult to get exact answers to questions in schedule and in different tests.
9) In translating different tests, though professional help was sought, it was difficult to find exact simplified words for technical terms.
10) Investigator was a full time lecturer at College of Social work, finding the time to consistently work on thesis was a limitation.

3.20 : Chapterisation:

- Chapter first is theoretical framework and situation analysis; which contents, facts about HIV, psycho social implications, efforts at combating with HIV/AIDS, national AIDS control programme, women and HIV, legal issues, concept of coping , adjustment, motivation, quality of life , behavior and personality.

  The other aspects about stigma, social support and social work intervention also are included in the chapter.
- Chapter second is literature review. It has references about women and HIV, about coping, coping mechanism, coping mechanism and intervention, study of quality of life of public of people of infected with HIV, experience of stigma and effect of social support.
- Third Chapter on research methodology covers origin of the problem, scope and universe of the study, criteria for sample selection, Hypothesis, objectives, tools for data collection, research design, tool design, aspects covered in the tools, phases of study, method of data collection, score calculations, limitations of the study and chapterisation.

- Chapter four presents the socio economic situation, that includes respondent's information about age, education, marital status, income, occupation, age at marriage, length of residence in pune, number of close relatives residing with them. The other aspects covered are frequency of visit to Native place, share of respondents in property. Next aspect is major development in the family, respondent's opinion about remarriage after the death of the spouse and major difference in the family.
- Fifth chapter on health status and problems includes problems and issues of the women, present health status that includes their CD4 count, weight, history of the delivery, total number of pregnancies, health status of children, spacing between children and use of contraceptive is other aspect included. The next point covered is referral for HIV testing, place of diagnosis, whether respondent received pre -test and post-test counseling, and age at the time of diagnosis. Other significant point was about drug adherence if CD4 count was not at desirable level. Sharing of diagnosis by spouse was another aspect, availability of care taker for caring of respondent and the help received were other few points included in this chapter.
- Sixth chapter on stigma and support includes points like reaction after diagnosis, partner infection, disclosure of diagnosis, relationship with spouse, precautions taken to avoid further transmission, doubt about partners sexual behavior, reaction of family. Other aspect covered was experience of stigma, feeling of insecurity, attitude of society, perception of rejection; another aspect covered was support and help received from family, friends, relatives and NGO's.
- Chapter Seven is on Social work intervention. It includes concept and methods of intervention and inputs on health care, coping like stress management, adjustment, improving the quality of life, about social skills, issue about disclosure to spouse and children is included. Management of emotions and managing money and time are the other aspects covered in the intervention.
- Chapter eight is impact of intervention on coping mechanism. It includes data about pre and post intervention. Impact on coping mechanism with

different categories mean scores with socio economic score, health score, family support and HIV background. The same method is followed to present adjustment scores with socio economic, health and family support and HIV background. Other test results on quality of life, motivation and personality are given further.

- Last nineth chapter on conclusions gives overall summary, conclusions and testing of hypothesis and few suggestions. .

  Throughout the chapter 5, 6 &7 there are case studies given in box, which describes women's conditions after being infected, vulnerability, children's condition, experience of stigma and support.

  Appendix

3.21 Summary

This Chapter elaborates the methodology and research design of the study. In this chapter the basic details of universe, study area, study population and respondents are presented. The sampling method and sample size for pre intervention and post intervention have been discussed. Various tools of data collection have been explained i.e. basic interview schedule containing identification data, information on health and nutrition, information on HIV, Weight CD4 count, referral for HIV, partner notification, support system and stigma were included. Apart from this there were five psychological test were used. The purpose of each tool and its content has also been explained. Attention is drawn to specification of various psychological tests, their origin and method of adaptation, process of administration which was unique to each of these tests. The scoring methods also have been mentioned. In addition, the statistical plan of analysis has been described. These details are condensed in table to indicate various aspects of methodology at a glance. The applicability of findings and limitations of the study are given in detail.

CHAPTER IV

SOCIO-ECONOMIC SITUATION

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SOCIO-ECONOMIC SITUATION

4.1 Introduction

The Socio-Economic condition plays a pivotal role in determining the quality of life. The socio-economic condition is a comprehensive term used to ascribe background factors of any social phenomenon. There are several definitions of socio-economic condition however the common factors such as age, education, occupation, family composition, income, surrounding atmosphere remains constant to explain cause and effect relation in a particular phenomenon. In view of the present study these factors have very close linkages with coping mechanism among the HIV infected persons.

Generally it is observed that HIV infection could be found in all stratum of the society irrespective of their socio-economic condition but it is also a fact that it is predominant in poor socio-economic population. This population has more chances to get HIV injection due to their occupational pattern and ignorance about precautionary measures of high risk behavior. The individuals that migrated from rural areas to urban areas for want of employment are engaged in unskilled jobs and staying in hygienically very poor atmosphere / living conditions. Due to various reasons this population has more chances to get various infections frequently and HIV is not exception to this process.

This study is concerned with assessing the coping mechanisms among HIV infected women the social factors play pivotal role at every stage of disease and also in day to day social life. On this background the information collected from the respondents is described below.

4.2 Age of the respondents

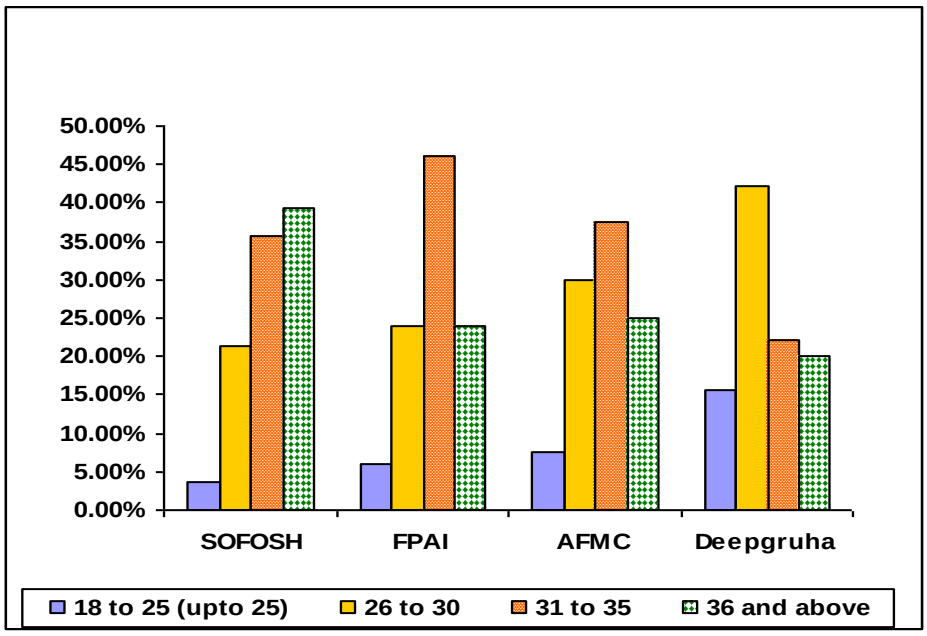
Age had a crucial significance to HIV infection. Among most of women, HIV infection is transmitted from spouse during sexually active years. The HIV is the leading cause of disease and death among women during reproductive stage (15 – 49). Worldwide women are at least twice more likely to acquire HIV from men during sexual intercourse than vice versa. After getting infection their entire life gets disturbed. The child bearing and rearing capacity is lost and women have to face

several problems, which affects their social status. Once the infection is diagnosed, their day to day life gets disturbed due to various reasons. Therefore, the age is an important aspect in the study of HIV infection. The details in this regard are given in Table.

Table 4.1
Distribution of Respondents according to Age

NGO Groups	Age Groups				Total
	18 to 25 (up to 25)	26 to 30	31 to 35	36 and above	
SOFOSH	2 3.6 %	12 21.4 %	20 35.7 %	22 39.3 %	56 100 %
FPAI	3 3.6 %	12 24.0 %	23 46.0 %	12 24.0 %	50 100 %
AFMC	3 7.5 %	12 30.0 %	15 37.5 %	10 25.0 %	40 100 %
Deepgriha	7 15.6 %	19 42.2 %	10 22.2 %	9 20.0 %	45 100 %
Total	15 7.9 %	55 28.8 %	68 35.6 %	53 27.7 %	191 100 %

Graph 4.1: Distribution of the respondents according to age groups



The above table show at SOFOSH 40% respondents are above the age of 36 years and 36 % respondents belongs to 31 to 35 years age group. The age between 18 to 25

years and 26 to 30 years are 21% and 4% respectively. At FPAI about half i.e. 46% respondents belongs to 31 to 35 years age group and 26-30 and 36+ years the proportion is 24%, whereas 6% respondents belonged to 18 to 25 years age group. In case of AFMC about 38% are in 31 to 35 years age followed by 30% in 26 to 30 and 25% are above 36 years age. About 8% respondents have age < 25 years. At Deepgraha Society highest proportion of respondents are observed in 26 to 31 years age group i.e. 42% and about 16% are< 25 years. remaining respondents are above 31 years age group. The overall situation indicates that highest proportion of the respondents is observed in 31 to 35 years age group and lowest in below 25 years age group.

4.3 Education of Respondents

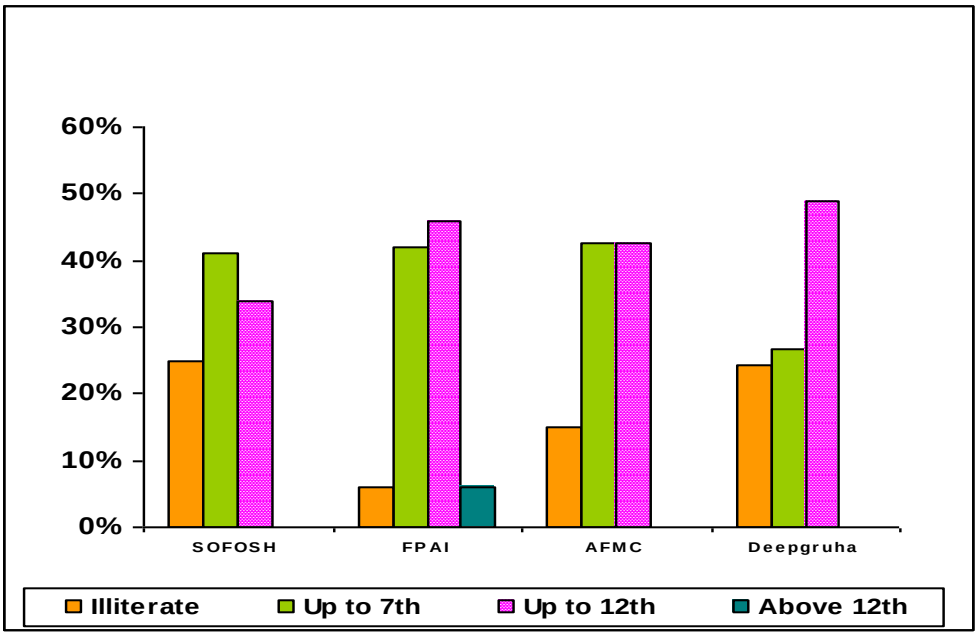
Education is believed to be opportunity to gain knowledge and information which helps to change value system. Person who is culturally rich, his thinking ability is enhanced. Education provides skills to live happy. It equips individual about how to face the situation. If individual is educated, he can think about various alternatives available with him to overcome the problem that he is facing. Education helps to

change attitudes, behavior and thinking and hence is considered one of the indicators of social status and employment for survival. The following table shows details in this regard.

Table 4.2 Distribution of respondents according to education

NGO Groups	Education of the respondent				Total
	Illiterate	Up to 7th	Up to 12th	Above 12th	
SOFOSH	14 25.0 %	23 41.1 %	19 33.9 %	0 0 %	56 100 %
FPAI	3 6.0 %	21 42.0 %	23 46.0 %	3 6.0 %	50 100 %
AFMC	6 15.0 %	17 42.5 %	17 42.5 %	0 0 %	40 100 %
Deepgriha	11 24.4 %	12 26.7 %	22 48.9 %	0 0 %	45 100 %
Total	34 17.8 %	73 38.2 %	81 42.4 %	3 1.6 %	191 100 %

Graph 4.2: Distribution of respondents according to education groups



Distribution of respondents according to education

The above table indicates the large variation between various organizations in educational level of respondents. One of the prominent observations is very negligible proportion of respondents had education more than 12th standard and 18% respondents were illiterate. About 38% respondents were educated up to 7th standard and only 42% respondents were educated up to 8th to 12th standard. This is the only group which might be aware about the cause and effect relationship of HIV. Those who were educated up to 7th standard may not be able to relate the cause and effect relationship as they are only able to read and write. Between NGOs SOFOSH and Deepgriha shows about 25% respondents were illiterate, whereas the education up to 7th standard, the respondent's trend remained more or less same i.e. 42% except Deepgriha 27%. As regard to the education up to 12th standard. FPAI, AFMC and Deepgriha, showed the same trend, and SOFOSH considerably less proportion of respondents were educated up to 12th standard. In brief it is to say that the educational level of the women inflicted by HIV is considerably low perhaps, very negligible percentage of women are educated beyond 12th standard.

4.4 Occupation of respondents

Occupation is mainly concerned with the livelihood resources. Especially among the poor people, their physical strength and labour is the only source for their livelihood. Inadequate education automatically leads to accept unskilled job. Majority of the respondents belong to the lower socio-economic category, their occupation naturally falls in the lower category. Survival and meeting the basic needs, is the main function of occupation. Occupation as a social entity also is closely associated with caste. Working on daily wages and unskilled job, hawkers, vegetable selling, self-employment or trading domestic work and construction work etc. are the main categories one can observe among lower strata. Naturally, they are not able to spare any amount on any other aspect except meeting the daily needs. The information on occupation either primary or joint is collected and given in table.

Table 4.3

Distribution of respondents according to occupational categories

Name of NGO	Occupational categories of the respondents						Total
	Labour	Service	Housemaid	Housewife	Self Employed	Nothing	
SOFOSH	7 12.5 %	6 10.7 %	6 10.7 %	9 16.1 %	5 8.9 %	23 41.1 %	56 100 %
FPAI	5 10.0 %	6 12.0 %	2 4.0 %	23 46.0 %	3 6.0 %	11 22.0 %	50 100 %
AFMC	7 17.5 %	7 17.5 %	7 17.5 %	12 30.0 %	5 12.5 %	2 5.0 %	40 100 %
Deepgriha	4 8.9 %	9 20.0 %	10 22.2 %	9 20.0 %	6 13.3 %	7 15.6 %	45 100 %
Total	23 12.0 %	28 14.7 %	25 13.1 %	53 27.7 %	19 9.9 %	43 22.5 %	191 100 %

There are 41 % women who are staying in NGOs they have no income however they get supports from SOFOSH. There are about 65 % respondents from AFMC doing something or the other work but they have no support from any NGO. Sixty five percent respondents work in Deepgriha, 22 % don't do anything. Hence about 50 % of the total sample are working and supporting their families.

4.5 Occupation V/s. Number of dependents

Table 4.4

Occupation V/s. Number of dependents

Occupational Categories	No. of dependents on the respondent			Total
	1 – 2	3 – 4	5 and more	
Labour	9 39.1 %	9 39.1 %	5 21.7 %	23 100 %
Service	17 60.7 %	9 32.1 %	2 7.1 %	28 100 %
Housemaid	10 40.0 %	12 48.0 %	3 12.0 %	25 100 %
Self-Employment	9 47.4 %	6 31.6 %	4 21.0 %	19 100 %
No Response	28 65.1 %	13 30.2 %	2 4.7 %	43 100 %
Total	112 58.6 %	60 31.4 %	19 9.9 %	191 100 %

The above table shows in labour category, 39 % of the respondents had 1 to 2 dependents and 39 % respondents had 3 to 4 dependents and 22 % respondents have 5 and more dependents. In service category 61 % of the respondents had 1 to 2 dependents, 32 % of the respondents had 3 to 4 dependents and 7 % respondents had 5 and more dependents. In this housemaid category, 40 % respondents had 1 to 2 dependents, 48 % respondents had 3 to 4 dependents and 12 % of the respondents have 5 and more dependents. In the category of housewife, 73 % of the respondents have 1 to 2 dependents, 21 % respondents had 3 to 4 dependents and 6 % respondents had 5 and more dependent. In self-employment category, 47 % of the respondents had 1 to 2 dependents, 32 % of respondents had 3 to 4 dependents and 21 % respondents have 5 and more than 5 dependents, about 22 % respondents chose to have not given any response to this question. From the above response, financial burden on the respondents has a crucial role in support system. Most of the respondents were

housewives and doing unskilled jobs, thus were unable to meet the expenses of health and nutrition of themselves and their dependents.

Occupation of family

It is a known fact that usually men are getting HIV infection,naturally the chance of loss of life of the husband is more than the wife; if husband dies the responsibility for meeting the needs of family members is on women.In the absence of education and skills, somehow women manage household expenses by undertaking domestic work or by working as a casual worker. If the husband is alive, he suffers fromseveral health and other problems hence, he hardly takes any responsibility to care for the family. Effort was made to see the way the family occupation was providing adequate resources to meet minimum needs of the family.

Table 4.5

Distribution of respondents according to occupational categories of husbands of the respondents

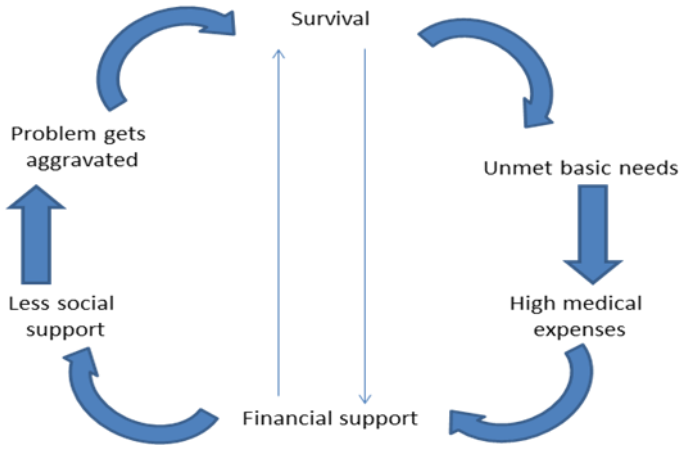
NGO Groups	Occupational categories of husband						Total
	Labour	Service	Self Employed	Nothing	Data not available	Not Applicable	
SOFOSH	3 5.4 %	8 14.3 %	2 3.6 %	3 5.4 %	6 10.7 %	34 60.7 %	56 100 %
FPAI	3 6.0 %	10 20.0 %	6 12.0 %	1 2.0 %	3 6.0 %	27 54.0 %	50 100 %
AFMC	4 10.0 %	8 20.0 %	1 2.5 %	0 .0 %	0 .0 %	27 67.5 %	40 100 %
Deepgriha	4 8.9 %	7 15.6 %	3 6.7 %	1 2.2 %	2 4.4 %	28 62.2 %	45 100 %
Total	14 7.3 %	33 17.3 %	12 6.3 %	5 2.6 %	11 5.8 %	116 60.7 %	191 100 %

Women from lower socio-economic group are vulnerable to receive infection due to an early age of marriage, low decision-making power, stigma due to HIV and widowhood and lack of support. This could be explained well with Yashoda's case.

Case Study 4.1: Multiple problems HIV infected person has to face.

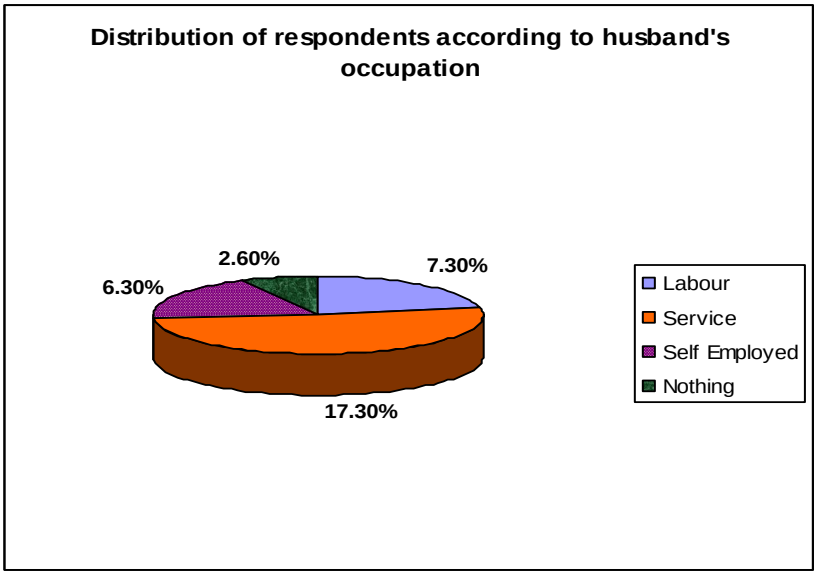
Yashoda, a 40 years old, illiterate HIV positive woman, has two of her children Nitin and Priya sero positive. Nitin has suffered opportunistic infection of meningitis. While Nitin was tested HIV positive, Yashoda and Priya also realized their infection in due course. Yashoda does not have any family support. Her mother in law and parents do not wish to take care of her and her two HIV infected children. Her elder son works in a shop and delivers newspapers. He is studying in a college with the help of Yashoda's employer. Nitin and Priya often blame their mother for transmitting HIV to them. Yashoda gets very upset about it. She is under stress of looking after her own health, children's health since they were diagnosed until starting ART to them. Even today she makes sure that the treatment is going well and they maintain their health. The elder son Nikhil feels, three of the infected family members are together, he is all alone and does not want to support them. Yashoda needs ventilation for her feeling of isolation, depression and self blame. She has no support. She is finding it difficult to 'cope' with the situation of caring for three HIV positive family members.

Figure 4.1: Multiple problems HIV infected person has to face



This figure 4.1 can be explained as there are unmet basic needs, hence health gets deteriorated which causes high medical expenses, there is less social support which aggravates the problems that leads to deterioration of chances of survival, where coping becomes difficult.

Graph 4.3: Distribution of respondents according to husband's occupation



Occupation of the husband

The above table shows about 61 % of the respondents were either widows or were deserted or had left the husband hence this question was not applicable and about 8.4 % respondents have reported that due to poor health, husband was not able to perform any task. There were 17.3 % respondents whose husbands were doing service, 7.3 % respondents' husbands were involved in labour work and 6.3 % were doing self employment. More than 60 % respondents were widows so question on the present occupation of the husband was not applicable, and 6 % of the respondents could not give any details about occupation of the husband. This indicates that the respondents had very poor financial support and due to their HIV status, there was no social support also.

4.6 Total income of family

The level of income decides the type of health care, social status and general living conditions. The family members have to meet their minimum needs by earning their livelihood. As regards to HIV infection income level is one of the proximate determinants of health and nutritional status of family members. It is essential that husband being the head of the family has to take the responsibility of the family expenses. In the absence of the husband, woman has to support the family as a changed role of breadwinner.

Table 4.6
Distribution of respondents according to monthly income groups V/s Occupational category

Occupati-onal Categories	Income Groups Vs Occupational Category					Total
	* Institutionalized / No income (0)	500 to < 2000	2000 to < 5000	5000 to < 10000	10,000 & above	
Labour	5 21.70 %	9 39.1 %	7 30.4 %	1 4.3 %	1 4.3 %	23 100 %
Service	4 14.30 %	6 21.4 %	12 42.9 %	4 14.3 %	2 7.1 %	28 100 %
Housemaid	2 8.00 %	8 32.0 %	11 44.0 %	4 16.0 %	0 0.0 %	25 100 %
Housewife	8 15.10 %	3 5.7 %	25 47.2 %	13 24.5 %	4 7.5 %	53 100 %
Business	1 5.30 %	2 10.5 %	7 36.8 %	4 21.1 %	5 26.3 %	19 100 %
Nothing	7 16.30 %	8 18.6 %	20 46.5 %	6 14.0 %	2 4.7 %	43 100 %
Total	27 14.10 %	36 18.8 %	82 42.9 %	32 16.8 %	14 7.3 %	191 100 %

The above table indicates 14 % of the respondents had no income, 19% were between Rs. 500 to 2000 income group, 43 % respondents were in Rs.2,000 to Rs.5,000 and 17 % of the respondents were between income group Rs. 5000 to 10000 and 7 % respondents were in the income group more than Rs.10,000. Majority of the respondents were in the income group Rs. 2000 to 5000.As respondents had lost their partners due to HIV / AIDS, they take support of parents, in the absence of any other support. In this case, their income is considered as family income as they were staying with their parental families. There were few respondents, who had no income, as they did not have education, training and any skill to acquire satisfactory employment. There were few (5) respondents who were institutionalized. In the absence of any employment and support, women infected with HIV, take up jobs as caretakers in institution for children suffering with HIV.

4.7 Number of dependents on respondents

Financial burden on the respondents has a crucial significance in support system. Most of the respondents were engaged in unskilled jobs. Thus they were unable to meet the expenses of education, health and nutritional etc. of themselves and their dependents.

Table 4.7

Distribution of respondents according to no. of dependents V/s income groups

Income Group	No. of dependents Vs Income Group on the respondent			Total
	1 – 2	3 – 4	5 and more	
No Income (0)	19 70.37 %	4 14.81 %	4 14.81 %	27 100 %
500 to < 2000	21 58.3 %	13 36.1 %	2 5.6 %	36 100 %
2000 to <5000	46 56.1 %	31 37.8 %	5 6.1 %	82 100 %
5000 to < 10000	19 59.4 %	6 18.8 %	7 21.9 %	32 100 %
10000 & above	7 50.0 %	6 42.9 %	7 7.1 %	14 100 %
Total	**112 58.6 %**	**60 31.4 %**	**19 9.9 %**	**191 100 %**

The above table indicates 59 % of the respondents had 1 to 2 dependents on them, 31 % respondents had 3 to 4 dependents and 10 % respondents had 5 and more dependents. Financial burden on the respondents has a crucial role in the support system. Most of the respondents were engaged in unskilled jobs and were unable to meet the expenses for daily needs. There was substantial number of respondents having 1 to 2 dependents. About 31 % respondents have 3 to 4 dependents.

4.8 Respondent's BPL status (below poverty line)

Ration Card is an identity proof, holding BPL card can provide the grains, kerosene at a cheaper rate under the Public Distribution System. Those who migrate from rural

areas in search of employment necessarily do not have ration cards. Yellow colour ration card holders get certain facilities and concessions as they are considered as BPL families. This indicates material support for respondents. Following table shows number of respondents holding BPL card.

Table 4.8

Distribution of Respondents according to income V/s BPL card

Income Groups	**ration card**		**Total**
	Yes	**No**	
No income (0)	8 57.1 %	6 42.9 %	14 100 %
500 to < 2000	20 55.6 %	16 44.4 %	36 100 %
2000 to <5000	41 50.0 %	41 50.0 %	821 100 %
5000 to < 10000	21 65.6 %	11 34.4 %	32 100 %
10,000 and above	9 64.3 %	5 35.7 %	14 100 %
No response	5 38.5 %	8 61.5 %	13 100 %
Total	104 54.5 %	87 45.5 %	191 100 %

** Though their income was high they manage to get BPL Card.*

The above table shows, 55 % of the respondents have ration card and 46 % of the respondents do not have the ration card which indicates below poverty line income group. The overall observation is 46 % of the respondents did not have the BPL card, which puts them into financial difficulties and it hampers their opportunity to receive few facilities and concessions, which affects their coping with HIV infection.

4.9 Marital status of respondents:

Women get HIV infection from their marital partners. It is due to the trust that women have on their marital partners, they generally do not insist on use of condom to save themselves from any infection. They hardly have any ‘say’ in sexual relationship with marital partners, in lower socio-eco strata. After marriage, woman has a role of wife

and as a mother. Traditionally, in our society, marriages are being arranged by elders in the family, with their own criteria for selecting the partner which includes family name, caste, character and boy's financial stability. We hardly see that the views or opinions of young boys and girls are considered important, while arranging marriages. It is expected to seek essential information of those who are getting married, about character, attitudes towards marriage, habits, premarital sexual exposure and addictions if any. Many of the girls do not have access to secondary education. Parents do not consider education, necessary for girls to equip them better to face life. Prospective husbands also prefer to have their partners less qualified than them, which hampers on their decision making ability. This results into low 'self esteem' and confidence of women. If a woman is married and living with husband who is HIV infected, has some moral support. Those women who are widows have no support and being HIV infected, they experience stigma in family and neighborhood.

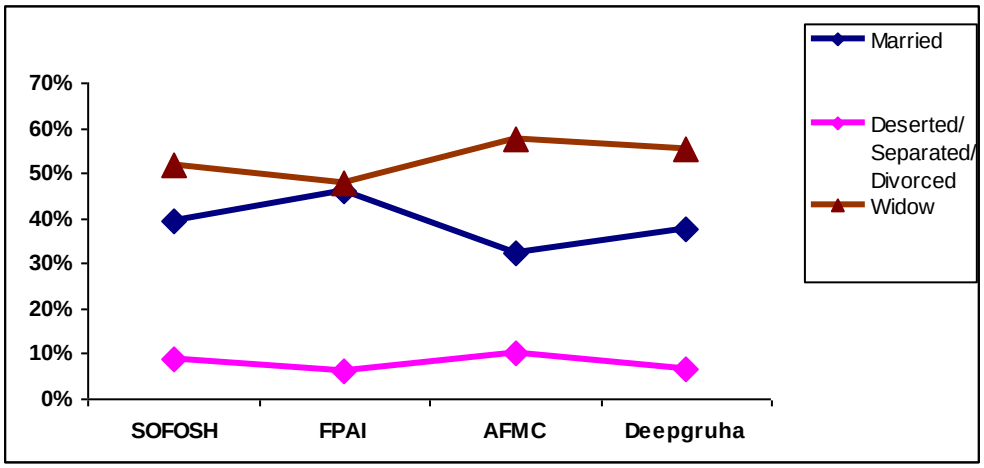
Table 4.9

Distribution of respondents according to marital status

NGO Groups	Marital Status			Total
	Married	Deserted / Separated / Divorced	Widow	
SOFOSH	22 39.3 %	5 8.9 %	29 51.8 %	56 100 %
FPAI	23 46.0 %	3 6.0 %	24 48.0 %	50 100 %
AFMC	13 32.5 %	4 10.0 %	23 57.5 %	40 100 %
Deepgriha	17 37.8 %	3 6.7 %	25 55.6 %	45 100 %
Total	75 39.3 %	15 7.9 %	101 52.9 %	191 100 %

An effort was made to see the association between marital status and income, number of dependents and marital status and occupation and chi-square was not seen significant.

Graph 4.4: Marital Status of the Respondents



The majority of the respondents were widows they had lost their husbands. Husbands were infected first and they passed on infection to their spouses. As they developed opportunistic infections, eventually they died. There were 39 % married women who were living with husbands and 9 % were separated or deserted. Once the HIV status of the partner is known, very few women have courage to desert the partner. As majority of the respondents were widows, they hardly had any source of income, apart from their work.

The above table shows, the marital status of respondents at SOFOSH, about 52% respondents were widows and 39% were married and 9% were separated. At FPAI also the 48% respondents were widows and 46% were married. At AFMC 57% were widows and 33% were married. At Deepgriha, 56% were widows and 37% were married. Overall about 53% were widows and 39% were married, overall trend shows very negligible percentage in deserted or separated category. It is seen as one spouse in marital relationship gets infected, it is but obvious that the husband dies first and hence about 53% respondents were widows.

4.10 Age of marriage of respondent

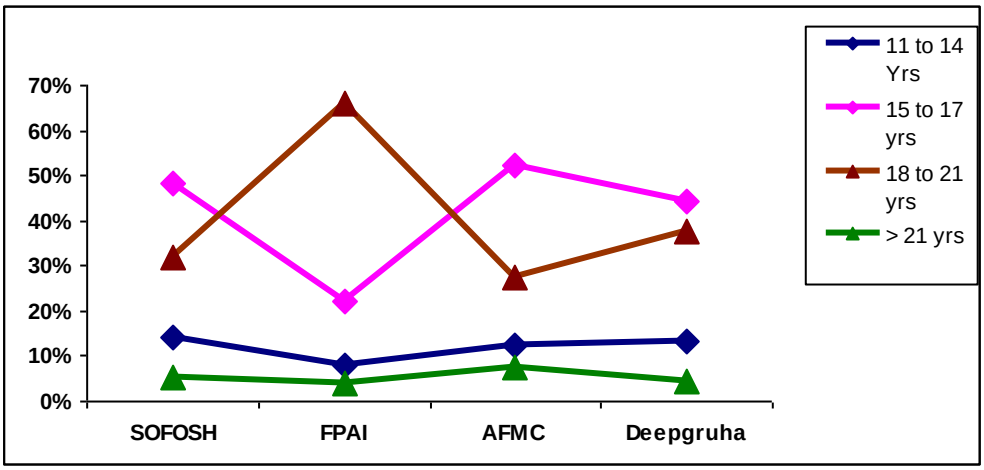
Legal age of marriage is 18 for girls and 21 for boys in India. There is a tendency to get girls married at an early age. People in our society assume that there are only two roles to women i.e. as wives and mothers. So to adjust into their in-law's families, they are expected to get married as earliest as possible. As a result, many times girls are not ready physically, emotional and psychologically to get married. The next role

they have is of a 'mother'. They also have to face pressure to give birth to a 'boy' child. If this does not happen, she has to face harassment, has to undergo sonography, test to identify the sex of the foetus.

Table 4.10
Distribution of respondents according to age at marriage

NGO Groups	Age at marriage				Total
	Less than 11 to 14 yrs.	15 to 17 yrs.	18 to 21 yrs.	> 21 yrs	
SOFOSH	8 14.3 %	27 48.2 %	18 32.1 %	3 5.4 %	56 100 %
FPAI	4 8.0 %	11 22.0 %	33 66.0 %	2 4.0 %	50 100 %
AFMC	5 12.5 %	21 52.5 %	11 27.5 %	3 7.5 %	40 100 %
Deepgriha	6 13.3 %	20 44.4 %	17 37.8 %	2 4.4 %	45 100 %
Total	23 12.0 %	79 41.4 %	79 41.4 %	10 5.2 %	191 100 %

Graph 4.5: Age at marriage of the respondents



The above table shows the age of marriage of the respondents, considerable number of i.e. 13 % respondents got married below the age of 14, at SOFOSH 48% respondents got married between 15 to 17 years, 32% in 18 to 21 years of age and very less i.e. 5% of the respondents got married when they were above 21 years.

About 66% respondents reported their age at marriage between 18 to 21 years. At AFMC 52% respondents reported their age at marriage was between 15 to 18 years and 28% respondents reported their age at marriage between 18 to 21 years. At Deepgriha, 45% respondents reported their age at marriage between 15 to 17 years, and 38% between 18 to 21 years, overall trend shows, that about 41% respondents were married in the age group 15 to 17 years and 42% between the age group 18 to 21 years. However, 12% respondents reported to have married below the age of 14 years. Overall it is observed that the norm for getting married is being followed, around the age of 18 years which is a legal age of marriage.

Legal age for marriage in India is 18 years for girls, however for many social reasons; girls get married at an early age. Girls suffer after marriage, conflicts, violence, harassment and finally separation. Some women for no fault of theirs receive HIV infection and face widowhood due to the death of husband due to HIV/AIDs. Those who become widow and are infected themselves; do not get support from their in-laws. Those who are separated already have lost the support. As they got married early, they received infection much earlier in life and have to live with it for many productive years. Out of 191 respondents, about 41 % were between 15 to 17 years, 41 % between 18 to 21 years, 12 % of the respondents were between 11 to 14 years. The remaining 5 % the respondents' age of marriage was 21 years. About 91 % of the respondents were married below the 21 years. As the age of marriage is less, chance of contracting HIV from the marital partner is higher.

4.11 Number of children of respondent

Birth of a child in the family is a very welcoming and wanted event. For a woman to bear a child is a very fulfilling role as a wife, mother and daughter-in-law and proving her capacity to bear a child and her femininity. She gets social status, approval after becoming a mother. If she gives birth to a male child, that is further an event for celebration. The number of children also indicates responsibility over family. Inspite of knowing the HIV status, women are forced to undergo the pregnancy and child birth. In the post test counselling couple is explained about implications of HIV on their children. This results into mother to child transmission of HIV and an added responsibility of a child in terms of child's health, education, nutrition and overall

development. If there are more children and infected with HIV, it is an additional responsibility on infected women.

Table 4.11

Distribution of respondents according to total no. of children

NGO Groups	Total no. of children					Total
	0	1	2	3	4	
SOFOSH	1 1.8 %	11 19.6 %	23 41.1 %	15 26.8 %	6 10.7 %	56 100 %
FPAI	6 12.0 %	17 34.0 %	22 44.0 %	5 10.0 %	0 .0 %	50 100 %
AFMC	7 17.5 %	7 17.5 %	17 42.5 %	3 7.5 %	6 15.0 %	40 100 %
Deepgriha	4 8.9 %	10 22.2 %	21 46.7 %	7 15.6 %	3 6.7 %	45 100 %
Total	18 9.4 %	45 23.6 %	83 43.5 %	30 15.7 %	15 7.8 %	191 100 %

An effort was made to see the association between number of children and dependents and the number of children with income however there was no significant relationship and the chi-square also was insignificant.

The above table shows the number of children the respondents had. At SOFOSH, 41% respondents reported they have two children and 27% respondents had three children. About 10 % respondents reported to have 4 children and 2 % reported to have 5 children. This shows the burden on the HIV infected woman that after she develops opportunistic infections the question will arise about caring of these children. AT FPAI same trend is observed 44% have two children, 34% reported to have one child and 10% have reported to have three children. At AFMC 43% of the respondents had two children, 18% had one child, 13% have reported to have 4 children and 3% have reported to have 5 children. This also indicates the burden on the infected woman. At Deepgraha 47% respondents had two children, 22% respondents had one child, 16% had 3 children and 7% had 4 children. Overall the trend shows the small family norm being followed by the respondents. However, there

were few respondents who had more than 3 children and their responsibility was a matter of concern.

4.12 Migration: Residential status of respondent

Residential status shows accessibility of respondents to government institutions or places where they can avail of few facilities

Table 4.12

Distribution of respondents according to migration

NGO Groups	Migrated		Total
	Yes	No	
SOFOSH	24 42.9 %	32 57.1 %	56 100 %
FPAI	27 54.0 %	23 46.0 %	50 100 %
AFMC	23 57.5 %	17 42.5 %	40 100 %
Deepgriha	17 37.8 %	28 62.2 %	45 100 %
Total	91 47.6 %	100 52.4 %	191 100 %

It is observed from the above table that at SOFOSH, 57% respondents were from Pune, itself and 43% had migrated from other places, respondents from FPAI, 54% were migrated, and 46% were from Pune and at AFMC about 58% were migrated and 43% were from Pune. At Deepgriha, it is observed that 62% were not migrated only 38% were migrants. Overall trend is 52% respondents were residents from Pune. The overall situation shows equal proportion of local residents and migrated families in study population. In continuation of residence a probing question was asked about length of residence at Pune, it is given in following table.

4.13 Length of residence

Length of residence indicates respondents' awareness and utilization about their neighbourhood, services around. This provides support and helps in better adjustment with the environment.

Table 4.13
Distribution of respondents according to length of residence in Pune

NGO Groups	Year of residence in Pune				Total
	Up to 10	10 to 20	20 Yrs +	Not Applicable	
SOFOSH	9 16.0 %	7 12.5 %	22 39.3 %	18 32.1 %	56 100 %
FPAI	14 28.0 %	8 16.0 %	8 16.0 %	20 40.0 %	50 100 %
AFMC	8 20.0 %	6 15.0 %	12 30.0 %	14 35.0 %	40 100 %
Deepgriha	4 8.8 %	12 26.6 %	11 24.5 %	18 40.0 %	45 100 %
Total	35 18.3 %	33 17.2 %	53 27.8 %	70 36.6 %	191 100 %

Thirty seven percent respondents were from Pune and other 27 % and 18 % have been staying at Pune for more than 10 years. People come to urban area like Pune, in search of employment. Their nature of employment is that in the absence of training and skill, they are involved in labour work. As they are involved on daily wage basis, they hardly can afford to take leave and visit often to their native place. They stay in urban slums, chawls, mostly get support from the neighbourhood area. Take resources and services from the nearby government institutions. As they were staying in Pune for more than 10 years they were well acquainted and well adjusted with urban living conditions.

The above table shows that at SOFOSH, about 39% of the respondents were staying at Pune for more than 20 years. At FPAI about 40 % respondents have replied to this question not applicable to them. Twenty eight percent respondents were residing at Pune for 10 years and 16 % were residing for 10 to 20 years. At AFMC about 35% respondents have answered not applicable to this question. Thirty percent respondents were residents of Pune for more than 20 years and at Deepgriha 40% have answered not applicable to this question and 27 % were residing for 10 to 20 years. Negligible percent of the respondents were residing for last 10 years in Pune.

4.14 Number of close relatives, residing with respondent

Family is the basic unit of society. Traditional Indian families have played significant role in supporting members of families in crisis, value inculcation, care of senior citizens and children. However, structural and functional changes have lead to transformation in families. Presently, in the era of globalization, fabric of society is vitiating, people have become materialistic, there are five I's, that have become very strong, those are Irritability, Impulsivity, Insomnia, Impatience and Isolation. This leads to stress and also the support system has become weak. This phenomenon is prevalent in urban areas, and it is gradually percolating in villages. This results into managing the life with stress without support. During crisis, if relatives, friends are around and extend support, it becomes an asset in coping with the situation. Diagnosis of HIV in family is a crisis, if during crisis, family members are in close vicinity, they can extend help to the family.

Table 4.14

Residing with close relatives (Multiple Response)

NGO Groups	Residing with close relatives								Total
	Father	Father-in-law	Brother	Brother-in-law	Mother	Sister	Mother-in-law	Sister-in-law	
SOFOSH	5 8.9 %	0 0.0 %	11 19.6 %	3 5.4 %	16 28.6 %	9 16.1 %	17 30.4 %	4 7.1 %	56 100 %
FPAI	6 12.0 %	6 12.0 %	9 18.0 %	4 8.0 %	18 36.0 %	2 4.0 %	10 20.0 %	1 2.0 %	50 100 %
AFMC	3 7.5 %	6 15.0 %	2 5.0 %	2 5.0 %	5 12.5 %	1 2.5 %	10 25.0 %	4 10.0 %	40 100 %
Deepgriha	5 11.1 %	7 15.6 %	3 18.0 %	4 6.7 %	5 11.1 %	6 13.3 %	12 26.7 %	2 4.4 %	45 100 %
Total	19 9.9 %	19 9.9 %	25 13.1 %	14 7.3 %	45 23.6 %	14 7.3 %	49 25.7 %	11 5.8 %	191 100 %

Above table shows 30 % of respondents were staying with mother-in-law at SOFOSH, 29 % of the respondents were staying with mothers followed by 20% with brothers and 16 % with sisters. At FPAI, 36 % respondents have responded to have been staying with mother, followed by 20 % with mother-in-law, 12 % with father-in-law and 18 % with brothers. At AFMC, 25 % were residing with mother-in-law,

followed by 13 % with mother and father, and at Deepgriha, 27 % were residing at mother-in-law's place and 13 % with mothers. It was observed that after the HIV diagnosis and death of the spouse women have a tendency to seek support from in-laws, but they don't provide support.In this critical situation women seek support from parents, where brother supports the family financially.

4.15 Nature of relation with native place

The nature of relation with native place indicates cohesion and solidarity in the family. It provides moral support to individual. Frequency of visit to native place indicates the nature of relationship, level of sharing and their hold on joint property, common decision making and overall control on behavior of the respondent and her spouse. In this category the data could not be received consistent and therefore has not been presented here.

Nature of relations is a relative term. Psychologically women have always good relations with parental family, as there is tendency among parents not to expose their kids of their mistakes (if they made). In all crisis situations there is support from parents; naturally every married woman has a healthier relation with parental family rather than in-laws family. The healthy relations become sound platform to cope with any adverse conditions rather it is the main pillar of social support.

As compared to parental family in laws family is not that supportive in most of the cases. Naturally a married woman always feels some amount of social insecurity of in-laws family. To measure the relation is a complex process and measuring it is also somehow complex. This is because whenever the type of relation is measured the state of mind of the respondents plays a pivotal role. The second weakness in the assessment is the perceptional differences about the quality of relationship. On this background an attempt is made to collect the qualitative information about the nature of relations. It was observed that:

(a) Respondents have described, that they visit their relatives at native place once or twice a year. Due to busy schedules in urban areas, the intimacy is less. If respondents visit frequently, there could be more interactions, sharing,

decision making and greater support to respondent. However, overall it is observed that the nature of relationship is not very strong.

(b) Respondents reported, as they were diagnosed with HIV and were on ART, they experienced stigma and they preferred to keep this information confidential to relatives and friends and reduced the number of visits to native place. As respondents don't get support, they develop their strength, coping on their own resources and capacities.

(c) Being infected with HIV, respondents go through both good and bad experiences. Through this, they develop coping abilities and their sense of responsibility towards their family which gives them strength to live life.

(d) As the nature of relationship with native place and relatives is not so close, hardly respondents could claim share in the property. If the native family reveals the reason of death of respondent's spouse is HIV, there is a likelihood of losing their right over family assets and resources.

4.15.1 Frequency of visit to native place

Frequency of visits indicates the level of intimacy, integration, support and interaction with family members at the native place. Families provide great support, care and extend their cooperation at the time of crisis. Nowadays we see, due to disruption of joint families, limited interactions and limited controls over our decisions by family members. We are getting individualistic. In rural areas, still some more cohesion, 'we feeling' is seen, but those who migrate, they hardly find time to visit and consult family members during crisis.As a result, they have to face the difficulties in life on their own. The respondents have expressed their views on frequency of visits only at the time of marriages or at festivals.

Table 4.15

Distribution of respondents according to frequency of visit to native place

NGO Groups	Frequency of visit to native place					Total
	Never	Limited (yearly visits)	Frequently (monthly visits)	Stays there	Not Applicable	
SOFOSH	2 3.6 %	10 17.9 %	7 12.5 %	29 51.8 %	8 14.3 %	56 100 %
FPAI	3 6.0 %	9 18.0 %	8 16.0 %	13 26.0 %	17 34.0 %	50 100 %
AFMC	3 7.5 %	11 27.5 %	7 17.5 %	14 35.0 %	5 12.5 %	40 100 %
Deepgriha	3 6.7 %	14 31.1 %	5 11.1 %	22 48.9 %	1 2.2 %	45 100 %
Total	11 5.8 %	44 23.0 %	27 14.1 %	78 40.8 %	31 16.2 %	191 100 %

The above table shows, 52 % of the respondents from SOFOSH reported to stay at native place. 18 % reported to stay at native place. 18 % reported they visit once in a year at native place and 13 % visit once in a month. At FPAI, 34 % have not responded to this question followed by 26 % respondents stay at native place, 18 % visit once in a year. At AFMC 35 % stay at native place, 28 % visit the native place once in a year, 18 % visit once in a month and 8 % never visit the native place. At Deepgriha 49 % respondents were residing at native place, followed by 31 % make yearly visit to native place and 11 % visit once a month. For the practical purpose of seeking support from family, respondents have not indicated any positive response.

4.16 Family assets and share

Most of the respondents were from lower socio-economic group. They were doing unskilled jobs, like domestic work, hawkers, vegetable vending, and construction work. To know respondent's financial support in the form of bank balance, house, land, plot, insurance policy and ornaments, information was collected. Although women are legally equal share holders in the property, families do not consider so. Once the daughters are married, they are not supposed to claim their share in the property. Women's share will be possible if her husband claims so. Being HIV

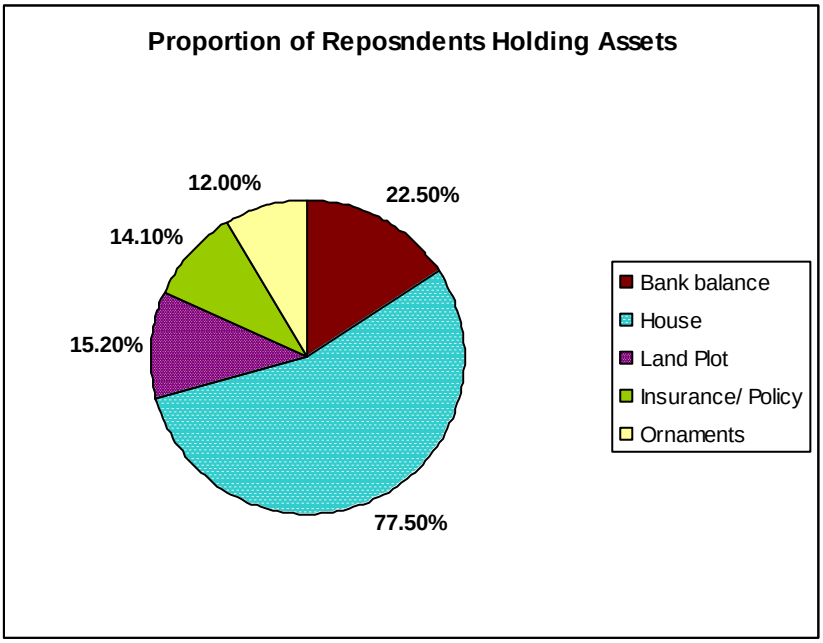
positive woman further loses her right to have a share in the property in any of the forms mentioned above.

Table 4.16

Distribution of respondents holding assets

NGO Groups	N	Bank Balance	House	Land Plot	Insurance / Policy	Ornaments
SOFOSH	56	13 23.2 %	22 39.3 %	6 10.7 %	7 12.5 %	9 16.1 %
FPAI	50	6 12.0 %	11 22.0 %	8 16.0 %	6 12.0 %	3 6.0 %
AFMC	40	10 25.0 %	15 37.5 %	11 27.5 %	7 17.5 %	5 12.5 %
Deepgriha	45	14 31.1 %	22 48.9 %	4 8.9 %	7 15.6 %	6 13.3 %
Total	**191**	**43 22.5 %**	**48 77.5 %**	**29 15.2 %**	**27 14.1 %**	**23 12.0 %**

Graph 4.6: Status of assets with respondents



The above table indicates distribution of respondents according to assets. At SOFOSH, 39% had house, 23% had bank balance, 16% were having ornaments, 13% have reported to have policy and a negligible percentage of respondents have reported (11%) to have land on their name. Similar trend is observed at both FPAI and AFMC,

however, at Deepgriha about 49% had house as an asset with the respondent. 31% had bank balance, 16% had insurance 13% were having ornaments and negligible number of respondents 9% had land as an asset with them. The overall trend shows, 76% respondents had at least house as an asset, 43% had bank balance, about 79% reported to either have ornaments, policy or land as an asset with them.

4.17 Regular income

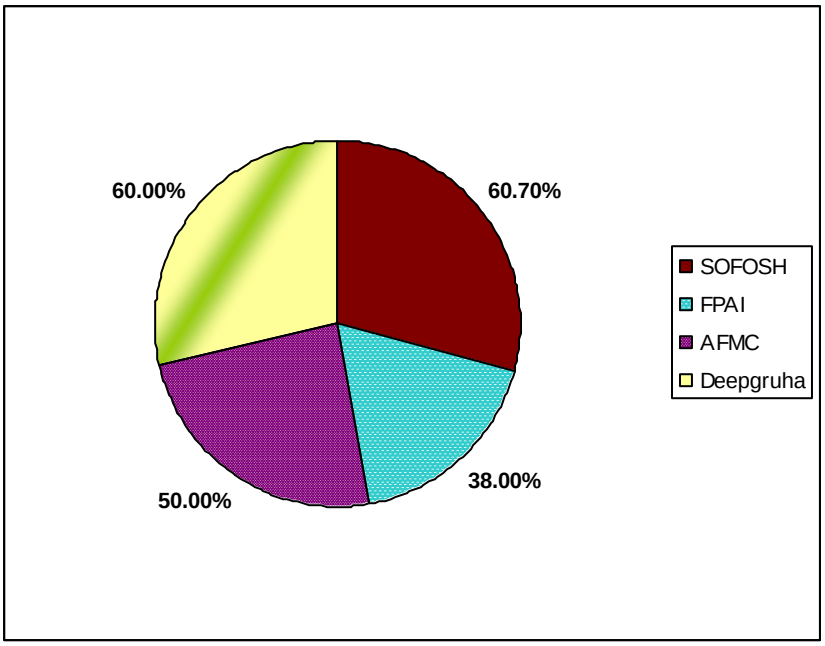
To fulfill basic needs, resources are needed. Every family has some or the other source of income for their daily living. Income of respondents was essential information to understand, source of income and its adequacy, the number of family members who are involved in earning.

Table 4.17

Distribution of respondents showing regular income

NGO Groups	Regular Income		Total
	Yes	No	
SOFOSH	34 60.7 %	22 39.3 %	56 100 %
FPAI	19 38.0 %	31 62.0 %	50 100 %
AFMC	20 50.0 %	20 50.0 %	40 100 %
Deepgriha	27 60.0 %	18 40.0 %	45 100 %
Total	100 52.4 %	91 47.6 %	191 100 %

Graph 4.7: Proportion of reposndents having regular income



About 48 % respondents do not have regular income. Respondents were involved in the occupation, which provide them very low income resources, those who stay with parents, don't even have BPL cards which can provide them few concessions, they being widows have left the in-laws or are staying on their own. They do not hold any property, due to lack of intimacy, and due to HIV status, in such situation they hardly can fulfill their special needs for being HIV infected women and they do also have to look after their dependent children, all this becomes very difficult task for them. It is observed that at SOFOSH, 61% respondents reported to have regular income and it is observed that about 39% do not have regular income. At FPAI about 62% respondents reported no regular income and only 38% have regular income at AFMC the distribution about this category is 50%. At Deepgriha the trend shows, that 60% have regular income while as 40% do not have regular income. Overall trend shows 52% respondents have regular income and 48% do not have it.

4.18 Perception of respondent about adequacy of income

Income and its adequacy is a relative concept. Respondents' income ranges between Rs. 3000/- to Rs. 3500/- per month and they have on an average 3 - 4 members in the family. Their major expenses were food, grocery, vegetables, milk, and education of children which includes books, fees uniforms, stationary, and rent of the house. The

income they receive is insufficient to maintain a household; they find it extremely difficult. Many of them cannot work up to optimum level due to their lowered health condition that is, low CD4 count. At such condition they are on Anti retroviral therapy. During the treatment they have to adhere to certain conditions to maintain health, in terms of food intake i.e. high protein diet, which they cannot afford and therefore some of them take nutritional help from NGOS. Table shows perception of adequacy of income.

Table 4.18

Distribution of respondents according to perception about adequacy of income

NGO Groups	Perception about adequacy of income		Total
	Adequate	Inadequate	
SOFOSH	20 35.7 %	36 64.3 %	56 100 %
FPAI	11 22.0 %	39 78.0 %	50 100 %
AFMC	10 25.0 %	30 75.0 %	40 100 %
Deepgriha	10 22.2 %	35 77.8 %	45 100 %
Total	51 26.7 %	140 73.3 %	191 100 %

The above table shows the perception of respondents about the adequacy of income. Significantly 73% respondents have responded inadequacy of income for the needs of respondents. At SOFOSH 64% have responded the inadequacy only 35% have said to have income adequate for the needs. At FPAI, AFMC and Deepgriha more than75% have expressed inadequacy of income.

4.19 Perception of respondents about remarriage

Legally one can get remarried on account of death of the spouse or in case of divorce. In the present study after the husband's death, women experience, loneliness, inadequacy of support and resources and loss of social status. However they can hardly think of remarriage. They have fear of having similar experience with the

spouse if they remarry. They are worried about responsibility of children and about their positive status.

Table 4.19

Distribution of respondents who ever thought of remarriage

NGO Groups	Ever thought of remarriage			Total
	Yes	No	Not Applicable	
SOFOSH	7 12.5 %	41 73.2 %	8 14.3 %	56 100 %
FPAI	3 6.0 %	42 84.0 %	5 10.0 %	50 100 %
AFMC	2 5.0 %	26 65.0 %	12 30.0 %	40 100 %
Deepgriha	9 20.0 %	24 53.3 %	12 26.7 %	45 100 %
Total	21 11.0 %	133 69.6 %	37 19.4 %	191 100 %

The above table shows at SOFOSH 73% respondents responded negatively to this question. At FPAI 84% respondents reported, that they never thought of remarriage, at AFMC 65% reported they never thought of remarriage and at Deepgriha 53% reported no thought of remarriage overall about 70% respondents have never thought of remarriage. As it is, remarriage in our society has not been very well accepted and after getting HIV infection, they were well aware about responsibility of children. The association between education and the thought of remarriage was tested and association as well as chi-square was not found to be significant.

4.20 Respondent's experience of sexual harassment

There are chances that, women can experience eve teasing and sexual harassment. They can be very easily deceived or can become a target for sexual harassment, especially women living alone. During the study, there was a significant observation that women were taking care of themselves and did not disclose their status as HIV infected person and as a widow. Irrespective of their marital status, they were observed to be wearing 'Mangalsutra' and wearing 'bindi', which is an indicator of

marital status among Hindus in Indian society. This practice has provided them protection from the anti-social element in the society.

Table 4.20

Distribution of respondents' experience of sexual harassment

NGO Groups	Experienced sexual harassment		Total
	Yes	No	
SOFOSH	8 14.3 %	48 85.7 %	56 100 %
FPAI	0 .0 %	50 100.0 %	50 100 %
AFMC	1 2.5 %	39 97.5 %	40 100 %
Deepgriha	7 15.6 %	38 84.4 %	45 100 %
Total	16 8.4 %	175 91.6 %	191 100 %

The above table shows experience of sexual harassment by the respondent. Significantly majority of the respondents have reported (91%) to have no such experience. At SOFOSH, 86%, at FPAI 100% responded that there was no such experience, at AFMC 98% did not experience it and at Deepgriha 84% reported negatively to this category of question. Overall trend is that respondents did not have any such experience.

4.21 Major difference in the family of respondent

Major differences in the family occur due to property issues, marriages outside community, socially unacceptable behavior like violence, addiction, gambling and anybody being diagnosed with stigmatized disease. Diagnosis of HIV shatters the marital relationship and relationship with the relatives. Persons find it very embarrassing to share it with anyone due to the fear of experiencing 'Stigma' isolation and discrimination. Gradually they start disowning them. Very few family members show concern about health of the infected person. This was correlated with

education of respondents and it was found that their education has no effect on the differences in the family.

Table 4.21

Distribution of respondents having major differences in the family

NGO Groups	Major differences in the family		Total
	Yes	No	
SOFOSH	14 25.0 %	42 75.0 %	56 100 %
FPAI	2 4.0 %	48 96.0 %	50 100 %
AFMC	3 7.5 %	37 92.5 %	40 100 %
Deepgriha	14 31.1 %	31 68.9 %	45 100 %
Total	33 17.3 %	158 82.7 %	191 100 %

The above table indicates majority of the respondents i.e. 83% have reported there were no major differences in the family. This indicates that in critical situations respondents approach their families and seek the support from them.

4.22 Summary

The socio-economic condition plays a significant role in quality of life. Socio-economic condition is a very comprehensive term which includes age, education, occupation, family composition etc. Age has a crucial role as far as effect and reaction of HIV is concerned. About 70 % of the respondents were in their productive age group, when they were diagnosed as HIV patients. As far as education is concerned, about 42 % of the respondents had education up to 10^{th} standard and 38 % had education upto 7^{th} standard. Education equips an individual to gain knowledge, and provides skills to live life meaningfully; it also helps in enhancing awareness. As the respondents reside in Pune since long time and are educated upto 7^{th} standard, their level of awareness about health in general and HIV in particular was better. Regarding the occupation of the respondents, it is observed that majority of them were involved

in unskilled jobs like vegetable vendor, hawkers, self-employment and domestic work. This could hardly give them adequate resources to fulfill their basic needs. As far as occupation of the family is concerned, 101 women respondents were widows, 15 were deserted. Most of the respondents belonged to the lower socio-economic strata they hardly had any income or financial resources to fulfill their basic needs. After revealing HIV infection of husbands, women experienced shock; eventually they have to face opportunistic infection and death of husband. Family members react with stigma and hatred towards infected women and the children. Women generally go to their parents for support, which is not a very desirable alternative for them. They do accommodate them for few months but gradually these infected women have to search their own means of livelihood. They have one or more dependent children on them. About 59 % of women had 1 to 2 dependents on them as a liability. About 55% of the respondents had BPL ration card, which could provide them few facilities. There were 75 respondents who were living with their spouses, 101 were widows and 15 respondents were deserted. Those respondents, who were living with spouses, at least had a moral support of their husbands, which helps them better in coping with the situation. Regarding the age at marriage, about 41 % of the respondents' age at marriage was between 15 to 17 and 41% respondents' age was between 18 to 21 years. This is significant to know how early respondents were married and within how many years of marriage they were infected with HIV. Their HIV status is generally known at antenatal clinic during pregnancy or at repeated hospitalization of husband. About 44 % of the respondents' age at the time of detection of HIV was between 20 to 25 years. Child birth in the family is perceived as a very happy and festive event. It is also a notion that the number of children indicates prosperity of the family. Earlier number of children indicated wealth, but with the gradual introduction of small family norm and consciousness about women's health, it is now expected to have two children. In the present study, number of children indicates the liability of the family after the women develops opportunistic infections. Inspite of knowing HIV status, women continue the pregnancy. It is revealed that 44 % of the respondents had 2 children followed by 24 % respondents having one child. The tendency is seen that as educational level is more, number of children born to women is less. With respect to residence, 52 % of the respondents were from Pune itself. They had fairly good idea about availability of resources at government and non-government organizations. As there were 52 % respondents from Pune, they visit once in a year at their native place,

a negligible percentage of them make monthly visit to native place. This indicates, practically no support during critical period of respondents. The nature of relation with family members, relatives indicates the bonding and control over the decision making in the family. Respondents have shared that they hardly could have such bonding with families at native place. About 78 % respondents had house as the only financial asset with them 23 % had bank balance, 15 % had land plot with them.

It is observed that, though legally they can claim their share in the property, in reality being HIV infected, they lose their status and position in the family and hardly can ask for share in the property. To fulfill the needs of the family, about 48 % of the respondents have indicated that there was no regular income to fulfill basic needs and special nutrition and health needs; naturally, their perception about adequacy of income is that it hardly fulfills their basic needs. They also reported that due to their health conditions, it is not possible to work at the optimum level. They needed support from NGOs. After the death of husband, about 70 % of the women have reported, that they did not intend to remarry. Women took care of themselves while living in the community and 92 % of them reported to have no experience of harassment. HIV diagnosis of the spouse is an important event, but as it evokes stigma, person prefers to keep is confidential; the moment it is being shared, the reaction of in-laws or parents is hatred or disownment. As a result, though may be there are major differences in the family, person with HIV, keeps it as a secret. This could be one of their coping mechanisms.

CHAPTER V

HEALTH STATUS AND PROBLEMS

5.1 Introduction

5.2 Problems and issues of women

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5.9 Major illness

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CHAPTER V

HEALTH STATUS AND PROBLEMS

5.1 Introduction:

Health means the overall condition of an organism at a given time. Health is defined as state of complete physical, mental, social and spiritual well-being and not merely an absence of disease and infirmity (WHO 1948). Health is reflective of an individual's ability to meet life's challenges and maintain his / her capacity for optimal functioning. This requires the various aspects of one's make up i.e. physical, mental, biochemical to maintain a level of functioning that has a positive influence and support for one another. When we eat correctly, develop healthy exercise and postural habits and combine these with maintaining a positive outlook, we offer ourselves the greatest opportunity to function at our best. If we neglect our diet, body requirements and view life with negative outlook, individual's health starts declining. The most important factor in assisting oneself to obtain optimal health is to treat them as a unique individual. While patient complains about health, it includes all possible childhood symptoms like illnesses, physical and emotional trauma, developmental delays, social experiences and family history. As we mature, the challenges at school, peer pressure, dietary habits, exercise, sexual relations, drug use and hormonal changes influence us. Quite often the decline in physical well-being and the accompanying discomfort and pain is parallel by life changes and personal choices. Health is a resource for everyday life, not an object of living. It is a positive concept emphasizing social and personal resources as well as physical capabilities. 'Otawa Charter' 2010 emphasizes few prerequisites for health which include peace, adequate economic resources, food and shelter and a stable economic system, sustainable resource use. This acknowledges inextricable links between social and economic conditions, the physical environment, individual lifestyles and health. Today health is regarded as a fundamental right.

Health is significant component in the present study. Health depends on physical, social, mental and spiritual well being. Individual should have desirable weight and height; he should have proper appetite, sleep-rest, and exercise to maintain health. He should have mental health meaning; he should be able to do day to day functions, should get along with people, should be able to manage stress, should concentrate and

should live satisfied life. He should cherish values and should experience mental peace. When individual interacts with the environment, there is imbalance and as a result, few individuals get diseases through entry of germs into body. Health depends on the kind of food intake, water intake, housing, standard of living health awareness and hygienic habits. Everywhere efforts are made to maintain health, to make health as fundamental right, or to achieve health for all by 2015. In the present chapter women's health and problems are discussed. Women's health problems occur due to the secondary social status they get (study in 2012) one of the significant issues of women's health presently is HIV / AIDS. In this, women's weights, CD4 count, age at marriage, age at first delivery were crucial factors. Total number of pregnancies and children indicate their control over the number of children born to them. Similarly use of contraceptives indicate, control over reproductive rights. Other information on health was sought about morbidity observed, prolonged illness and any opportunistic infection. Their age at diagnosis of HIV indicates the vulnerability to receive infection for no fault of them.

India has more than 50% of its population below the age of 25 and more than 65% hovers below the age of 35. Population – 2011, shows decline in population growth rate, an improvement in the ratio of men to women, remarkable increase in literacy, among women

Literacy –

Men - 76 %

Women - 54 % census of India.

There are 532.1 million males and 496.5 million females in India.(World Bank report)

Sex ratio – 927/1000

5.2 Problems and Issues of Women :

Sexual harassment, abuse, gender inequality, prenatal diagnostic test, dowry deaths and domestic violence are some of the problems that women face. India is one of the few countries in the world where women and men have nearly the same life expectancy at birth. The fact that the typical female advantage in life expectancy is not seen in India suggests there are systemic problems with women's health. Indian women have high mortality rates, particularly during childhood and in their reproductive years. The health of Indian women is intrinsically linked to their status in

society. Research on women's status has shown that the contribution Indian women make to families often are overlooked and instead they are viewed as economic burdens. There is a strong son preference in India, this result in ill-treatment of daughters. Indian women have low levels of education and formal participation. They have very little autonomy and have to live under the control of father, husbands and sons. All these factors exert a negative impact on the health status of Indian women. Poor health results into low birth weight infants. They also are likely to be able to provide food and adequate care for the children. While women in India face many serious health concerns, there are five key issues : reproductive health, violence against women, nutritional status, unequal treatment of boys and girls and HIV/AIDS (Dec. 1998).

Our immune system contains different types of cells that help protect the body from infection. One of these types of specialized cells called CD4 or T-cells. HIV attacks these types of cells and uses them to make more copies of itself, in doing so; HIV weakens the immune system, making it unable to protect the body from illness and infection. When CD4 drops below 250 CD4 cells, you are classified as having AIDS; your body immune system is no longer strong enough to prevent illness and infections.

5.3 Present health status of respondent

Women neglect their health, since birth they experience discrimination in the treatment at family and at society, especially in the nutrition, health, education and access to resources. At the age of 18 years, they are expected to get married and have a child within a year after marriage. This leads to a vicious circle of low level of health, low health awareness, low health seeking behavior. She is pressurized by the multiple roles and hardly her health remains as a priority. Family members also don't pay attention to her small health complaints. It is only, when she has tremendous difficulties attending her work and household responsibilities, she is attended by family. In the absence of doctors and especially gynecologist, many gynecological complaints of women remain unattended. Similarly it is seen in sexually transmitted disease and in HIV infection. Women are not informed by their spouses about their HIV status, it is only when spouses develop severe symptoms and are hospitalized, and women realize HIV status of their spouses. Eventually symptoms of spouse

become severe and they face death of spouses. In the whole process, they never realize that they also must have contracted HIV. Degraded health, low ‘self-concept’, and low awareness results in unprotected sex with spouse which in turn leads to transmission of HIV to themselves. As they get infected with HIV, their level of immunity gets lowered. Following table shows their present health condition

5.4 Health, Nutrition, Illness

95th Centile values of Weight (Kg), height (cm) and BMI by age and gender : Rural India (16 States) (WHO standards)

Table 5.1: Distribution of respondents according to weight

Age (Years)		Mean Weight (Kg) Indian Standards	SOFOSH	FPAI	AFMC	Deepgriha	Total
18-19	N		0	0	1	0	1
	Mean Wt (Kg)	44.1 (5.7 SD)	0	0	49	0	49
20-24	N		1	1	1	3	6
	Mean Wt (Kg)	44.5 (5.9 SD)	50	50	45	46 (7.9 SD)	47.2 (5.5 SD)
25-29	N		7	5	6	15	33
	Mean Wt (Kg)	44.8 (6.4 SD)	48.1 (3.8 SD)	45.6 (8.1 SD)	47.3 (5.2 SD)	43 (5.9 SD)	45.3 (6.0 SD)
30-34	N		16	22	14	16	68
	Mean Wt (Kg)	45.4 (7.0 SD)	47.1 (9.8 SD)	48.1 (8.6 SD)	43.6 (5.6 SD)	47.5 (8.4 SD)	46.8 (8.3 SD)
35-39	N		22	13	15	6	56
	Mean Wt (Kg)	45.9 (7.7 SD)	47.3 (7.5 SD)	47.1 (8.03)	46.5 (8.3 SD)	45.2 (5.9 SD)	46.8 (7.6 SD)
40-44	N		6	7	3	3	19
	Mean Wt (Kg)	46.2 (8.2 SD)	52.3 (9.1 SD)	53.1 (21.7 SD)	43.3 (5.8 SD)	49.0 (5.6 SD)	50.7 (14.1 SD)
45-49	N		2	2	0	2	6
	Mean Wt (Kg)	45.8 (8.5 SD)	45.0 (7.1 SD)	49.5 (9.2 SD)		41.0 (1.4 SD)	45.2 (6.5 SD)
50-54	N		1	0	0	0	1
	Mean Wt (Kg)	45.2 (8.6 SD)	45.0				45.0
55-59	N		1	0	0	0	1
	Mean Wt (Kg)	41.1 (8.4 SD)	45.0				45.0
							191

The above table shows the weight of the respondents as per the standards given by WHO. These may be due to the nutritional support that the respondents have received.

5.5 CD4 Concept, responsibilities of CD4

HIV-I Pathogenesis, an increased viral load correlates with CD4 lymphocyte depletion and disease process (1995). CD4 – Cluster of differentiation 4 is a glycoprotein expressed on the surface of T helper cells, monocytes, macrophages and dendritic cells. It was discovered in the late 1970s and was originally known as a leu-3 and T4 before being named CD4 in 1984. In humans, the CD4 protein is encoded by the CD4 gene. CD4 is a member of the immunoglobulin super family. HIV-I uses CD4 to gain entry into host T-cells and achieves this by binding of the viral envelope protein known as gp120 to CD4. HIV infection leads to a progressive reduction in the number of T cells expressing CD4. Medical professionals refer to the CD4 to decide when to begin treatment during HIV infection. Normal blood values are 500 – 1200x $10^{6/L}$ CD4 count test measures the number of T cells expressing CD4. Results are usually expressed in the number of cells per microliter (or cubic millimeter mm) of blood. It assesses the immune system of the patients. Less than 250 cells per microliter in an HIV positive individual are diagnosed as AIDS. As per new guidelines of NACO, below 350 CD4, Anti-retroviral therapy is started. (en.wikipedia.org/wikiCD4)

Table 5.2: Status of CD4 among respondents

NGO Groups	CD4						Total
	Upto 250	More than 250 to 500	More than 500 to 750	More than 750 to 1000	More than 1000	Not tested	
SOFOSH	2 3.6 %	21 37.5 %	21 37.5 %	7 12.5 %	1 1.8 %	4 7.1 %	56 100 %
FPAI	2 4.0 %	24 48.0 %	12 24.0 %	7 14.0 %	1 2.0 %	4 8.0 %	50 100 %
AFMC	14 35.0 %	11 27.5 %	5 12.5 %	2 5.0 %	0 .0 %	8 20.0 %	40 100 %
Deepgriha	8 17.8 %	9 20.0 %	10 22.2 %	3 6.7 %	1 2.2 %	14 31.1 %	45 100 %
Total	26 13.6 %	65 34.0 %	48 25.1 %	19 9.9 %	3 1.6 %	30 15.7 %	191 100 %

The above table shows the CD4 count of the respondents. As the respondents were diagnosed, HIV depending on their basic health status, they lose weight and CD4 very fast. About 38% at SOFOSH respondents reported to have CD4 in the range 250 to 500 per cc. Thirty eight percent respondents reported it having more than 500 to 750 and a very negligible proportion of respondents have reported to have CD4 more than 750. At FPAI about 48% respondents reported CD4 ranging from 250 to 500. Twenty four percent respondents reported their CD4 more than 500 and only 14% had their CD4 more than 750. At AFMC, 35% respondents reported their CD4 below 250, which is alarming for the care of respondents, 28% have reported it be in the range 250 to 750, about 20%.

5.6 Weight v/s CD4 Count

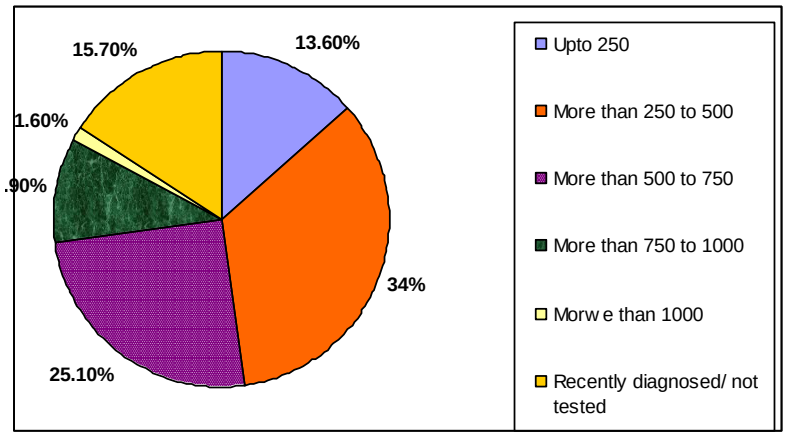
As stated earlier, after contracting HIV depending on the health status of the patient, his/her weight and CD4 goes down. Patient's immunity also get reduced. Table 5.3 indicates about 34% of the respondents had their CD4 between 250 to 500.However there were 14% of the respondents who had their CD4 below 250.

Table 5.3

Weight v/s CD4 Count

Weight	CD4 Count						Total
	Upto 250	More than 250 to 500	More than 500 to 750	More than 750 to 1000	More than 1000	Don't Know	
35 to 45	12 14.6 %	29 35.4 %	22 26.8 %	2 2.4 %	2 2.4 %	15 18.3 %	82 100 %
45 to 55	13 16.9 %	25 32.5 %	18 23.4 %	10 13.0 %	1 1.3 %	10 13.0 %	77 100 %
55 and more	1 3.2 %	11 35.5 %	8 25.8 %	7 22.6 %	0 .0 %	4 12.9 %	31 100 %
Don't know	0 .0 %	0 .0 %	0 .0 %	0 .0 %	0 .0 %	1 100.0 %	1 100%
Total	26 13.6 %	65 34.0 %	48 25.1 %	19 9.9 %	3 1.6 %	30 15.7 %	191 100 %

Graph 5.1: Distribution of all the respondents according to CD4 count



There is a relationship between weight and CD4 count. They are health indicators. If we observe category 700 to 1000 CD4 count the proportion of women having this high CD4 increases as their weight increases.

5.7 History of delivery

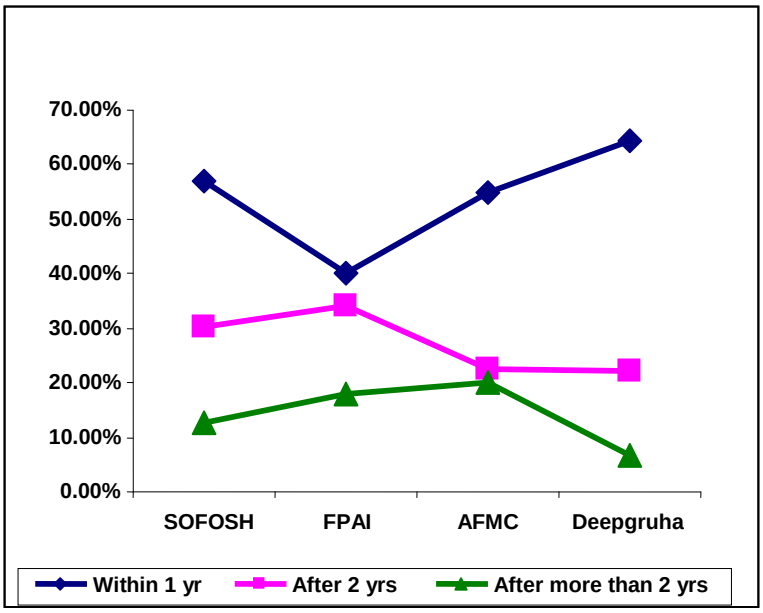
As stated earlier, woman's prime role is of a wife and a mother both at rural as well as urban areas. She is expected to conceive within a year after marriage, irrespective of her age. She has to be ready physically, mentally, emotionally for pregnancy, and is hardly given choice about use of contraception and the number of children she would have. It is within a year, that the woman conceives and gives birth to an undernourished and unhealthy child. To avoid any complications during pregnancy and childbirth, woman is expected to attend antenatal and post natal clinic services. In this period one of the essential tests is HIV test.

Table 5.4

Distribution of respondents showing first pregnancy after marriage and delivery

NGO Groups	First pregnancy after marriage				Total
	Within 1 yr	After 2 yrs	After more than 2 yrs	Not Applicable	
SOFOSH	32 57.1 %	17 30.4 %	7 12.5 %	0 .0 %	56 100 %
FPAI	20 40.0 %	17 34.0 %	9 18.0 %	4 8.0 %	50 100 %
AFMC	22 55.0 %	9 22.5 %	8 20.0 %	1 2.5 %	40 100 %
Deepgriha	29 64.4 %	10 22.2 %	3 6.7 %	6 6.7 %	45 100 %
Total	103 53.9 %	53 27.7 %	27 14.1 %	8 4.2 %	191 100 %

Graph 5.2: Distribution of the respondents showing duration for first pregnancy after marriage



The above table shows distribution of respondent's first pregnancy after marriage. At SOFOSH, 57% respondents reported that they had pregnancy within first year after marriage 30% respondents reported to have it within 2 years and 13% reported to have first pregnancy after 2 years. At FPAI within a year 40% respondents reported first pregnancy and 23% reported to have it after two years and 20% after two to three years. At AFMC 55% respondents reported to have 1st pregnancy within a year, 23% after 2 years and after more than two years 20%respondents reported to have first pregnancy. At Deepgriha 64% respondents reported to have it within a year and 22% within 2 years after marriage. Overall tendency is observed that respondents had their first pregnancy (54%) within a year after marriage.

Age at the time of first delivery : Fabric of the society is determined by the family and marriage as social institutions. In India, during pre independence era, marriages were decided by patriarchal heads of the family. The young boys and girls hardly had any choice of mate. Early marriage was the characteristic of traditional joint families. These were intended to have better adjustment of girls, with the in-laws' families and child bearing at an early age. Eventually, later on due to impact of social reform, many structural and functional changes were introduced. One of the factors in this change was social legislations. There was child marriage restraint act, which prohibited child marriages. Though, legal age for marriage is 18 years, people do practice early marriages, they consider marriage as the ultimate aim of girl's life. As per family's expectation, within a year or two, the woman should conceive. Early marriage leads to early pregnancy.

Table 5.5

Distribution of respondents showing age at the time of first delivery

NGO Groups	Age at the time of first delivery				Total
	14 to 17	18 to 20	21 and more	Not Applicable	
SOFOSH	11 19.6 %	37 66.1 %	8 14.3 %	0 .0 %	56 100 %
FPAI	5 10.0 %	26 52.0 %	15 30.0 %	4 8.0 %	50 100 %
AFMC	11 27.5 %	9 47.5 %	8 20.0 %	2 5.0 %	40 100 %
Deepgriha	7 15.6 %	28 62.2 %	7 15.6 %	3 6.7 %	45 100 %
Total	34 17.8 %	110 57.6 %	38 19.9 %	9 4.7 %	191 100 %

Above table shows about 58% respondents have reported to be aged between 18 to 20 years at the time of 1st delivery. Twenty percent respondents reported to have their age 21 and more than 21 years at the time of first delivery. About 18% respondents have reported their age between 14 to 17 years at the time of first delivery, which is certainly not a very desirable situation for woman and child's health. Though legal age of marriage is 18 years, still people follow earlier practices. Education seems to have no effect on age of pregnancy.

5.8 Total number of pregnancies

Child bearing is the prime role, women are expected to perform. In pre independence era women used to give birth to number of children as there was high mortality among mothers and infants. Gradually effective antenatal, post natal care services were introduced. With the help of programmes like National Safe Motherhood Programme, Maternal and Child Health and Reproductive and Child Health Programs, a decline is seen in maternal and infant mortality. Now on an average number of children each couple has is about 2.3(Park & Park, 1997). In the reproductive years number of pregnancies decides health of mother and child.

Table 5.6

Distribution of respondents showing total number of pregnancies

NGO Groups	Total number of pregnancies				Total
	1 – 2	3 – 4	More than 4	Not Applicable	
SOFOSH	23 41.1 %	26 46.4 %	7 12.5 %	0 .0 %	56 100 %
FPAI	37 74.0 %	9 18.0 %	0 .0 %	4 8.0 %	50 100 %
AFMC	24 60.0 %	10 25.0 %	4 10.0 %	3 6.7 %	40 100 %
Deepgriha	21 46.7 %	17 37.8 %	4 8.9 %	3 6.7 %	45 100 %
Total	105 55.0 %	62 32.5 %	15 7.9 %	9 4.7 %	191 100 %

Legal age of marriage for girls is 18 years. However they get married early and have pregnancy also at a very younger age. Early marriages lead to early infection and there are chances of longer life of living with HIV, mostly without support. Women are expected to give birth to children for individual and family reasons. If woman gets infected and gives birth to the children, she has a life with infection, without any support and with stigma.

Above table shows, at SOFOSH, 46% of the respondents have reported to have 3 to 4 pregnancies, while 41% have reported 1 to 2 pregnancies, about 13% have reported to have more than 4 pregnancies. At FPAI, 74% respondents reported to have 1 to 2 pregnancies, 18% had 3 to 4 pregnancies. At AFMC respondents reported to have 1 to 2 pregnancies and 25% had 3 to 4 pregnancies. At Deepgriha 47% respondents have reported to have 1 to 2 pregnancies, about 9% of them have more than 3 to 4 pregnancies. Overall observation is that 55% respondents have 1 to 2 pregnancies. Eighteen women were childless although it is shown 9 of them must have got pregnant but must not have full term delivery due to HIV.

5.9 Major illness in last year

Women have a tendency to neglect their health and nutrition as they keep their health as a last priority. They continue to work at home and at workplace as they can. Women are socialized in such a manner that they need to tolerate difficult circumstances. It is observed that since childhood, they are taught to ignore small health problems, accept discrimination in resources in terms of nutrition, health and education. They should never complain against any unjust behavior of family members. Woman's role in our society is glorified. Due to neglect, women suffer health problems. After being diagnosed as HIV, depending on their immunity level, CD4 count goes down and they suffer opportunistic infection like TB pneumonia, jaundice and Herpes zoster.

Table 5.7

Distribution of respondents according to major illness

NGO Groups	Major illness during last 1 year		Total
	Yes	No	
SOFOSH	22 39.3 %	34 60.7 %	56 100 %
FPAI	10 20.0 %	40 80.0 %	50 100 %
AFMC	9 22.5 %	31 77.5 %	40 100 %
Deepgriha	11 24.4 %	34 75.6 %	45 100 %
Total	52 27.2 %	139 72.8 %	191 100 %

Above table shows major illnesses the respondents suffered were TB, anemia, typhoid, chikun guniya, diarrhea, rash, fever, cough, headache, throat infection, herpes, kidney stone, operation, tumors. There is a tendency to have major illness due to HIV diagnosis or even otherwise also. On an average 73% of the respondents reported to had no major illness during last year. During the post test and adherence counseling health care was emphasized. Women were observed to take care of their health. Only 27% respondents had major illnesses like TB, Herpes, and anemia.

Table 5.8

CD4 count vs. major illness during last 1 year

CD4 count	major illness during last 1 year		Total
	Yes	No	
Upto 250	6 23.1 %	20 76.9 %	26 100 %
More than 250 to 500	22 33.8 %	43 66.2 %	65 100 %
More than 500 to 750	11 22.9 %	37 77.1 %	48 100 %
More than 750 to 1000	5 26.3 %	14 73.7 %	19 100 %
More than 1000	2 66.7 %	1 33.3 %	3 100 %
Don't know	6 20.0 %	24 80.0 %	30 100 %
Total	52 27.2 %	139 72.8 %	191 100 %
Chi Square value =	0.326		

About 73 % of the respondents had no major illness and they had better i.e. more than 350 CD4 count. About 54 % of the respondents reported their CD4 below 500. There is a relationship as CD4 increases there is less number of people reporting morbidity.

Table 5.9

Age at marriage V/s major illness during last 1 year

Age at marriage	Major illness during last 1 year		Total
	Yes	No	
11 to 14 years	5 21.7 %	18 78.3 %	23 100 %
15 to 17 years	25 31.6 %	54 68.4 %	79 100 %
18 to 21 years	19 24.1 %	60 75.9 %	79 100
More than 21 years	3 30.0 %	7 70.0 %	10 100 %
Total	52 27.2 %	139 72.8 %	191 100 %
P value =	0.666		

An association between age of marriage, first pregnancy and major illness was computed, and the chi-square value was also tested. However, there was no significant relationship between these 3 variables.

5.10 Pregnancy and major illness:

Table 5.10

First pregnancy after marriage vs. is there major illness during last 1 year

First pregnancy after marriage	major illness during last 1 year		Total
	Yes	No	
Within 1 year	30 29.1 %	73 70.9 %	103 100 %
After 2 years	13 24.5 %	40 75.5 %	53 100 %
After more than 2 yrs	8 29.6 %	19 70.4 %	27 100 %
Not applicable	1 12.5 %	7 87.5 %	8 100 %
Total	52 27.2 %	139 72.8 %	191 100 %
P value =	0.72		

More than 70 % of the respondents reported to have first pregnancy within a year after marriage and had no morbidity during last year. There was no relationship found at the age at the time of first delivery and major illness.

5.11. Total number of pregnancies vs. major illness

Table 5.11

Total number of pregnancies vs. major illness during last 1 year

Total number of pregnancies	major illness during last 1 year		Total
	Yes	No	
1 – 2	25 23.8 %	80 76.2 %	105 100 %
3 – 4	19 30.6 %	43 69.4 %	62 100 %
More than 4	6 40.0 %	9 60.0 %	15 100 %
Not applicable	2 22.2 %	7 77.8 %	9 100 %
Total	52 27.2 %	139 72.8 %	191 100 %
P value =	0.506		

Overall it is observed that women have problems of reproductive system. Number of pregnancies and major illness has a relationship. The association was computed 76 % of respondents had 1 to 2 pregnancies and had no major illness. However there were 40 % of the respondents who had more than 4 pregnancies and had illness during last year. As the number of pregnancies increase the chances of major illness also increase.

5.12 Prolonged illness of respondents

Neglect of one's own health is very common among women. They do not have access to health care, especially in the absence of female medical practitioners and medical / health services and absence of affordable services in our country. As a result, small health problem sometimes turns into chronic illness. After contracting HIV, due to low level of immunity women suffer from chronic illness which leads to further deterioration of their health.

Table 5.12

Distribution of respondents showing prolonged illness

NGO Groups	Major illness		Total
	Yes	No	
SOFOSH	14 25.0 %	42 75.0 %	56 100 %
FPAI	8 16.0 %	42 84.0 %	50 100 %
AFMC	5 12.5 %	35 87.5 %	40 100 %
Deepgriha	5 11.1 %	40 88.9 %	45 100 %
Total	32 16.8 %	159 83.2 %	191 100 %

Prolonged illnesses mentioned were TB, tumor, addiction, ear infection, loss of mental balance. HIV/AIDS infection reduces the immunity. As a result chances of having opportunistic infections increases. In all the NGOs the respondents have answered negatively to this question, i.e. about 83% of the respondents did not have any prolonged illness in the last one year. This shows that care and treatment has helped the respondents to maintain their health. However, 17% had the incidence of prolonged illness.

Table 5.13 Presence of any one or more morbid conditions V/s prolonged illness during last 1 year

Are you suffering from any opportunistic infection	prolonged illness during last 1 year		Total
	Yes	No	
Yes	32 22.2 %	112 77.8 %	144 100 %
No	0 .0 %	47 100 %	47 100 %
Total	32 16.8 %	159 83.2 %	191 100 %

An attempt was made to understand association between opportunistic infection, morbid condition and prolonged illness. However, it was found that there was no association between the three among the respondents.

5.13 Health status of children

Mother to child is one of the modes of transmission of HIV. In several cases it is observed that, women are expected to conceive and give birth to children even after diagnosis of HIV. During the antenatal care, women are tested for HIV as a precautionary measure. If they are detected to be HIV positive, there are effective medicines to prevent mother to child transmission. However there are few mothers, who do not receive antenatal care and intervention. As a result, children are born with HIV infection. One of the concerns in the post test counseling is that the women are provided counseling and guidance about the choice to continue or terminate the pregnancy depending on the gestation period. The instinct of motherhood is so strong that women choose to continue pregnancy and experience the joy of motherhood. To understand extent of infection among children, this information was sought, and it is observed that about 73% of the respondents have responded that their children did not have HIV, due to availability of effective medicines for preventing mother to child HIV transmission. There were 17.3% respondents whose children were diagnosed as HIV.

Table 5.14 : Distribution of respondents showing health status of children

NGO Groups	Health status of children			Total
	Yes	No	Not Applicable	
SOFOSH	40 71.4 %	15 26.8 %	1 1.8 %	56 100 %
FPAI	42 84.0 %	2 4.0 %	6 12.0 %	50 100 %
AFMC	25 62.5 %	8 20.0 %	7 17.5 %	40 100 %
Deepgriha	33 73.3 %	8 17.8 %	4 8.9 %	45 100 %
Total	140 73.3 %	33 17.3 %	18 9.4 %	191 100 %

Maternal and child health is a very important aspect of health. India had high infant and maternal mortality in the pre independence era. Presently also, although government is making an effort by way of providing ante-natal and post-natal care services, still, many women have complications during pregnancy and at the time of delivery. So the number pregnancies do not necessarily indicate number of deliveries. In the present study, reference is made about being an HIV patient, either the woman is advised to terminate the pregnancy or woman gives birth to the child with HIV infection and that child dies eventually.

Numbers of pregnancies are more than number of children. It is not necessary if a woman gets pregnant she has those many numbers of children. There were 18 women who were childless.

5.14 Spacing between children

It is essential for women to decide when they should become a mother and to decide the spacing between two children. This would result in better care of mother and child to provide sufficient health care, nutrition and attention. Sufficient spacing between two children promotes better child care and health of the mother. This requires adequate knowledge and acceptance of family planning methods. Women prefer to have two or three children without using any contraceptives and undergo permanent contraception in the form of tubectomy.

Table 5.15

Distribution of respondents showing spacing between two child (yrs)

NGO Groups	Average spacing between two children (yrs)						Total
	<= 1 year	2-3 years	4-5 years	More than 5 years	No Response	Not Applicable	
SOFOSH	7 12.5 %	27 48.2 %	4 7.1 %	2 3.6 %	4 7.1 %	12 21.4 %	56 100 %
FPAI	10 20.0 %	11 22.0 %	2 4.0 %	0 .0 %	4 8.0 %	23 46.0 %	50 100 %
AFMC	3 7.5 %	19 47.5 %	3 7.5 %	0 .0 %	1 2.5 %	14 35.0 %	40 100 %
Deepgriha	2 4.4 %	23 51.1 %	4 8.9 %	2 4.4 %	0 .0 %	14 31.1 %	45 100 %
Total	22 11.5 %	80 41.9 %	13 6.8 %	4 2.1 %	9 4.7 %	63 33.0 %	191 100 %

Spacing is related to the number of pregnancies with number of children those who have any one pregnancy not mentioned anything about spacing. In the above table it is seen, at SOFOSH, 48%, respondents reported to have 2 to 3 years spacing and 16% reported to have one year gap and negligible percent of respondents reported 4-5 years and 5 years gap between 2 children. At FPAI 22% respondents reported this question was not applicable that means they have one child or no child. Overall tendency is observed that 42% respondents had 2 to 3 years gap between 2 children, 33 % respondents have responded no applicability of this question.

5.14.1 Use of contraceptive

1. Contraceptive has been a single most important intervention to reduce burden of unwanted pregnancy and promote healthy living among young women. In India, early onset of sexual activity and desperate demand on young adult to have child is a very common phenomenon. In such a socio-cultural politico setting, individual access to or promotion of contraception among young adults is very limited. In a study it is stated (Usha Ram 2006) since last 2 decades use of modern spacing methods, predominantly condom use has doubled and there

seems to be stagnation in the use of sterilization at an early stage of life. There is an increase in the demand for family planning contraception aims to prevent sexual intercourse from causing pregnancy and also from protecting the body from STI. NFHS (1992-93) survey showed that knowledge of contraceptive is almost universal among Indian women, but only 41% are actually using contraceptive.

2. Family Planning in India is based on efforts largely sponsored by Government. In the 1965-2009, the contraceptive usage has more than tripled (from 5.7 in 1966 to 2.6 in 2009), but the national fertility rate is still high enough to cause long term population growth. India adds up to 10 lakh people to its population every 15 days. (Wikipedia)
3. Couple's decision regarding use of contraceptive methods is influenced by lots of factors, one of which is influence of behavior of other household members (Madhumita Das 1998).

Table 5.16

Distribution of respondents showing contraceptives use

NGO Groups	Contraceptives used				Total
	No contraceptives used	Condom	Pills	Cu T	
SOFOSH	44 78.6 %	6 10.7 %	4 7.1 %	2 3.6 %	56 100 %
FPAI	41 82.0 %	7 14.0 %	0 .0 %	2 4.0 %	50 100 %
AFMC	29 72.5 %	11 27.5 %	0 .0 %	0 .0 %	40 100 %
Deepgriha	29 64.4 %	8 17.8 %	2 4.4 %	6 13.3 %	45 100 %
Total	143 74.9 %	32 16.8 %	6 3.1 %	10 5.2 %	191 100 %

Table 4.11 shows at SOFOSH 79% of the respondents did not use any contraceptive, at FPAI 82% did not use any contraceptive, at AFMC also 73% did not use an contraceptive but 28% used condom, at Deepgriha, 60% respondents did not use

contraceptive, only 18% used condom. Overall tendency is observed that 75% respondents did not use any contraceptive. Use of contraceptive depends on education and awareness about it. Those who were educated upto 12 std. 56 % respondents have used condoms and 80 % have used Cu T. Tendency is observed to have 1 or 2 children and then undergo sterilization.

5.15 Referral for HIV testing

There are (ICTCS) integrated counseling and testing centres for HIV testing at every district. Generally as per the modes of transmission, those who are at risk are having multiple sexual partners who practice unsafe sex, injectable drug users, recipient of blood transfusion and children born to HIV infected mothers are referred at ICTCs. Patients observe opportunistic infection and meet their doctors, after knowing the history of illness; doctors refer the patient for HIV testing. Doctors and other health care workers are now trained to diagnose HIV, as the opportunistic infections are observed, in the patient for early diagnosis and treatment; doctors refer the patients to Integrated Counseling and Testing Centers (ICTC's).

Table 5.17

Distribution of respondents who referred for testing HIV

NGO Groups	Referral for testing HIV			Total
	Doctor	Health Worker	Others	
SOFOSH	48 85.7 %	2 3.6 %	6 10.7 %	56 100 %
FPAI	46 92.0 %	3 6.0 %	1 2.0 %	50 100 %
AFMC	32 80.0 %	4 10.0 %	4 10.0 %	40 100 %
Deepgriha	29 64.4 %	7 15.6 %	9 20.0 %	45 100 %
Total	155 81.2 %	16 8.4 %	20 10.5 %	191 100 %

The nature of HIV and the modes of transmission of HIV are such, that though people have involved into high risk behavior, basically people deny, that they could be

diagnosed as HIV. It is only when there are repeated opportunistic infections which require hospitalization, people go for testing. In the absence of expertise on the part of the health worker, very negligible i.e. 8.4 and 11 % of the respondents were referred for HIV testing. Above table shows maximum number of respondents i.e. 81% were referred by doctors for HIV testing. Very negligible numbers of respondents were referred by health worker for HIV testing.

5.16 Stage of HIV detection

Women receive HIV in about 85% cases by their marital partners. At the time of marriage, no one informs the spouse about any of their health problems. Women do not suspect any risk behavior or problem in their partner and trust them. In the subsequent years spouse develops opportunistic infection and either doctors or health care professionals counsel them to do HIV test during post test counseling or when women get pregnant and attend antenatal clinic, they discover their HIV status. Women who were diagnosed within last 3 to 5 years were included in the study.

Referral for testing

Doctors and health care professionals suspect symptoms of opportunistic infections; especially every TB patient is referred for HIV test. Doctors provide complete professional secrecy; those who give history of risk behavior are referred to testing centre, with a referral note. HIV tests are done at every district hospitals, counseling services are offered to patients these centres are called Integrated Counseling and testing centres. The details in this regard are as follows:

Table 5.18

Distribution of respondents showing when referred for HIV test

NGO Groups	Referral for HIV test					Total
	During pregnancy	When husband died / diagnosed for HIV	Husband was seriously sick	Frequent / serious health complaints	Tested by NGO / camp	
SOFOSH	17 30.4 %	4 7.1 %	1 1.8 %	34 60.7 %	0 .0 %	56 100 %
FPAI	7 14.0 %	5 10.0 %	1 2.0 %	35 70.0 %	2 4.0 %	50 100 %
AFMC	12 30.0 %	5 12.5 %	4 10.0 %	19 47.5 %	0 .0 %	40 100 %
Deepgriha	11 24.4 %	12 26.7 %	1 2.2 %	20 44.4 %	1 2.2 %	45 100 %
Total	47 24.6 %	26 13.6 %	7 3.7 %	108 56.5 %	3 1.6 %	191 100 %

Above table indicates the time of referral. At SOFOSH 61% respondents reported that while serious, frequent health complaints were seen, they were referred for HIV testing, 30% were referred during pregnancy. At AFMC, 48% reported, when health complaints were observed, at FPAI also 70% respondents reported the same, 30% at ANC period, at Deepgriha 44% were referred with serious health complaints were seen, 27% were referred after the husband's death and 25% of respondents were referred during pregnancy. Overall tendency is observed that 57% of the respondents were referred for HIV test after frequent health problems were faced by respondents.

When referred for HIV test		
	Frequency	**Percent**
In first pregnancy	22	46.8
In second pregnancy	17	36.2
In third pregnancy	6	12.8
During 4^{th} pregnancy	1	2.1
During fifth pregnancy	1	2.1
Total	**47**	**100**

During Ante-natal care women are expected to examine HIV testing and 47 % respondents were referred for testing in first pregnancy. Hence, the message of early detection is gradually reaching.

5.17 Place of diagnosis

A person with a risk behavior suspects, few symptoms and experiences fear, guilt about contracting HIV, but he finds a safe place to share his feelings with a doctor or counselor at counseling centre. Some people prefer to go at other town, district places for reasons of stigma and confidentiality, but now due to awareness, people know, there are ICTCS at Government hospitals and they go to those hospitals, those who afford private practitioners' fees, test their blood at private clinics, but to confirm the diagnosis they come to ICTCS.

Table 5.19

Distribution of respondents showing place of diagnosis

NGO Groups	Place of diagnosis				Total
	ICTC	Hospital	NGO / Camp	NARI	
SOFOSH	13 23.2 %	38 67.9 %	3 5.4 %	2 3.6 %	56 100 %
FPAI	3 6.0 %	45 90.0 %	2 4.0 %	0 .0 %	50 100 %
AFMC	3 7.5 %	37 92.5 %	0 .0 %	0 .0 %	40 100 %
Deepgriha	13 28.9 %	29 64.4 %	2 4.4 %	1 2.2 %	45 100 %
Total	32 16.8 %	149 78.0 %	7 3.7 %	3 1.6 %	191 100 %

The above table shows place of diagnosis. At SOFOSH, 68% respondents reported to have test done at Hospitals, while 23% respondents reported to have test done at Intergraded Counseling and Testing Centre (ICTC). At FPAI 93% respondents were tested at Hospital and negligible proportion of respondents reported to have test done at ICTC. At AFMC also 93% respondents were tested in hospital and at Deepgriha 65% of the respondents reported that they have done HIV test at Hospitals, and 29%

at ICTC. Overall it is seen 78% of the respondents have done their HIV test at hospital.

5.18 Pretest counseling of respondent

HIV is a stigmatized disease. It has yet no sure cure. It is linked with high risk behavior. People experience 'Stigma', after the diagnosis of HIV individual reacts with shock, guilt, depression, suicidal thoughts and so, prior to HIV blood test and after the blood test, counseling by trained counselor is mandatory. Blood test reports are shared, positive or negative only with the person who is being tested. At all government centres, pretest and post test counseling services are provided.

Adherence counseling is a counseling to follow the treatment. It is provided, when patient's CD4 count goes down below 350, (As per new NACO guidelines) patient is provided with Anti-retroviral treatment (ART) free of cost at government hospitals. In ART or adherence counseling patients are counseled for continuation of treatment, nutrition, guidance, reduction of risk behavior recognizing symptoms of opportunistic infection and appropriately taking treatment, and living with HIV.

Table 5.20

Distribution of respondents received pre test counseling

NGO Groups	pre test counseling		Total
	Not received	Received	
SOFOSH	24 42.9 %	32 57.1 %	56 100 %
FPAI	11 22.0 %	39 78.0 %	50 100 %
AFMC	36 90.0 %	4 10.0 %	40 100 %
Deepgriha	23 51.1 %	22 48.9 %	45 100 %
Total	94 49.2 %	97 50.8 %	191 100 %

The above table shows at SOFOSH 43% of the respondents have not received pretest counseling, 57% respondents have received pre test counseling. At FPAI 78%

respondents have received pretest counseling 22% did not receive counseling at AFMC 90% respondents did not receive counseling. At Deepgriha about 50% response is seen for both category of question. Overall observation is 50% of the respondents have received the counseling however there were 50% respondents who have not received the pretest counseling. This is the area where one has to work further.

Table 5.21

Distribution of respondents receiving post test counseling

NGO Groups	Post-test counseling		Total
	No	Post-test	
SOFOSH	23 41.1 %	33 58.9 %	56 100 %
FPAI	8 16.0 %	42 84.0 %	50 100 %
AFMC	6 15.0 %	34 85.0 %	40 100 %
Deepgriha	20 44.4 %	25 55.6 %	45 100 %
Total	27 29.8 %	134 70.2 %	191 100 %
Chi Square value =	0.001		

The above table shows 59% respondents at SOFOSH have received post test counseling while 41% have not received. At FPAI 84% of respondents have received post test counseling and 16% have not received it. At AFMC 85% respondents have reported to have received post test counseling. At Deepgriha 56% respondents have received post test counseling and 44% have not received it. Overall, it is observed that 70% respondents have received post test counseling but 30% still have responded negatively to this question.

5.19 Adherence to HIV treatment (Ow Fong) : Drug adherence is a key part of highly active antiretroviral therapy (HAART). It refers to the whole process from choosing, starting, managing to maintaining a given therapeutic medication regimen

to control HIV viral replication and improve function of the immune system. Non-adherence is the discontinuity or cessation of part or all of the treatment such as dose missing, under dosing, or over dosing, and drug holidays. The significance of adherence to treatment has become recognized, which is important in optimizing the patient's response to therapy. In contrast, non-adherence can lead to treatment failure, a rise in plasma viral load, and the development of drug-resistant HIV strains.

5.20 Drug adherence counseling programme development: (M. Morin 2003)

Today, treatment adherence has become an important medical, financial, psychosocial and health policy issue. World Health Organisation (WHO) recommends a period of education and preparation aimed at maximizing adherence before commencing HAART. The development of a practical process of programme that optimizes patient goals, improves medication, adherence to HAART and supports patient education through the different stages of drug adherence, counseling is essential.

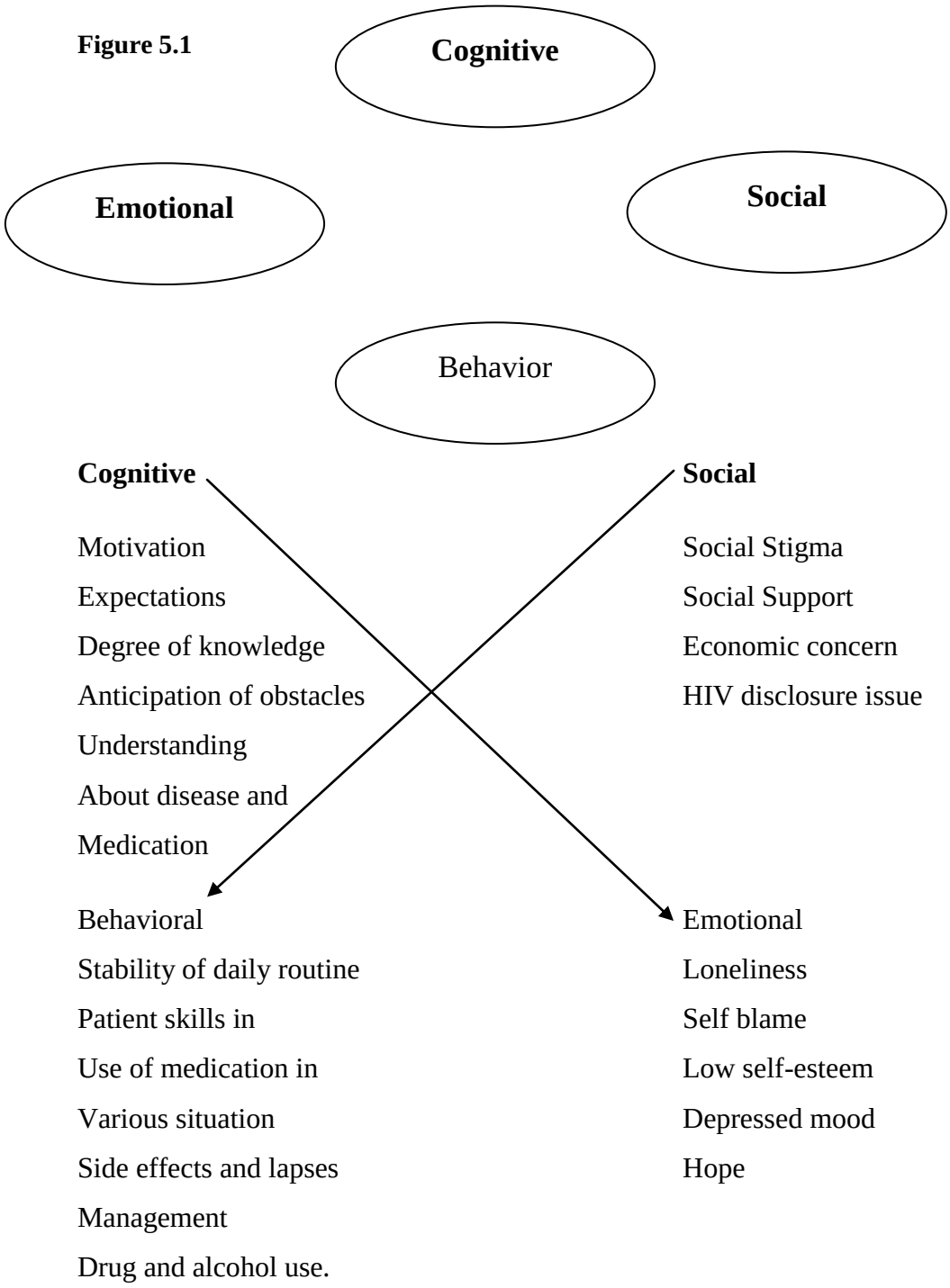
A systematic approach is essential in promoting drug adherence in HIV patients. The aim of a drug adherence counseling programme is to enhance adherence to HAART for maximizing treatment outcome. This would achieve the target of improving individual health clinically and lowering HIV infectivity on a public health level. Drug adherence counseling is preferentially integrated in other targeted risk reduction measures, which serve the purposes of sustaining the maintenance of a low HIV risk in the community.

The main objectives of drug adherence counseling are, to:

(a) Support patients in making informed choice on HIV treatment according to individual needs
(b) Assist patient in adopting drug adherence behavior
(c) Enhance patient's ability in managing and maintaining the treatment.

Therapeutic adherence defines the capacities of an individual to take his / her medication as prescribed. There are 4 components of adherence.

Figure 5.1



A patient focused intervention

- It empowers patient to continue their personal growth and to develop self-care management strategies.

- Considers motivation as a dynamic and fluctuating state, motivation is interactive and can be modified.
- Helps HIV patient to develop adaptive and effective ways of coping with HIV.
- Helps patient to anticipate critical incidents and train them to build skills to manage obstacles.

Poor adherence to HIV treatment can lead to drug resistance and inadequate treatment.

Adherence Counseling involves behavior change. It involves the patient in the treatment process. Counselors are expected to emphasize on following aspects in adherence counseling.

Medication : a) explain the timings remind the strategies, storage of pills, not to stop the medicines till doctor advices, b) side effects, c) continuation of medicines , d) explain about importance of nutrition, e) safer sex practices, f) partner notification, g) self care and follow up.

Table 5.22

Distribution of respondents showing adherence counseling

NGO Groups	adherence counseling		Total
	No	Adherence	
SOFOSH	38 67.9 %	18 32.1 %	56 100 %
FPAI	39 78.0 %	11 22.0 %	50 100 %
AFMC	37 92.5 %	3 7.5 %	40 100 %
Deepgriha	35 77.8 %	10 22.2 %	45 100 %
Total	149 78.0 %	42 22.0 %	191 100 %

This table shows about 78 % of the respondents have not received adherence counseling. This contains guidance about health, nutrition, ART, its side effects, use of condom and limiting the number of children after being diagnosed HIV. There is still so much scope and need for adherence counseling in future.

Table 5.23

Distribution of respondents showing duration of diagnosis of HIV

NGO Groups	Duration of diagnosis of HIV						Total
	Less than 1 year	1 yr to <3 yrs	3yrs to <5 yrs	5 yrs to < 10 yrs	10 yrs and above	Could not specify clearly	
SOFOSH	1 1.8 %	1 1.8 %	12 21.4 %	23 41.1 %	3 5.4 %	16 28.6 %	56 100 %
FPAI	2 4.0 %	3 6.0 %	11 22.0 %	23 46.0 %	7 14.0 %	4 8.0 %	50 100 %
AFMC	2 5.0 %	11 27.5 %	5 12.5 %	16 40.0 %	5 12.5 %	1 2.5 %	40 100 %
Deepgriha	4 8.9 %	7 15.6 %	18 40.0 %	9 20.0 %	4 8.9 %	3 6.7 %	45 100 %
Total	9 4.7 %	22 11.5 %	46 24.1 %	71 37.2 %	19 9.9 %	24 12.6 %	191 100 %

5.21 Duration of diagnosis: Those who were diagnosed within last 3 to more than 5 years and willing to participate in the study, were selected. It is also observed that there is denial on the part of respondents; hence, though they know their diagnosis they are not exactly aware of the duration of infection. Association between duration of diagnosis of HIV and CD4 count was computed, but no significant association was found. Table shows, respondent's duration of diagnosis, 37% of the respondents reported to have the duration of diagnosis more than 5 years, 24% reported to have between 3 to 5 years. About 13% reported that they cannot specify when they were diagnosed. Overall it is observed, 37% respondents knew their diagnosis between 5 to less than 10 years.

5.22 Age of respondent at the time of detection

Significance of age has been already discussed. Age of woman at the time of detection, explains how long woman has to live with HIV, care for herself, care for children in addition to infected child. Mostly as said earlier, women get married at an early age, they bear the child also at a very young age and in the absence of any barrier during 'sex', receives infection of HIV. So women were found to have detected HIV at a very young age i.e. 20 and above.

Case study 5.1 : Vulnerability

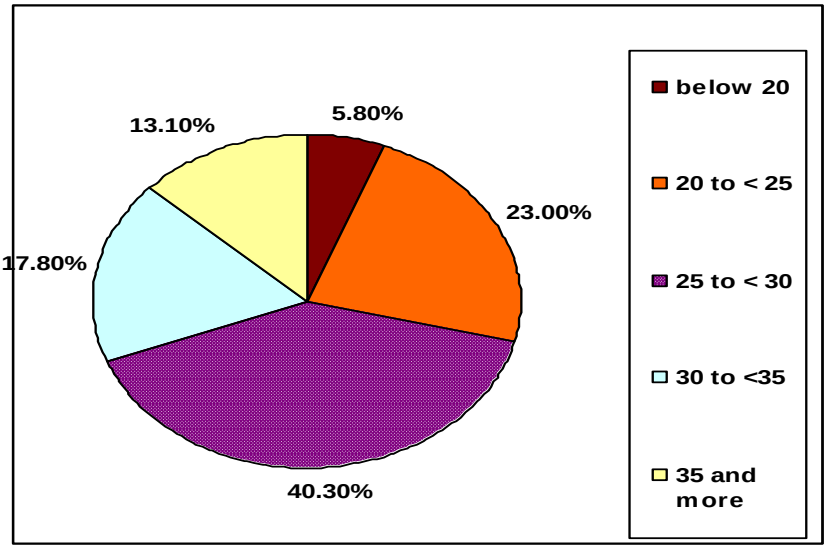
Pallavi a 23 year old 9th std. pass married having 55 Kg weight had a normal CD4 count. Married at the age of 15, had 3 pregnancies but 1 child died, her husband is HIV positive; he does not do any work and does not take any family responsibility. She does not have any share in the property and except for mother in law and brother in law, does not have support. She experiences sexual harassment from husband. Her father in law also died of HIV. Her mother in law discriminates her, does not provide her food, Pallavi's husband has never practiced safer sex. He always is suspicious about Pallavi's relation outside home. He beats her also. He does not allow her to work, nor does he work himself. Mother in law works and gets some income but she does not provide money to this couple. She takes all decisions in family. Pallavi realized her HIV status in the third pregnancy. Presently Pallavi has support from her mother. Mother works as a domestic servant. Though Pallavi knows caring, nutrition to be followed, due to inadequate resources and inaccessibility she cannot follow it. She received only adherence counseling at one of NGOs. She experiences stigma and discrimination hence has not disclosed her status to friends and relatives.

Table 5.24

Distribution of respondents showing age at the time of detection

NGO Groups	Age at the time of detection					Total
	Below 20	20 to <25	25 to <30	30 to <35	35 and more	
SOFOSH	3 5.4 %	10 17.9 %	21 37.5 %	15 26.8 %	7 121.5 %	56 100 %
FPAI	4 8.0 %	10 20.0 %	23 46.0 %	6 12.0 %	7 14.0 %	50 100 %
AFMC	3 7.5 %	10 25.0 %	17 42.5 %	3 7.5 %	7 17.5 %	40 100 %
Deepgriha	1 2.2 %	14 31.1%	16 35.6 %	10 22.2 %	4 8.9 %	45 100 %
Total	11 5.8 %	44 23.0 %	77 40.3 %	34 17.8 %	25 13.1 %	191 100 %

Graph 5.3: Age of the Respondents at the time of detection of HIV



At SOFOSH, 38% of the respondents were in the age group between 25 to 30 years followed by 27% in the age group 30 to 35 years, when they were detected as HIV positive. At FPAI also the same tendency is seen, at AFMC 43% respondents were detected HIV positive in the age group 25 to 30 years followed by 25% in the age group 20 to 25 years. At Deepgriha also the same trend is being observed. Overall 40% of the respondents were in their age of 25 to 30 years at time of HIV diagnosis, which is a productive age group. The pie chart is shown. Association between age at the time of detection of HIV CD4 count and weight was also computed but there was no significant association.

5.23 Number of children at the time of diagnosis

Women discover the HIV status of their spouse at repeated hospitalization during opportunistic infections and gradual deterioration of health of husbands. Until then, they continue to have unsafe sex with infected spouse. There are chances of mother to child transmission either or they themselves are tested positive at antenatal care clinics. If intervention for prevention of infection is possible, children can be saved.

Table 5.25

Distribution of respondents showing number of children at the time of detection

NGO Groups	No. of children at the time of detection				Total
	0	1 – 2	3 – 4	More than 4	
SOFOSH	6 10.7 %	34 60.7 %	15 26.8 %	1 1.8 %	56 100 %
FPAI	9 18.0 %	37 74.0 %	4 8.0 %	0 .0 %	50 100 %
AFMC	9 22.5 %	22 55.0 %	8 20.0 %	1 2.5 %	40 100 %
Deepgriha	8 17.8 %	28 62.2 %	9 20.0 %	0 .0 %	45 100 %
Total	32 16.8 %	121 63.4 %	36 18.8 %	2 1.0 %	191 100 %

In the above table it is shown at SOFOSH 61% respondents reported to have 1 to 2 children at the time of detection, while 27% respondents had 3 to 4 children. At FPAI 74% respondents reported to have 1 to 2 children and 18% did not have any child. At AFMC, 55% reported to have one to two children 22% did not have child, and 20% have reported to have 3 to 4 children at the time of HIV detection. At Deepgriha, 62% respondents replied to have 1 to 2 children followed by 20% who reported to have 3 to 4 children at the time of HIV detection. Overall it is observed that 62% respondents have 1 to 2 children.

5.24 Opportunistic Infections :

1. Immune system is a complex network of cells organs responsible for protecting body from harmful substances including infections.
2. An infection by micro-organism that does not cause disease but becomes pathogenic when body's immune system is impaired and unable to fight off infection.
3. An infection that occurs because of weakened immune system. This is dangerous particularly for people who suffer from HIV/AIDS. HIV virus itself

cannot cause death, but the opportunistic infections that occur because of its effect on the immune system can do so.

4. Opportunistic infection by a micro-organism that normally does not cause disease but does so when lowered resistance to infection is caused by impairment of body's immune system.
5. Opportunistic infection is an infection caused by pathogens, particularly opportunistic pathogens – those that take advantage of certain situations – such as bacterial, viral, fungal or protozoan infection that does not cause disease in a healthy host that is one with a healthy immune system. A compromised immune system however, presents an opportunity for the pathogen to infect. The causes are malnutrition, recurrent infections, and immune suppressing agents for organ transplant recipients, advanced HIV infection, chemotherapy for cancer, genetic predisposition, and skin damage. The treatment depends on types of opportunistic infection, but usually involves different antibiotics.
6. HIV and Opportunistic Infection: People with advanced HIV infection are vulnerable to infections and malignancies that are called opportunistic infections. Because they take advantage of the opportunity offered by a weakened immune system.

List of opportunistic infections:

Tuberculosis, Pneumonia, Septicemia, herpes zoster virus, different conditions occur at different stages of HIV infection. Prevention and treatment of opportunistic infection not only helps HIV positive people to live longer, healthier lives but also can help prevent TB and other opportunistic infections from spreading to others. HIV positive people can reduce their exposure to some of the germs that threaten their health by taking self care.

5.25 Opportunistic infection of respondent

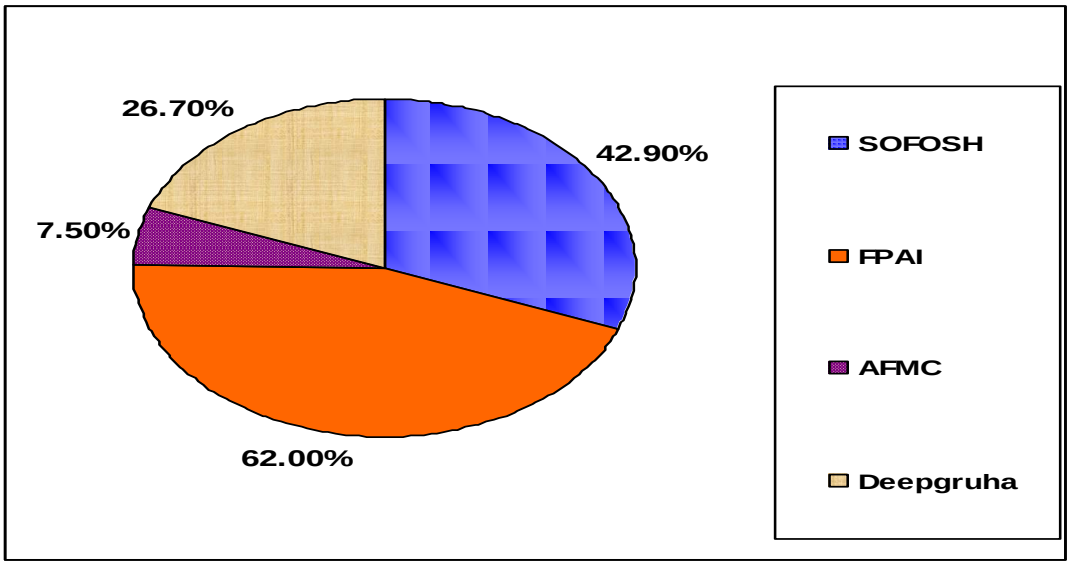
Women are stronger by nature; physically, emotionally and mentally also. They acquire HIV infection from spouse, but as they neglect health from childhood to adulthood due to so many social reasons, they eventually develop opportunistic infections much faster.

Table 5.26

Distribution of respondents showing opportunistic infection

NGO Groups	Incidence of opportunistic infection		Total
	Yes	No	
SOFOSH	24 42.9 %	32 57.2 %	56 100 %
FPAI	31 62.0 %	19 38.0 %	50 100 %
AFMC	3 7.5 %	37 92.5 %	40 100 %
Deepgriha	12 26.7 %	33 73.3 %	45 100 %
Total	70 36.6 %	121 63.3 %	191 100 %

Graph 5.4: Respondents Suffering from Opportunistic Infections



The above table shows, at SOFOSH 57% of respondents reported to have no opportunistic infection and 43% reported to have opportunistic infection. At FPAI 62% suffered opportunistic infection and 38% did not have opportunistic infection. At AFMC, 93% respondents reported to have no opportunistic infection and at Deepgriha also the same observation can be seen. Overall it is observed that 63% respondents

reported to have no opportunistic infection due to effect of ant-retroviral therapy, however 37% did have the opportunistic infection.

Table 5.27

Presence of any one or more morbid conditions vs. opportunistic infection

Presence of any one or more morbid conditions	opportunistic infection			Total
	Yes	No	Data not available	
Yes	63 43.8 %	80 55.6 %	1 .7 %	144 100 %
No	7 14.9 %	40 85.1 %	0 .0 %	50 100 %
Total	70 36.6 %	121 63.3 %	1 .5 %	191 100 %
Chi Square value =	0.001			

There was no association found between opportunistic infection and morbid condition.

5.26 Method of treatment

Till today there is no sure cure for HIV. In the 80's, when HIV was newly found, it was known as dreadful, stigmatized disease which is fatal. Since, then as many patients were found in Africa and U.S. Many researches were conducted to provide relief to the patient. We in India have a tendency to reason out any disease, disability as wrong doing in past birth and self blame. However, HIV was a global concern and research on treatment and prevention is continuously been done for the patient's relief. Effective education and awareness and condom promotion programmes helped in reducing fear and stigma for HIV. As a result, people do not try for domestic treatment but accept guidance provided by health care professionals and hence the result is shown in table below.

There were traditional methods of healing like Bhagat or Mantrik or witchcraft. Over the years people have realized importance of scientific ways of healing. There is no such assured cure for HIV, yet we see different medicinal products and we go ahead with trying those in the hope to get cured.

Table 5.28

Distribution of respondents showing method of healing

NGO Groups	Treatment Taken			Total
	Domestic	Scientific	Nothing	
SOFOSH	3 5.4 %	51 91.1 %	2 3.6 %	56 100 %
FPAI	0 .0 %	50 100.0 %	0 .0 %	50 100 %
AFMC	1 2.5 %	39 97.5 %	0 .0 %	40 100 %
Deepgriha	3 6.7 %	42 93.3 %	0 .0 %	45 100 %
Total	7 3.7 %	182 95.3 %	2 1.0 %	191 100 %

This table shows significant observation that 95% respondents have used scientific method of healing for HIV.

5.27 Partner's infection

Diagnosis of HIV generates denial, shock, shame and guilt in the mind of a person. In the post test counseling one of the important aspects to be covered is partner notification. It is expected that patient should inform about his infection to the spouse. It requires great strength and courage to talk about HIV status to the partner. Women respondents were asked when they realized about their partner's infection. After HIV is diagnosed, person can live up to 7 to 8 years. However, women have reported they were not informed about HIV status of their husbands by themselves. It was after the husband developed opportunistic infections and required repeated hospitalization they revealed HIV status of husbands.

Persons once diagnosed HIV are provided post test counseling which covers areas: informing diagnosis to partner, practicing safe sex, care of opportunistic infections and decision about child bearing. Generally, in the absence of desirable communication between spouses, partners do not inform about their infection. They

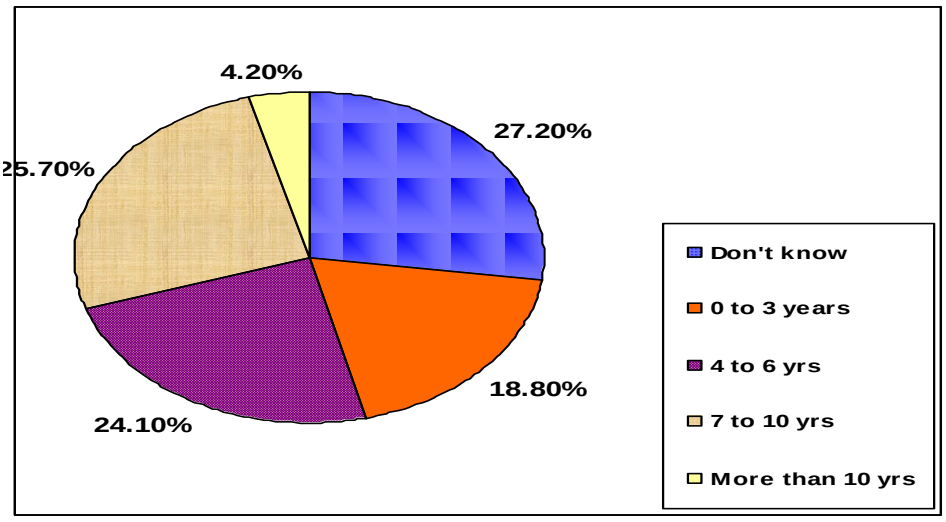
keep it as a secret and infect partners. HIV attacks, on immunity, if they neglect health, their condition deteriorates fast.

Table 5.29

Distribution of respondents showing duration of partner's infection

NGO Groups	No. of years of infection to marital partner					Total
	Don't know	0 to 3 years	4 to 6 years	7 to 10 years	More than 10 years	
SOFOSH	9 16.1 %	13 23.2 %	15 26.8 %	18 32.1 %	1 1.8 %	56 100 %
FPAI	13 26.0 %	5 10.0 %	15 30.0 %	15 30.0 %	2 4.0 %	50 100 %
AFMC	17 42.5 %	8 20.0 %	4 10.0 %	8 20.0 %	3 7.5 %	40 100 %
Deepgriha	13 28.9 %	10 22.2 %	12 26.7 %	8 17.8 %	2 4.4 %	45 100 %
Total	52 27.2 %	36 18.8 %	46 24.1 %	49 25.7 %	8 4.2 %	191 100 %

Graph 5.5: Respondents reporting length of partner's Infection



The above table indicates duration of partner's infection. At SOFOSH 32% of the respondents reported husband's infection for 7 to 10 years followed by 26% between

4 to 6 years followed by 23%, between 0 to 3 years, about16% respondents did report they do not know when husband was detected to have HIV. At FPAI 30% respondents each reported to have detection of HIV between 4 to 6 years and 7 years, followed by 26% who reported their ignorance about husband's HIV infection. At AFMC 43% respondents reported they did not know, when the husband was detected HIV, followed by 20% in 0 to 3 years and between 7 to 10 years. Respondents were not sure about opportunistic infection of husband, its reason and its connection with husband's death.

5.28 Care by respondent

After the diagnosis of HIV, taking self care is of utmost importance. At the preventive level few practices for self care were observed, as immunity gets lowers it is expected to avoid infection from food, water, avoiding visits to crowded places, which was also observed. In post test counseling, risk reduction behavior is emphasized. Majority of the women were widows hence, there was no question of this practice. So far, as cleanliness is concerned, they are expected to take bath regularly, wash hands before cooking, eating, and cutting nails regularly. While cooking, cutting vegetables they need to be very careful, if there is injury and bleeding is seen, they need to be aware about using disposable pads while menstruation, and take care of preventing infection further. So far as limiting deterioration in health is concerned, whoever has CD4 count less than 350, need to take ART from clinics and go for regular checkups to keep themselves healthy? It is necessary to do exercise and practicing 'yoga'. But that was not possible for the respondents.

Table 5.30 'A'

Distribution of respondents showing self care (Multiple Response)

Taking own care - I					
NGO Groups	**SOFOSH**	**FPAI**	**AFMC**	**Deepgriha**	**Total**
Avoiding outside food	50 89.3 %	34 68.0 %	36 90.0 %	38 84.4 %	158 82.7 %
Avoiding outside water	48 85.7 %	32 64.0 %	36 90.0 %	31 70.5 %	147 77.4 %
Avoiding crowded places	40 71.4 %	19 38.0 %	30 75.0 %	33 73.3 %	122 63.9 %
Avoiding sex	47 83.9 %	37 74.0 %	32 80.0 %	39 86.7 %	155 81.2 %
Washing hands	54 96.4 %	50 100 %	40 100 %	2 4.4 %	187 97.9 %
Taking bath regularly	56 100 %	50 100 %	40 100 %	45 100 %	191 100 %
Restrict from chewing tobacco	32 57.1 %	41 82.0 %	32 80.0 %	37 82.2 %	142 74.3 %
Taking care during menstruation	46 82.1 %	45 90.0 %	38 95.0 %	41 91.1 %	170 89.0 %
N	56	50	40	45	191

Table 5.30 'B'

Distribution of respondents showing self care (Multiple Response)

Taking own care - II					
NGO Groups	**SOFOSH**	**FPAI**	**AFMC**	**Deepgriha**	**Total**
Care in case of injury	53 94.6 %	53 94.6 %	40 100.0 %	44 97.8 %	186 97.4 %
Cutting nails regularly	53 94.6 %	50 100.0 %	40 100.0 %	44 97.8 %	187 97.9 %
Taking medicines regularly	55 98.2 %	48 96.0 %	39 97.5 %	43 95.6 %	185 96.9 %
Take guidance for opportunistic infections	52 92.9 %	46 92.0 %	39 97.5 %	41 91.1 %	178 93.2 %
exercise regularly	11 19.6 %	8 16.0 %	7 17.5 %	12 26.7 %	38 19.9 %
Regular medical check ups	49 87.5 %	36 72.0 %	38 95.0 %	38 84.4 %	161 84.3 %
N	**56**	**50**	**40**	**45**	**191**

5.29 Morbid condition in respondent

Morbidity indicates the prevalence of disease in any community. Women's health problems have a circular relationship. Since childhood, girl child experiences gender inequality in nutrition, health, and immunization. At the birth girls are strong, after the age of five, they experience inequality. As they reach puberty, their Hb level goes down. They do not develop appropriate weight as per their age (WHO standard weight). Due to neglect in health care, undernourishment and lack of access to efficient health care women have health problems like anemia, backache, blood pressure, urinary tract infection and gyneac problems. Women experience morbid conditions due to social and physical factors. Especially after getting HIV infection, chances of developing morbidity are more.

Table 5.31

Distribution of respondents showing morbidity

Morbidity experienced by the respondents (Multiple Response)							
NGO Groups	back ache	knee trouble	Feeling sad	Feeling anemic	Getting numb fingers	dry skin	N
SOFOSH	26 46.4 %	26 46.4 %	15 26.8 %	29 51.8 %	7 12.5 %	8 14.3 %	56
FPAI	29 58.0 %	11 22.0 %	11 22.0 %	16 32.0 %	3 6.0 %	3 6.0 %	50
AFMC	13 32.5 %	7 17.5 %	4 10.0 %	16 40.0 %	1 2.5 %	6 15.0 %	40
Deepgriha	13 28.9 %	11 24.4 %	6 13.3 %	23 51.1 %	5 11.1 %	7 15.6 %	45
Total	81 42.4 %	55 28.8 %	36 18.8 %	84 44.0 %	16 8.4 %	24 12.6 %	191

Women suffer from various health problems, due to their socio-cultural status in the family and the society. They generally report under-nourishment which leads to anemia, which results into back ache, pain in joints. Apart from being HIV patient, they had these morbid conditions.

The above table shows morbidity experienced by respondents. Maximum i.e. 44% of the respondents have reported to have feeling anemic as one complaint followed by 42% back ache and then 29% had knee trouble which is related to specific health problems of women, having anemia and other nutritional deficiencies. Respondents being HIV positive, these complaints were seen more.

5.30 Complaint about menstruation

Adolescence is a phase in development where women start menstruation. They are socialized in such a manner, that they should not complain about health, nutrition, education and any unjust behavior with them. They perceive trouble in menstruation as normal. According to the table, at SOFOSH 11 respondents reported to have painful and irregular menstrual periods followed by 7 respondents having excessive bleeding. At FPAI, 12 respondents reported to have painful periods followed by 8

having irregular periods. At AFMC, 8 respondents reported to have painful periods and 6 reported to have irregular periods. At Deepgriha 9 respondents reported to have white discharge, 8 respondents reported painful period and 6 having irregular periods.

Table 5.32

Distribution of respondents showing menstrual complaints

(Multiple response table)

Distribution of respondents showing menstrual complaints							
NGO Groups	Irregular	Frequent	Prolonged	Painful	Excessive bleeding	excessive fatigue	White Discharge
SOFOSH	11 44.0 %	2 8.0 %	1 4.0 %	11 44.0 %	7 28.0 %	6 24.0 %	3 12.0 %
FPAI	8 42.11 %	0 .0 %	1 5.26 %	12 63.16 %	2 10.53 %	1 5.26 %	2 10.53 %
AFMC	6 40.0 %	2 13.33 %	4 26.27 %	8 53.33 %	3 20.0 %	5 33.33 %	2 13.33 %
Deepgriha	6 30.0 %	0 .0 %	4 20.0 %	8 40.0 %	3 15.0 %	4 20.0 %	9 45.0 %
Total	31 39.24 %	4 5.06 %	10 12.66 %	39 49.37 %	15 18.99 %	16 20.25 %	16 20.25 %

The above table shows menstrual complaints. As SOFOSH, 44 % each respondents have responded to have irregular and painful menstruation. 28 % have responded to have excessive bleeding and 24 % have excessive fatigue and 12 % have white discharge. At FPAI 63 % respondents have reported painful menstruation, 42 % had irregular menstruation, 11 % have white discharge and excessive bleeding. At AFMC 53 % have reported to have painful menstruation, 40 % have irregular periods followed by 27 % have prolonged periods, 33 % have fatigue. At Deepgriha, 45 % have reported white discharge, 40 % have painful menstruation, 30 % have irregular and 20 % have prolonged menstruation. Overall it is observed to have 49 % respondents had painful menstruation, excessive fatigue and white discharge complaints were reported by 20 % respondents each.

An effort was made to see the association between age at marriage, age at first pregnancy and age at first delivery. It was observed that 82 % respondents had married between the age group 15 to 21 years. They had no menstrual complaints.

Similarly 54 % of the respondents had their first pregnancy within one year after the marriage and 52 % had no menstrual complaints.

5.31 Explanation about Anti-Retroviral Therapy (ART)

Anti Retroviral Therapy is now available at government hospitals, it helps in increasing longevity of life of HIV infected patient. Initially it was available only with the private practitioners and also very costly. Now as per government policy ART is available at all civil hospitals free of cost. ART is started when the person's CD4 goes down below 350. Once ART is started it has to be continued till death, it has side effects. Efforts by counsellors are made, that person's CD4 is maintained at a desirable level. There are certain steps followed to make ART effective. There has to be a caretaker, for medication, health, nutrition and observing side effects of medicine. Caretakers and patients initially are explained about HIV, ART, its side effect and importance of continuation of medication. Initially medicines are given for 15 days, patient's caretakers are expected to observe side effects and report to the doctor, then the doctor prepares dosage for patient for a month and all these steps are included in ART counseling.

Table 5.33

Distribution of respondents taking ART

NGO Groups	Taking ART		Total
	Yes	No	
SOFOSH	46 82.1 %	10 17.9 %	56 100 %
FPAI	42 84.0 %	8 16.0 %	50 100 %
AFMC	37 92.5 %	3 7.5 %	40 100 %
Deepgriha	35 77.8 %	10 22.2 %	45 100 %
Total	160 83.8 %	31 16.2 %	191 100 %

As the patient is diagnosed HIV, their immunity goes down and they suffer from various opportunistic infections. Especially TB, Jaundice, diarrhea, pneumonia are very common infections. As the patient attends outpatient care department and consults the doctor, doctors invariably advice the patient to check the CD4 count and if CD4 is below 350, they are provided ART/adherence counseling, it is ensured that, there is someone to care for the patient after ART is started. Patient is thoroughly explained, care and patients follow religiously guidance given by counselors and doctors and maintain their CD4 at the expected level.

Above table shows about 84% respondents were on ART, those 16% who were not on ART a very small percentage who were maintaining their CD4 as per requirement. This shows patients suffering from HIV do require medical support, care and treatment.

Table 5.34

Distribution of respondents received explanation from doctor and counselor about ART

NGO Groups	Understanding the significance of ART Information		Total
	Yes	No	
SOFOSH	44 95.7 %	2 4.3 %	46 100 %
FPAI	40 95.2 %	2 4.8 %	42 100 %
AFMC	37 100.0 %	0 .0 %	37 100 %
Deepgriha	32 91.4 %	3 8.6 %	35 100 %
Total	153 95.6 %	7 4.4 %	160 100 %

The above table shows at SOFOSH, 96% respondents reported to have received explanation from doctor and counselor about ART containing side effects and importance of treatment. At FPAI also 95% respondents have received the

explanation about ART, followed by at AFMC 100% respondents have received explanation about ART. ART is a very effective treatment for HIV patients, though it has side effects, those are explained to patients, overall it is observed that 96% of respondents have received explanation about Anti retroviral therapy.

5.32 Effect of ART on respondent

Anti Retroviral Therapy is proved to be effective method of treatment for HIV since last 7 to 8 years. Initially it was very costly and was available with private clinics and hospitals. However, since last 7 years it is available at district hospitals free of cost. Though ART is effective, it has many side effects. Patient needs to take treatment lifelong, he has to follow very strict time schedule for medication.

Side effects of ART : Giddiness, nausea, restlessness, headache, low appetite, bad dreams, vomiting, sleeplessness and itching all over the body. While the person is on ART, he experiences, guilt, fear, anxiety, uncertainty of life. He is also concerned about inquisitiveness of people about his medication and following strict restrictions about it. Many times patients are under the impression, that ART will cure HIV, but it is not so, it only controls viral load and increases the longevity of life.

Table 5.35

Distribution of respondents according to side effects of ART

	Side effects of ART							
NGO Groups	Head ache	Giddiness	Nausea	Sleeplessness	Depression	Restlessness	Vomiting	N
SOFOSH	12 26.1 %	7 15.2 %	9 19.6 %	7 15.2 %	2 4.3 %	5 10.9 %	9 19.6 %	46
FPAI	15 35.7 %	6 14.3 %	7 16.7 %	5 11.9 %	1 2.4 %	0 .0 %	4 9.5 %	42
AFMC	3 8.1 %	6 16.2 %	5 13.5 %	1 2.7 %	1 2.7 %	2 5.4 %	7 18.9 %	37
Deepgriha	6 17.1 %	6 17.1 %	5 14.3 %	2 5.7 %	0 .0 %	1 2.9 %	5 14.3 %	35
Total	36 22.5 %	25 15.6 %	26 16.2 %	15 9.4 %	4 2.5 %	8 5.0 %	25 15.6 %	160

Other complaints reported were low hemoglobin, acidity, anemia, body ache, burning sensation, convulsions, dry skin and other skin problems like rash and itching, feeling sleepy, cramps in legs, sleeplessness, low appetite and stomach complaints.

Above table shows multiple side effects, overall 23% of respondents have reported to have headache followed by 16% having nausea, 16% giddiness, and 16% vomiting. Patients are explained side effects and initially, medicines are given on trial basis and if side effects are seen medicine combination is changed. There is a close association between weight, CD4 count and opportunistic infection. If the weight and CD4 count goes down there are chances of developing opportunistic infection.

Table 5.36

Distribution of respondents according to side effects of ART & Weight

	Weight				
	35 to < 45	35 to < 45	55 and more	Don't know	Total
Yes	45 48.9 %	36 39.1 %	11 12.0 %	0 .0 %	92 100 %
No	25 36.8 %	29 42.6 %	14 20.6 %	0 .0 %	68 100 %
Not Applicable	12 38.7 %	12 38.7 %	6 19.4 %	1 3.2 %	31 100 %
Total	82 42.9 %	77 40.3 %	31 16.2 %	1 0.5 %	191 100 %
Chi Square Value =	0.184				

Association between weight and side-effects of ART was computed and it was found that those respondents whose weight was between 35 to 45 kg, about 49% of them had side-effects. It is observed that, as the weight increases, the side-effects are less.

Table 5.37

Distribution of respondents according to side effects of ART vs. CD4 count

	CD4 count						
	Upto 250	More than 250 to 500	More than 500 to 750	More than 750 to 1000	More than 1000	Don't Know	Total
Yes	16 17.4 %	34 37.0 %	24 26.1 %	7 7.6 %	1 1.1 %	10 10.9 %	92 100 %
No	9 13.2 %	25 36.8 %	12 17.6 %	9 13.2 %	2 2.9 %	11 16.2 %	68 100 %
Not Applicable	1 3.2 %	6 19.4 %	12 38.7 %	3 9.7 %	0 .0 %	9 29.0 %	31 100 %
Total	26 13.6 %	65 34.0 %	48 25.1 %	19 9.9 %	3 1.6 %	30 15.7 %	191 100 %
Chi Square Value =	0.071						

There is an association between CD4 count and side-effects of ART. About 37% respondents who had their CD4 count in the range 250-500 reported to have side-effects. Even those who had CD4 more than 500 which was about 26%, also experienced side-effects. Hence care of patient is very essential. This is the group who face coping difficult.

5.33 Difficulties in adhering instruction

Taking medicines, following doctors' instructions is difficult for people. Patient's behavior is being observed by family members, relatives, friends, neighbours. Patients make efforts to hide their diagnosis and taking treatment. During the treatment process following the advice about health and nutrition care becomes very difficult due to financial conditions and curiosity of the family members about special treatment being provided to HIV infected persons. Hence it is difficult to carry medicine and water with them while they travel for different purposes.

Table 5.38

Distribution of respondents facing difficulty in adhering to the instructions of counselor

NGO Groups	Difficulties experienced		Total
	Yes	No	
SOFOSH	18 39.1 %	28 60.9 %	46 100 %
FPAI	16 38.1 %	26 61.9 %	42 100 %
AFMC	3 8.1 %	34 91.9 %	37 100 %
Deepgriha	5 14.3 %	30 85.7 %	35 100 %
Total	42 26.2 %	118 73.8 %	160 100 %

Above table shows, difficulties faced by respondents at SOFOSH 61% respondents reported they did not have any difficulty in adhering instructions of counselor. Thirty nine percent reported to have difficulties. In FPAI, 62% did not face difficulties, 38% respondents found difficulties in adhering the instruction. At AFMC, 92% respondents did not face difficulties, at Deepgriha also 86% respondents did not face any difficulty overall it is observed 74% respondents did not face difficulties in adhering the instructions by counsellors. Once, the person accepts that he has to live with HIV; he makes an effort to accept it better.

5.34 Respondent's competence to overcome difficulties

Ideally there should be a caretaker for HIV infected women. Conditions like lower socio-economic resources, stigma, low self-esteem results into lowering a desire and motivation to live for themselves. However, they feel very responsible towards family and children, they develop competence to overcome these difficulties, and live with HIV.

Table 5.39

Distribution of Respondents showing competence to overcome difficulties

NGO Groups	Perception about competency		Total
	Yes	No	
SOFOSH	16 88.9 %	2 11.1 %	18 100 %
FPAI	17 100 %	0 .0 %	17 100 %
AFMC	3 100 %	0 .0 %	3 100 %
Deepgriha	6 85.7 %	1 14.3 %	7 100 %
Total	42 93.3 %	3 6.7 %	45 100 %

The above table shows 93% of the respondents found themselves competent to overcome the difficulties. Their health complaints were taken care of due to ART; they found themselves better prepared to face the difficulties with the help and support by health care professionals.

Association between education, competence to overcome the difficulties arising out of being diagnosed as HIV and the number of dependents was computed and it was observed that there were 57 % respondents had 1 to 2 dependents and they were competent to overcome the difficulties they were facing due to HIV.

5.35 Senior person to help

Earlier, care of the sick and the disabled was the prime responsibility of the joint family. Over the years, due to medical advancement in diagnosis and treatment procedures and social changes now the multidisciplinary team cares for the treatment. It is expected that since HIV is being diagnosed, the women must have support, help from senior person from the family. Women staying near their parents are in critical situations and seek support from them.

Table 5.40

Distribution of respondents showing availability of senior person to help

NGO Groups	Availability of senior person for caring		Total
	Yes	No	
SOFOSH	9 50.0 %	9 50.0 %	18 100 %
FPAI	15 88.2 %	2 11.8 %	17 100 %
AFMC	0 .0 %	3 100 %	3 100 %
Deepgriha	4 57.1 %	3 42.9 %	7 100 %
Total	28 62.2 %	17 37.8 %	45 100 %

At SOFOSH, 50% of respondents reported to have senior person to seek help in self care, 50% respondents reported, they did not have anyone to take care, at FPAI 88% respondents reported to have senior person only 12% did not have anyone. At AFMC 100% have reported there was no one to care for them. At Deepgriha, 57% have reported availability of a senior person for caring. Overall it is observed that 62% respondents have senior person for caring and 38% did not have anyone to care. Those who did not have any one, need more support for coping better.

5.36 Help from friends

To seek help from any one, we need to be closely associated emotionally. HIV infected women have chosen not to disclose their status to relatives. They have a fear of being stigmatized, discriminated; hence they have reduced the number of visits to relatives and friends. The following table shows availability of friends.

Table 5.41

Distribution of respondents showing availability of friends or relatives to help

NGO Groups	Availability of friends			Total
	Yes	No	Not disclosed	
SOFOSH	28 50.0 %	22 39.3 %	6 10.7 %	56 100 %
FPAI	39 78.0 %	9 18.0 %	2 4.0 %	50 100 %
AFMC	27 67.5 %	12 30.0 %	1 2.5 %	40 100 %
Deepgriha	28 62.2 %	16 35.6 %	1 2.2 %	45 100 %
Total	122 63.9 %	59 30.9 %	10 5.2 %	191 100 %

At SOFOSH 50% respondents have friends to help, 39% respondents reported to have no help from friends, at FPAI, 78% reported to have friend or relative to help. At AFMC, 68% have reported to have friend or relative to seek help and 30% did not have friend or relative. At Deepgriha, 62% have reported to have relative or friend for help. Overall, it is observed, 64% respondents have friend or relative to help, while 31% respondents reported they don't have any one to help, 5% have chosen not to disclose their status. Intervention is needed in this area also.

Association between availability of friends and relatives and the help from support group was computed and it was found, support group helps respondents in morale boosting, which is very essential to cope with the crisis of being diagnosed as HIV patients.

5.37 Need to visit doctor

All of us know the importance of health care, especially in case of incurable disease condition. A strong desire to live, and self care leads to take care and seek advice from doctor regularly. Following table shows the need to visit the doctor.

Table 5.42

Distribution of respondents showing need to visit doctor regularly

NGO Groups	Need to visit the doctor		Total
	Yes	No	
SOFOSH	38 67.9 %	18 32.1 %	56 100 %
FPAI	42 84.0 %	8 16.0 %	50 100 %
AFMC	4 10.0 %	36 90.0 %	40 100 %
Deepgriha	22 48.9 %	23 51.1 %	45 100 %
Total	106 55.5 %	85 44.5 %	191 100 %

An association between education and the need to visit doctor regularly was computed, education has an effect on the awareness of the person about health complaints. However there is also association between availability and accessibility of the health services for its effective use. It was observed that the nature of HIV is such, that respondents who have education between 7^{th} to 12^{th} standards felt the need to visit the doctor regularly.

5.38 Instructions by counselors

The entire explanation about HIV diagnosis, treatment, importance of partner notification, decision about marriage and child bearing needs thorough discussion between patient and health care professionals. Nature of HIV transmission and absence of any sure cure, leads to many emotional reactions in patients like anxiety, guilt, fear, loneliness. It is the concern of every health care professional to empathies with the patient. Due to non-availability of sensitive and trained professionals many doubts remain in the mind of patients.

Table 5.43

Distribution of respondents' comprehension of instructions by the counselor

NGO Groups	Comprehension of instructions		Total
	Yes	No	
SOFOSH	56 100 %	0 .0 %	56 100 %
FPAI	50 100.0 %	0 .0 %	50 100 %
AFMC	40 100.0 %	0 .0 %	40 100 %
Deepgriha	42 93.3 %	3 6.7 %	45 100 %
Total	188 98.4 %	3 1.6 %	191 100 %

The table shows, almost in all NGOs, about 93 to 100% respondents have reported to have understood the instructions given by counsellors, regarding health care, side effects of medicine and importance of nutrition etc. In all the NGOs respondents have reported that they follow the instructions given by the counselors irrespective of whether they have pre test, post test, adherence counseling.

5.39 Satisfaction of respondent by counseling

Study was undertaken in Pune city. Respondents come here from nearby rural areas and urban slums at NGO's. Counsellors appointed by NGOs are all trained. They are expected to be sensitive, resourceful, committed, most of them explain required aspects of pretest, post test and adherence counselling to the patients. Patients, experience stigma, rejection and discrimination, sharing with counselors gives them courage to face difficulties, stigma and rejection.

Table 5.44

Distribution of Respondents showing satisfaction with the counseling

NGO Groups	Satisfied with the counseling		Total
	Yes	No	
SOFOSH	56 100 %	0 .0 %	56 100 %
FPAI	49 98.0 %	1 2.0 %	50 100 %
AFMC	36 90.0 %	4 10.0 %	40 100 %
Deepgriha	42 93.3 %	3 6.7 %	45 100 %
Total	183 95.8 %	8 4.2 %	191 100 %

Above table shows respondents' satisfaction with the counselling. In almost all NGOs, 93 to 100% respondents have received instructions about care and counselling and they were satisfied with the instructions provided to them. Only 4% respondents have responded that they were not satisfied with the counseling.

5.40 Food choice of respondent (Veg-Non Veg)

After diagnosis of HIV, person's immunity is deteriorated; it is necessary to take high protein diet. People from poor living conditions cannot afford nutritious food. The kind of their food intake and possible provision of nutrients of patient's is shown in table.

Table 5.45

Distribution of Respondents having vegetarian / non vegetarian food

NGO Groups	Vegetarian / non vegetarian			Total
	Veg	Non-veg	Data not available	
SOFOSH	13 23.2 %	39 69.6 %	4 7.1 %	56 100 %
FPAI	9 18.0 %	28 56.0 %	13 26.0 %	50 100 %
AFMC	8 20.0 %	28 70.0 %	4 10.0 %	40 100 %
Deepgriha	8 17.8 %	35 77.8 %	2 4.4 %	45 100 %
Total	38 19.9 %	130 68.1 %	23 12.0 %	191 100 %

Dietary pattern of the respondents at SOFOSH, 70% of the respondents have reported their pattern as non-vegetarian and 23% have reported as vegetarian. At FPAI 56% respondents were non-vegetarian, and 18% as vegetarian. At AFMC 70% were have reported to have non-vegetarian pattern of diet and 20% vegetarians at Deepgriha78% were non-vegetarians and 18% were vegetarians. Overall 68% of the respondents were non-vegetarian, hence it is observed, that their dietary patterns was such, that it could provide them necessary proteins to increase ‘immunity’.

5.41 Dietary pattern

Dietary pattern of people is decided on their living conditions, caste, community, their orientation, financial conditions, occupation, by and large among vegetarians chapatti and Bhaji are common items in food. Many of the families cannot afford breakfast and preparations of variety and inclusion of all nutrients in their diet practice. Fruits, milk also is beyond the reach of the people from lower income group. In the post test counseling it is emphasized to raise the immunity.

Table 5.46

Meals taken by the respondents

Meals taken by the respondents						
NGO Groups	**Breakfast**	**Lunch**	**Tea Time**	**Dinner**	**Mid time snacks**	**N**
SOFOSH	51 91.1 %	55 98.2 %	36 64.3 %	56 100 %	14 25.0 %	56
FPAI	48 96.0 %	49 98.0 %	38 76.0 %	50 100.0 %	4 8.0 %	50
AFMC	34 85.0 %	38 95.0 %	32 80.0 %	40 100.0 %	24 60.0 %	40
Deepgriha	40 88.9 %	44 97.8 %	29 64.4 %	45 100.0 %	13 28.9 %	45
Total	173 90.6 %	186 97.4 %	135 70.7 %	191 100.0 %	55 28.8 %	191

The above table shows the meals taken by respondents. At SOFOSH 91% take breakfast, 98% take lunch, 64% take tea, and 100% take dinner, mid time snacks and tea is not taken by all, due to work timings and non-affordability. At FPAI almost 98-100% respondents take breakfast, lunch, dinner and tea but mid time snacks only 8% respondents could take. The same observation is seen at AFMC and Deepgriha. Majority (Cross table with on ART Pts.) of the respondents were on ART, they were explained about effects and side effects of medicine and importance of nutrition.

5.42 Care of diet

After the post test counseling, patient is expected to change the dietary pattern, timings of meals and develop lot of health care habits. Effort was made to understand whether women patients were observing fasting or caring for their nutrition.

Table 5.47

Distribution of respondents showing care about diet

NGO Groups	Take care about diet		Total
	Yes	No	
SOFOSH	39 69.6 %	17 30.4 %	56 100 %
FPAI	38 76.0 %	12 24.0 %	50 100 %
AFMC	27 67.5 %	13 32.5 %	40 100 %
Deepgriha	28 62.2 %	17 37.8 %	45 100 %
Total	132 69.1 %	59 30.9 %	191 100 %

Table shows that 69% of the respondents take care of their diet. Only 31% have responded negatively to this question.

5.42.1 Care of diet and nutrition

Effort was made to understand awareness among women about importance of nutritious food, its functions, ingredients in which proteins, vitamins are available. Women make efforts to include green leafy vegetables, jiggery, groundnut, fruits in their food intake but for a family of 3-4 members, it is not possible to exclusively eat nutritious food by patient.

5.43 *Summary*

The analysis of various aspects of health of women respondents is presented in this chapter. It discusses essential components and prerequisites of health, problems and issues of women. Those are abuse, gender inequality, sexual harassment, female feticide and domestic violence. Health of the women in general and HIV in particular is linked with the social status of women in our country. Women also have very little autonomy, control over the decisions taken about their lives in relation to their

education, age at marriage, child bearing use of contraceptives. Her multiple roles and in accessibility restricts her health seeking behavior. Women respondents under study were from lower socio-economic strata. Effort was made to see the health status of women. As majority of them were seeking help from government institutions for medicines, fortunately their weight was as per standards, and automatically medicines for HIV influences on CD4, hence their CD4 levels also were satisfactory. Women's prime role in family and society is child bearing. An effort was made to study history of delivery, on an average women had 2, 3 children and they conceived within a year after marriage. Many have reported to have married below the legal age (18) of marriage. They had hardly used any contraceptives. There was spacing of 2-3 years between 2 children. Regarding the major and prolonged illness during last year, majority of the respondents did not have any such illness, it may be due to following strict instructions of health workers. It was one of the concerns to know children's HIV status, as women had children and then they were detected HIV positive, other possibility was, that at Ante-natal care, women who are detected positive, given intervention to prevent transmission of HIV to fetus.

About referral for HIV, it was observed, that husbands/partners did not share their HIV status with the spouse, it was after the opportunistic infections and repeated hospitalizations, women realized the HIV of husband. Testing of HIV is now at government hospitals, hence majority of respondents though had not received pre test counseling, at least reported to have received post test counseling. As far as the age of detection of HIV is concerned about 60 % of the respondents were in their productive years i.e. 20 to 30 years. As many of the respondents were taking self care and were on ART, they did not suffer from any opportunistic infection. Almost all of them have tried scientific treatment for HIV, this shows awareness among the respondents; similarly, they were well aware about the need of nutritious food after being on ART. They had someone to care for them, those who did not have any one, found competent to care for themselves.

CHAPTER VI

STIGMA AND SUPPORT

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CHAPTER-VI

STIGMA AND SUPPORT

6.1 Introduction:

Diagnosis of any stigmatized disease leads to the judgmental attitude towards the person suffering from a particular disease. Stigma means a differential treatment anyone receives due to deviation from normal condition. Person experiences reactions like hatred, discrimination, stopping of any communication with a person with unacceptable behavior. The person diagnosed with HIV experiences stigma, people look down upon him. They don't want any acquaintance with such a person, they discriminate him from social interaction, do not allow him for work, do not allow taking admission in schools and colleges. The moment, person discloses his HIV status, he gets discriminatory behavior. He himself experiences shock, anxiety and guilt; in addition with stigma, they further experience depression and suicidal ideas. Earlier, people have experienced stigma to such an extent, that HIV infected person was not allowed to live in a particular community by people, the person was treated differently at work place, even after death, people are afraid of touching the body of a person who had suffered from opportunistic infections due to HIV. However, since last 15 years, due to inventions in HIV/AIDS, there are effective measures for treatment and prevention and there is increase in awareness among people about HIV /AIDS. Hence stigma has been reduced to a large extent.

Anyone, while suffering from any crisis, needs support from family, relatives and friends. Support is mainly required to cope with the critical situation, i.e. emotional, financial and family support to take up the responsibility of the changed situation. If family is not supportive, person tries to seek support from outside agencies. In the present study, support to women from family of parents, of in-laws and from relatives is presented. Then comes support from professionals in terms of counseling and other required services, support from support groups. The support groups are group of people suffering from same difficulties. They meet at regular intervals at a given place, share their problems, try to find solutions and learn to live positively with HIV/AIDS. Visiting a doctor and undergoing various investigations to diagnose medical conditions is not a very pleasant experience. This generates fear, uncertainty

and anxiety among the patients. The following table gives the respondents' reaction after diagnosis.

6.2: Reaction after diagnosis

The moment women were referred to ICTC, they had a doubt, that something was very serious, because by then they had experienced infection, its effects, and deterioration of health of the husband. As a result they experienced fear of undergoing the same stage. Reaction was seen as they felt stigmatized, depressed due to these feelings, loss of 'self-esteem'. Some of the women could not control tears while answering this question.

Table 6.1

Distribution of respondents - reaction after diagnosis

NGO Groups	Loss of self esteem	Anger	Loneliness / stigma / frightened	Depressed	Nothing	N
SOFOSH	14 25.00 %	8 14.29 %	27 48.21 %	23 41.07 %	3 5.36 %	56 100 %
FPAI	27 54.00 %	15 30.00 %	8 16.00 %	30 60.00 %	3 6.00 %	50 100 %
AFMC	12 30.00 %	6 15.00 %	7 17.50 %	30 75.00 %	5 12.50 %	40 100 %
Deepgruha	8 17.78 %	9 20.00 %	25 55.56 %	24 53.33 %	1 2.22 %	45 100 %
Total	61 31.94 %	38 19.90 %	67 35.08 %	107 56.02 %	12 6.28 %	191 100 %

Any disease condition is not liked by any one of us. We do have a fear which is seen in avoiding consultation with the doctor. For few dreadful diseases like cancer, HIV, heart problems, one needs to have emotional strength to undergo medical tests and accepting the diagnosis. Reaction to any medical diagnosis depends on the personality of the individual and the moral support from the family. Moral support is extended only if the person who is diagnosed with HIV is a bread winner or has been loved by all family members or he has taken maximum responsibilities. Reaction after

diagnosis could be self-blame, loss of self-esteem, 'why me?' or anger, loneliness and feeling of being stigmatized which leads to depression.

The above table shows reaction after diagnosis of HIV. At SOFOSH, 48% of the respondents felt loneliness, stigma. 41% were depressed, 25% felt loss of self-esteem. 15% were angry. At FPAI 60% respondents were depressed, 54% felt loss of self-esteem, 30% were angry and 16% were feeling loneliness and experience of stigma. Overall it is observed, 56% respondents were depressed, 35% felt stigma and 32% felt loss of self-esteem, to tackle these reactions, further intervention is needed.

6.3: Partner's infection

Women get infection of HIV from their spouse (WHO 1990). In the post test counseling every patient is explained importance of partner notification. Men who are diagnosed prior to marriage do not share their status at the time of marriage. When they are living with spouse, they have fear of shattering of marital relationship; in addition we live in patriarchal family set up, so many things men do not share with their spouse. Men being a part of patriarchal society, are socialized in such manner that they consider women as having secondary status. They being heads of the family, assume, that women cannot participate in decision making about family. Overall tendency is seen men are very secretive about their views, decisions about their habits and attitudes. They do not share their place of work, salary, extra marital relations, and addictions. HIV status is one of such confidential information which has to be shared with an intimate partner. However, tendency is seen that men do not share this information. On the contrary – women have less awareness about HIV, its modes of transmission and methods of precaution, on the top of it, male dominate about having sex without protection.

Table No. 6.2

Distribution of respondents according to partner infection

NGO Groups	Yes	No	Total
SOFOSH	51 91.1 %	5 8.9 %	56 100 %
FPAI	49 98.0 %	1 2.0 %	50 100 %
AFMC	35 87.5 %	5 12.5 %	40 100 %
Deepgruha	44 97.8 %	1 2.2 %	45 100 %
Total	179 93.7 %	12 6.3 %	191 100 %

The above table shows in almost all NGOs that more than 90% respondents' partners were infected. In earlier studies it is seen, that the highest proportion of transmission of infection is through heterosexual relationship.

6.4: Communication about infection

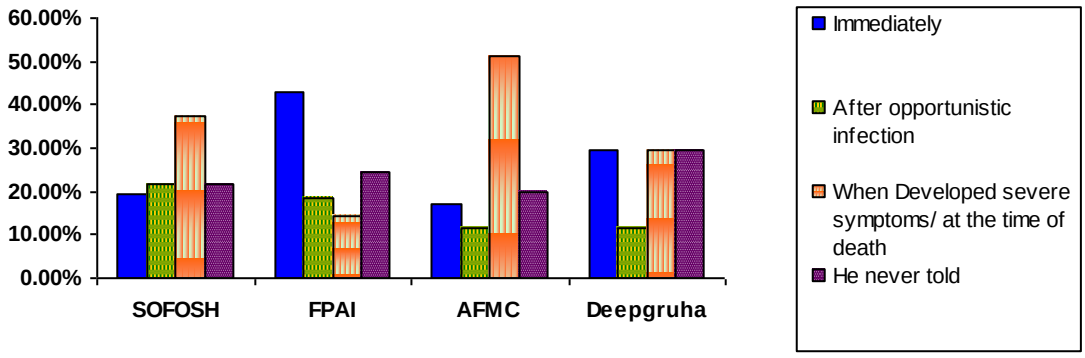
Free communication, interaction is an indication of healthy family relationship. In families we communicate our joys, happiness, and sorrows. We live together; we get support from each other. Most of our needs are fulfilled in families. It is a very trusting, loving and intimate relationship. During illnesses, disability conditions, and in any other crisis, family members, care for the affected and that too, at majority times, those caretakers are women. During the diagnosis and treatment process, it is one of the important moral duties of the infected spouse, to inform the HIV status to other spouse. In our patriarchal society, we do not have free communication, many of our decisions are driven by heads of the family, men have a tendency, to keep secrets from their spouses, it is only when their health condition deteriorates, women as caretakers need to care for them.

Table 6.3

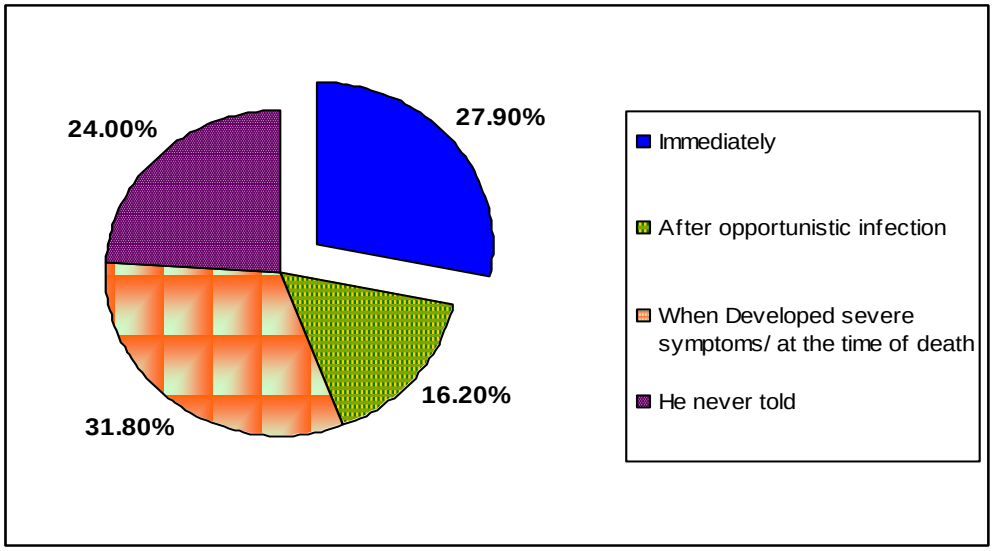
Distribution of respondents according to communication with spouse about infection

NGO Groups	Immediately after detection	After opportunistic Infection	After Development of severe symptoms	Never communicated	N
SOFOSH	10 19.6 %	11 21.6 %	19 37.3 %	11 21.6 %	51 100 %
FPAI	21 42.9 %	9 18.4 %	7 14.3 %	12 24.5 %	49 100 %
AFMC	6 17.1 %	4 11.4 %	18 51.4 %	7 20.0 %	35 100 %
Deepgruha	13 29.5 %	5 11.4 %	13 29.5 %	13 29.5 %	44 100 %
Total	50 27.9 %	29 16.2 %	57 31.8 %	43 24.0 %	179 100

Graph 6.1: When did partner talk about his infection: NGO wise



Pie chart 6.1: When did partner talk about his infection



From the above table, it is observed the time the partner has shared the diagnosis with the spouse. Ideally after the diagnosis, it is to be shared with the sexual partner and safer sex practices are to be followed. In SOFOSH, 37% of the respondents reported that as their spouse started developing severe symptoms and required repeated hospitalization or at the time of terminal stage of the disease they realized the partner's status. Twenty two percent respondents reported that after, developing opportunistic infections respondents revealed the diagnosis. About 20% reported that they knew about infection HIV immediately, there were 22% of the respondents who could never know their spouse's diagnosis. At FPAI, 43% respondents reported to know the HIV status of partner immediately and 18% and 14% realized after partners started developing opportunistic infections, here also 25% of respondents reported, they were never disclosed about HIV diagnosis. At AFMC 51% reported to know about infection after severe symptoms were developed by partner. Seventeen percent of the respondents reported to know it immediately, 20% respondents could never know the diagnosis. At Deepgriha about 30% each reported to know it immediately, then after developing severe symptoms and 30% could never know about the HIV status of the husband. Overall it is observed, that male partners had hesitation to talk about their HIV status with their female partners. This area also needs to be emphasized in intervention further.

Case study 6.1: Loss of support

Any crisis in the family in the form of illness, disability has to be shared with family members, especially with spouse. However, the nature of HIV is such that, the spouse does not wish to share it in family. Care during illnesses and in critical circumstances is provided by women, but they do not know the critical circumstances their partner is experiencing. The following case is an example of this behavior in the family. From the narration, it can be observed, that Sheela had no support, she had a pressure to undergo pregnancy after being diagnosed with HIV. She remarried to a HIV positive person he refuses to care for family and they cannot live happily. Sheela, 38 years old woman infected with HIV, illiterate, from poor socio-eco strata, her first husband had HIV. He did not share his status with Sheela, while husband developed serious opportunistic infections; she came to know his status. She was very upset. Husband later shared his status with relatives, friends and neighbors due to whom Sheela experienced stigma and discrimination especially in family. She was not allowed to live with in-laws, not allowed to cook and take part in any 'get together' of family. She had pregnancy while she was infected, but she was unaware of this fact. Later her child was born with HIV, this child also experiences stigma by grandparents. Sheela now has lost her parents also, but her two dependent brothers are with her. After a year or two, she met her present husband, who also is HIV positive, he is an alcoholic. Sheela has given birth to another child; this child is HIV negative so far. Her present husband does not take responsibility of family. Sheela repents on her decision of remarriage. She had tried suicidal attempt in state of helplessness, and depression. Presently also, she has only the support from professionals in NGOs.

6.5: Relationship with partner after diagnosis

In the group under study (lower socio-economic group) very commonly observed relationships are strained relationships between spouses, between parents and children. They have difficulties like involvement in addiction, extra marital relation, gambling, practice of violence, abuse, shirking of family responsibilities. Relationship and its intimacy, is a relative concept. It is observed that, husband – wife and children are staying under one roof, for the sake of social status. They don't provide any

support, bonding, commitment to each other. After the diagnosis ideally spouse should adhere to safe sex practice. Women in the absence of any knowledge about HIV cannot insist on use of condom. It results into strained relationship, feeling of being deceived and fear of uncertainty and stigma.

Case study 6.2 : Vulnerability of women

Women have very low status and low 'self-image' across communities. They do not have decision making power about their education, career and marriage. In the following case of Najma had three children when she remarried to her brother-in-law (Devar). Her husband cares for all children. However, in the very weak health status, Najma feels stressed, depressed and feels like running away from reality. This shows the emotional state of the HIV infected women.

Najma 32 year old illiterate had four dependents. She had no close relative, but had support of financial assets when her first husband died. She remarried to his brother; she had 3 children from first husband and has one child from new husband. She does not know her CD4. She had total 5 pregnancies and had not tested HIV status of children. (Women could not use any contraceptive with their partners). She was detected positive 6 months back when she had frequent health complaints. Presently, she is on ART. In this scenario, she feels stressed, feels like running away from reality. In a scenario like this it is quite obvious that Sheela contracted infection through her husband who was HIV positive, yet she still believes that she has received the infection from an infected syringe (injection). So far she has not disclosed her status to in-laws, there are no reactions seen by them, her total support is the second husband. According to Najma she is a weak and submissive personality, she is cared by her second husband.

Case study 6.3 : Suffering of women in minority community.

Shakila's case describes the low status, restraint on feeling of expression and lack of control over any decision being taken in case of a woman in a particular religion / community. Discovering the husband's first marriage is a shock to Shakila, which further puts her in doubt as to what was the source of HIV infection she received. Her parents were also HIV infected. In addition to this, her husband was suspicious about Shakila's character. Shakila is all alone without any support. Her health condition also is not so well. This talks about the reality of womens' condition in marginalized and minority communities.

Shakila 20 years old 7^{th} standard pass works at a shop and earns Rs.3,500/- pm. She has been deserted by her husband. She has a 2 month old male child. She has no one staying with her, she has no financial support. She faced major development in her family, as her own marriage, child's birth and she discovered her husband's first marriage. Since Shakila has delivered a baby, and discovered her status as positive during ante-natal-check up, her husband has deserted her and he is doubtful about Shakila's character. Husband's first wife and children are HIV negative. Shakila's weight is 40 and her CD4 is just above 200. Her parents were also positive she has no support as parents died long back. She is being given nutritional support by one of the NGOs. After the diagnosis Shakila was very depressed, she cried a lot. Since she discovered her HIV status, her relationship with the husband was not satisfactory, since then she has been all alone. She is finding it very difficult to live with the child and live with HIV, for how long, no one knows !

Case study6.4: Partner Notification.

There are guidelines about sharing the diagnosis to the person who has been tested for HIV/AIDS. The modes of transmission, especially the heterosexual multi partner unsafe sex behavior puts the person in to a high risk category. As there is no cure for HIV, person reacts with shock, denial, guilt, depression and suicidal ideation. Generally doctors and health care professionals prefer to share the diagnosis with the patient. However, the nature of HIV makes it difficult for professional and family members to share it with the patient. In Sangeeta's case, family has been very secretive and supportive about her husband's care. Family is more worried about Sangeeta's husband's reaction after knowing HIV. However, eventually patient needs to be told his / her diagnosis for his better participation in the treatment process.

Sangeeta 30 years old 10^{th} standard, pass is a housewife, has one son and daughter. She is HIV positive and living with the husband, she has no financial support except house, her weight was tremendously low i.e. 35 Kg. Her husband being positive, developed some problem in the brain so was admitted in one of the hospitals. Doctors explained to family members about HIV, but family has chosen to keep it as a secret. Family members are afraid about Sangeeta's husband's reaction, that he may run away, so they have decided not to disclose his diagnosis to him. The family has been supportive, they are caring for Sangeeta's husband; she has decided not to disclose it to friends or neighbours. Her reaction to diagnosis was depression and as if, everything is over. Her parents have been supportive and she has been caring for her husband. Due to the support from family and from NGOs she feels she is managing / coping with the critical situation.

6.6: NGO groups V/s relationship-

An effort was made to see the relationship of respondent with the partner and their association with the NGO after the HIV diagnosis. As respondents keep attending OPD at NGO's, they receive counseling, guidance in which they learn the modes of transmission of HIV and reveal that their partners have not disclosed this fact with them. Hence there is no question of relationship of partners after diagnosis, it is not satisfactory.

Table 6.4

Distribution of respondents showing NGO groups

V/s relationship with partner

NGO Groups	Relationship with partner			Total
	Satisfactory	Non-satisfactory	Not Applicable	
SOFOSH	21 37.5%	19 33.9 %	16 28.6%	56 100 %
FPAI	29 58.0%	8 16.0 %	13 26.0 %	50 100 %
AFMC	15 37.5 %	13 32.5 %	12 30.0 %	40 100 %
Deepgruha	20 44.4 %	11 24.4 %	14 31.1 %	45 100 %
Total	85 44.5 %	51 26.7 %	55 28.8 %	191 100 %
Chi Square Value =	0.305			

Above Table shows distribution of respondent in different NGO's and their relationship with partner. Maximum i.e. 58% respondent form FPAI have reported to have satisfactory relationship. At other NGO's respondent were not having satisfactory relationship after knowing the diagnosis. About 45% of the respondents have reported to have satisfactory relationship with the partner. Satisfaction is a relative concept; perception of respondents about satisfactory relationship is minimum necessary communication, taking care and responsibility of children and keeping away from undesirable habits like addiction. Very few respondents could spell it out. About 43% respondents were not satisfied with their partners. Out of 55, 43 respondents partners did not disclose the status, 12 respondents partners were not infected. Overall respondents have reported to have satisfactory relationship with the partner. This is the group, with whom one needs to work further. Association between relationship after the diagnosis and the disclosure of the diagnosis with the partner was computed and about 78 % of the respondents having satisfactorily relationship have disclosed their status immediately after diagnosis.

6.7: Precautions taken

In our society, pattern of communication between husband and wife is very crucial. It depends on age, education, flexibility, attitudes, freedom of expression. An effort was made to understand, when and how the husband had communicated about his HIV status to his most intimate partner. Discussing about relationship, about sex, these subjects between husband and wife have 'taboo'. In the present study the respondents belonged to the lower socio-economic group. Obviously, it has effect on their sharing of feelings with the partner, a very confidential matter like HIV diagnosis. Hence in the absence of any free communication, women do not know HIV status of their spouses. They don't have knowledge about male, female condoms and about any other contraceptive to prevent HIV. In the absence of the above mentioned conditions taking precautions to prevent HIV becomes difficult. It was very difficult to get this information from the respondents. Women hardly have any say in sexual relations and about use of contraceptives. They are expected to be loyal to their partner and accept the desire of the partner.

Table 6.5

Distribution of respondents showing precaution taken during this period

NGO Groups	Precaution taken during this period				Total
	Safer Sex Practices	Did not take any precaution	Forced not to take any precaution	No contacts	
SOFOSH	22 43.1 %	19 37.3 %	4 7.8 %	6 11.8 %	51 100 %
FPAI	27 55.1 %	10 20.4 %	0 .0 %	12 24.5 %	49 100 %
AFMC	16 45.7 %	3 8.6 %	0 .0 %	16 45.7 %	35 100 %
Deepgruha	17 38.6 %	11 25.0 %	2 4.5 %	14 31.8 %	44 100 %
Total	82 45.8 %	43 24.0 %	6 3.4 %	48 26.2 %	179 100 %

After knowing the diagnosis of HIV, infected person has to follow safer sex practices. At SOFOSH 43% respondents reported that they have followed safer sex practices. Thirty seven percent did not take any precautions, about 12% respondents reported to have no sexual contact. At FPAI 55% respondents have followed safer sex practices 25% practiced abstinence. Twenty one percent did not take any precaution. At AFMC 45% each, have practiced safer sex practice and about 46% have practiced abstinence. At Deepgriha, 37% have followed safer sex practices, 32% practiced abstinence and 25% did not take precaution. Overall 71% respondents are following precautions there are ¼ th of the respondents do not take precautions, this needs further intervention.

6.8: Pressure about pregnancy

Women don't have right to decide the number and sex of the child and use of contraceptive. As it is they have no control over the situation, under the situation of knowing HIV status of spouse women have a pressure from family members and from themselves to conceive and give birth to the child, the number of children and the pressure to have child.

Table 6.6

Distribution of respondents according to pressurization to undergo pregnancy after knowing HIV

NGO Groups	Yes	No	Total
SOFOSH	12 23.5 %	39 76.5 %	51 100 %
FPAI	5 10.2 %	44 89.8 %	49 100 %
AFMC	2 5.7 %	33 94.3 %	35 100 %
Deepgruha	6 13.6 %	38 86.4 %	44 100 %
Total	25 14.0 %	154 86.0 %	179 100 %

There are four modes of transmission of HIV, as stated earlier; one of them is through mother to child transmission. It is a well known fact now, that those who are

diagnosed as HIV infected – pregnant women, during the post test counseling, they are explained the modes of transmission and chances of mother to child transmission. There are now effective medicines to prevent this transmission. However, there are few situations, in which women could be pressurized to undergo pregnancy even after being diagnosed as HIV. An effort was made to see, whether women experienced this pressure and it is seen that almost at all NGOs, respondents have reported that they have not taken chance to undergo pregnancy after knowing HIV status, as they do not wish to make life of children miserable.

Association between education and pressure about pregnancy after knowing HIV was computed and it was found that there was no pressure about undergoing pregnancy irrespective of education. Similarly association between age at marriage and doubt about sexual behavior of the partners of respondent was computed however, as stated earlier there were very few women who reported to have doubt about sexual behavior of the partner and were reluctant to talk. About 58 % of the women had no doubt about sexual behavior of the partner.

6.9: Doubt about sexual behavior :

Marriage is a social institution; it regulates sexual behavior of individuals. Marriage provides stability, security, trusting relationship to the boy and girl. It is a socially approved way for procreation and sexual gratification. In the process of development, education has made an impact on this social institution of marriage, and we have developed criteria for marriage like age, caste, and horoscope, character of a person, financial stability and physical fitness. These criteria's are also undergoing changes. Now people believe on autonomy, freedom, in marital relationships, it is perceived as companionship. There is a possibility about premarital or extra marital sexual exposure. This problem is not shared while getting married. We do not have any mechanism to know the person prior to getting married. In the absence of any choice, given to young boys and girls about mate selection, especially women believe on their would be spouse. As a result, while getting married, no one doubts about the undesirable habits or high risk behavior of the partner. It is only after marriage; women realize the HIV status of their partners that it is a result of multi partner unprotected sexual behavior. Due to absence of exposure to women, as well as they

feel totally committed themselves in the marital relationship they don't doubt about their partner's sexual behavior.

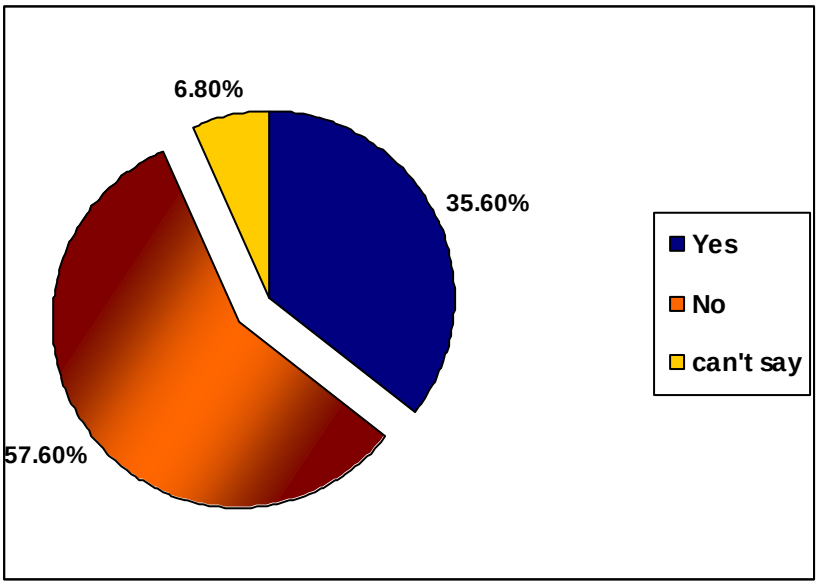
Table 6.7

Distribution of respondents reporting doubts about sex behavior of partner

NGO Groups	Yes	No	Can't say	Total
SOFOSH	25 44.6 %	26 46.4 %	5 8.9 %	56 100 %
FPAI	10 20.0 %	37 74.0 %	3 6.0 %	50 100 %
AFMC	16 40.0 %	24 60.0 %	0 0.0 %	40 100 %
Deepgruha	17 37.8 %	23 51.1 %	5 11.1 %	45 100 %
Total	68 35.6 %	110 57.6 %	13 6.8 %	191 100 %

The above table shows about 58% of the respondents have reported to have no doubt about the sexual behavior of their partner. Thirty six percent of the respondents reported that they have a doubt about extra marital or premarital sexual behavior of the partner. About 7% women could not give any answer to this question. It is as if accepting the fact that husband had extra marital relationship, which is not an acceptable behavior.

Pie chart 6.2: Respondents having doubts about sex behavior of husband



Association between age and feeling of insecurity was computed and it can be observed as the age is advancing, respondents are getting older, they are worried about their own health, children's future and uncertainty about life.

Counter reaction of respondent

As stated earlier, marriage is perceived as a life time commitment. Women look at it, as something that provides protection, bonding, status and supposedly satisfaction too. When women discover the HIV status of their partners, they do realize high risk behavior, so initially they get angry, they blame themselves but they have children. In our society, deserted married women are looked down upon, or divorce has stigma, so women continue to tolerate the behavior of partner even if they are involved in beating, alcoholism, addiction and extra marital relations. They do not generally react to leave the husband/partner, as this is the time, when partners need them most for caring. While reacting to this behavior of partner, 'denial' was observed. No one appreciates extramarital relations of partners. To protect herself and image of the family, she keeps mum about it.

6.10: Feeling of insecurity by respondent

Marriage and family provides security to men and women. While women experience disease, disability, addiction of their partner they experience insecurity. They have a

support of partner and other members while living in family. Diagnosis of HIV of partner shatters their stability in marital relationship. Repeated hospitalization, financial crisis due to ill health, further aggravates the situation. Later on there are discussions about her partner's ill health, undesirable habits. Another additional factor in this is feeling of insecurity is of 'age' the woman is in her youth in 21 to 30 year age group, when generally she realizes all this, hence there is a insecurity feeling, feeling of chances of being exploited sexually.

Table 6.8 Age group v/s feeling of insecurity

Age Group	Yes	No	Total
18 to 25 (up to 25)	5 33.3 %	10 66.7 %	15 100 %
26 to 30	23 41.8 %	32 58.2 %	55 100 %
31 to 35	30 44.1 %	38 55.9 %	68 100 %
36 and above	25 47.2 %	28 52.8 %	53 100 %
Total	83 43.5 %	108 56.5 %	191 100 %

$\mathbf{X^2}$ =0.802, d.f.3 Sig 0.01

Feeling of security one can experience in family, by the support, by sharing, by financial provision and the strong bonding among husband and wife. An effort was made to understand whether women had feeling of insecurity being diagnosed as HIV. Overall it is observed that as the age is advancing they are getting older, they are worried about their own health, child's future and uncertainty about life. This needs further intervention. Relationship between education and feeling of insecurity was tested statistically, and it was found as the education increase insecurity feeling was low because education can equip the person to be financially independent. There was no significant relationship found about the income group and feeling of insecurity. Feeling of insecurity was further computed with marital status and it was found that those 53 % who were deserted and 47 % widows had feeling of insecurity as against 37 % who were married, though there is less difference women did find support by husbands.

6.11 Mutual understanding in respondents and their partners

There is very little communication among spouses in the group understudy. While understanding the nature of relationship, it is realized that men and women marry when they are not prepared for. They hardly develop emotional bonding. They have children, but this responsibility is not perceived as a commitment. There is very little communication observed about taking up responsibilities, socializing children, imbibing values and overall family functioning. While women were asked about feeling of insecurity they expressed insecurity feeling, being HIV positive young widow, having at least 1 to 2 dependents on them. In mutual understanding it was expected, to know how was the communication between husband and wife about family functioning, role performance. Women respondents from low socio-economic strata have expressed, there was very less communication, there was hardly any division of work, about sharing of financial responsibility. Women have also expressed about husbands' undesirable habits of drinking and about having extra marital relations. However, women in our society are socialized in such a manner, that they have a very low self-image; they submit themselves, to the patriarchal head of the family and experience helplessness. They accept the husband as he is, to maintain their own status and image.

Table 6.9

Distribution of respondents having mutual understanding

NGO Groups	Mutual understanding			Total
	Yes	No	Not Applicable	
SOFOSH	14 25.0 %	35 62.5 %	7 12.5 %	56 100 %
FPAI	10 20.0 %	27 54.0 %	13 26.0 %	50 100 %
AFMC	8 20.0 %	12 30.0 %	20 50.0 %	40 100 %
Deepgruha	10 22.2 %	16 35.6 %	19 42.2 %	45 100 %
Total	42 22.0 %	90 47.1 %	59 30.9 %	191 100 %

Above table shows at SOFOSH, 63% respondents have reported that there was no mutual understanding regarding, life after discovering HIV and 25% have reported to have mutual understanding. At FPAI, 54% have reported to have no understanding, only 20% respondents had understanding. At AFMC 30% respondents reported to have no understanding, 50% respondents reported the question was not applicable as they were widows, and only 20% of them had mutual understanding. At Deepgriha, 42% reported no applicability for this question due to widowhood, 35% reported no mutual understanding and 22% only have said to have mutual understanding. Overall it is observed that 47% respondents reported that there was no mutual understanding. This observation also needs further intervention. Pressure to undergo pregnancy after knowing HIV and mutual understanding was computed and 70 % respondents reported there was no pressure, and no understanding.

Case Study 6.5: Infection to children.

There are 10-15% chances of mother to child transmission of HIV. In the following case, Shobha being widow was vulnerable. She got friendly with the servant in the bungalow, where she worked. Being HIV positive, Shobha and her friend did not take precaution to avoid HIV transmission. She hid information about her pregnancy from her dear ones. Further, she neglected her baby girl and decided independently to give over the child into adoption. In the entire situation one can see her helplessness and her effort to seek support.

Shobha HIV positive aged 27 years passed fifth standard came in labour pain in one of the hospitals in Pune City. Shobha is maid servant. She is a widow since her husband expired 8 years back. She delivered a baby girl and has another 7 year old daughter. Shobha stays with her mother at Mulshi. Shobha rejected her 2nd baby girl. She was not ready to breastfeed her. After the 2nd day of delivery she was tested HIV positive. Hospital provided Nevirapin dose to the child and put the child in the critical care unit. Shobha was counseled. She gave no reaction to the positive status of the child. Being widow, working as a maid servant at one bungalow in Pune, she met a care giver. Sunil from U.P. lived in same house and developed sexual relations with her. In the meantime, she conceived; however, she hid the pregnancy and delivery from her mother and brothers.

To her misfortune her employer told everything to her brothers. As Shobha did not want this pregnancy, she had decided to give away the child into adoption. She went to the court for formalities. Brothers got this information and they came to hospital. Shobha was shocked to realize, brothers knew all her plans. Shobha was very depressed, confused. She was counseled to undergo sterilization operation. She refused this idea. In the meanwhile she lost her job as a maidservant. She was also told to test the HIV status of her first daughter and hand over the baby for adoption.

One of the modes of transmission is mother to child transmission (10-15%). There are very effective medicines to prevent it. There are antenatal care clinics, when expectant mothers are provided care which includes mandatory HIV test. Those women, who could attend ANC, received intervention to protect their children.

Table 6.10

Distribution of respondents reporting about children's infection

NGO Groups	Children's infection				Total
	Yes	No	Not Applicable	Don't Know	
SOFOSH	29 51.8 %	23 41.1 %	1 1.8 %	3 5.4 %	56 100 %
FPAI	9 18.0 %	30 60.0 %	5 10.0 %	6 12.0 %	50 100 %
AFMC	9 22.5 %	24 60.0 %	7 17.5 %	0 .0 %	40 100 %
Deepgruha	13 28.9 %	26 57.8 %	4 8.9 %	2 4.4 %	45 100 %
Total	60 31.4 %	103 53.9 %	17 8.9 %	11 5.8 %	191 100 %

Chi Square Value = 0.002 Not significant

The above table shows the number of children infected at SOFOSH, 52% of the respondents reported to have their children infected with HIV and 41% were not infected. At FPAI 60% respondents reported children were not infected, and 18% were infected, at AFMC 60% respondents reported that their children were not infected and 23%, were infected at Deepgriha, 58% responded to have not infected children and about 29% have infected children. Overall it is observed that about 58% of the respondents did not have children with HIV infection. Those who were having living children this question was applicable. Not applicable means category showing that those respondents did not have children, 11 respondents did not know the child's HIV status. Eighteen respondents have '0' children, one respondent shows that she was pregnant and delivered a baby but the baby expired due to HIV. So she is having '0' children but infected 'yes'.

6.13: Reaction of family members

Family provides emotional bonding, security, a sense of belonging to its members. Family members share their feelings with each other and get support for both undesirable and desirable things that happen with them. Presently due to various reasons family fabric itself is vitiating, closeness and sharing has lowered. At the time of crisis family members support each other, in reality the person in the situation has to face it. Respondents were asked about reactions of parents and in-laws. As observed at other situations, in laws don't support women in critical situation of HIV infection but parents feel 'sorry' for the 'fate' of their daughter and have to support them.

Table 6.11

Distribution of respondents reporting change in behavior of people after knowing HIV status (Multiple response)

NGO Groups		Relationship after knowing HIV status by relatives						Total
		Acceptance / Supportive / positive behaviour	Do not understand the seriousness	Negative behavior / reaction	Not disclosed to them	No reaction / Neutral	Worried / felt sad	
SOFOSH N=56	In Laws	21	0	40	19 22.4 %	5 5.9 %	0 .0 %	85 100 %
	Parents	39 58.2 %	2 3.0 %	15 22.4 %	6 9.0 %	3 4.5 %	2 3.0 %	67 100 %
Total		60 39.5 %	2 1.3 %	55 36.2 %	25 16.4 %	8 5.3 %	2 1.3 %	152 100 %
FPAI N=50	In Laws	7 13.0 %	0	15 27.8 %	24 44.4 %	8 14.8 %	0 .0 %	54 100 %
	Parents	16 17.4 %	0	12 13.0 %	23 25.0 %	41 44.6 %	0	92 100 %
Total		23 15.8 %	0	27 18.5 %	47 32.2 %	49 33.6 %	0	146 100 %
AFMC N=40	In Laws	25 37.9 %	0	20 30.3 %	13 19.7 %	7 10.6 %	1 1.5 %	66 100 %
	Parents	51 61.4 %	0	3 3.6 %	17 20.5 %	8 9.6 %	4 4.8 %	83 100 %
Total		76 51.0 %	0	23 15.4 %	30 20.1 %	15 10.1 %	5 3.4 %	149 100 %
Deepgruha	In Laws	22 29.3 %	1 1.3 %	28 37.3 %	9 12.0 %	13 17.3 %	2 2.7 %	75 100 %
N=45	Parents	34 54.8 %	2 3.2 %	5 8.1 %	8 12.9 %	6 9.7 %	7 11.3 %	62 100 %
Total		56 40.9 %	3 2.2 %	33 24.1 %	17 12.4 %	19 13.9 %	9 6.6 %	137 100 %

The above table is showing multiple responses of the respondents. Diagnosis of HIV in the family can evoke many negative reactions in the minds of the family members. There could be no reaction, sadness and worrying for the person diagnosed with HIV, or negative reaction and stopping communication with the person. Family members may not know the seriousness of HIV diagnosis and may not give any reaction. Very

few family members and relatives will accept the diagnosis, support the patient and family and show positive behavior. However, reaction to diagnosis of HIV by family members and relatives depends on the intimacy and the concern towards the patient. HIV being stigmatized disease, there are different reactions by in-laws and parents. Some respondents have chosen to not to disclose their HIV status to their family members and relatives. Parents of women generally are supportive in the crisis situation.

Above table shows that at SOFOSH 39 %, respondents have given reaction of acceptance, 36 % have reacted negatively, 16% have not disclosed their status and 5.3 % were neutral. At FPAI, 16 % respondents have responded that there was acceptance, 32 % have not disclosed, 34 % have given neutral reaction. At AFMC, 51 % had acceptance, 20 % did not disclosed the status, 15% had negative behavior from relatives. At Deepgriha, 41 % had acceptance, 24 % had negative behavior, 12% have not disclosed, there were 14 % respondents who did not experience any reaction.

6.14: Behavior change after diagnosis

HIV is a stigmatized disease. Generally patients do not share their status, however, when there are repeated health problems reported and suddenly death takes place, family members have doubt about infected person and keep themselves away from the family where HIV is detected. Women do not disclose their status themselves, but they also reduce interaction with family members to avoid their curiosity, ridicule about HIV infection. Change in the behavior in terms of less interaction is obvious.

6.15: Experience of stigma

Being diagnosed as HIV is certainly a shock to women. They initially deny this fact, but as their health condition deteriorates they accept it. As the people in family come to know their status, they make it obvious for woman that they better maintain the distance, do not visit their place, and do not attend any social gathering. Women do realize the change in the behavior of relatives, friends and in-laws and reduce the interaction with them by reducing the number of visits to them. They realize, hence forth they cannot expect any support from these relatives and friends and need to develop strength on their own to face the difficult situations.

HIV is a stigmatized disease. Gradual awareness has created about its transmission and people know very prominently that it is due to multi partner unsafe sexual relationships and they have a doubt about the character of a person. The moment, it is diagnosed, people discriminate the infected, they reduce interaction with them, do not invite them for social functions, and do not wish to recognize them in public. In families, infected person is not allowed to cook, wash, mix-up freely with each other. At workplace if the status of HIV is known, person is not allowed to work, irrespective of the nature of work, in schools children are discriminated. In communities, neighborhood, women experience stigma while filling water, purchasing anything or they are not allowed to attend social functions. To avoid all the above-mentioned discrimination many of them have a tendency to hide their HIV status. Presently, due to health awareness HIV/AIDS education programs, stigma is reduced, but in rural areas and in slums it is still experienced. The data shows that respondents residing with the in-laws comparatively experienced fewer stigmas.

The study result shows experience of stigma by respondents at SOFOSH, 59% respondents experience of stigma by making 33% less visits at in-law's place, even at parents place, followed by visits to neighbours 31% resulted into attending less social functions 11% and they preferred, no help to be sought in difficult situations by anyone. At FPAI 75% of the respondents reported that they made less visits to neighbors, followed by less visits to parents 56%, then less visits to in-laws and made limited social interactions 31% and 13% reported they did not ask for any help from others. At AFMC, 54% respondents reported they made less visits to neighbors, followed by less interactions and attending social functions by 46% followed by 31% each experienced less visits to in-law's place and their preference of not receiving any help in difficult situations. At Deepgriha, 39% of the respondents reported they made less number of visits to their in-law's place, 83% of the respondents made less visits to their neighbors followed by 28% each respondents reported less visits to parents and reduced their interactions by avoiding social functions.

Case Study 6.6: Stigma experienced.

Vulnerability of women has been discussed in the study earlier. Here is a live example; Himansi was rejected by her family of in-laws and parents. Hence she joined as care taker in one NGO. In the isolation, depression and desperation, she searched for support and sharing. She met another caretaker. Asha in this institution and they got involved in lesbian relationship. This shows, somewhere some emotional deprivation and rejection.

Himansi; 32 years HIV positive woman's husband was admitted in a hospital in Pune. Her husband expired within a week. Husband knew his status, however he married to Himansi. They were from Gujarat. They have no children, as the husband died within 2 years after marriage. Himansi's in-laws and parents chucked her out from the house. She came to Pune and stayed in one of the NGO's working for HIV infected children. She started working as a caretaker. She was doing her job sincerely. She was good looking, efficient. But in the desperation of isolation, depression she got friendly with one of the female inmates in the institution and they developed lesbian relationship. Everybody came to know about it. Though they were counseled about this relationship and its effects, they could not come out of this unacceptable behavior and decided to leave the institution. They started living on rental basis. Asha was an alcoholic. Both of them were earning adequately to survive. Both were on ART at District Hospital. Both joined support group, later they joined at red light area. Eventually Himansi developed health problems and expired, nobody came for her funeral. Now no one knows what happened to Asha. Even after death also infected persons do experience stigma and discrimination.

6.16: Reaction of respondent

Person experiences stigma after disclosing the HIV status. We cannot decide how others should behave, but we can decide our reaction. Persons with HIV initially do experience stigma but gradually they realize that they cannot blame their partner or anybody else. Whatever, has happened with them is a 'truth' a 'reality' one has to

accept it. They do feel sorry, lost, loneliness but they have life ahead, to take up responsibilities.

Table 6.12

Distribution of respondents reporting their reaction on experiencing stigma (Multiple answers)

Name of NGO	Anger	Anxiety	Depression	Felt embarrassed	None of them, calm, acceptance	N
SOFOSH	15 38.46 %	6 15.38 %	7 17.95 %	8 20.51 %	13 33.33 %	39
FPAI	4 25.00 %	2 12.50 %	13 81.25 %	1 6.25 %	3 18.75 %	16
AFMC	6 46.15 %	4 30.77 %	5 38.46 %	6 46.15 %	1 7.69 %	13
Deepgruha	4 22.22 %	4 22.22 %	8 44.44 %	7 38.89 %	5 27.78 %	18
Total	29 33.72 %	16 18.60 %	33 38.37 %	22 25.58 %	22 25.58 %	86

The above table shows reaction of respondents. At SOFOSH, 38% respondents reported that they were angry to know their status, 33% reported they accepted calmly their diagnosis and had no reaction of anxiety, depression, or embarrassment, 21% reported they felt embarrassed after knowing their diagnosis, 18% of respondents reported to have depressed followed by 15% experienced anxiety. At FPAI, 81% of the respondents experienced depression, 19% respondents reported no reaction, 13% reported to have anxiety and negligible proportion of the respondents reported embarrassment. At AFMC, 46% each, respondent reported to experience anger and embarrassment followed by 39% experienced depression and 31% experienced anxiety. At Deepgriha 44% respondents reported depression, 22% each reported anger and anxiety and 28% reported they had no reaction, they calmly accepted the diagnosis.

6.17: Difficulties in life

Difficulties are faced by every one of us. Difficulties are the distance between expected reality and the reality itself. We have physical difficulties, difficulties in family and marital relationships, at work place and financial difficulties. Infected women can have difficulties in accepting their diagnosis, maintain their health, managing nutritious food, managing other needs of the family members and emotional stress of being infected and constant threat to life.

Table 6.13

Distribution of respondents facing difficulties in life

NGO Groups	Facing difficulty in life		Total
	Yes	No	
SOFOSH	54 96.4 %	2 3.6 %	56 100 %
FPAI	43 86.0 %	7 14.0 %	50 100 %
AFMC	34 85.0 %	6 15.0 %	40 100 %
Deepgruha	37 82.2 %	8 17.8 %	45 100 %
Total	168 88.0 %	23 12.0 %	191 100 %

The above table shows the difficulties faced by respondents in life. At SOFOSH, 96% respondents faced difficulties, at FPAI 86% respondents faced difficulties at AFMC 85% respondents had difficulties and at Deepgriha 82% respondents faced difficulties. Overall it is observed, that more than 85% of the respondents faced difficulties after being diagnosed as HIV infected.

Association between close relatives, regular income, education and difficulties in life was computed and there was no significant relationship found in education and income group and difficulties. Those who stay with family they approach family members at the time of difficulties.

Table 6.14a

Distribution of respondents showing types of difficulties in life

Name of NGO	Health related difficulty	Economic difficulty	Difficulty in relationships	Difficulty in family	Psychological difficulty
SOFOSH	43 76.8 %	42 75.0 %	24 42.9 %	18 32.1 %	33 58.9 %
FPAI	35 70.0 %	36 72.0 %	13 26.0 %	9 18.0 %	15 30.0 %
AFMC	29 72.5 %	26 65.0 %	18 45.0 %	12 30.0 %	12 30.0 %
Deepgruha	22 48.9 %	33 73.3 %	15 33.3 %	19 42.2 %	22 48.9 %
Total	129 67.5 %	137 71.7 %	70 36.6 %	58 30.4 %	82 42.9 %

Graph 6.2 Difficulties faced in life by the respondents

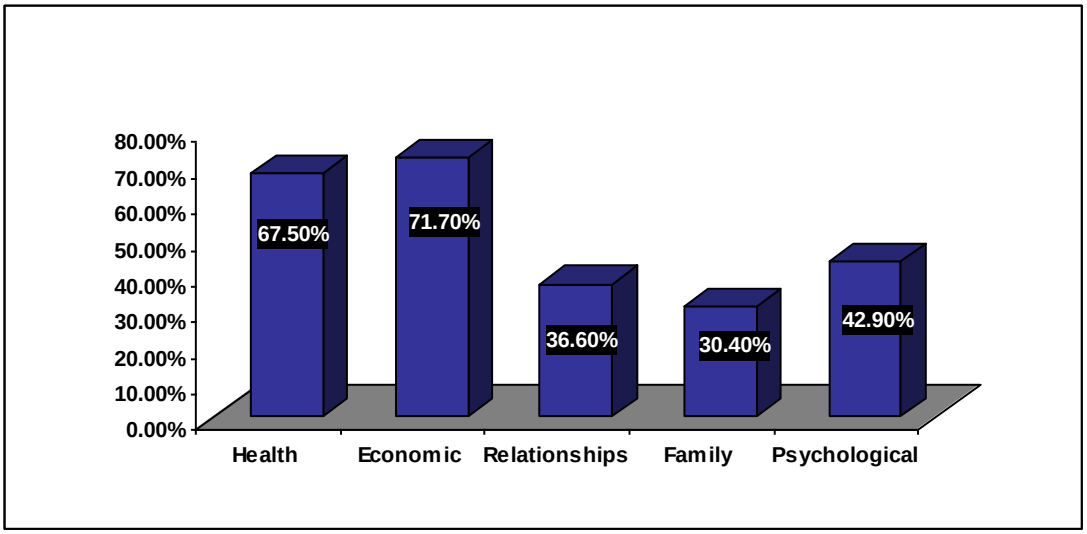


Table shows 72% of the respondents have reported to have economic/financial difficulties, followed by 68% of them have reported difficulties about maintaining health followed by 43% have reported to have psychological difficulties, 37% of the respondents found difficulties in maintaining relationships with the relatives and 30% have reported difficulties in family relations and related matters. Overall it is observed that there is a need for intervention in financial, psychological and health related aspects of respondents.

Case study 6.7: Couples efforts to combat with HIV

There is a very close link between poverty and HIV persons from lower socio-economic strata have to migrate in search of employment. They experience the vicious circle of poor food intake, poor quality of life, poor immunity, chances of risk behavior and being diagnosed as HIV. One can also observe from the description that support from family and good understanding between spouse and strengthen their coping abilities. Similarly support from NGO for nutrition and child's education also has helped Rukmini to survive.

Rukmini belonged to the lower socio-economic category. She was also illiterate, got married very early at the age of puberty. Her husband worked as a rikshaw driver and Rukhmini is a housewife. Rukhmini's husband developed severe symptoms of opportunistic infections of HIV; he was admitted to the hospital and got well. Rukhmini has 3 children, two of them are twins, from among the twins, and one female child is born with HIV. Rukhmini did not know her status, while she was pregnant. But later husband shared his status and they have presently good understanding about HIV and related illness. Eventually, Rukhmini developed opportunistic infections and her CD4 deteriorated below 50. She had fear of death, but then she followed the advice of doctors and health care professionals and now is on ART and doing well. It was due to support from her husband and from NGOs, Rukhmini could survive. She is a very smiling person. She has a worry about a daughter who is positive, she observes growth retardation in infected daughter, and she is not doing well in school also. But for her, it is important that they are all living together. Hence, health condition and family support both are important to face crisis of diagnosis of HIV. Rukhmini says, support, understanding by husband and support from professionals has helped her in coping with the reality. Her aim in life is to protect her infected daughter.

6.18 Respondent seeking help (approach)

At the time of difficult situation, we turn first to our family members. As far as possible we fight against difficulties with our own personal strengths and the resources and support in family. Before marriage, women have total support from

their parents, after marriage, they are expected to get support from partner and in-laws. Support is extended or we can approach the family members while in difficulties, only when, we are closely associated with them, or they are aware about the life events in our life. Close interaction, sharing among family members, is necessary to share joys and sorrows. It is a personal characteristic to approach any one for help at the time of crisis.

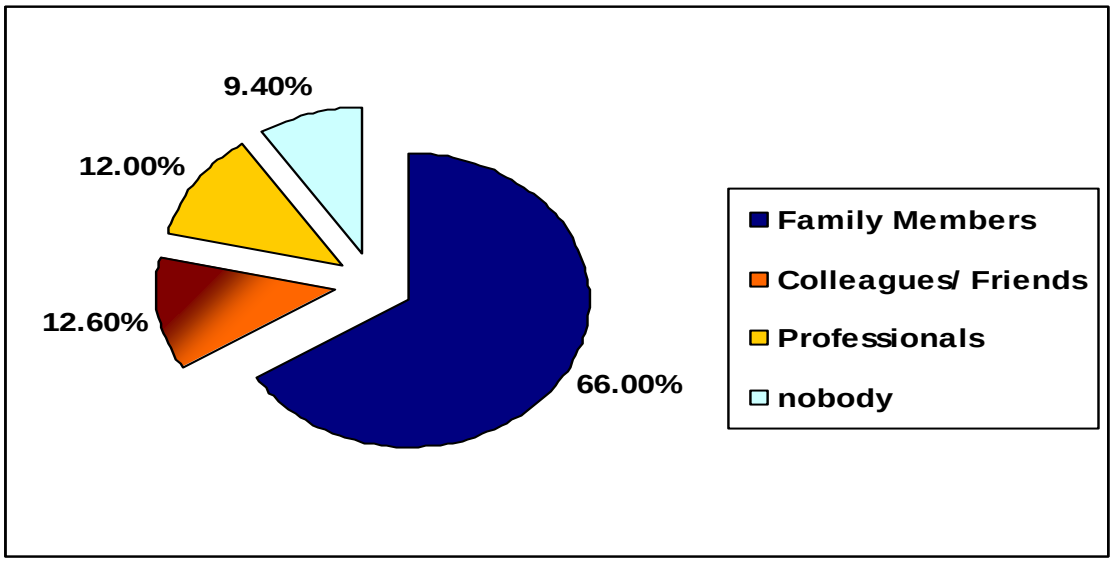
Table 6.15

Distribution of respondents according to help from persons

At the time of difficulties

NGO Groups	Approach at time of difficulties				Total
	Family members	Colleagues / friends	Professionals	Nobody	
SOFOSH	30 53.6 %	15 26.8 %	9 16.1 %	2 3.6 %	56 100 %
FPAI	34 68.0 %	4 8.0 %	6 12.0 %	6 12.0 %	50 100 %
AFMC	31 77.5 %	2 5.0 %	3 7.5 %	4 10.0 %	40 100 %
Deepgruha	31 68.9 %	3 6.7 %	5 11.1 %	6 13.3 %	45 100 %
Total	126 66.0 %	24 12.6 %	23 12.0 %	18 9.4 %	191 100 %

Pie chart 6.3 Respondents approaching persons at the time of difficulties



At all the NGOs, maximum number i.e. 66% of respondents has approached family members at the time of difficulties followed by 13% to colleagues and friends and 12% to professionals. Nine percent are observed who still do not approach anyone for help.

Table 6.16a

Major differences in the family V/s approach at time of difficulties

Major differences in the family	**Family Vs approach at the time of difficulties**				**Total**
	Family members	**Colleagues / friends**	**Professionals**	**Nobody**	
Yes	21 55.3 %	2 5.3 %	10 26.3 %	5 13.2 %	38 100 %
No	105 68.6 %	22 14.4 %	13 8.5 %	13 8.5 %	153 100 %
Total	126 66.0 %	24 12.6 %	23 12.0 %	18 9.4 %	191 100 %
Chi-Square value =	0.009				

It can be seen from the above table that though there were major differences in the family, the respondents have approached family members for support due to the strong family system. During any crisis situation we first approach to our family members.

6.19: Sharing feelings

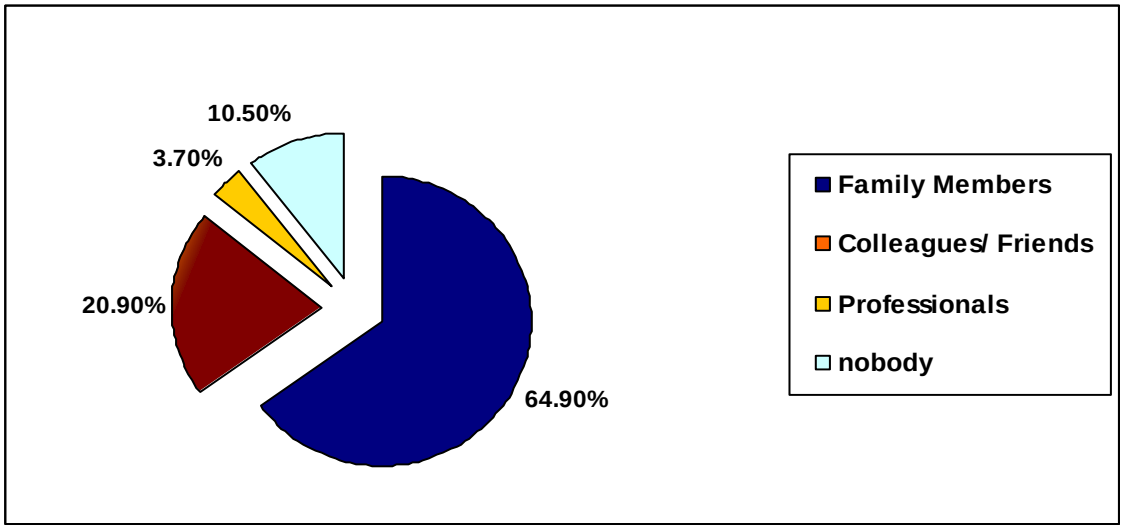
Normally individuals share feelings with the persons with whom they get along, they feel comfortable and those who are interested in them. In the family, there are spouse, children, parents and cousins with whom we share our feelings. We get the support and guidance to overcome the difficult situations. Especially in disability, stigmatized illness, life threatening situations we need someone to share feeling and seek support.

Table 6.17

Distribution of respondents reporting about sharing of feelings

NGO Groups	Sharing the feelings				Total
	Family members	Colleagues / friends	Professionals	Nobody	
SOFOSH	28 50.0 %	17 30.4 %	4 7.1 %	7 12.5 %	56 100 %
FPAI	36 72.0 %	10 20.0 %	1 2.0 %	3 6.0 %	50 100 %
AFMC	31 77.5 %	4 10.0 %	1 2.5 %	4 10.0 %	40 100 %
Deepgriha	29 64.4 %	9 20.0 %	1 2.2 %	6 13.3 %	45 100 %
Total	124 64.9 %	40 20.9 %	7 3.7 %	20 10.5 %	191 100 %

Pie chart 6.4: Respondents sharing feelings with



The above table shows at all NGOs, 65% of the respondents share their feelings with family members, followed by 21% with colleagues and friends and 11% did not share feelings with anybody. Association between relatives residing with the respondents and sharing of their feelings with them was computed and it was found that more than 65 % of the respondents share their feelings with the family members. Also it is

observed that there were very few professionals available for sharing of feelings with the respondents.

6.20: Problems as young widow

Young widow means, who has lost her husband prematurely. Women everywhere experience low status, gender discrimination and are made target of abuse, violence, harassment. Women are expected to have a male partner to protect them and it is assumed in marital relationship. After the death of spouse due to HIV they become widow or are deserted or are divorced and further lose their status and position in the society. In the absence of marital partner, women experience eve teasing, taunting and sexual harassment. Widowhood has a stigma, and how a woman has lost her partner becomes important here. HIV being stigmatized disease, when woman's status as widow and as HIV is known, people react like pity and hatred.

Table 6.18

Distribution of widow respondents replying that they have problems

NGO Groups	Being a young widow, do you have any problems		Total
	Yes	No	
SOFOSH	12 41.4 %	17 58.6 %	29 100 %
FPAI	2 8.3 %	22 91.7 %	24 100 %
AFMC	2 8.7 %	21 91.3 %	23 100 %
Deepgruha	14 56.0 %	11 44.0 %	25 100 %
Total	30 29.7 %	71 70.3 %	101 100 %

Above table shows, more than 60% of respondents reported to have no problems being faced by them due to their status as widow except at Deepgriha. It is observed that 30% had problems being widows. During the study, it was observed that in spite

of being widow women have continued the practice of wearing ‘mangalsutra’ and ‘Bindi’. Seventy percent of the respondents did not have problems being widow.

6.21: Personality of respondent

Personality indicates outer and inner characteristics of individual. Study was concerned about understanding inner characteristics of respondents i.e. like person’s emotional strength, motivation, perception, attitudes, problem solving ability, judgment and decision making, ability. These inner characteristics help us facing any difficult situation in life. Personality is made by the inputs he/she has received in the socialization process and realization of those strengths to face reality. Table shows responses of the respondents about their perception of their personality.

Table 6.19

Distribution of respondents describing own personality

NGO Groups	Perception of personality			Total
	Strong	Weak	No Response	
SOFOSH	36 64.3 %	20 35.7 %	0 .0 %	56 100 %
FPAI	22 44.0 %	25 50.0 %	3 6.0 %	50 100 %
AFMC	34 85.0 %	5 12.5 %	1 2.5 %	40 100 %
Deepgruha	36 80.0 %	9 20.0 %	0 .0 %	45 100 %
Total	128 67.0 %	59 30.9 %	4 2.1 %	191 100 %

Except for FPAI at 44%, other NGOs, more than 65% of the respondents responded they have a strong personality, and 31% respondents responded to have weak personality i.e. they were not emotionally strong. They need intervention. Relationship between the personality of the respondents and whom they do approach at the time of difficulties was computed and it was found that irrespective of their personality 67 % of the respondents reported to have strong personality and they approach the family members. Similarly personality and sharing of feelings also was

computed and it was found that though their personality was strong about 69 % of the respondents share their feelings with the families.

6.22: Attitude of society

Attitude is a point of view towards an individual. It is formed with experiences of a particular individual in terms of his behavior, thinking, interaction pattern, view points on a particular issue. Society's attitude means, attitude of relatives, friends, neighbours, colleagues. Those are formed as per our behavior, interaction with different members of the society. If we behave in a desirable manner, society does not interfere in our day to day life situations. If there are some abnormalities, problems seen, society looks at individual in a different manner. Table shows attitude of society towards respondent.

Table 6.20

Distribution of respondents describing attitude of society

NGO Groups	Attitude of society towards respondent				Total
	Excellent – better	Okay – can manage	Negative attitude	No response / Don't know	
SOFOSH	11 19.6 %	31 55.4 %	14 25.0 %	0 .0 %	56 100 %
FPAI	17 34.0 %	27 54.0 %	0 .0 %	6 12.0 %	50 100 %
AFMC	24 60.0 %	13 32.5 %	1 2.5 %	2 5.0 %	40 100 %
Deepgruha	12 26.7 %	26 57.8 %	4 8.9 %	3 6.7 %	45 100 %
Total	64 33.5 %	97 50.8 %	19 9.9 %	11 5.8 %	191 100 %

The above table shows 50% of the respondents reported attitude that they can manage and can live with it. Thirty four percent have reported excellent attitude. About 10% have reported negative attitude towards them. It was observed that, as the respondents experience stigma after disclosing their HIV status, they prefer to keep it confidential and therefore, 6% respondents have not responded to this question.

Attitude of society towards respondents was computed with the following variables.

1. Relationship with the partners
2. Mutual understanding with the partner
3. Difficulties faced in life
4. Personality of the respondents
5. Sharing of the feelings
6. Whom do the respondents approach at the time of difficulties
7. Discrimination at work place
8. Stigma

It was found that the 56 % of the respondents experienced satisfactory attitude from the society. There was no significant relationship found between mutual understanding and society's attitude. Regarding the stigma and society's attitude respondents have reported that though they experienced stigma they can still manage. About difficulties in life and the personality of the respondents it was observed that about 51 % of the respondents can manage and they have a strong personality. Irrespective of the society's attitude respondents share their feelings with the family.

6.23: Respondent's perception about rejection

Rejection is experienced by a person in difficult or in undesirable situations like addiction, alcoholism, extra marital relationships, gambling and violent behavior. People express rejection by obvious taunting, avoiding them in social gatherings. Individuals learn many things by seeking approval for their behavior and they do lot of efforts for it and getting membership in any group. Group provides us support, sense of belonging and opportunity for growth. If obvious rejection is experienced, individual may get totally lost and finds life meaningless. Being HIV patient, women experience stigma, discrimination and rejection.

Table 6.21

Distribution of respondents reporting rejection by family

NGO Groups	Rejection by family			Total
	Yes	No	Not disclosed	
SOFOSH	31 55.4 %	23 41.1 %	2 3.6 %	56 100 %
FPAI	13 26.0 %	29 58.0 %	8 16.0 %	50 100 %
AFMC	10 25.0 %	26 65.0 %	4 10.0 %	40 100 %
Deepgruha	18 40.0 %	26 57.8 %	1 2.2 %	45 100 %
Total	72 37.7 %	104 54.5 %	15 7.9 %	191 100 %

Above table shows after disclosing the HIV status, respondents did experience stigma hence, some of them have a tendency to hide their status. It is observed in the table, 55% of the respondents did not experience rejection by family 38% have experienced rejection about 8% of the respondents have chosen not to disclose their status, to avoid rejection.

Table 6.21a

Distribution of respondents reporting occupational categories V/s rejection by family

Occupational categories	Rejection by family			Total
	Yes	No	Not disclosed	
Labour	10 43.5 %	11 47.8 %	2 8.7 %	23 100 %
Service	18 64.3 %	10 35.7 %	0 .0 %	28 100 %
Housemaid	9 36.0 %	14 56.0 %	2 8.0 %	25 100 %
Housewife	13 24.5 %	34 64.2 %	6 11.3 %	53 100 %
Self employed	4 21.1 %	13 68.4 %	2 10.5 %	19 100 %
No Response	18 41.9 %	22 51.2 %	3 7.0 %	43 100 %
Total	72 37.7 %	104 54.5 %	15 7.9 %	191 100 %
Chi Square Value =	0.088			

Association between occupational categories and rejection by family and relatives staying with the respondent, age group, total number of children and rejection by family was computed. It was observed that those who reside with family do not experience rejection. Around 7 % to 8 % of those who are residing with family have not disclosed their HIV status and have not experienced rejection. Respondents do have the fear to get ostracized; hence somehow they manage to keep their HIV status a secret.

6.24: Discrimination at workplace

For any kind of employment, physical and mental fitness is necessary. No one generally discloses any disease, inability at the time of recruitment, unless medical examination is mandatory for joining the work. Women from lower socio-economic group are doing jobs like domestic worker, construction worker or vegetable vendor. The person diagnosed with HIV, experiences, guilt, shock and shame. People living with HIV, experience stigma and discrimination. In the 80's there was very low level of awareness about HIV and one of the reasons of contracting HIV is through hetero sexual mode of transmission. People perceive HIV persons as persons with lose character. However, since 1986, there have been a lot of awareness programmes at various levels, which have helped in reducing the stigma about HIV, in urban areas. But in villages and slums peoples still have reservations about interacting with HIV positive persons. Children infected with HIV are denied admissions in school. Each patient has different experiences of stigma and discrimination.

Table 6.22

Distribution of respondents reporting discrimination at workplace

NGO Groups	Discrimination at workplace			Total
	Yes	No	Not disclosed	
SOFOSH	15 26.8 %	29 51.8 %	12 21.4 %	56 100 %
FPAI	1 2.0 %	38 76.0 %	11 22.0 %	50 100 %
AFMC	0 .0 %	32 80.0 %	8 20.0 %	40 100 %
Deepgruha	4 8.9 %	29 64.4 %	12 26.7 %	45 100 %
Total	20 10.5 %	128 67.0 %	43 22.5 %	191 100 %

Table shows, most of the respondents were working as labour, on daily wages and as vendors, and there was no question of experiencing discrimination at workplace. Majority i.e. 67% of the respondents did not experience discrimination at workplace. There were 23% of the respondents, who did not disclose their status at workplace and another 11% were experiencing discrimination at the workplace. Majority of the respondents have responded that they do not experience stigma. As they were working on daily wage basis, while employing as house maid servant, very few details are sought about the persons, their earlier place of working and work habits are more important from the security point of view. Those who are in need of job, prefer to tell their expectations about monthly wages and holidays. During the discussion about nature of work, infected persons take care, that they do not infect others by remotest chance of interacting with others. Those who experienced discrimination prefer to keep it as secret. As a result they have not experienced stigma. It is a positive sign of acceptance of HIV patients. However, this is not a reality everywhere. Since last 15 years, now this issue is taken up as human rights issue and those who experience discrimination can fight through network of positive people. Feeling of insecurity and discrimination of work place were statistically analyzed and it was found that there is no significant relationship between the two.

Table 6.22a

Attitude of society Vs discrimination at workplace

Attitude of society towards	**Discrimination at workplace**			**Total**
	Yes	**No**	**Not disclosed**	
Excellent better	3 4.7 %	45 70.3 %	16 25.0 %	64 100 %
Okay-can manage	9 9.3 %	69 71.1 %	19 19.6 %	97 100 %
Negative attitude	8 42.1 %	7 36.8 %	4 21.1 %	19 100 %
No response / Don't know	0 .0 %	7 63.6 %	4 36.4 %	11 100 %
Total	20 10.5 %	128 67.0 %	43 22.5 %	191 100 %

The above table shows the interdependence between society's attitude and discrimination. About 42% of the respondents experienced discrimination and had negative attitude by the society. Those who do not have awareness about HIV/AIDS have misconceptions and they discriminate people living with HIV, they show negative attitude towards them.

6.25: Difficulty in school admission of children

Children born to HIV infected mothers are likely to give birth to infected child if interventions not sought. For admitting such children in schools, if their HIV status is disclosed, they are denied admissions. Peer, friends do not take children while playing. This happens, due to lack of awareness among school authorities. Ideally, no one should be discriminated, but in reality, experiences of women are shown.

Table 6.23

Distribution of respondents reporting difficulty in admitting children in school

No. of Children	Difficulty in admitting children in School				Total
	Yes	No	Not disclosed	Not Applicable	
0	0 .0 %	0 .0 %	0 .0 %	18 100.0 %	18 100.0 %
1 – 2	11 8.6 %	98 76.6 %	12 9.4 %	7 5.5 %	128 100.0 %
3-4	4 9.3 %	34 7913 %	4 9.3 %	1 2.3 %	43 100.0 %
5 and more	0 .0 %	2 100.0 %	0 .0 %	0 .0 %	2 100.0 %
Total	15 7.9 %	134 70.2 %	16 8.4 %	26 13.6 %	191 100.0 %

About 70 % of the respondents had no difficulty in admitting the children in the school. It is either the children were already admitted in school or respondents have not disclosed their status.

Case study 6.8 : Relation between coping and support group.

In earlier chapters, discussion about low social status of women has been done. In case of Parvati, she has been neglected by her grown up son. He wants share from her property but he is not ready to care for her. Property rights are given to women by law in our country, but it is hardly seen in reality. Parvati though is illiterate, is well aware about guarding her property and so stays in the same house suffering harassment by daughter in law. Her coping has improved tremendously after joining support group.

Parvati is forty five years (45) old widow, who has been diagnosed as HIV positive. She is illiterate and from lower socio-eco strata. Her husband died thirteen (13) years ago. Her both children are negative. Her daughter got married five years back and son got married a year back. After the death of Parvati's husband, she worked as a domestic worker and looked after the children. Children are aware about her status; however, they do not care for her. Presently Parvati suffers from opportunistic infections, and is on ART, but after her son's marriage, he obviously neglects and discriminates her daughter-in-law harasses Parvati. She experiences rejection being TB and HIV patient. In spite of all such ill treatment, Parvati has been staying in the same home, her son has left her. Now Parvati needs nutrition, medicines, care and support, financial support through government scheme. Parvati has the house as property on her name; her son wants Parvati to give over her right to him. Parvati feels this is the only support she has in her hands and is determined to fight for ownership of house. Parvati is now independent; she desires to help others who are suffering. After she has joined the 'support group', she feels, she has become more confident and wants to live for the cause of rights of HIV infected women.

6.26: Improvement in coping

It is expected that pretest, posttest, adherence counseling certainly improves coping, in terms of facing the life, accepting oneself as they are, maintaining own health, child's health, managing family matters effectively and become more stronger emotionally.

Table 6.24

List of responses mentioning the way coping has improved after counseling

Proper care taken, nothing will happen
Positive attitude towards life
Accepted situation, faced difficulties
Aware about self health
Became strong
Better acceptance
Better informed, positive attitude, confidence, normal life
Boost, support, mental support
Can express feelings
Change in view, not scared of illness
Could not tell
Could stand up because of counseling
Depression gone
Do not help
Do not talk with others, take only medicines for CD4
Do not think about illness, live for children
Doubts get cleared and helped to keep mind in peace
Feels calm, relaxed, good
Feels more strong, capable of handling life problems, positive approach
Get strength, motivation

Got confidence, got strength, joined job again,
Got importance of taking medicines
Got mind power
Increased self-confidence, got information
Live good life, no tension, take regular medicines,
Live happy life, do not think about illness
Mental support, got strength in decision making
No change
No need of counseling as I am not worried
No seriousness of illness, understands only taking medicines
No fear of death, if taken medicines
Not received
Positive living
Recovered from depression, feels relax
Recovering, cook myself, live for children
Still scared of death, but take proper care

This question was qualitative and multiple answers are there, the results are presented in the table form. The respondents have responded their coping has improved after counseling. Following is the list of responses.

- Positive attitude was developed
- Accepted reality
- Gained awareness about self care
- Developed confidence
- Change in attitude towards life

- Morale was boosted up
- Hope was built to live life with HIV
- Mental peace, feel relaxed
- Developed strength
- Decision making ability improved

Although majority of the respondents have responded coping has improved after counseling. There are few respondents who still have fear of death due to deterioration of health, some of them have not received counseling, intervention is necessary for these respondents.

6.27: Experience of funeral of husband

This information cannot be presented in table form. Few years ago when patient used to develop HIV/AIDS and opportunistic infection, gradually his/her condition used to get deteriorated, severe weight loss, loss of CD 4, count multiple infections and death was obvious. However, over the last 7-8 years, there are effective medicines to control HIV, to increase immunity; awareness among people has been improving. Hence the dreadfulness of the disease is reduced. Stigma is also comparatively less. Earlier when there was death due to HIV, certificate indicated opportunistic infection, people did not maintain confidentiality, somehow or the other people in the neighbourhood used to realize, death was due to HIV and they had a fear about, even touching the body. Earlier practice was body used to be wrapped in plastic cover. At such time people hardly used to attend last funeral and rites after death, women responded positively, that people in the neighborhood attended funeral and they were cooperative during the mourning period. This shows that gradually stigma is reducing.

Table 6.25

Experience of funeral of husband

Response	Frequency
Everybody came	41
Bad experience, relatives didn't come	3
Data not available	34
Didn't informed about death	1
Felt everything was over	1
Felt sad	4
Normal, clothes thrown in river	1
No one came, tied nose and mouth	2
Nothing, already left him, no contact, didn't attend	6
Suicide	2
Took from home hastily	3

Majority of the respondents have responded positively to this question. Few respondents did not give information on this question, some of the respondents had negative experiences like, relatives did not attend funeral, respondents felt sad, depressed after the death of the spouse and they did not inform the relatives, people showed hesitance to touch the dead body, they tied their nose and mouth, they were afraid of getting infection.

6.28: Support group membership

Support groups are the group of people suffering from common problems. In the process of getting diagnosis, taking treatment people infected with HIV meet at hospitals, NGOs and at other health care centres. They share their feelings; get to know more information about latest medicines and other facilities. They provide each

other emotional strength to each other. Being in the same situation, persons with HIV develop courage to accept diagnosis and develop ability to cope with it. Once they agree to form the group, they decide objectives, frequency of meetings, agenda and the venue of the meetings. As persons living with HIV talk to each other in group, they feel the need to be the member of this group.

Table 6.26

Distribution of respondents reporting that they are member of a support group

NGO Groups	Member of a support group		Total
	Yes	No	
SOFOSH	36	20	56
% within Name of NGO	64.3%	35.7%	100.0%
FPAI	38	12	50
% within Name of NGO	76.0%	24.0%	100.0%
AFMC	8	32	40
% within Name of NGO	20.0%	80.0%	100.0%
Deepgruha	25	20	45
% within Name of NGO	55.6%	44.4%	100.0%
Total	107	84	191
% within Name of NGO	56.0%	44.0%	100.0%

Support group, is a group of people suffering from similar problem. While the members come together, they realize, that they are not the only ones, who suffer the difficulties, this gives them support, strength and provides alternatives to face problems, it provides them a platform to share their feelings.

6.29: Help from support group

We live in groups; it provides us sense of belonging, support. Support groups are formed by women themselves. There was a time, when no patient would disclose status and was very reluctant to join any group activity. Through support groups, platform is provided to share, they all attend the activity on a stipulated day, as per

their convenience. Support group boosts up their morale and they are informed about resources, facilities and ways of coping with the reality.

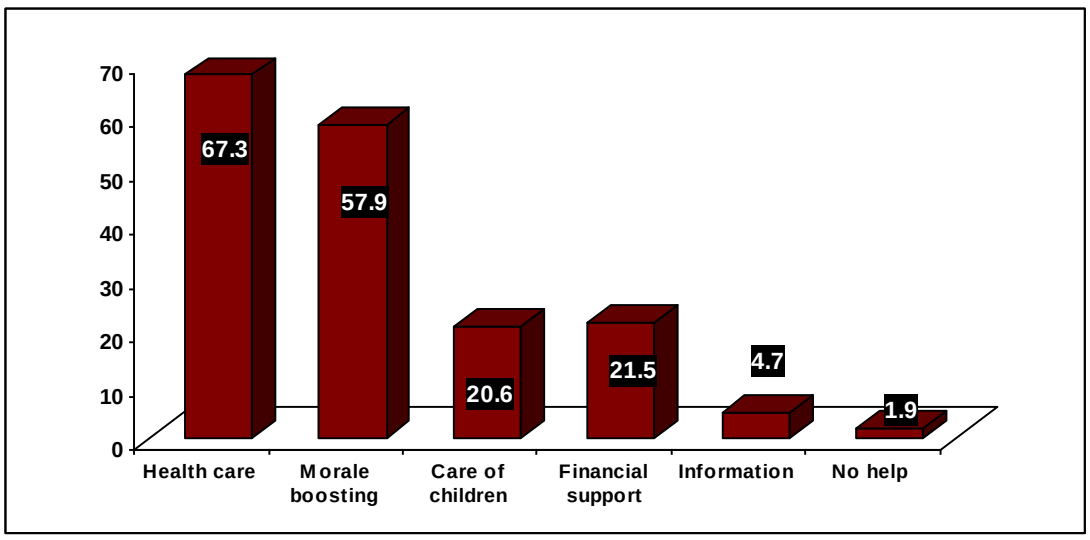
Table 6.27

Distribution of respondents reporting the way support group helps them (Multiple response)

Name of NGO	Help from support group						N
	Health care	Morale boosting	Care of children	Financial support	gets info	No help	
SOFOSH	27 75 %	16 44.4 %	10 27.8 %	6 16.7 %	5 13.9 %	1 2.8 %	36
FPAI	32 84.2 %	35 92.1 %	3 7.9 %	0 0 %	0 0 %	0 0 %	38
AFMC	2 25 %	1 12.5 %	1 12.5 %	5 62.5 %	0 0 %	0 0 %	8
Deepgruha	11 44 %	10 40 %	8 32 %	12 48 %	0 0 %	1 4 %	25
Total	72 67.3 %	62 57.9 %	22 20.6 %	23 21.5 %	5 4.7 %	2 1.9 %	107

N = Those who are member of support group as per table 5.27

Graph 6.3: Help of support group



6.30: Support provided at the time of anxiety

Support means in any happy or sad events, there is someone in the family or among the friends, who provide emotional strength, suggest alternative way to sort out the situation. Apart from emotional support, there is financial support, in any financial difficulty, person exhausts all resources and in the absence of any savings or policy, insurance, individual can only bank upon family members or friends. Social support means in a crisis situation, cooperation or at least attention to difficulty is expected. In case of women in social, emotional and financial difficulties, they turn to their parents or if possible to brothers.

Table 6.28

Distribution of respondents reporting support during anxiousness/ sadness/ depression

Name of NGO	Who gives support when anxious / sad / depressed				Total
	Family Members	Colleagues / Friends	Professionals	Nobody	
SOFOSH	46 82.1 %	0 .0 %	4 7.1 %	6 10.7 %	56 100 %
FPAI	41 82.0 %	6 12.0 %	0 0.0 %	3 6.0 %	50 100 %
AFMC	34 85.0 %	2 5.0 %	0 .0 %	4 10.0 %	40 100 %
Deepgruha	36 80.0 %	4 8.9 %	1 2.2 %	4 8.9 %	45 100 %
Total	157 82.2 %	12 6.3 %	5 2.6 %	17 8.9 %	191 100 %

The above table shows at SOFOSH, 82 % of the respondents receive support from family members while they are anxious, 7 % of them receive support from professionals and 11 % have reported they do not have anybody to turn to, for support while they are anxious or depressed. At FPAI, 82 % respondents reported to have

support from family members and 12 % receive support from colleagues and friends. At AFMC, 85 % respondents receive support during depression and anxiety, from family members and 10 % do not receive support from anyone. Respondents from Deepgriha, about 80 % of them receive support from family members, 9 % from colleagues and friends and 9 % from no one. This indicates, to share feelings and provide support, respondents do require help.

Association between the personality of the respondent and who provide support while respondents are anxious of depressed was computed. It was found that irrespective of the personality type in maximum cases family members are providing the support when the respondents are anxious and depressed.

Case Study 6.9 : Disclosure of HIV to children

Yashoda 40 year old unskilled, illiterate widow is HIV positive. She works as a domestic worker. Her son and daughter are positive. Her son developed meningitis. Now all three of them are on ART. For last 7-8 years Yashoda is taking care of her both HIV infected children. She has no support from both parents and in-law's family. Yashoda's elder son used to work in shop, worked for delivering newspaper and washing cars. But now he is studying in college with educational sponsorship. Now infected children Nitin and Priya blame Yashoda for infecting them with HIV. Yashoda feels very sorry for this, she cries, gets depressed. She feels, for all 7-8 years she has been caring for infected children but they do not realize it, that they are surviving because of the care being provided by the mother. She repents for her thankless job now. As a result of childrens' anger, Priya does not share any responsibilities at home. Elder brother is fed up with the health problems and conflicts of the three infected persons in the family. Now he also wants to shirk the responsibility. In this situation Yashoda is fighting at all fronts alone. She has to look after her own health, stress and other responsibilities; she is concerned about children's reaction to HIV and how to handle them. She feels she has no one to listen to her.

6.31: Caring while feeling irritated

Person experiences guilt, shame, depression anxiety, loneliness and anger after being diagnosed as HIV, he expects to have somebody to share feelings. In our culture,

expressing emotions is not seen. Especially, though women are expressive, they are supposed to be tolerant about behavior of family members, spouse, and children. As they suppress emotions, they further experience stress, irritation, frustration and a feeling of 'why me'? Generally when person is irritated, he can share or can throw irritation of the one who is most nearest or who can support the affected one.

Table 6.30

Distribution of respondents reporting who takes care when they are irritated

Name of NGO	Takes care when irritated				Total
	Family Members	Colleagues / Friends	Professionals	Nobody	
SOFOSH	45 80.4 %	0 .0 %	2 3.6 %	9 16.1 %	56 100 %
FPAI	35 70.0 %	5 10.0 %	2 4.0 %	8 16.0 %	50 100 %
AFMC	32 80.0 %	1 2.5 %	0 .0 %	7 17.5 %	40 100 %
Deepgruha	32 71.1 %	0 0.0 %	2 4.4 %	11 24.4 %	45 100 %
Total	144 75.4 %	6 3.1 %	6 3.1 %	35 18.3 %	191 100 %

The above table shows that at SOFOSH, 80 % of the respondents have responded to have been cared by family members. There were 16 % of the respondents who did not have any one to take care while respondents were irritated. At FPAI 70 % of the respondents reported family members take care while they were irritated and 18 % did not have anyone. At Deepgriha, 71 % respondents reported availability of family members, but 24 % respondents did not have any one to take care during emotional upsets.

Relationship between care offered to the respondent while she was irritated was computed with following variables:

1. Age
2. Income
3. Close relatives
4. Feeling of insecurity

5. Mutual understanding
6. Who do they approach at the time of difficulty
7. Attitude of society towards respondent
8. Rejection by family

It was found that majority of the respondents are being taken care of while they are irritated by their family members. Very negligible percent of respondents reported (29 %) to have nobody to care for them while they were irritated.

6.32: Help to respondent

Social support is sought by sharing problem, feelings, and crisis situation with the person, who can understand better, empathize and care for the affected. Support is expected from the dear ones i.e. spouse, parents, friends, and children. If there is good rapport, communication, it is easy to seek support. We have some of our relatives or friends, who provide support, cooperation, resources while we are in difficulties. The help is expected in the form of sharing, monetary help or guidance about decision making.

Table 6.31

Distribution of respondents reporting who might take risk and helps them in a difficult situation

Name of NGO	May take risk and helps you when in a difficult situation				Total
	Family Members	Colleagues / Friends	Professionals	Nobody	
SOFOSH	48 85.7 %	0 .0 %	2 3.6 %	6 10.7 %	56 100 %
FPAI	42 84.0 %	5 10.0 %	1 2.0 %	2 4.0 %	50 100 %
AFMC	35 87.5 %	1 2.5 %	1 2.5 %	3 7.5 %	40 100 %
Deepgruha	37 82.2 %	1 2.2 %	1 2.2 %	6 13.3 %	45 100 %
Total	162 84.8 %	7 3.7 %	5 2.6 %	17 8.9 %	191 100 %

The above table, in seeking social support one expects help to the extent, that one can take the risk, will not care for the time, money or resources are being spent for the

person in crisis. In the above table at SOFOSH, 86 % respondents reported this kind of help being provided by family members at all four NGOs, maximum i.e. 83 % have received help from family members. There are 11 to 13 % of respondents who reported to have no one to take help. As stated earlier, family is the only place where unconditional love is expressed at difficult times or at critical situations. Respondents also have reported that they had a tremendous support from the family members to the extent that may take risk and help the respondents.

6.33: Unconditional love experienced by respondent

Unconditional love means irrespective of your biases about a person in terms of difficult situations like, addiction, gambling, marital problems, alcoholism, violence you love the person. Unconditional love is expressed irrespective of sex, age, relationship, disability, disease condition. The person is accepted as he or she is. While anyone gets diagnosed with HIV, society, family members, colleagues discriminate him or her. They look down upon person's character and reject him. Yet there are few individuals, who have a personal quality to empathies, a quality of being sensitive, matured, and they being nearest relative or friend, love the person unconditionally, this is one of the criteria of social support.

Table 6.32

Distribution of respondents reporting who loves them unconditionally

Name of NGO	Loves respondent unconditionally				Total
	Family Members	Colleagues / Friends	Professionals	Nobody	
SOFOSH	52 92.9 %	1 1.8 %	0 0.0 %	3 5.4 %	56 100 %
FPAI	42 84.0 %	5 10.0 %	1 2.0 %	2 4.0 %	50 100 %
AFMC	36 90.0 %	1 2.5 %	0 .0 %	3 7.5 %	40 100 %
Deepgruha	41 91.1 %	1 2.2 %	0 .0 %	3 6.7 %	45 100 %
Total	171 89.5 %	8 4.2 %	1 0.5 %	11 5.8 %	191 100 %

Family is the basic unit of the society. It comprise of husband wife and children. Family provides most of the care, love, attention to its members and fulfill most of our basic needs in family. The base of family is that in all crises or in happy moments all of the family members will be together. There is love, care, sharing, joy and unconditional acceptance for its members. An effort was made to understand being a HIV patient, a woman respondent who loves her unconditionally, and obviously it is seen almost in more than 80 % cases family loves them unconditionally.

From the above table it is seen, that in SOFOSH, 93% of the respondents have responded that family members love them unconditionally, followed by 84% at FPAI and 90% of the respondents have responded family members are the one, who love the respondent unconditionally and at Deepgriha also same observation is seen i.e. 91% are loved unconditionally and they are the only support in difficult situation. Association between respondent's personality and the unconditional love they receive, was computed and it was found that irrespective of their personality type, they are unconditionally loved by family members and they are the sole support to the respondents.

6.34: Dependence for assistance

In any crisis situation, we turn to family members, they generally help us throughout our life in 'bad' or 'good' times. Any difficult situation is first shared with parents during childhood, with spouse after marriage, if there is desirable communication, we can expect any emotional help, financial help or cooperation, we turn to family.

Table 6.33

Distribution of respondents according to dependence for assistance

Name of NGO	Can depend for assistance / help				Total
	Family members	Colleagues / friends	Professionals	Nobody	
SOFOSH	49 87.5 %	0 .0 %	1 1.8 %	6 10.7 %	56 100 %
FPAI	40 80.0 %	5 10.0 %	1 2.0 %	4 8.0 %	50 100 %
AFMC	36 90.0 %	1 2.5 %	0 .0 %	3 7.5 %	40 100 %
Deepgruha	32 71.1 %	1 2.2 %	6 13.3 %	6 13.3 %	45 100 %
Total	157 82.2 %	7 3.7 %	8 4.2 %	19 9.9 %	191 100 %

At all the four NGOs more than 70% respondents have responded they can depend on family members for assistance during difficult times, those family members are from parent's family.

6.35: Meeting the relatives

In our families, we meet, share, seek cooperation, support, over meetings, depending on frequency of meetings, family members know the activities of their relatives. We share both joys and sorrows; get guidance, suggestions, and alternatives for difficulties. We ventilate our feelings, some relatives live in same town but some live at distant places. Intimacy depends on the emotional bonding between family members. Qualities like sensitivity, maturity, empathy, are necessary to have unconditional love. Being infected with HIV, patients feel they are stigmatized, rejected, as people realize their status, they decide to reduce the frequency of visits.

Table 6.34

Distribution of respondents reporting that relatives met recently

NGO Groups	Relatives meet recently		Total
	Yes	No	
SOFOSH	37 66.1 %	19 33.9 %	56 100 %
FPAI	34 68.0 %	16 32.0 %	50 100 %
AFMC	33 82.5 %	7 17.5 %	40 100 %
Deepgruha	29 64.4 %	16 35.6 %	45 100 %
Total	133 69.6 %	58 30.4 %	191 100 %

After knowing the HIV status, of respondents more than 65% of the respondents have continued to meet, visit their relatives, this shows that gradually 'stigma' is being reduced, however there were 30% of the respondents who have not visited their relatives, after knowing their HIV status. It is observed, that especially after death of the husband women experience discrimination and taunting. They are expected to present, behave like a widow, they are asked number of questions about sudden death of the husband, instead of answering to questions they prefer to reduce number of visits to the relatives.

6.36: Referral to NGO

During the pretest and posttest counseling, patients are provided guidance about health care, sharing of feelings, and nutrition, financial help and care for children. There are counselors and doctors who refer patients to NGOs, for help.

Table 6.35

Distribution of respondents reporting who referred them to NGO

Name of NGO	Who referred to NGO				Total
	Family members	Colleagues / friends	Professionals	Nobody	
SOFOSH	1 1.8 %	7 12.5 %	48 85.7 %	0 .0 %	56 100 %
FPAI	1 2.0 %	8 16.0 %	39 78.0 %	2 4.0 %	50 100 %
AFMC	1 2.5 %	1 2.5 %	37 92.5 %	1 2.5 %	40 100 %
Deepgruha	4 8.9 %	10 22.2 %	30 66.7 %	1 2.2 %	45 100 %
Total	7 3.7 %	26 13.6 %	154 80.6 %	4 2.1 %	191 100 %

After knowing the HIV status, the respondents experienced discrimination and no support. At such times, at SOFOSH, 86% of the respondents reported that they were referred to NGO by professionals. At FPAI 78% of the respondents were referred to NGO by professionals. At AFMC 93% of the respondents were referred to NGOs and at Deepgriha 68% of the respondents were referred to NGOs.

6.37: Kind of services from NGOs

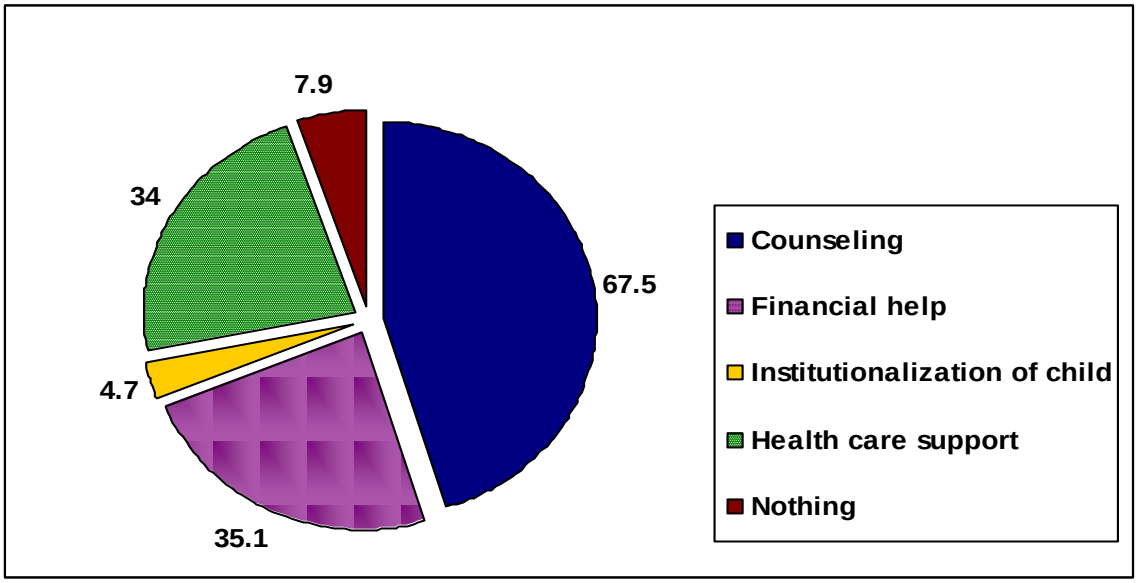
The social support, in terms of emotional sharing, cooperation, and financial help is not received from family, relatives and friend's circle. The affected person gets information from outpatient departments of the hospitals about various NOGs working for HIV patients, which provide counselling services, nutritional help, legal help and help for care for children. This information also is shared during post test counselling by counselor. Following table shows the kind of services they seek from NGOs.

Table 6.36

Distribution of respondents reporting the services received from NGO

Name of NGO	Counseling	Financial help	Instituio-nalization of child	Health care support	Nothing	N
SOFOSH	46 82.1 %	32 57.1 %	2 3.6 %	16 28.6 %	2 3.6 %	56 100 %
FPAI	44 88.0 %	13 26.0 %	0 .0 %	12 24.0 %	3 6.0 %	50 100 %
AFMC	5 12.5 %	2 5.0 %	0 .0 %	27 67.5 %	10 25.0 %	40 100 %
Deepgruha	34 75.6 %	20 44.4 %	7 15.6 %	10 22.2 %	0 0.0 %	45 100 %
Total	129 67.5 %	67 35.1 %	9 4.7 %	65 34.0 %	15 7.9 %	191 100 %

Pie chart 6.5: Services received by the NGOs



At SOFOSH, 82% of the respondents have reported to have counseling and 57% received financial help, at FPAI 88% have reported to have received counseling service. At AFMC, significantly only 13% of the respondents have reported to have received counseling, and 68% have reported to have received health care support. At Deepgriha 76% of the respondents have received counseling and 44% have received

financial help. Overall 68% of the respondents have received counselling and 35% respondents have received financial help.

6.38: Visits to NGO

There are number of NGOs working in the field of HIV/AIDS, at National, State, District levels. They work at preventive level in terms of spreading awareness, in condom promotion programmes. Some work at curative level, they provide counselling, nutritional help. Some provide rehabilitative services like income generating activities and help for institutionalizing children, legal advice, and now there are networks of people living with HIV. All these NGOSs have their own way of functioning. They arrange meetings once in a month or twice in a month.

Case study 6.10 : Stigma and rejection

Meena 37 year old, illiterate woman from a poor family got married at the age of fifteen. She lives in joint family. She has two sons and one daughter. Her daughter is now married. Meena's husband suffered HIV/AIDS. When her husband was diagnosed, he started avoiding her, he never returned home at nights. He passed away six years ago. Husband suffered opportunistic infections and within a year he died. He did not share his HIV status with Meena. Presently she is working as a peon in one school. She has not disclosed her status being positive while getting job in anticipation of fear of stigma and discrimination and not disclosed it while getting married her daughter. Meena's family members at natal family and in-laws also are supportive. She is allowed to work in home, except for preparing food, but that she justifies that she takes care to avoid transmission of HIV. Since two years Meena was diagnosed HIV, she collapsed, she had a fear of death, she cried, she was depressed, but after she took help from professionals, she could gain confidence, her hopelessness changed into positive outlook. Her coping mechanism has been, praying, listening to music, talking to people. When she joined the support group, and listened to the problems of others, she realized her strengths. She feels importance of joining support group activities. It can be seen, that though Meena belongs to lower socio-economic category, her family support was strong, so coping was better.

Case study 6.11: Effect of support.

Sunita, HIV positive widow, illiterate, was admitted in one of the hospitals in Pune for opportunistic infections of HIV/AIDS. Her husband also had died due to HIV, however Sunita did not know the reason for his death. Sunita has one daughter 'Gauri' who is HIV negative. Sunita was very anxious, disturbed, depressed due to the knowledge of HIV, reason for husband's death and her own status. Sunita was helped through counseling. She did not have support from both families. She was economically poor and had the responsibility of her daughter. She was helped to accept the diagnosis and suggested to join the support group. She attends the meetings of support group very regularly. In one of the support group meetings a resource person from PLWHA people living with HIV/AIDS was invited. Resource person explained the group members, importance of developing confidence, being independent and overcoming the anxiety of being HIV positive. Sunita was offered a job. She worked very well. Sunita is on ART. She now looks after herself very well and she has started a shop of her own at Khadakwasla. Support group meetings and counseling has helped her to cope with the reality and face the situation confidently.

Table 6.37

Distribution of respondents describing frequency of visiting NGO

Name of NGO	How often do you visit NGO				Total
	Daily / State at NGO	<= once a month	As and when required / more than once a month	No response	
SOFOSH	0 .0 %	51 91.1 %	5 8.9 %	0 .0 %	56 100 %
FPAI	1 2.0 %	34 68.0 %	12 24.0 %	3 6.0 %	50 100 %
AFMC	4 10.0 %	28 70.0 %	2 5.0 %	6 15.0 %	40 100 %
Deepgruha	13 28.9 %	18 40.0 %	14 31.1 %	0 .0 %	45 100 %
Total	18 9.4 %	131 68.6 %	33 17.3 %	9 4.7 %	191 100 %

The above table shows, that about 91% of the respondents at SOFOSH, visit NGO once in a month, at FPAI 68% have reported to visit once in a month at NGO, at AFMC 70% of the respondents have reported to visit once a month and at Deepgriha 40% of the respondents visit NGO once a month, 31% respondents visit the NGO more than once and 29% have responded to visit daily, they visit NGO. The frequency of visit depends on the needs of the respondents and the services offered to them by NGOs.

From the cases explained, it is clear how the women respondents experienced stigma, vulnerability to infection, inadequate resources while living with HIV. Similarly, there was no support from in-laws as well as parental family, they had multiple responsibilities, and they have suffered multiple opportunistic infections and the problems in communication between the spouses and disclosure about HIV status in the family

6.39: Summary :

This chapter provides an understanding about stigma and support experienced by the respondents. It starts with the respondent's reaction after diagnosis. Respondents did feel loss of self-esteem after being diagnosed as HIV. They have shown reaction as being depressed, loneliness and fear of death and stigmatization. Women respondents' major source of infection was from the spouse. They do not communicate their HIV status till they develop very severe opportunistic infections. Women have reported the communication gap between the two of them. Relationship was also strained. Ideally speaking if there is an understanding about HIV diagnosis, both of them are supposed to take precautions to prevent the further infection and complications. Women have shown reluctance to talk about this topic. Women did not have pressure to undergo pregnancy after being diagnosed HIV. They did not have any doubt about the sexual behavior of the husband. The kind of social milieu the women live, hardly can talk about these issues. Marital status has provided the respondent the feeling of security. It was observed, women have accepted the husband with all their undesirable behavior and habits. They have very little control over any decision that takes place in family. Infection to children is explained further. As a precautionary measure, all women in ante natal care are presently undergoing HIV test. If blood is tested positive, appropriate intervention is done. During the crisis, respondents have taken

support from family. Respondents do experience stigma in some cases they have kept their status confidential and those who live in cities, have comparatively less chances of experiencing stigma. They faced difficulties, especially financial difficulties and health related difficulties. However, few respondents had difficulties in maintaining relationships. In such difficult situations, mostly the respondents have approached family members who love them unconditionally and they prefer to share feelings with them. Respondents have responded to have their personality as strong one and though some of them were young widows, they could manage with the society's attitude towards them. The kind of work respondents were doing, they did not experience discrimination and have now learnt to keep it as a secret. Even they had no difficulty in admitting their children in school. Earlier people had fear to attend funeral of a person, died of HIV, but now gradual change in attitude is seen and respondents received cooperation from the relatives and neighborhood. Counselling plays a significant role in improving coping of the infected person and they have responded positively in this regard. Support group improves capacity to face the difficulties in life. Support group's contribution to respondent is explained. Overall observation is, that at all difficult situations, crisis, respondents have approached the families for support.

CHAPTER VII

SOCIAL WORK INTERVENTION

7.1 Social Work intervention.

Concept of intervention

7.2 Methods tool, techniques

7.3 Intervention on studies and their methodology

Need of HIV infected

7.4 Intervention and coping mechanism

7.5 Tests used

7.6 Pretest data.

7.7 Intervention

- Health-self care
- Coping
- Stress Management
- Adjustment
- Quality of life
- Life skills
- Time Management
- Parenting
- Disclosure of HIV
- Anger Management
- Financial Management
- Spiritual health for morale boosting.

7.8 Summary

CHAPTER VII

SOCIAL WORK INTERVENTION

7.1 Social Work Intervention

Introduction:

There are difficulties, problems and unforeseen events in human life, that requires intervention. The dictionary (Sahni 2001) meaning of intervention is, to come in between to mediate. This mediation is necessary to come out from the difficult situation. Social work intervention has been defined as a profession which promotes social change, problem solving in human relationships. It promotes empowerment, liberation of people and enhances wellbeing (Steven Walker 2003). Social work utilizes theories of human behavior and social systems; it intervenes at the point, where people interact with their environment. Principles of human rights and social justice are fundamental to social work. Social workers provide interventions to industries, families, individuals and groups in order to assist them with their needs and issues. Interventions aim at helping the clients in alleviating problems impending their well-being. Hence, social workers require a sound knowledge of social work intervention. Social work operates in an environment of competing professionals like psychologists, health care professionals and health science personnel. A unique characteristic of social work is that its multi-disciplinary knowledge base, skills in dealing with people, methods of social work, empathetic understanding of the person in need of help and resourcefulness, for extending required services for the clients. Social worker takes a holistic view of a person's life and situation; he assesses the need and offers the support and care.

7.2 Methods, Tools, Techniques

a. The key characteristics of social work.

- Social work focuses on person's life, their social context and environment.
- Social work believes in building trust with the person in need of help and then extends help.
- Social workers are often engaged in handling difficult, risky situations.
- Social workers need to possess qualities like sensitivity, empathy, persuasion, persistence, resourcefulness, interest in working with people and maturity.
- Social work professionals are expected to follow principles and ethics.

- Social workers work for establishing equality, justice and to protect the human rights especially for the marginalized groups.

In all, there are six methods of social work, those are, case work, group work, community organization, social action, social welfare, administration and social work research. In the present study, intervention was done, and mainly case work, counseling and group counseling was used. Let us understand principles of case work. Acceptance, by acceptance of problem and person, counselor develops warm, trusting relationship with the client; client also is helped to accept his problem. Another important principle is non-judgmental attitude; this provides unconditional positive regard for the person / client. Confidentiality, i.e. keeping the information confidential which is sought from client, the right of self determination, that is, it believes the capacity of the individual to solve his problem and the last but very important principle is individuality of a person, that is each individual is unique. He has different capacities, social cultural context. Counselors help clients to ventilate their emotions, but with controlled emotional involvement in the client's problems.

b. Case work method has tools like communication, home visit, interview, intake sheet and recording, and to name the few techniques are, assurance, facilitation of expression of feelings, empathy, reality orientation, use of guilt feeling, building confidence, providing emotional support, motivation, counseling, providing material resources, correcting perception etc.

c. Group Work – Group living is a tendency of human beings, they feel security, belongingness, they learn a lot through group living experience. People get support while they are in a group. We are born and brought up in family as a group, we learn patterns of behavior, norms in group, working with group is one of the methods of social work, as stated earlier. This method also has following principles.

- Every group has a specific objective – Through that group members work and achieve them.
- Planned group formation – Those who wish to come together think about objective and plan to form a group.
- Purposeful relationship – Group worker is well aware about the reason of group meeting to build specific relationship for specific purpose.

- Guided interaction – Group worker is well aware to guide interactions among group members to achieve the expected objective.
- Progressive programme planning – Group worker organizes series of activities to achieve objective and implements them.
- Democratic decision making – Group members have the control over decision regarding programme planning, implementation and achieving the objective.
- Flexibility – As stated earlier, every individual is unique, while we are in group, each one needs to exert their interests, opinions about planning and implementation of activities, group worker needs to be flexible to accommodate every member and each one be given opportunity to participate.
- Continuous evaluation – As every activity is planned, it is essential to take feed back to know, how far objective is achieved, so that it will provide guideline for further planning.
- Resource utilization – Group worker can use internal resource from among members or from outside group. He needs to be resourceful and having good social network.

Group work method also uses following tools:-

- Group work as an instrument for change and development.
- Use of relationship.
- Conflict resolution.
- Verbal and non-verbal communication.
- Purposeful creation of environment.
- Fishbow technique.

In the present study, researcher has used case work, group counseling / group work method, and has done pre intervention and post intervention study of coping mechanisms of HIV infected women.

7.3 Intervention studies and its methodology: Methodological problems of home based intervention research suggest key issues as follows (Susan Grayatal 1980).

(a) Congruence between goals and methods.
(b) Sample selection and retention.
(c) Measurement and design.

Researchers found it difficult to decide about goals, sampling, comparison, design measures and analysis. In another study (Garry Troia 1999) problems of intervention studies are described as, inadequately described samples, poor measurement sensitivity. Methods for comparing event rates in intervention studies when the unit of allocation is a cluster, standard statistical methods are not appropriate for these designs (Allen Donner and Nell Klam 1994).

Interventional studies are often performed in laboratories and clinical studies to establish beneficial effects of drugs or procedures. The main intervention study design is the randomized controlled trial (www.healthknowledge.org 2012). In a study conducted to measure the impact of water supply and sanitation investments or Diarrheal Diseases (Deborah Blum 1983) it was observed that several methodological problems hampered drawing the definite conclusions. It was revealed, that there were eight methodological problems like, lack of adequate control, the one to one comparison, confounding variables health indicator recall, health indicator definition and failure to analyze by age, failure to record usage and the seasonality of impact variables. In a study by Nelson – Zlupko et al., on gender difference in drug addiction and treatment implications for social work intervention with substance abuse women, drug use was a coping mechanism used by women and it helped them to identify unhealthy and oppressive stressors. It was suggested that social workers can use their advocacy and outreach skills for these clients.

Elements of Coping are stated as follows:-

- Control - while facing any unforeseen event or even day today life event, if the person can control his reactions and respond appropriately.
- Relaxation – Even under difficult circumstances , person can think in a relaxed manner, it indicates desirable coping.
- Self efficacy – Person having emotional, strength, can handle difficult situation and cope well.

Important elements for successful coping in the context of HIV (ipopi.org 2012)

1. Be knowledgeable about disorder .
2. Maintain positive attitude.
3. Accept limitations and bring change in one's life style.

4. Have a support system.
5. Have a healthy spiritual life;
    - Ego strength
    - Self confidence
    - Realistic perception of self
    - Role clarity
    - Patience
    - Determination
    - Acceptance of reality
    - Social attractiveness, meaning being cheerful, friendly, having emotional maturity and sincerity (ipopi.org2012).

7.4 intervention and Coping mechanism: There are two distinct literatures contributed to tremendous growth of interest in coping. The first consists of descriptive studies that have used coping checklist. This literature is in crisis because of its failure to yield substantive findings concerning the role of coping in adaptation that cannot be dismissed as truism, trivia or the product of confounding of stress, coping and distress. The second literature concerns intervention to improve adaptation by enhancing coping. It provides evidence of the efficacy of intervention but provides little understanding of crucial ingredients, mechanisms of change or barriers to maintaining gains. Both literatures would benefit from cross fertilization process studies of interventions designed to improve coping provide an alternative to fruitless and potentially misleading correlation studies using checklist. Such studies help in understanding and refining intervention strategies (Coyne, James et al 2000).

While intervening, counseling, client's reactions are seen as, disbelief, anger, bargaining, denial and then finally acceptance. Shock is expressed in very many ways like stunned silence, crying and anger towards self and others. This emotional distress is to be handled. Other problems that accompany HIV infection like stigmatization, rejection and loss also can cause emotional distress. Emotional turmoil is seen and adjustment with changed situation becomes difficult. Several studies have demonstrated that a negative emotional status affects the PLWHA'S CD4 count adversely (Burak, et al 1995) client needs to be motivated to develop a positive mental attitude. In this situation, client needs ventilation of feelings. Counsellor needs

to generate help and support from the family and friends to establish emotional stability as follows:

- **Issue of partner notification and disclosure** - Partner notification and disclosure of one's positive status to others poses a big problem for PLWHAs. They fear rejection and ridicule about risk behavior. Fear of consequences like loss of trust and intimacy, anger, betrayal and rejection inhibits many people from disclosing their HIV status. Counsellor is expected to help the client to disclose his / her status if he / she so desires.
- **Health maintenance plan** – one of the tasks of counselor is to help the client form a plan to maintain health after being infected with HIV. For this, client needs to understand and accept the need for plan. This plan should consider life st yle of the client, health condition, assess the need to change, network with other organizations.
- **Self help groups** – This can be of great help, these groups provide a platform for sharing. Group of women can be formed with their participation and consent. Group provides an opportunity for universalization, which itself is so soothing, that infected person can accept oneself better. While sharing women learn how others are living with HIV, their concerns and their ways of coping and problem solving. In few of the NGOs, under study such groups were formed, there is still a scope to form such groups, researchers has met respondents in 2, 3 meetings and has provided intervention on suggested topics.
- In the present intervention study, in the 1st phase, itself women participants shared lot of feelings like denial, shock, and finally acceptance. Researcher talked to respondents, she provided them empathetic understanding about their conditions. The very intervention situation provided the respondents a platform for sharing their concerns, fears, respondents could feel total non-judgmental attitude, by saying whether interviewer was aware of HIV status of the respondents.
- This unconditional positive regard helped respondent to respect herself as a person, and right to live happily. While discussing different aspects of tests, respondent expressed unawareness about many concepts during data collection period, like stress, mechanisms for coping, self identity, happiness, pleasure,

and positive qualities in her personality. Interview provided an opportunity to listen to respondent's concerns about her own health, care of children, availability of support at family of in-laws and at parents' family. There was lot of exchange of health messages on self care, hygiene, about handling emotions, about being an HIV patient. This relationship itself provided warmth and unconditional positive regard to respondent which helped in understanding her coping mechanism. Respondents were given credit to what, how they are coping with situation. Individually, respondent expressed how encouragement by counselors and interviewer has provided them an opportunity, for confidence building while interviewing, respondent was assured about confidentiality which helped in sharing most intimate events from her life. While the study was being undertaken, there was no control over the other resources i.e. help that was being received from respondents. However, respondents have shared, the way researchers were interacting in a very matured way, most of their queries were answered this helped in increasing motivation and provided encouragement. They could learn the new concept like quality of life and the way the smallest thing in life can give us happiness and pleasure. Even many of women were not aware about their personality characteristics and strengths. During interview session, they realized how they have developed strength to face reality, by living with HIV/AIDS.

As stated earlier, along with the interview schedule following five psychological tests were used. Test description is as follows:

Psychological Tests

1) Adjustment Test
2) Coping Checklist
3) Quality of Life
4) Motivation Test
5) Personality Test

Adjustment Concept (Hinshaw, R.P. 1942) Term adjustment used in the fields of personality, mental hygiene and social psychology. It assumes an individual psychological factor and an environmental factor, operating in a specific frame of

reference. In social psychological usage it implies a minimum amount of conflict between an individual's behavior and the existing social institutions. In general psychology, it means integration, a term which implies harmonious cooperation of the various levels of the personality (PSYCINFO database 2012).

The term adjustment means to what extent individual's personality functions effectively; it is a harmonious relation between the person and the environment. A well adjusted personality is well prepared to play the roles which are expected of him within given environment. Psychologists view adjustment from two important points of view.

- Adjustment as an achievement
- Adjustment as a process.

Adjustment as an achievement means the effective way an individual could perform his duties in different circumstances, business, and education and other social activities needs efficient and well adjusted men for progress and well being of country.

Adjustment as Process: To analyze the process we should see development of an individual longitudinally from his birth onwards. The child is dependent for need satisfaction, but gradually learns to control his needs. His adjustment depends largely on his external environment and internal environment, as he gets matured, he learns to articulate the details of it through process of sensation, perception and conception.

Characteristic of adjustment mechanism : Adjustment mechanism is almost used by all people, they are ideas which are inferred from the behavior of the individuals. These are used to protect or enhance the persons self esteem against dangers, they increase satisfaction.

Adjustment is a relationship which comes to be established between the individual and the environment. Individual has position in his social relations, he is trained to play his role in such a way that his maximum needs will be fulfilled, so that he will get satisfaction. If this does not happen he may be frustrated.

Adjustment inventory, developed by Dr. M.N. Palsane, University of Pune was used for present study. The assessment of adjustment status in the different areas allows location of specific maladaptation's of an individual.

Purpose :- The test can be used to tackle problems in areas like home, family adjustment, personal and emotional adjustment, social adjustment, educational adjustment and health adjustment.

Description of each area of adjustment: - The very fundamental area of adjustment is home. Individual is the product of his home environment. He has to live life time in the home and family. There are many situations and personalities which call for specific adjustments. The inventory has statements regarding individual's home adjustment, i.e. his relations with his parents, siblings and their attitude toward him, his position in the home. Individuals scoring high tend to be unsatisfactorily adjusted to their home surroundings, low scores indicates satisfactory home adjustment. There were 366 total questions in the inventory. The test was adapted as per the requirement of the study. In home area, originally there were 56 questions out of which 15 questions were taken for study.

Social adjustment :- In social adjustment, the person's relations with other individuals and social institutions are included. The questions are related to person's sociability, his popularity and his social status, this aspect had 81 questions in original test, we asked 15 questions from this area.

The 3rd area of inventory was personal and emotional adjustment.

Personal and emotional adjustment :- This is related to individual's personal and emotional poise. Person's over critical view fault finding or critical nature can be understood from the statements in this area. Emotional adjustment covers fluctuations of mood, feelings of guilt, worry, loneliness, excitability and control over emotions. This area measures emotional maturity. Persons with low score tend to be emotionally stable and those who score high, tend to be emotionally unstable. This area had 120 questions, study included 35 questions.

Educational adjustment :- Statements in this area were concerned about individual's satisfaction about education, improvement, relationship with teachers and students high score indicates difficulties in adjustments in school. Educational adjustment, since study was not concerned about education out of 61 questions 7 questions were included in the study.

Health adjustment :- This covered individual's health problems, it covered health problems, disease, pains, and aches. High scores indicate unsatisfactory health adjustment, low score indicate satisfactory adjustment. Health aspect had 48 questions, study included 17 relevant questions.

Adjustment

Sr.	Area	Score
1	Home and Family Adjustment	Individuals scoring high tend to be unsatisfactorily adjusted to their home surrounding.
2	Social Adjustment	Score high indicates submissive and retiring in their social contacts. Low score indicate individuals are good in social contacts.
3	Educational adjustment	High score indicates difficulties in adjustment. Low score indicate better functional relationship.
4	Personal and Emotional	High score indicates emotional instability. Low score indicate emotional stability.
5	Health	High score indicate unsatisfactory health adjustment. Low score indicate satisfactory adjustment.

Adjustment – 366 questions

	Original	Considered for Study
Family Home	56	15
Social Adjust	81	15
Personal Emotional	120	35
Educational	61	07
Health	48	17
Total	**366**	**89**

Pre/Post results lower the score higher is the adjustment.

Adjustment – in the context of HIV. After being diagnosed, patient undergoes denial, shock, bargaining and finally acceptance stage. Adjustment means how the patient has absorbed the diagnosis. The implications on patient's life in the context of various relationships in family, neighbourhood and society. Patient experiences constant threat to life and to marital relationship. While disclosing it to partner, he/she experiences stress. There is a fear, if the diagnosis is known, whether marital partner would accept it or reject it. Then comes decision about child bearing being positive, patient can decide to have the child, then questions arises as who would take care of the child, in the absence of respondent, whether HIV will be transmitted to child, is another worry of the respondent. Further, the patient experiences stigma and discrimination, and hence he makes an effort to keep it as a secret. However, gradual deterioration of health, leads to opportunistic infections and health maintenance becomes a priority for the patient. Managing with all the above mentioned circumstances demands lot of adjustment and adaptability. In the present study, adjustment in the context of family, education, social adjustment, health adjustment and personal and emotional adjustment has been studied.

Coping Checklist (see appendix)

Coping checklist developed by Dr. Kiran Rao, Professor from NIMHANS, Dept. of Psychology was used for assessment of coping (Way Lindop 1982). Coping is an action at the resolution or mitigation of a problematic situation. There are number of ways in which this may be attempted. Coping reduces stress either by dealing with demands and stressor or with their effects on the individual (M. Clarke 2006). The purpose of the checklist is to find out how people deal with or handle difficult situations that they have to face. The list provides commonly used methods of handling stress and reducing distress. Minimum score is 0, maximum is 70.

Coping Checklist

Description. E.g. relations stress fatalistic.

7 subscales are developed.

Problem focused Scale – Problem solving (10 items)

1, 12, 30, 44, 52, 53, 54, 55, 56, 70.

Emotion Focused

Distraction – (Positive 14 items)

4, 10, 11, 22, 29, 37, 40, 45, 48, 50, 57, 59, 63, 64.

Distraction (Negative 14 items)

8, 14, 17, 24, 34, 46, 58, 60, 69.

Acceptance – Redefinition (11 items)

2, 5, 13, 16, 18, 20, 28, 41, 43, 47, 61.

Religion / faith (9 items)

9, 21, 25, 27, 33, 36, 39, 62, 66.

Denial, blame (11 items)

6, 19, 23, 31, 32, 35, 38, 49, 51, 67, 68.

Problem and emotion focused.

Social support (6 items)

3, 7, 15, 26, 42, 65.

Higher the score better is the coping.

Quality of Life – In health care

Within the field of healthcare, quality of life is often regarded in terms of how it is negatively affected, on an individual level, a debilitating weakness that is not life threatening illness that is not terminal, natural decline in the health of an elder, an unforeseen mental / physical decline of a loved one, chronic, end-stage disease process. Researchers at University of Toronto-define Quality of life as the degree to which a person enjoys the important possibilities of his / her life (www.ncbi.nih.gov.).

Quality of Life – Personal satisfaction with the cultural or intellectual conditions under which you live, a level of satisfaction (Thomas J. Leonard 1998). Test was used which had 100 questions. Higher score indicate better quality of life.

Test on quality of life

The term quality of life is used to evaluate the general well being of individuals and societies. It is used in the context of international development, health and politics. It is different from standard of living, quality of life indicators include wealth and employment, infrastructure, physical, mental health, education, recreation, leisure time and social belonging. It also indicates concepts like freedom, human rights.

However, happiness is a subjective term and hard to measure. Happiness does not necessarily come from comfort and income.

Quantitative measures – Presently researchers distinguish two aspects of personal well being i.e. emotional well-being, in which the quality of peoples' every day emotional experiences, the frequency and intensity of the experience e.g. joy, stress, sadness, anger and affection and life evaluation in which think about life in general and evaluate it against a scale, such measurements are human development index, this combines measures of life expectancy, education and standard of living in an attempt to quantify options available to individual within a given society. The physical quality of life index is a measure developed by sociologist Morris. David Morris in 1970, based on literacy, infant mortality and life expectancy. The Happy Plant Index introduced in 2006, is unique among quality of life in addition to standard determinants of well-being, it uses each country's ecological foot print as an indicator.

Quality of life in health care within the field of healthcare, quality of life is often regarded in terms of how it is negatively affected, on an individual level, a debilitating weakness that is not life threatening illness that is not terminal, natural decline in the health of an elder, an unforeseen mental / physical decline of a loved one, chronic, end-stage disease process. Researchers at University of Toronto-define quality of life as the degree to which a person enjoys the important possibilities of his / her life.

Quality of Life – Personal satisfaction with the cultural or intellectual conditions under which you live and the level of satisfaction. The third component of coping was quality of life. Test developed by Thomas J. Leonard was used for the present study. It had 100 questions on following aspects.

- Family relationships.
- Career / business.
- Money and finances.
- Joy and delight.
- Effectiveness and efficiency
- Personal foundations / self-responsibility.
- Personal development and personal evolution.
- Self care and well being.

- Happiness
- Pleasure

Answer to the questions on the above aspects had 'Yes', 'No' options. It was expected to add up the number of 'yes' or positive answers and calculate score as per the key 90-100 y's indicate 'awesome' performance i.e. high score and living great life.

However, while this test was used for study, only 50 questions were applicable. As this concept of quality of life itself is so foreign to Indians, especially the kind of respondents selected for the study. It was very obvious, that quality of life is associated with availability of better socio-economic resources. Hence, though we tried this test, later on it was realized, that there was very poor conceptual clarity and understanding about quality of life among respondents. Majority of them could not answer for questions about happiness and pleasuring life.

Quality of Life

Scoring System (Thomas Leonard)

Sr.	Score	Grade
1.	90 to 100	High Score
	80 to 89	Excellent
2.	70 to 79	Very Good
	60 to 69	Pretty Good (there is need to work on it)
3.	50 to 59	Average (Make your life a priority)
	40 to 49	Not to feel bad but need to make changes in life.
4.	30 to 39	Weak
	20 to 29	Let us get serious, to make the most of life.
5.	10 to 19	Not paid attention to your life so far.
	0 to 9	Why the score is low ? is your self esteem low! Or is there an emotional stress.

Questions 90 to 100 indicating positive opinion have high score

Motivation : Motivation is a term that refers to a process that elicits, controls and sustains certain behaviors, e.g. if an individual is hungry, as a response, he or she eats and diminishes feeling of hunger. Adjustment to various theories, motivation may be rooted in a basic need to minimize physical pain and maximize pleasure, motivation is related to, but distinct from emotion. Motivation is a basic psychological process. Along with perception, personality, attitudes and learning, motivation is a very important element of behavior. Nevertheless, motivation is not the only explanation of behavior. It interacts with and acts in conjunction with other cognitive process. Motivating is the management process of influencing behavior based on the knowledge of what makes people tick (Luthans, 1998). Motivation and motivating both deal with the range of conscious human behavior – somewhere between two extremes :

- Reflex actions such as a sneeze or flutter of the eyelids and
- Learned habits such as one's teeth or handwriting style (Wallace & Szlag 1982)

Achievement Motivation test : The test by V.P. Bhargava, was used it consists of 50 items of incomplete sentence completion test. The other feature of the test is that items are repeated more than once to know the level of consistency with which the subject is, answering the test. Test was adapted as per the need of the study only relevant questions were included.

Kundu Introversion Extroversions Inventory

The inventory developed by Dr. Ramnath Kundu, (1976) was used to assess the personality of the respondents. Purpose of the inventory is to obtain a reliable measure of introversion, extroversion dimension of adult behavior or to use it for diagnosis, selection and career guidance. It is developed according to Indian socio-cultural pattern. The test consists of 70 items with uneven number of response choices divided into 5 blocks – A, B, C, D, E. It is found that people are different in their likes, dislikes, personality and hobbies. Within this test, there are questions on these aspects, questions indicate the personality type of the subject / respondent. There are no rights or wrong answers to any questions. There are several options given from among which subject can pick up the most appropriate answer for them. This test also was

adapted, the scoring method is as under. Personality has biological factors, environmental and social factors and psychological factors.

Method of Scoring –The general order of scoring is such that high score indicates introversion i.e. negative response is indicative of introversion. But some of the items have been framed in such a way that negative response in these items would indicate extraversion. The different categories of responses are given different weights depending on the degree of introversion extroversion they measure. No scoring key is required. Count the tick (√) in each row in each block and enter the figure under the column T against the respective row.

As per test proportion of maximum score

Table shows the computation method of personality test scoring:

Original Score Category	Proportion of higher limit to maximum limit	Categories modified according to proportion for current study	Category Name
Minimum 70 to 89	36.9	47 to 68.4	Extremely extravert
90 to 130	53.9	68.5 to 99.9	Slight to moderate - extrovert
131 to 171	70.9	100 to 131.3	Ambivert
172 to 199	82.5	131.4 to 153.6	Slight to moderate introvert
229 and above	Above 82.5	153.7 and above	Extremely introvert

As the personality test was adapted for the study, the maximum score was 185 and minimum score was 47, in the original test scores were 70 minimum and 247 was maximum. Hence to suit the score to fit in the categories, proportion of the higher limit to the maximum score was considered, to make categories for the present data. The differences between the categories are mentioned in the above table.

Pre interventions mean score for coping. Each question in coping was given score of ‘1’. The coping test positive answer in the question had score ‘1’. Negative answer

question had score ‘0’. Thus maximum score of this test is 70. The total sample shows pre intervention score as 34.8.

We have made an attempt to classify the data of 1 to 5 tests in the various categories that is higher, moderate and lower and it was found that most of the data is concentrated in moderate category; therefore the chi-square values of all tables are observed to be not significant. Hence scores of various tests are given in terms of mean only. One of the reasons to be recorded here is that, in post test the number of respondents is very less; hence it was not felt necessary to compute chi-square test for group data.

Pre Intervention data

While selecting the NGO’s for study, one of the criteria was, that NGO’s offer few services like counseling, nutritional support, sponsorship for education of children. Another criteria was regular contacts, rapport of respondent with NGO’s. As the group members meet each other at NGO regularly, there is group bonding among them. They are benefitted by sharing their experiences and hence in the table 7.1 and in graph it can be observed that in SOFOSH, respondents avail the facility of counseling and support meeting.

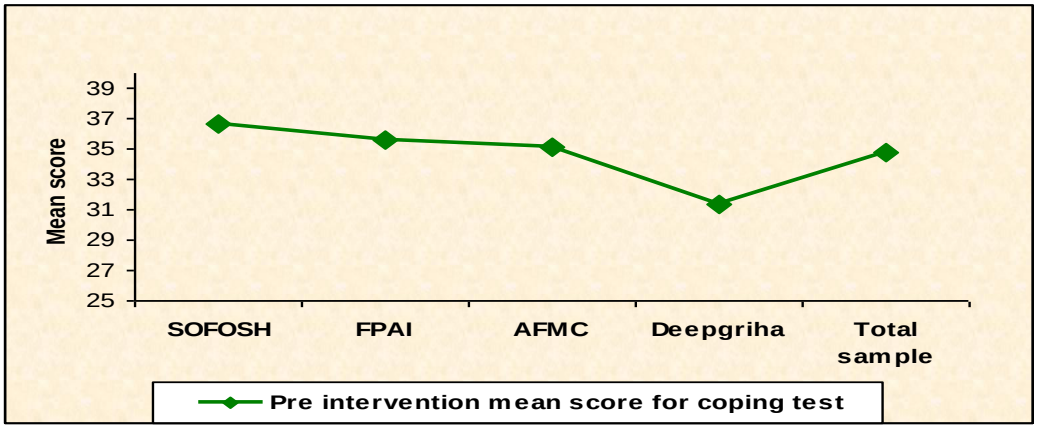
Table 7.1

Pre Intervention mean score for coping test

NGO Groups	N	Mean	Std. Deviation	Coefficient of variance
SOFOSH	56	36.7	7.5	55.8
FPAI	50	35.6	8.7	75.6
AFMC	40	35.1	6.0	35.7
Deepgriha	45	31.4	8.1	64.9
Total	191	34.8	7.9	62.0

F value = 4.425 not significant.

Graph No.7.1: Pre intervention mean score for coping test



The total sample shows pre intervention score as 34.8 with a standard deviation (S.D.) of 7.9, respondents from SOFOSH shows maximum mean score as 36.7. It is observed that, regularity in attending meeting and counseling support influences the coping of respondents.

Table 7.2

Coping score with Socio-economic score

NGO Groups		Poor	Middle Class	Higher Class
SOFOSH	N	27	29	0
	Mean	37.48	35.9	
FPAI	N	22	27	1
	Mean	35.91	35	46
AFMC	N	8	29	3
	Mean	35.5	34.34	41
Deepgriha	N	12	30	3
	Mean	30.67	31.03	38
Total	N	69	115	7
	Mean	35.57	34.03	40.43

With reference to the composite scores, it was thought that there could be some relation between psychological test and composite scores, socio- economic condition might have effect on coping, a try was made to see if better socio economic condition has a positive effect on coping.

This table shows mean coping score highest among the higher socio-economic score, although the number of respondents is small, followed by the maximum score is observed by poor socio-economic score than middle class. Comparatively better the socio-economic condition, better the coping is observed. However, this number is small, among the lower income group coping was observed higher due to their level of adaptation, less botheration about what society would think about them. Paired T test does not show any significant difference.

Coping among health score category:

Health condition of an HIV infected person does have an effect on coping. If respondent is free from opportunistic infections and hospitalization his /her coping can be better. In the following normal health condition in the scores assumes that there is absence of morbidity, prolonged and major illness, opportunistic infections, and need to visit doctor. Moderate health indicates one or two of the above conditions are present. Poor health indicates most of the above conditions present

Table 7.3

Table showing score of coping among health score category

NGO Groups		Poor health condition	Moderate health condition	Normal health condition
SOFOSH	N	4	36	16
	Mean	32.25	37.28	36.38
FPAI	N		35	15
	Mean		37.29	31.73
AFMC	N	1	10	29
	Mean	33	34.5	35.34
Deepgriha	N	1	20	24
	Mean	19	33.1	30.5
Total	N	6	101	84
	Mean	30.17	36.18	33.51

The table 7.3 indicates that the coping is better among those who have moderate health condition followed by normal health condition. Since they have repetitive health complaints, they are required to take help from professionals which in turn, helps better coping. This is followed by normal health condition although there is no need to take clinical help. Presently the anxiety, stress regarding future might have resulted into comparatively low coping. Since they have health problems, further it is seen that their coping is poor compared to other two groups.

Table 7.4

Coping score among family support category

During any suffering or crisis period, if family is very supportive, the person who is infected with HIV can cope with it better. This relationship is examined and shown in the following table.

NGO Groups		Poor family support	Moderately family support	Good family support
SOFOSH	N	5	36	15
	Mean	27.8	37.36	37.93
FPAI	N	1	25	24
	Mean	26	35.84	35.79
AFMC	N	1	16	23
	Mean	33	34.31	35.7
Deepgriha	N	7	18	20
	Mean	30.29	30	33.05
Total	N	14	95	82
	Mean	29.29	35.05	35.49

There is a clear cut observation that those who had good family support, had better coping score 35.49 was the maximum score observed in the sample. Good family support indicates respondents residing with elders, in-laws with maternal family and don't have conflict with them and there is a family acceptance.

Table 7.5

Mean coping score with HIV background supporting coping

Factors such as partner's communication, opportunistic infection and diagnosis are considered together in HIV background supporting coping. These factors have definitely helped in better coping.

NGO Groups	HIV background helping coping	Poor	Moderate	Positive
SOFOSH	N	1	28	27
	Mean	51.0	36.64	36.15
FPAI	N	1	23	26
	Mean	28	34.74	36.69
AFMC	N	2	23	15
	Mean	25.5	35.17	36.2
Deepgriha	N	4	30	11
	Mean	27.5	32.37	30.18
Total	N	8	104	79
	Mean	30	34.66	35.51

Mean of Positive 'HIV background supporting coping' indicates coping score as maximum i.e. 35.51. Comparatively poor HIV background indicates lowest score for coping. Positive HIV background indicates, partner's communication about HIV with spouse, safer sex practice, maximum duration of diagnosis of both spouses and maximum age at the time of diagnosis. Hypothesis number one is, stronger the coping mechanism, lesser the implication of HIV. This is being seen in 7.5 table that positive HIV background i.e. partner has communicated the diagnosis with respondent, they are practicing safer sex practice and are living with HIV for longer period, this has helped to have less implications of HIV.

Coping score among counseling and NGO support category

Counseling has a definite role in helping the respondent in improving coping. There is pretest, post test and adherence counseling that surely helps in finding better

alternatives for the critical situation. Similarly support in the form of nutrition, educational sponsorship for children were extended by NGO's. shown in the following table.

Table 7.6

Coping score among counseling and NGO support category

NGO Groups	HIV background helping coping	Poor	Moderate	Positive
SOFOSH	N	1	28	27
	Mean	51.0	36.64	36.15
FPAI	N	1	23	26
	Mean	28	34.74	36.69
AFMC	N	2	23	15
	Mean	25.5	35.17	36.2
Deepgriha	N	4	30	11
	Mean	27.5	32.37	30.18
Total	N	8	104	79
	Mean	30	34.66	35.51

Mean coping score with counseling and NGO support was indicated by respondents which was not provided by researcher. Total sample shows, maximum coping score in positive counseling and NGO support scores, followed by moderate and poor. Coping score declines as the score declines. Respondents in SOFOSH and Deepgriha indicate maximum coping in moderate support scores. This might indicate, that although there could be less service, the quality of counseling is better enough to improve coping of respondents.

Adjustment Test

One of the elements of coping is adjustment therefore adjustment test develop by Dr. M.N. Palsane was used. This test consisted of 375 questions, with following aspects.

1. Family
2. Emotion

3. Education
4. Health

Relevant questions from each aspect were taken up for study, from which maximum 89 questions were asked, the lower score indicates higher adjustment.

Pre Intervention mean score for Adjustment Test:

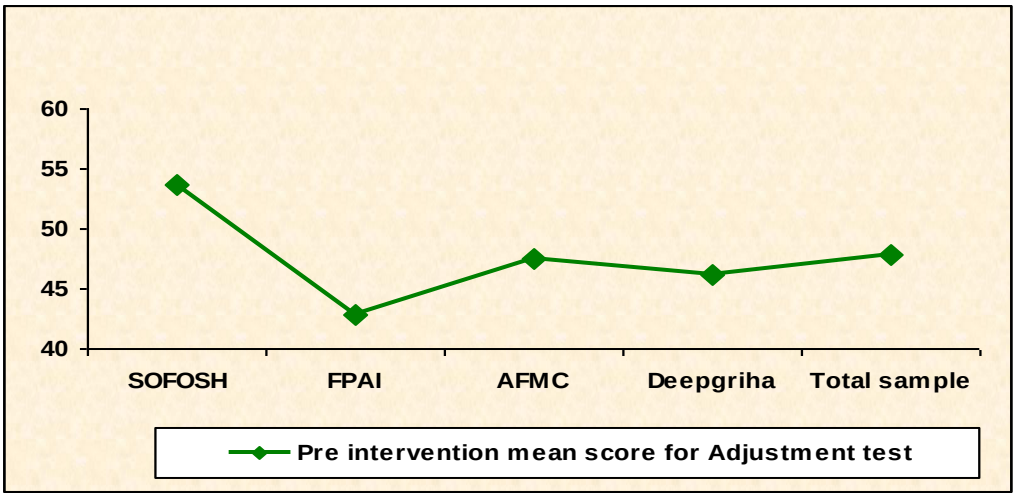
Adjustment is a capacity to adapt to the circumstances, being more flexible, adaptive to the circumstantial demand. As per adjustment test lower score indicates high adjustment. Table 7.7 shows comparison of mean of adjustment test among NGO's. Respondents from FPAI show maximum adjustment. This could be because of support extended in the form of meetings, nutrition and the counseling services. Comparative graph 7.7 indicates the same.

Table 7.7

Pre Intervention mean score for Adjustment Test

NGO Groups	N	Mean	Std. Deviation	Coefficient of variance	F value
SOFOSH	56	53.6	7.7	59.8	
FPAI	50	42.9	7.5	56.8	
AFMC	40	47.5	7.7	58.7	
Deepgriha	45	46.2	10.2	104.4	
Total	191	47.8	9.2	84.9	15.24

Graph 7.2 Pre intervention mean score for adjustment test



Mean adjustment score with Socioeconomic score:

It was tried to see that how socio- economic score affects on adjustment capacity of a respondent. Poor people are always having a tendency that they need to adjust, however following table shows a different picture, i.e. middle class people have better adjustment.

Table 7.8

Mean adjustment score with Socioeconomic score

		Socio-economic score		
NGO Groups		**Poor**	**Middle Class**	**Higher Class**
SOFOSH	N	27	29	0
	Mean	53.3	53.79	
FPAI	N	22	27	1
	Mean	43.14	42.81	40
AFMC	N	8	29	3
	Mean	47.5	47.21	50
Deepgriha	N	12	30	3
	Mean	49.58	44.4	
Total	N	69	115	7
	Mean	48.74	47.1	49.14

This table shows mean adjustment score 47.1 among the middle class respondents. (Refer Socio economic score).

Mean adjustment score with health score:

Adjustment capacity could be better with better health condition, if he /she is in proper physical and mental framework to adjust with the environment.

Table 7.9

Mean adjustment score with health score

		Health Score		
NGO Groups		**Poor health condition**	**Moderate health condition**	**Normal health condition**
SOFOSH	N	4	36	16
	Mean	54.75	53.61	53.12
FPAI	N		35	15
	Mean		43.91	40.53
AFMC	N	1	10	29
	Mean	48	49.4	46.79
Deepgriha	N	1	20	24
	Mean	46	45.55	46.83
Total	N	6	101	84
	Mean	52.17	48.24	46.89

This table indicates mean adjustment score with health score. Normal health conditions show more adjustment that is 46.89. Those who have normal health conditions, they naturally have better adjustment. As they have less health problems they can think of adapting with the environment or environmental demands.

Mean adjustment score with family support score:

Support means, in the family, there is someone to bank upon, to share emotions, to support, provide financial assistance. An effort was made to see whether this kind of support helps adjustment.

Table 7.10

Mean adjustment score with family support score

		Family Support		
NGO Groups		**Poor family support**	**Moderate family support**	**Good family support**
SOFOSH	N	5	36	15
	Mean	45	54.97	53
FPAI	N	1	25	24
	Mean	37	43.48	42.54
AFMC	N	1	16	23
	Mean	46	48.06	47.13
Deepgriha	N	7	18	20
	Mean	44.29	44.22	48.75
Total	N	14	95	82
	Mean	44.14	48.75	47.26

The respondents in the study were from poor socio-economic strata. They were well aware about the poor support. After marriage women, hardly are considered to be the part of the natal family. However, after realizing the daughter's HIV status, parents are helping them. As the respondents knew they had no one to bank upon, they had to adjust with the environment and had to cope with the reality. Hence the above table shows, poor family support have better adjustment.

Mean adjustment score with HIV background supporting helping coping:

It was thought that those who have positive background helping coping could have better adjustment capacity, however following table indicates that moderate HIV background has better adjustment capacity. This could be because as most of the conditions were favorable, they didn't face the crisis in which adjustment was required, whereas in moderate, few conditions were favorable but at few places conditions were not favorable. Hence, their adjustment could have been better.

Table 7.11

Mean adjustment score with HIV background supporting helping coping

		HIV Background		
NGO Groups		**Poor HIV background helping coping**	**Moderate HIV background helping coping**	**Positive HIV background helping coping**
SOFOSH	N	1	28	27
	Mean	65	51.5	55.26
FPAI	N	1	23	26
	Mean	41	42.65	43.19
AFMC	N	2	23	15
	Mean	40.5	46.74	49.53
Deepgriha	N	4	30	11
	Mean	52	46.13	44.45
Total	N	8	104	79
	Mean	49.38	46.94	48.7

Mean adjustment score with Counseling and NGO support category:

If there is counseling input & NGO support, respondent does not need to adjust. Hence moderate counseling & NGO support is helping adjustment.

Table 7.12

Mean adjustment score with Counseling and NGO support category

		NGO Support		
NGO Groups		**Poor counseling and NGO support**	**Moderate counseling and NGO support**	**Good counseling and NGO support**
SOFOSH	N	5	40	11
	Mean	56.4	53.65	51.91
FPAI	N	4	41	5
	Mean	39.75	43	44.6
AFMC	N	21	17	2
	Mean	48.05	46.71	48
Deepgriha	N	2	35	8
	Mean	46.5	46.37	45.62
Total	N	32	133	26
	Mean	48.22	47.56	48.27

The above table indicates moderate counseling and NGO support is helping adjustment.

Pre Intervention means score for Quality of Life Test:

The next tool was test on quality of life. Maximum score was expected 49, as per the quality of life test, the mean score was observed to 46.6, which is indicating a good quality of life. Researcher feels, for most of the questions, they have replied affirmatively. Hence this score in pre interventions phase as shown so high.

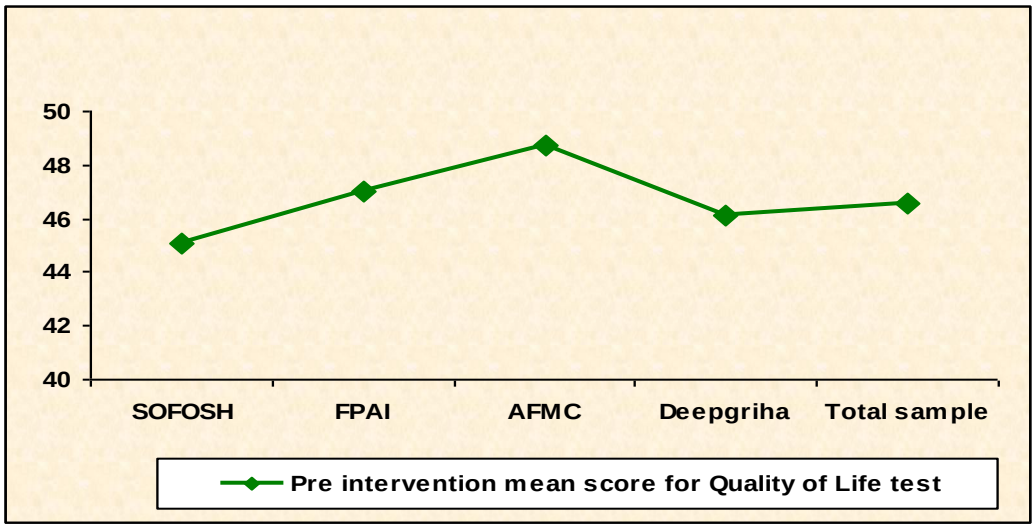
Table 7.13

Pre intervention means score for quality of life test:

NGO Groups	N	Mean	Std. Deviation	Coefficient of variance
SOFOSH	56	45.1	8.7	76.5
FPAI	50	47.0	7.5	56.6
AFMC	40	48.7	0.5	0.3
Deepgriha	45	46.1	8.5	72.3
Total	191	46.6	7.4	55.2

F value = 1.97. Mean score indicates 46.6.

Graph 7.3 Pre Intervention Mean Score for Quality of Life Test



Mean quality of life score with socio economic category

Quality of life was one of the components of coping mechanisms observed in the study. Quality of life means joy, happiness, satisfaction of an individual. Quality of life is normally in higher socio-economic class. Quality of life is better; hence an effort was made to see how far this is relevant in the present study and the table shows-

Table 7.14

Mean quality of life score with socio economic category

NGO Groups	Socio-economic index	Poor	Middle Class	Higher Class
SOFOSH	N	27	29	
	Mean	43.89	46.14	
FPAI	N	22	27	1
	Mean	46.64	47.26	48
AFMC	N	8	29	3
	Mean	48.5	48.72	48.33
Deepgriha	N	12	30	3
	Mean	42.42	47.37	48.33
Total	N	69	115	7
	Mean	45.04	47.37	48.29

This table shows quality of life is good in higher socio-economic class. Quality of life is very foreign concept. Investigator tried to simplify the concept however, it was realized that conceptual understanding of respondents was poor.

Mean quality of life score with health category:

Health is one of the important aspect of quality of life, if health is good, individual can fulfill his /her role more efficiently, mentally he or she can concentrate better, can enjoy life. An effort was made to understand association between health and quality of life.

Table 7.15

Mean quality of life score with health category

NGO Groups		Poor health condition	Moderate health condition	Normal health condition
SOFOSH	N	4	36	16
	Mean	36.25	45.19	46.94
FPAI	N		35	15
	Mean		46.37	48.47
AFMC	N	1	10	29
	Mean	48	49	48.55
Deepgriha	N	1	20	24
	Mean	48	44.9	47.04
Total	N	6	101	84
	Mean	40.17	45.92	47.8

This table indicates better quality of life is seen when there is normal health condition i.e. when the score is 12 to 15 (Refer scores). While respondents did not have any prolonged illness and opportunistic infections, no morbidity and other health complaints are observed and no side effects of ART are experienced.

Mean quality of life score with family support category:

Quality of life means the level of joy, happiness, satisfaction of an individual. It is a relative concept .It is a relative concept .It has components like wealth, health, family relationships, social network etc. An effort was made to see how far HIV has made an impact on the quality of life of an infected person and can intervention help in improving the quality of life.

Table 7.16

Mean quality of life score with family support category

NGO Groups		Poor family support	Moderately family support	Good family support
SOFOSH	N	5	36	15
	Mean	43	44.44	47.2
FPAI	N	1	25	24
	Mean	46	46.44	47.62
AFMC	N	1	16	23
	Mean	48	48.75	48.61
Deepgriha	N	7	18	20
	Mean	44.14	46.67	46.3
Total	N	14	95	82
	Mean	44.14	46.12	47.5

Table indicates better mean i.e. 47.5 quality of life where good family support was seen (Refer family support score). This index consists of respondent's residence, differences in family, reaction of family after knowing HIV status, whom do they approach in difficulties, sharing of feelings, who loves them unconditionally etc. When family extends the support, respondents do get strength to face the reality, they feel motivated and can maintain and live better quality of life.

Mean quality of life score with HIV background category:

An effort was made to see relationship between quality of life & HIV background category.

Table 7.17

Mean quality of life score with HIV background category

NGO Groups		Poor HIV background helping coping	Moderate HIV background helping coping	Positive HIV background helping coping
SOFOSH	N	1	28	27
	Mean	48	45	45
FPAI	N	1	23	26
	Mean	52	47.65	46.23
AFMC	N	2	23	15
	Mean	49	48.61	48.67
Deepgriha	N	4	30	11
	Mean	47.75	45.9	46.09
Total	N	8	104	79
	Mean	48.62	46.64	46.25

Above table shows mean score 48.62 of quality of life in poor HIV background (Refer appendix). This indicates those respondents whose age was less , the duration of diagnosis was less, those who were practicing safer sex habits and there is a partner notification, due to which quality of life was found better.

Mean score of quality of life with counseling and NGO support category:

Association between quality of life, counseling & NGO support was seen and is shown in the table

Table 7.18

Mean score of quality of life with counseling and NGO support category

NGO Groups		Poor counseling and NGO support	Moderate counseling and NGO support	Good counseling and NGO support
SOFOSH	N	5	40	11
	Mean	42.2	46.15	42.36
FPAI	N	4	41	5
	Mean	47.5	48	38.4
AFMC	N	21	17	2
	Mean	48.62	48.65	49
Deepgriha	N	2	35	8
	Mean	49	45.4	48.5
Total	N	32	133	26
	Mean	47.5	46.84	44

The above table shows mean quality of life in poor counseling and NOG support. (Refer appendix). These were the respondents who were diagnosed recently, so they had NGO support and counseling, their age was also less while they were diagnosed.

Motivation test: The next test was used in pre intervention and post intervention phase was motivation test. The scoring system is as follows:

Scoring system – Range / Category

Motivation Test

Category	Score	Grade
High	23 and above	* Outstanding worth appreciation
Above average	20 to 22	Superior than average, casual appreciation
Average	17 to 19	Average – nothing worth mentioning
Below Average	14 to 16	Simpler than routine
Low	11 to 13	Performance lower than ordinary one.

Original motivation test had 50 questions; however, as per the study requirements the number of questions was reduced to 32. The category wise classification of scores of these tests percentile norm were then modified, they are as follows:

	Score	Graded Category
Adapted modified score as per data	15 and above	High - *
	13 – 14	Above average
	11 – 12	Average
	9 – 10	Below average
	8 – 6	Low
	6 – 0	Very low

The mean score was found 8.2 which lies in low, category of motivation.

Distribution of respondents:

Motivation means an innate desire to act, work take initiative .This depends on each person's personality, social background the inputs during socialization process and the will aspiration to do the best .one of the component s of coping mechanism was motivation. Motivation can be affected due to surrounding circumstances, ill health conditions, lack of support from family, friends, colleagues. An effort was made to see how respondents were coping with critical situation of being diagnosed as HIV patients .prior to intervention, their motivation was low, it was obviously due to diagnosis of stigmatized, disease & threat to life

Table 7.19

Distribution of respondents

Motivation	Frequency	Percentage
Very low	35	18.3
Low	58	30.4
Below average	67	35.1
Average	24	12.6
Above average	07	3.7
Total	191	100

The table 7.19 shows, that more than 80 % of the respondents are in the category of below average and average category.

Pre intervention mean score of motivation test:

Table 7.20 shows pre intervention mean score of motivation of different NGO's.

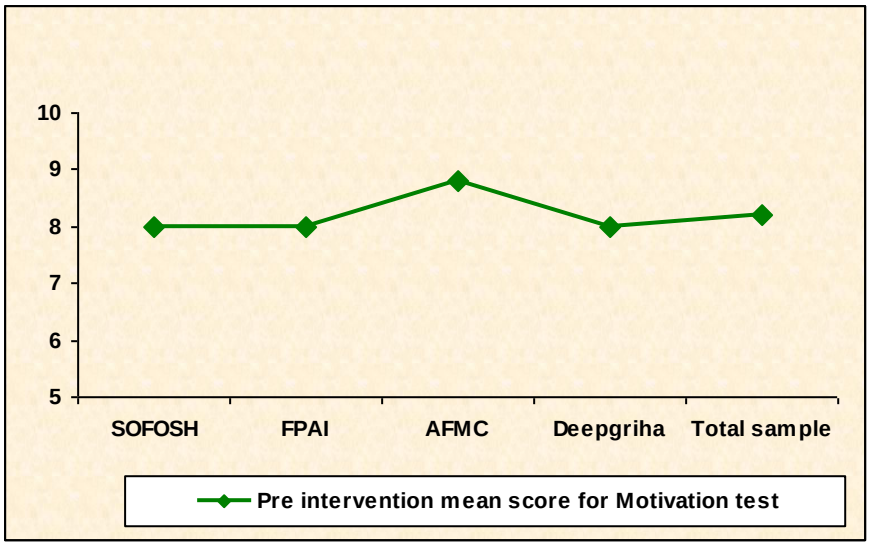
Table 7.20

Pre intervention mean score of motivation test

NGO Groups	N	Mean	Std. Deviation	Coefficient of variance	F Value
SOFOSH	56	8.0	3.1	9.5	
FPAI	50	8.0	2.5	6.1	
AFMC	40	8.8	2.5	6.1	
Deepgriha	45	8.0	3.5	12.5	
Total	191	8.2	2.9	8.6	0.458

Motivation maximum score is 32. Prior to intervention motivation was very low.

Graph 7.4 Pre intervention mean score for motivation test



Mean score of motivation with Socio-economic score:

Socio-economic condition indicates the social background, financial conditions. If there are resources, person can fulfill needs and then further secondary higher second class conditions are better hence motivations of person can be better, but as there are poor conditions his /her motivation to live, to make an effort seems poor.

Table 7.21

Mean score of motivation with Socio-economic score

		Socioeconomic score		
NGO Groups		**Poor**	**Middle Class**	**Higher Class**
SOFOSH	N	27	29	
	Mean	7.48	8.48	
FPAI	N	22	27	1
	Mean	8.64	7.44	10
AFMC	N	8	29	3
	Mean	8.88	8.83	8.33
Deepgriha	N	12	30	3
	Mean	8.08	7.83	9.33
Total	N	69	115	7
	Mean	8.12	8.16	9

Table 7.21 shows distribution of mean score of motivation N-ach among socio-economic score. Higher socio-economic score shows mean score on a slightly higher side.

Mean motivation score with health Score:

Motivation is one of the components of coping mechanism. Motivation can be innate or can be developed during personality development. Motivation depends on one's own physical, mental, emotional wellbeing & his/her surroundings. For the study purpose motivation test was used. In the pre intervention phase, respondents motivation. An effort was made to see, its relationship with health score and it can be seen in the table that motivation is related to health condition. Lowest motivation is seen among respondents who had poor health condition.

Table 7.22

Mean motivation score with Health Score

NGO Groups		Poor health condition	Moderate health condition	Normal health condition
SOFOSH	N	4	36	16
	Mean	4.5	7.67	9.62
FPAI	N		35	15
	Mean		8.54	6.8
AFMC	N	1	10	29
	Mean	7	8.2	9.07
Deepgriha	N	1	20	24
	Mean	0	8.8	7.67
Total	N	6	101	84
	Mean	4.17	8.25	8.37

Table shows lowest motivation among those who have poor health condition. Poor health indicates low CD4 count, frequent opportunistic infections, repeated hospitalization; this naturally results into lowering the motivation of respondents to live life.

Mean motivation score with family support score:

Another factor for motivation was studied that is family support. If family is supportive help, taking care of the respondent, then respondents can have motivation to live. They can look forward to get care & support from them. Hence the relationship between motivation & family support was computed & it has a positive relationship.

Table 7.23

Mean motivation score with family support score

NGO Groups		Poor family support	Moderate family support	Good family support
SOFOSH	N	5	36	15
	Mean	8.6	7.36	9.33
FPAI	N	1	25	24
	Mean	0	8.16	8.21
AFMC	N	1	16	23
	Mean	9	8.88	8.74
Deepgriha	N	7	18	20
	Mean	7.71	7.28	8.75
Total	N	14	95	82
	Mean	7.57	7.81	8.7

Table indicates relationship between good family support has comparatively slightly higher motivation. Motivation is inspiration, continuous source of energy, desire to reach to a goal. As once the respondent discloses his / her HIV status in the family, he/she experiences stigma and discrimination. In addition to that, they have fear, threat to life, they lose their morale. In such a situation, if there is a desirable family support, individual can live with better motivation and enthusiasm.

Distribution of respondents according to HIV background:

HIV background has relationship with motivation. As the person is young at the time of diagnosis, motivation to live is better and as there is partner who is infected also makes a difference in motivation to live that is there is someone to share the suffering.

Table 7.24

Distribution of respondents according to HIV background

NGO Groups		Poor HIV background helping coping	Moderate HIV background helping coping	Positive HIV background helping coping
SOFOSH	N	1	28	27
	Mean	8	9.07	6.89
FPAI	N	1	23	26
	Mean	8	8.57	7.54
AFMC	N	2	23	15
	Mean	11	8.52	8.93
Deepgriha	N	4	30	11
	Mean	7.25	8.47	7
Total	N	8	104	79
	Mean	8.38	8.66	7.51

Table shows highest i.e. 8.66 score in moderate HIV background. It is combination of some positive & negative factors Therefore motivation could be high. Respondents could depend on positive factors to improve their health status & living with positive status. In case of positive HIV background, since all the factors are favorable, respondents didn't have motivation. They had other positive thing s in their hand there is no crises as such. In case of poor HIV background, if there is depression or nervousness, that affects the motivation.

Mean motivation score with counseling and NGO support score:

Counseling is provided to give guidance to raise motivation level, to bring about change in perception & attitude. An effort was made to see relationship between counseling, NGO support & motivation.

Table 7.25

Mean motivation score with counseling and NGO support score

NGO Groups		Poor counseling and NGO support (5-7)	Moderate counseling and NGO support (8 to 11)	Good counseling and NGO support (12 to 15)
SOFOSH	N	5	40	11
	Mean	7	7.55	10.09
FPAI	N	4	41	5
	Mean	8.75	7.76	9.6
AFMC	N	21	17	2
	Mean	9.14	8.24	10
Deepgriha	N	2	35	8
	Mean	9	8	7.75
Total	N	32	133	26
	Mean	8.75	7.82	9.27

It is seen from the above table that highest scores are observed with good counseling and NGO support. However, followed by these the higher scores are observed among those who have poor counseling and NGO support. There could be chances that who have poor counseling and NGO support might have other conditions favorable such as economic background, family support, which helps them to raise their motivation.

Pre intervention mean score for personality test:

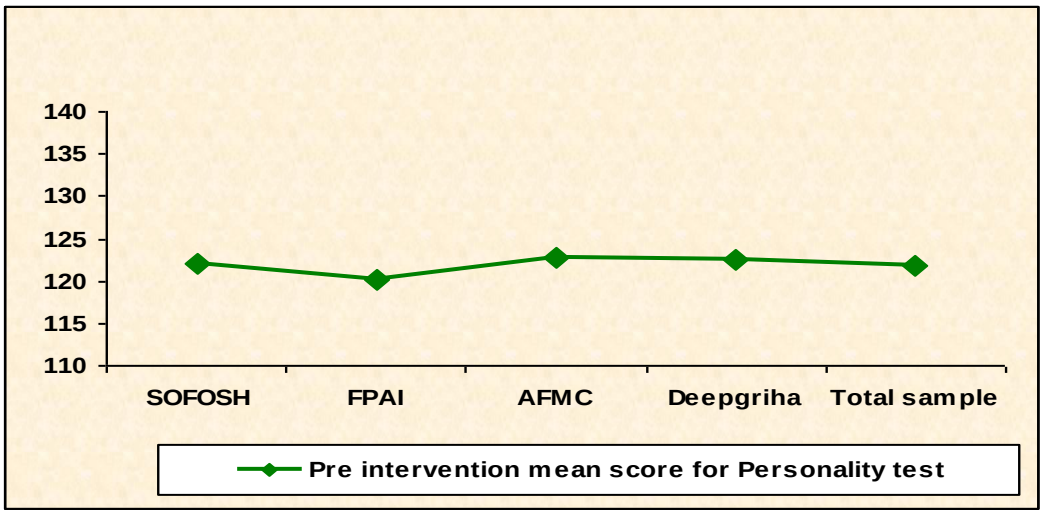
Personality was considered another component of coping mechanism. As stated earlier, personality also has many facets and minute characteristics, which are developed over the personality development process. The test results show that it has no variations between NGO's.

Table 7.26

Pre intervention mean score for personality test

NGO Groups	N	Mean	Std. Deviation	Coefficient of variance	F Value
SOFOSH	56	122.0	14.0	197.2	
FPAI	50	120.1	11.3	126.6	
AFMC	40	122.7	9.8	95.5	
Deepgriha	45	122.6	12.8	163.9	
Total	191	121.8	12.2	148.4	0.771

Graph 7.26 Pre intervention mean score for personality test



The mean score of personality test is 121.8; it doesn't vary among the NGOs. This lies in ambivert category as per personality test used for the study.

Mean personality score with Socio-economic score:

Personality has an effect of socio economic condition of a person. However, since the respondents were from more or less similar socio economic background, (society as a whole) hence, there was no significant difference observed.

Table 7.27

Mean personality score with socio-economic score

NGO Groups	Socio-economic index	Poor	Middle Class	Higher Class
SOFOSH	N	27	29	
	Mean	121.78	122.14	
FPAI	N	22	27	1
	Mean	119.05	120.67	128
AFMC	N	8	29	3
	Mean	119.75	124	118
Deepgriha	N	12	30	3
	Mean	117.67	124.4	124
Total	N	69	115	7
	Mean	119.96	122.85	122

Table indicates no significant difference within socio-economic score.

Mean Score of personality with Health Score:

Personality score from 100 to 131.3 comes under ambivert category. The above category is ‘introvert’. Declining score indicates that the respondents are shifting towards extrovertness. All the score in table 7.28 indicate that respondents are in ambivert category.

Table 7.28

Mean Score of personality with Health Score

NGO Groups		Poor health condition	Moderate health condition	Normal health condition
SOFOSH	N	4	36	16
	Mean	131.75	117.56	129.44
FPAI	N	--	35	15
	Mean	--	119.11	122.4
AFMC	N	1	10	29
	Mean	116	124.8	122.21
Deepgriha	N	1	20	24
	Mean	126	121.6	123.25
Total	N	6	101	84
	Mean	128.17	119.61	123.92

Table also indicates that respondents from moderate health condition are close to extrovert category.

Mean score of personality with family support score

An effort was made to see association between personality and family support however there was hardly any difference seen in the scores.

Table 7.29

Mean score of personality with family support score

NGO Groups		Poor family support	Moderately family support	Good family support
SOFOSH	N	5	40	11
	Mean	120.8	120.1	129.27
FPAI	N	4	41	5
	Mean	122	120.2	117.8
AFMC	N	21	17	2
	Mean	120.9	124.47	126.5
Deepgriha	N	2	35	8
	Mean	123	122.71	121.88
Total	N	32	133	26
	Mean	121.16	121.38	124.58

Mean score of personality with HIV background supporting coping:

There are hardly any chances of personality can get influenced by HIV background supporting coping. Because personality is multi-dimensional development and long term process, and factor which are considered for HIV background score are very recent in the lives of the respondents. However those who had poor HIV background, the tendency is seen, that the mean personality score lies towards extrovertness as compared to remaining two categories.

Table 7.30

Mean score of personality with HIV background supporting coping

NGO Groups		Poor HIV background helping coping	Moderate HIV background helping coping	Positive HIV background helping coping
SOFOSH	N	1	28	27
	Mean	110	121.07	123.33
FPAI	N	1	23	26
	Mean	135	119.7	119.88
AFMC	N	2	23	15
	Mean	119.5	122.96	122.73
Deepgruha	N	4	30	11
	Mean	111.5	123.33	124.55
Total	N	8	104	79
	Mean	116.25	121.84	122.25

Mean score of personality with counseling and NGO support score:

In the pretest, those who were falling towards introvertness, show that, they consistently sought help from the counselor. In general the tendency of people in our community observed to be solving the problems with one's own ability as far as possible and to keep it as a secret. Good counseling is considered here, as consistency and regularity in seeking help. Since there are chances that, as respondents had communication with the counselors regarding positive attitude and ways of coping with current problems, they had started thinking about coping with the crisis of HIV, on their own.

Table 7.31

Mean score of personality with counseling and NGO support score

NGO Groups		Poor counseling and NGO support (5-7)	Moderate counseling and NGO support (8 to 11)	Good counseling and NGO support (12 to 15)
SOFOSH	N	5	40	11
	Mean	120.8	120.1	129.27
FPAI	N	4	41	5
	Mean	122	120.2	117.8
AFMC	N	21	17	2
	Mean	120.9	124.47	126.5
Deepgriha	N	2	35	8
	Mean	123	122.71	121.88
Total	N	32	133	26
	Mean	121.16	121.38	124.58

So far we have seen the pre-intervention scores in different tests.

7.7 Intervention in the form of group and individual counseling:

In the IInd phase of the study, intervention was provided on following aspects. It was in the form of group counseling. There are support groups formed in one or two NGOs, while finalizing the universe for the study, those NGOs, which gave permission for intervention and those respondents who were ready to come three to four times for study, were selected. Once in a month the intervention group counseling meetings were held with the interval of one month. During individual interview also women had expressed their concerns as well as researcher had decided topics based on elements of coping mechanisms and accordingly the sessions were planned.

Health and Nutrition

The first and foremost important intervention in group was on health, hygiene and nutrition.

Tips to keep positive physical health.

- Self care, including nutrition and rest.
- Maintain CD4, Hb, weight: tips were given to increase Hb and weight.
- Take bath regularly for cleanliness to avoid infections.
- Carry tiffin with oneself to maintain physical strength.
- Avoid eating outside to prevent infection.
- Carry water bottle to avoid infections.
- Check on opportunistic infection
- Avoid fasting to maintain strength.
- Avoid 'mishri', tobacco, alcohol consumption habits and addictions.
- Eat fresh, nutritious food. Dishes were suggested, containing high proteins and which were affordable.
- Few suggestions about preparing all vegetables and pulses, without considering likes and dislikes but its nourishing component were given.
- Practice safe sex those who have their partners they can avoid sex or can have protected sex.
- Respondents were suggested names of NGOs which offer supplementary nutrition to maintain good health.
- Tips on preserving nutritional value of ingredients like washing vegetables before cutting.
- Not to eat stale food.
- Keep food covered.

Money management - Group of women discussed their concerns about managing expenses at home in a given limited resources.

- It was suggested that, those who can physically work, should work and earn their living or at least support the income of the family, this would help in maintaining their self respect also.
- Cut on unnecessary expenses.
- Use transport concession or Bus pass.
- Make small savings join saving groups (Bachatgat)
- Think about future of children, their education, marriage and save in the bank and plan accordingly.
- Avoid taking loans, if it is inevitable; repay it in a stipulated period.

- Set priorities for expenses and accordingly spend money, in the priority of health and nutrition. This session was made very simple to understand by giving examples.
- Understand one's capacity, strength, start any small self generated occupation and do it in a small way to supplement the family income.

  (Mayo 2012)

Stress Management

Stress, tension is very common in this century, the distance between expected reality and the reality and reaction to it leads to stress. Similarly we have expectations from ourselves, others also expect many things from us in different roles, this creates stress. Respondents did not know word 'stress', but knew tension, irritation, role confusion, conflicts and they do face problems in managing this stress. Stress is a demand from oneself and from others on individual and the distance between the two. Today, everybody experiences stress about managing tasks in a particular time frame, facing competition, facing the boss and several challenges in environment while performing different roles. Stress starts very early in life and continues till death. As we are in different developmental stages, there are demands of those stages by developmental tasks. Those who can face these stresses in a balanced manner, do not feel anxious or stressed but there are few individuals who by their nature, personality and bringing up feel stressed out with multiple responsibilities. While respondents are suffering from HIV, they have stress of their own health maintenance, managing the expenses, managing health and nutrition, managing parents and in-laws and live positively. Hence, it was suggested to identify the stressors e.g. health, financial crisis, stigma and discrimination, relationship problems. Try to first learn to protect one's own interest, maintain immediate relationships, manage money by doing family budgeting, balancing income and expenditure.

Tips were:

- Do not spend unnecessarily.
- Do not take loans.
- Do not give money to anyone unnecessarily when you yourself are in crisis.
- Save money every month.
- Reduce needs.

- Try to seek help from different sources.
- Plan your activities in time and conduct them.
- Keep realistic expectations, goals from self.
- Do not compare yourself with others.
- Take a break after a hectic schedule.
- Do visit to a religious place with family members.
- Always remember, whatever best we can do, we must do, but the things which are beyond our control, we should learn to accept it with courage.
- It was emphasized, that engaging oneself in any constructive activity can help reduce stress, develop a hobby.
- Listen to the music.
- Enjoy small things in the company of family and children.
- Do not indulge in any addiction to do away with stress.
- Join some saving group 'Bachat gat', attend their meetings and expand your social network.
- Do exercises; go for a walk if you can.
- Focus on your strengths.

Stress due to financial problems can be handled by improving on income sources. If one maintains the health, one can manage by sitting at home also few short/small self employment generation can be done e.g. selling fruits, vegetables, stitching work, making soft toys, beauty parlour work, etc. As one gets involved into such self employment, there is income generation which helps enhance self-esteem which keeps better mental health (Wellness Reproductions & Publishing 2005).

Stress – Genes, personality and life experiences all influences the way one respond to and cope with stress. Identify stress, explore problem, look for ways to solve.

- Tips to manage stress (Treisman 2010)

(1) Identify what is stressful for you, list the factors and then work on gaining control over them.
(2) Get organized – while under stress one finds every task overwhelming. But organizing one's life can put stressors in perspective create a plan to manage.
(3) Learn to prioritize – Many response priority – Most Imp Least

(4) Manage emotions help pt. to manage their emotions this would help to see life events in proper perspective and people can be motivated to act.

(5) Seek professional support.

(6) Get depression under control. Medication, therapy and change in life study. You can control it.

(7) Lean on loved ones find a friend, relative or a support group to stay with you, to share, someone cares for you can help to reduce stress .

(8) Set a daily goal of good health eat healthy, exercise, sleep, good care of body and mind.

Anger management :

1. Anger – Take a time out take a few moments to breathe deeply and count 10.
2. Once you are clam – now express anger.
3. Get some exercise – do a physical activity, which will provide outlet for emotions.
4. Think before you speak take a few minutes to collect your thoughts.
5. Identify possible solutions – work on resolving the issue at hand.
6. Occupy yourself in constructive activity.
7. Accept the reality
8. Wait – learn to wait, have patience.
9. Avoid situations that causes anger, have control over emotions.
10. Improve social skills.
11. Think it, after l0 years, your anger will be same ?
    What is the worst consequence of my anger ?
    Forgive
    Close your eyes.

Spirituality

Practice meditation at least for 15 minutes

Be happy, be contented.

Have a peace of mind.

Spirituality is inner awakening, becoming aware of inner being – rising of consciousness. Willpower, mind power, self discipline, power of concentration. Spiritual growth is the basis for a better and more harmonious life for everyone, a life

free of tension, fear and anxiety, a new way to look at life. We learn not to let outer circumstances influence our inner being and state of mind.

We become more responsible, happier and can live balanced life. Introspect, look at positive side of life. Your will power and decision making abilities, let it grow, have a control on mind and emotions, thank the universe for everything you get, develop patience and tolerance, consideration for other read.

To maintain happiness, the key is to improve communication and interaction patterns. Communication is very essential for human beings to live life. It is necessary for fulfilling daily needs, for interaction, for building relationships. While two persons live together, it is very essential that they share their feelings and emotions, joys and sorrows; communication encompasses a meaningful expression, sharing of experience and interactions between a person and the environment. It helps in smooth functioning and performing of roles of individuals. Communication is very essential while living together in family and in society for stabilizing the relationships. Respondents were given inputs about communication among family members. First it was understood, how do they communicate and then it was realized, that majority of the times, half the things. Women do not know, about husband's activities, financial matters, their company, nature of job, they are not consulted at many important decision making events. Women hardly have necessary sharing / communication with their husbands. This gap of communication is due to gender inequality low status of women and patriarchy. During intervention session, women were addressed on this issue and were told to consciously improve communication by following manner.

Tips to improve communication:

- Talk to all family members.
- Care for them, receive care from them.
- Show concern.
- Express your emotions.
- Learn to appreciate positives – qualities in other family members.
- Trust each other / on their potentials.
- Show confidence in everyone.
- Distribute responsibilities among family members.

- Take decisions with everyone's consent.
- Understand likes and dislikes.
- Respect each other.
- Don't discriminate or don't show favoritism.

Among husband and wife, there should be no barrier; they should share their work life, likes, dislikes, interests with each other. One of the intimate things they must share with spouse's their HIV status. This is in the interest of the other spouse. This sharing would help him/her to take better care of the infected and to prevent transmission. It is only the spouse, who can help in the critical time and can extend co-operations care. Those respondents, who had lost their spouses, where living with their parents. During intervention, researcher emphasized the need to disclose / communicate their HIV status, as they were the sole caretakers of the respondents. If this disclosure takes place immediately after the HIV diagnosis, acceptance of the infected spouses becomes easier and much faster. This helps in boosting up morale of the infected one. Even other joys and sorrows also be shared in free environment by all family members and to create such an atmosphere is a responsibility of everyone in the family. Give the family members feeling of security. Give proper direction for disciplined ways of behavior. Respect privacy of every member in the family, create a bond among all members cherish, independence, of love. Talk / take complementary roles. Spend quality time with each one, welcome periodic guests, celebrate festivals.

Enjoy your leisure time also in constructive way to seek pleasure, take the joy in giving others.

Taking charge of your own life, becoming proactive. In everyday situations, human beings have to adjust to many unforeseen situations and have to successfully handle them to live happily. However, we do not have control over the environment around us; hence we can control yourself not to react to situations but to respond to people and situations. In psychological terms, it is called being 'proactive'. Once it's decided to become proactive, there are effective ways which helps in this goal.

1) Assertiveness : It is a social skill whereby one learns to balance one's needs with those of others, and to express one's needs without getting into a confrontation and without surrendering one's rights. An assertive person does not resort to the 'fight-or-fight' short cut i.e. he does not attack others and does

not run away from facing interpersonal issues. Assertive person can develop strong relationships as people over long time start respecting an assertive person. Hence, avoid reacting immediately.

- Ignore meaningless abuse or criticism.
- Do not accept wrong or injustice.
- Admit the plus points of others.

Assertiveness keeps control over relationships. It helps the assertive person to maintain self-respect. Women particularly in India are not taught to be assertive. Their lives begin with unquestioning obedience to parents, which is then supposed to change to worshipping the husband as a god, as they grow, sons dominate them. Thus, it is not surprising that women rarely develop the art of assertiveness. Women were explained to be more aware about their rights. So as you feel uncomfortable situation at home or at workplace, take a deep breath and assert yourself for what you feel is right.

2) Self Motivation : Self motivation plays an important role in how much one will strive towards one's goals. As per Maslow's Pyramid where one stands. The individual has to be motivated himself, no one can motivate him if he himself is not.

Hierarchy of needs.

a) Basic needs
b) Safety and security needs
c) Need for love and belonging
d) Self esteem fulfillment
e) Self actualization

Keeping one's motivation level requires continuous work and efforts.

3) Building hope :- This goes a long way in giving a push to our life, we all live on hope. As long as there is hope, one can face any hurdle in life and hope comes out of being able to look carefully and find the light somewhere. We can look at the positive aspects of life this empowers us to keep moving when matters appear bleak.

4) Positive mental attitude : Attitude is shaped during the formative years of our life, it can definitely be changed at any age. Even when things don't work out fine, positive mental attitude gives peace of mind.

5) Goal setting, selecting priorities :- These are obvious needs of life. Many of us are scared to set goals because we feel, if they cannot be achieved, we will be disappointed. Hence divide the goals like short term realistic and time bounds practical ones and the other, very idealistic and long term goals. Every time when we achieve short term goals, our motivation level becomes higher. We can develop confidence to handle challenges. Remember, that goals can always be changed or modified to suit changing circumstances. Accept and correct mistakes and take a modified route when there are hurdles (Ali Kwaja 2006).

6) **Time management**: - Many of us complain we do not get time for studied exercise, for entertainment or many people feel, 24 hours of the day are so busy for them. This happens because; there is no motivation to do these things. One needs to be motivated to do things in time; it requires organized efforts and getting priorities of work. Dividing office work and house work. One has to decide to keep the time for oneself, for this, start your day early in the morning make a list of activities to be done on a particular day and the time available. To have this kind of a motivation, one needs to be alert, energetic organized, determine and taking pains to achieve goal. So divide your work as follows:

a) Urgent and necessary.
b) Urgent but not absolutely necessary.
c) Not urgent but eventually necessary.
d) Not urgent and not absolutely necessary.

This categorization helps us to decide what should take up immediately and what we can postpone. Realising your priorities will give you a boost and a better control over your life and available time will be adequate for you.

Decision Making :- We take decision every minute, minor or major that may have short term or long term effects on our life. The better our ability for decision making, the more we will be empowered to take control of our life.

We need to take right decision at right time. Many a times we procrastinate and lose the opportunity. Sometimes we become impulsive in decision making. Those as per norms and precedents, we have no problems in decision making, but when decisions are very difficult, we need to take care while we take decisions.

Follow the tips while taking decisions.

- It should be your decision.
- Remember its pros and cons.
- Look for alternatives.
- Take several small decisions.
- Set a deadline
- Listen to your institution.
- Sacrifice to gain something.
- Think of your decision negatively at least once.
- Fantasize your decision
- Trust your decision and yourself

As important as taking the right decision is how you convey that decision. If one can convince the team member / family member and involve them in decision making, it is giving them credit that it is their decision, the results will be more effective and everyone will be satisfied and motivated.

7) Doing Vs not doing :- Whenever we need to take up a task, there are two choices before us – either we do it or not to do it. One can easily decide not to do it. This often inhibits us from taking initiative. Our satisfaction would come only if we determine to do the task. Have a policy of detachment that helps us become more confident in decision making and give us the courage to face life will all its ups and downs.

Parenting:

Every child is a joy in this world. Birth of the child in the family is a very happy and welcoming event all over the world. Parenting is a very enjoyable experience in families.

Following are the tips for better parenting:

- Give more care and attention.
- Give quality time.
- Do not succumb to tantrums under certain circumstances.
- Do not feel guilty if you cannot give time.
- Toys and gadgets cannot replace human company.
- Teach the child patience, especially to delay gratification.
- Encourage child to be in group.
- Give responsibility to child.
- Let him learn to adjust, may be by interacting with relatives and siblings.
- Make him express emotions, sharing.
- Do not over protect due to his / your illness, hospitalization.
- Be firm if he misbehaves.
- Do not indulge.
- Keep the child busy in some activity.
- Be transparent to answer his questions.
- Explain what changes may come and role reversal the child may have to do, to adjust to new family routine.
- Teach the child to be independent.
- Make the child caring, sensitive, good in interpersonal relationships.
- Express your love, care, attention for the child (Dr.Ali Kwaja 2006).

Disclose your HIV status to the child in the process of development at the appropriate age and the care you require and how best care the child is capable of providing, entrust his/her potential to take responsibility of taking care of himself and you.

All the above mentioned inputs as per the requirement of respondents were given in two group counseling sessions. Those who could remain present in pre and post intervention session did respond very positively that the tips given were very useful, it has helped them in coping better with their HIV crisis, they could handle disclosure of HIV to spouse and children in a better way and could overcome depression and anxiety due to HIV diagnosis.

7.8: Summary :

This chapter in the beginning itself gives meaning of intervention i.e. to come in between to mediate for the unforeseen events in human life. Social work intervention as a profession, promotes social change and problem solving in human relationships. It empowers people and promotes well-being. It requires sound knowledge of psychology of a person, social environment in which problems occur and the skills to deal with it carefully. It has six methods, having principles of dealing with people, which includes acceptance, confidentiality non-judgmental attitude and right to self determination. As researcher has mainly used counseling and group counseling while providing intervention, it will be apt to give here importance of groups in individuals life, i.e. individual is born in group, he is brought up, socialized in group. He gets support, feeling of security, a bond to live with. Later, few studies are given, which discusses, style of conducting intervention studies and its problems like, sample selection, retention and measurement. There is lack of adequate control, comparison and problem of impact assessment. Further coping mechanism and intervention study references are given, which emphasizes the association between coping mechanisms, personality, well-being and satisfaction. Study also suggests, education helps in reducing stress and patients can develop better coping mechanisms and reduces depression and anxiety. Close association between stress, physical health, psychosocial resources and coping also is given. Another study discusses quality of life of HIV / AIDS is significantly lower than that of general population, and this is related to their severity of disease and lack of support. Linkage between stress and depression among HIV / AIDS leads to poor care also has been underlined. In such a situation person living with HIV needs guidance about consulting the doctor for diagnosis and treatment to share the diagnosis and negative feelings related to it, and needs motivation to develop positive attitude. Person also needs support to share his HIV status to the partner, to disclose it to family members and making health maintenance plan.

In this chapter intervention given has been stated, but before that in the 1st phase of study psychological tests were used. A small description of tests is provided here for reader's referral. Then the scoring method is given. These scores were calculated to know, if there was any effect on respondent. Each score had 'five' questions, each question have three scores. The total of these scores was then divided into '3' main

categories. Then the pre intervention mean score of coping, with socio-economic score, health family support, HIV background supporting coping and counseling and NGO support scores are given. Here it is seen that, positive HIV background supportive coping mean indicates coping score as maximum and comparatively poor HIV background indicates lowest score for coping. Similarly next test is adjustment, its lowest score indicates higher adjustment, it is seen that adjustment has improved among the respondents under study. Next test was, on quality of life. There was no change found as conceptual understanding about this concept among respondents was poor. Next test was about motivation. It was assumed that motivation to live may be poor, and it was observed to be poor prior to intervention. Last test was on personality. There is no change in introverted or extroverted personality train of the respondents, they are in 'ambivert' category.

In the intervention or second phase, interventions on following aspects were given the form of group counseling in all NGOs.

- Health Care
- Money Management
- Stress Management
- Management of emotions especially 'anger'.
- Spirituality
- Developing positive attitude
- Improving communication with family
- Disclosure of HIV to children
- Parenting
- Time Management.

The total sample shows, pre intervention score as 34.8, while the respondents from SOFOSH show maximum mean score of 36.7. It was observed that coping score highest among the higher socio economic score. Among the lower income group coping was observed to be higher due to their level of adaptation. Coping was better among those who have moderate health condition followed by normal health condition e.g. (table 7.3). Similarly, it was observed, that those who had good family support had better coping e.g. (Table 7.4). Positive HIV background supporting coping indicates 35.51.Comparatively poor HIV background indicates lowest score

for coping. This means, partner has not communicated HIV diagnosis, age at the time of diagnosis was low and there is no practice of safer sex this affects coping. Counseling and NGO support has effect on coping. In some of the NGO's, these services are provided and it has helped the respondents.

- About adjustment e.g. (Table 7.8) it was observed that middle class people have better adjustment. Those who have normal health conditions have better adjustment. About family support, those who were from poor socio economic class had better adjustment. Further it was observed that moderate HIV had better adjustment capacity e.g. (table 7.11), similarly moderate counseling and NGO support is helping adjustment.
- Quality of life – In this test maximum score was expected 49, the mean score was observed to be 46.6 (Table 7.13) which is indicating a good quality of life in pre intervention phase. Better Quality of life is seen when there is normal health condition and with good family supports e.g. (Table 7.15, 7.16). Association between HIV background and quality of life is shown in (Table 7.17), it can be observed that respondents age, duration of diagnosis and practice of safe sex has affected positively. Those who were diagnosed recently were receiving support and counseling.
- Motivation- Motivation was another component of coping mechanism. Prior to intervention motivation was low e.g. (Table 7.20). In poor class motivation was low. An effort was made to see its relationship with health score and it was found that those who had poor health conditions had low motivation. Similarly those who had family support to care for their condition had better motivation. If person is young at the time of diagnosis, motivation to live is better since there are now effective medicines are available and if partner is alive, there is further support and motivation to live e.g. (Table 7.24).So far as counseling and support is concerned highest scores are observed with good counseling and NGO support.
- Personality- Last components of coping mechanism were personality. Personality is developed over a long period of time. There were no significant differences found in its relationship with socio economic condition, health family support health condition and HIV background and counseling and NGO support categories, in the pre intervention phase.

CHAPTER VIII

IMPACT OF INTERVENTION ON COPING MECHANISM

8.1 Introduction

8.2 Pre – post comparison- coping

8.3 Adjustment test

8.4 Quality of life test

8.5 Motivation test

8.6 Personality test

8.7 Summary

CHAPTER VIII

IMPACT OF INTERVENTION ON COPING MECHANISM

Impact of intervention pre and post test:

8.1 Introduction :

The study was about assessing the coping strength before and after intervention. Researcher is working in the field of HIV since a long time. HIV produces stigma and discrimination in the mind of the people and fear, shock, threat in the mind of the patient diagnosed with HIV. It was presumed that, coping with HIV needs, emotional strength, motivation, support and personality qualities. To handle this diagnosis, deterioration of health condition, opportunistic infection and loss of infected partner patient needs intervention in the form of counseling and support to live with positive status. Literature review also has revealed that there were very few studies about intervention with HIV patients. Hence, to understand use of intervention in the form of counseling, guidance, education and group counseling the study was conducted. It was expected that, we should have had exhaustive intervention of 2, 3 sessions with maximum number of respondents. However, we could follow 52 respondents till the end for pre and post results. Coping mechanism should have been strengthened; adjustment and motivation also should have increased.

In the intervention study, there were 191 respondents. In the intervention session, women respondents attended group counseling session. Those were on health care, nutrition, safer sex practices, life management skills, management of emotion, handling stress, parenting and issue of disclosure of HIV to children. Group intervention was done twice, response from the respondents was very encouraging. Researcher could contact the respondents through NGO reference, women used to attend support meetings or one or two NGO's used to distribute ration to the beneficiaries i.e. positive women this day of programme was decided to meet them. Prior to study women were explained the three phases of study and those who could agree to attend 3, 4 times the agency, they were included in the study. However, till the 3, 4^{th} meeting i.e. in post intervention phase, very few i.e. 52 respondents only could remain present consistently to give all 5 psychological tests. In the post

intervention phase, again identification data was not repeated. Only the 5 tests were refilled, and then the results in pre intervention and post intervention are compared. Coping test results clearly indicate same in the total sample. However, in Deepgriha NGO, there is considerable change observed in pre and post scores.

8.2 Coping Mechanism: pre intervention and post intervention comparison

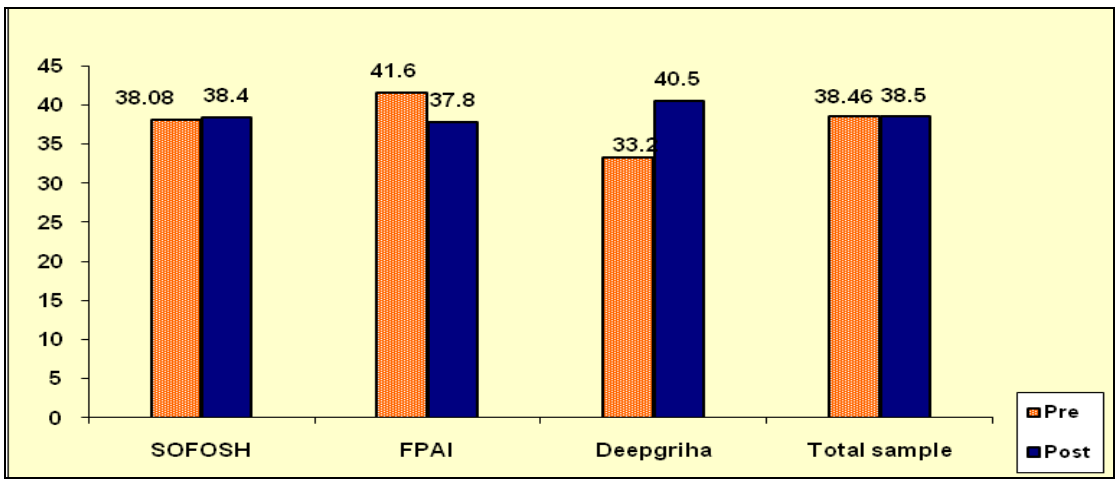
As discussed in earlier chapter, the standardized test of coping was administered to the respondents to understand the changes took place due to intervention. Therefore, the scores of the coping test at initial stage and the scores of coping test after intervention was computed and given in following table.

Table 8.1

Pre intervention and post intervention of mean scores of coping

NGO Groups	Mean Coping Scores	
	PRE	**Post**
Maximum Score	70	70
SOFOSH (N=36)	38.08 ± 7.2	38.4 ± 7.4
FPAI (N=12)	41.6 ± 8.1	37.8 ± 5.5
Deepgruha (N=4)	33.2 ± 5.3	40.5 ± 6.6
Total Sample (N=52)	**38.46 ± 7.5**	**38.5 ± 6.9**
T=-0.052 df. 51 P ≤0.01 & P≤ 0.05		

Graph 8.1 NGO wise Pre post comparison of mean score of coping



Coping has increased in Deepgriha NGO.

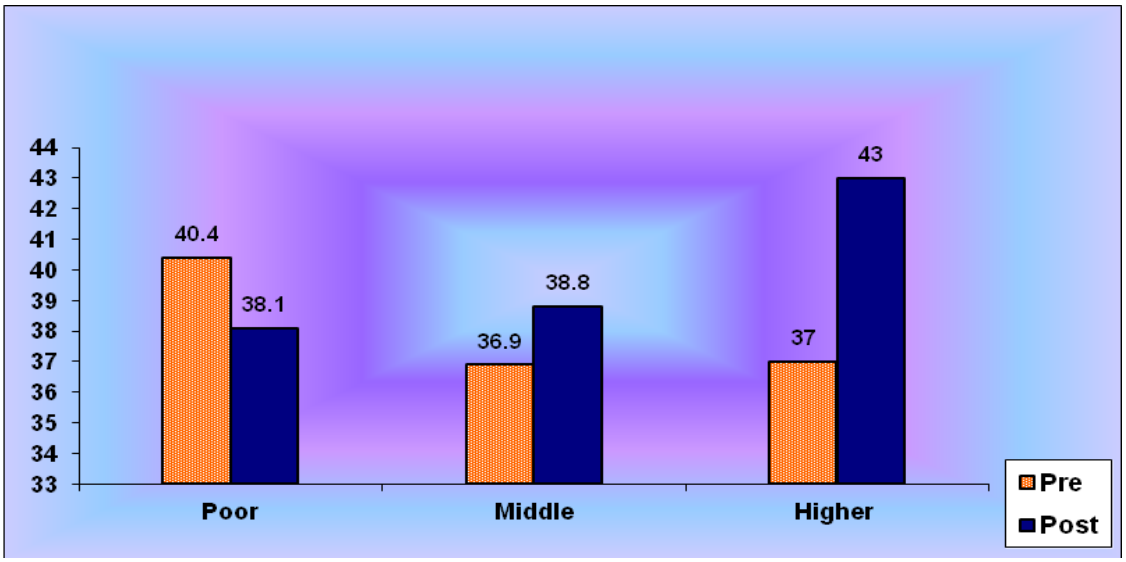
At initial stage, the scores of coping mechanisms ranges between 33 to 41 without large variation, however FPAI observed to be at higher side followed by SOFOSH and Deepgriha. As regard to the post test, the score obtained for the same test doesn't show any change. At Deepgriha the mean post test score, increased by 7 points but it doesn't means, it is statistically significant. For rest of the NGOs, the post test scores are almost equal to the pretest. Two possible reasons, can explain this phenomena that, coping is an individual strength, which exclusively depends on endurance capacity and prevalent circumstances. The circumstances may vary from time to time which affects the inner strength that is endurance capacity. This capacity controls and governs the behavioral output in an expected way. The favorable conditions always help to think various alternatives to overcome day to day difficulties. This capacity gets impetus through the past experiences which are the part and parcel of the attitude indeed, it is one of the more influencing elements of coping strength. The entire process is very gradual and long term, to get the positive change in coping scores, may take considerable time for expected outcome. Hence, major variations in pre test and post test are not observed. **Table 8.2**

Coping Mechanism

Comparison of mean scores of pre and post test of coping

NGO Groups	Socioeconomic score	N	PRE	Post
SOFOSH	Poor	17	39.47	37.8
	Middle Class	19	36.84	39.1
FPAI	Poor	4	44.5	39.75
	Middle Class	7	39.29	37.9
	Higher Class	1	46	30
Deepgriha	Middle Class	3	31.33	39.3
	Higher Class	1	39	44
Total	**Poor**	**21**	**40.43**	**38.1**
	Middle Class	**29**	**36.86**	**38.8**
	Higher Class	**2**	**37**	**43**

Graph 8.2 Pre and post intervention mean scores of coping test with socio economic scores



Coping seems to be increased among the respondents from higher and middle class.

Although broadly we could not see any change within socio-economic score, middle class and higher class show slight improvements in coping during post intervention.

Coping :- Coping is an ability to face the situation. Human beings live in the environment . There are various demands on them about their roles and responsibilities. Coping mechanism is an ability to face the environmental demands and be responsible, to do the best in his or her capacity. Coping mechanism also is a system developed over a period of time in the process of development to face the critical situation. It was assumed that, coping has an association with socioeconomic condition. As stated earlier the scores of coping test before and after were computed and are given in table 9.2. Although broadly we could not see any change within socio-economic score, respondents for middle class and higher class show slight improvements in coping during post intervention, along with this, normal health conditions and poor family support helps improvement in coping due to intervention. Better socio-economic conditions helps to think various alternatives to overcome day-to-day difficult situations.

Comparison of pre and post test means score within health score:

Coping is an ability to face difficult circumstances. It was assumed that health has a definite role of play in coping capacity of the respondent. As the health is maintained it helps in coping. As health deteriorates i.e. respondents lost weight, they developed opportunistic

infections and their CD4 deteriorated- Table 8.3 shows relationship between coping and health.

Table 8.3

Coping

Comparison of pre and post test means score within health score

NGO Groups	Health Score	N	PRE	Post
SOFOSH	Poor health condition	2	33.5	29
	Moderate health condition	24	39.38	39.6
	Normal health condition	10	35.9	37.5
FPAI	Moderate health condition	9	39.89	35.7
	Normal health condition	3	46.67	44.3
Deepgriha	Moderate health condition	3	35.33	42
	Normal health condition	1	27	36
Total	**Poor health condition**	**2**	**33.5**	**29**
	Moderate health condition	**36**	**39.17**	**38.8**
	Normal health condition	**14**	**37.57**	**38.9**

Another component of coping was associated with health. The table shows, coping has slightly improved, while there was normal health condition, i.e. (refer. Appendix for normal health condition). During intervention respondents were guided to take care of themselves about maintaining their CD4, Hb and maintain immunity to avoid opportunistic infections. However, given intervention more intensively can bring positive results. As respondents had normal health, they could concentrate and adhere more on the inputs given.

Comparison of pre and post test means score within family support score:

We live in family as a group, family plays a significant role in shaping of our personality, it provides us support at the time of crisis. However in some of the critical situations like undesirable deviant behavior or during diagnosis and treatment of stigmatized disease, family hesitates to support the sufferer. An effort was made to see whether family support has any role in changing coping mechanism due to intervention.

Table 8.4

Coping

Comparison of pre and post test means score within family support score

NGO Groups		N	PRE	Post
SOFOSH	Moderate family support	27	37.59	37.4
	Good family support	9	39.56	41.3
FPAI	Moderate family support	5	44.4	38.4
	Good family support	7	39.57	37.4
Deepgriha	Poor family support	1	31	34
	Moderate family support	1	27	36
	Good family support	2	37.5	46
Total	**Poor family support**	**1**	**31**	**34**
	Moderate family support	**33**	**38.3**	**37.5**
	Good family support	**18**	**39.33**	**40.3**

Out of 191 respondents in the pre intervention phase, 52 only could sustain till the post intervention phase, who were having better situation in terms of health, family support, HIV background and NGO support. The next category of score in coping was family support. Family support is lost in case of stigmatized diseases. In the present study, respondents were HIV infected and also widows. Socially widowhood is not a very acceptable situation. Many respondents were experiencing loss of support after the death of partner and contracting HIV/AIDs. Majority of them were staying with their parents and were supported in the sense that, they were provided accommodation, food, childrens' education and few women used to supplement the family income with very minor jobs. In the table it is seen, that those who had good family support their coping has slightly improved, intervention was an additional input, which enhanced their morale.

Comparison of pre and post test means score within HIV background score:

As stated earlier coping is an ability to face critical situation. Human being live in an environment where they have to face various demand on them about their roles and responsibilities. Coping mechanism is a system developed over a period of time in the

process of development to face the critical situation. It was assumed that intervention about time management, stress management, disclosure of HIV to family can help improvement in coping.

Table 8.5

Coping

Comparison of pre and post test means score within HIV background score

NGO Groups		N	Total coping PRE	Total coping score post
SOFOSH	Poor HIV background helping coping	1	51	51
	Moderate HIV background helping coping	15	37.9	37.6
	Positive HIV background helping coping	20	37.6	38.5
FPAI	Poor HIV background helping coping	5	39.6	40.8
	Positive HIV background helping coping	7	43	35.7
Deepgriha	Moderate HIV background helping coping	3	31.3	39.3
	Positive HIV background helping coping	1	39	44
Total	Poor HIV background helping coping	**1**	**51**	**51**
	Moderate HIV background helping coping	**23**	**37.4**	**38.5**
	Positive HIV background helping coping	**28**	**39**	**38.0**

Above table shows slight change in pre post mean score within moderate HIV background scores (circumstances related to infection such as age, duration of diagnosis, partner communication and precaution). Although a considerable change is observed at Deepgriha, the sample size is small to make a statement. Hence a more rigorous study with more sample can be undertaken in future.

Comparison of pre and post test means score within counseling score:

Intervention in the form of counseling has an effect on enhancing coping ability of an individual. Following table throws light if any changes have occurred in coping among various categories of those who have received counseling and NGO support.

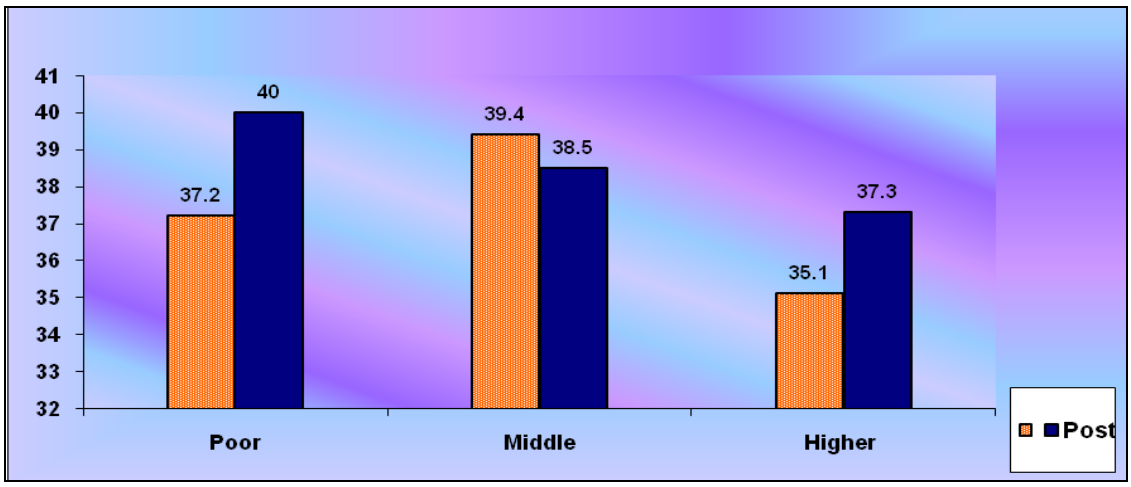
Table 8.6

Coping

Comparison of pre and post test means score within counseling score

		N	**Total coping PRE**	**Total coping score post**
NGO Groups	Counseling_score_cat		4	4
SOFOSH	Poor counseling and NGO support (5-7)	4	36.75	39
	Moderate counseling and NGO support (8 to 11)	25	39.16	39.12
	Good counseling and NGO support (12-15)	7	35	35.7
FPAI	Moderate counseling and NGO support (8 to 11)	12	41.58	37.8
Deepgriha	Poor counseling and NGO support (5-7)	1	39	44
	Moderate counseling and NGO support (8 to 11)	2	29	35
	Good counseling and NGO support (12-15)	**1**	**36**	**48**
Total	Poor counseling and NGO support (5-7)	**5**	**37.2**	**40**
	Moderate counseling and NGO support (8 to 11)	**39**	**39.38**	**38.5**
	Good counseling and NGO support (12-15)	**8**	**35.12**	**37.25**

Graph 8.3 Pre and post intervention mean scores of coping test within counseling scores



Coping has improved among those who either had poor counseling or had good counseling and NGO support. However, the number among these groups is small to conclude anything.

8.3 Adjustment Test

Concept of adjustment: Adjustment is a relationship which comes to be established between the individual and the environment. Individual has position in his social relations, he is trained to play his role in such a way that his maximum needs will be fulfilled, so that he will get satisfaction. If this does not happen he may be frustrated. Term adjustment (Hinshaw, R.P.1942) used in the fields of personality, mental hygiene and social psychology. It assumes an individual psychological factor and an environmental factor, operating in a specific frame of reference. In social psychological usage it implies a minimum amount of conflict between an individual's behavior and the existing social institutions. In general psychology, it means integration, a term which implies harmonious cooperation of the various levels of the personality (PSYCINFO database 2010). Term adjustment refers to the extent to which an individual's personality functions effectively in the world of people. It is a harmonious relation between the person and the environment. A well adjusted personality is well prepared to play the roles which are expected of him within given environment. One of the elements of coping is adjustment therefore adjustment test developed by Dr. M.N. Palsane was used, this test consisted of 375 questions.

It has following aspects.

1. Family
2. Emotion
3. Education
4. Health

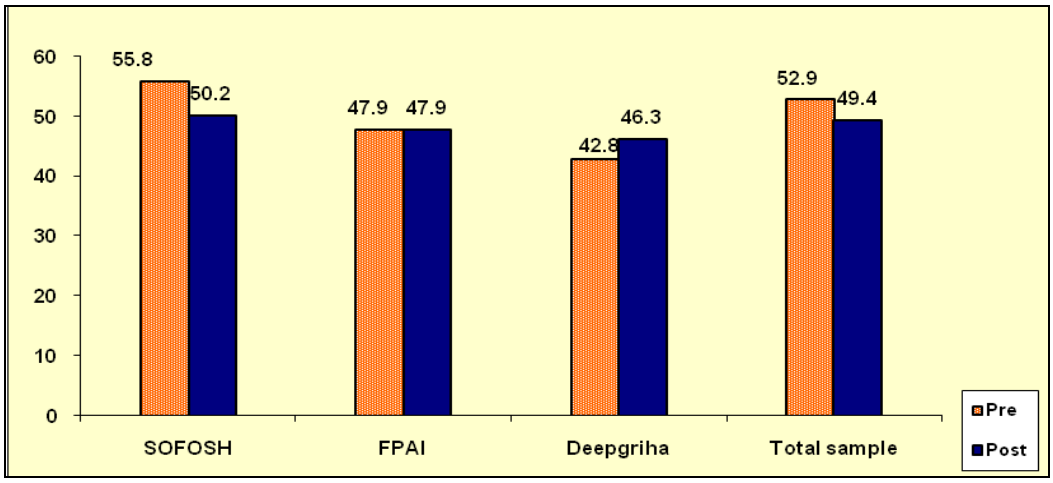
Relevant questions from each aspect were taken up for study maximum 81 questions were asked.

Table 8.7

Comparison of mean scores of Pre and Post test of Adjustment

NGO Groups	**Mean Coping Scores**	
	PRE	**Post**
Maximum Score	74	74
SOFOSH (N=36)	55.8 ± 6.9	50.2 ± 7.4
FPAI (N=12)	47.9 ± 6.0	47.9 ± 7.2
Deepgruha (N=4)	42.8 ± 5.7	46.3 ± 9.6
Total Sample (N=52)	**52.9 ± 7.9**	**49.4 ± 7.5**
Paired T test		
T- value	2.71	
d.f.	51	
sig. (0.05%)	0.009	

Graph 8.4 NGO wise pre post comparison of mean score of adjustment



Except for SOFOSH all table and graph indicates changed in adjustment.

Lower score indicate highest adjustment. There is significant positive change observed for adjustment score, with 0.009 P value. Among the NGOs respondents from SOFOSH show, highest positive changes compared to other NGOs. Although significant positive change is observed in overall sample of 52, it is observed only in SOFOSH. FPAI shows a constant score whereas, Deepgriha is showing negative change, since the sample size is too small that it is not worth to comment on. During crisis, one needs to accept and adjust with the circumstances, respondents had such vulnerable situation that they well accepted suggestions given during inputs about home and family, health, emotional response and social personal aspects.

Table 8.8

Comparison of pre and post test means score of adjustment within Socioeconomic score

NGO Groups	Socioeconomic score	N	Total adjustment PRE	Total adjustment Post
SOFOSH	Poor	17	57.65	48.4
	Middle Class	19	54.05	51.9
FPAI	Poor	4	49.75	49.5
	Middle Class	7	48	47.7
	Higher Class	1	40	43
Deepgriha	Middle Class	3	41.67	46
	Higher Class	1	46	47
Total Sample	**Poor**	**21**	**56.14**	**48.6**
	Middle Class	**29**	**51.31**	**50.3**
	Higher Class	**2**	**45**	**48.5**

Score analysis shows that, adjustment capacity is significantly improved among poor socio-economic class. Pair T test is '0' which is highly significant.

Respondents from poor socio-economic condition are habituated to get adjusted with the surrounding environment. They are the most needy people; they required inputs in communication, interrelation within family members and with children.

Comparison of pre and post test means score of adjustment within Health score:

In the pre intervention results, better adjustment capacity was observed among those who have normal health condition. Following table shows whether the remaining categories of health score have any effect on adjustment capacity due to intervention.

Table 8.9

Comparison of pre and post test means score of adjustment within health score

NGO Groups	Health Score	N	PRE	Post
SOFOSH	Poor health condition	2	57.5	45.5
	Moderate health condition	24	56.17	50.2
	Normal health condition	10	54.4	51.2
FPAI	Moderate health condition	9	47.22	47.1
	Normal health condition	3	50	50.3
Deepgriha	Moderate health condition	3	44	50.7
	Normal health condition	1	39	33
Total Sample	**Poor health condition**	**2**	**57.5**	**45.5**
	Moderate health condition	**36**	**52.9**	**49.5**
	Normal health condition	**14**	**52.3**	**49.7**

(P value = 0.03) of $\mathbf{X^2}$

(P value = 0.02) of $\mathbf{X^2}$

Respondents having moderate health conditions show significant changes in adjustment. Those respondents were having better adjustment. They have experienced some health problems although, it is not a worst situation they are well aware about the problems in future that might require more adaptation with circumstances.

Comparison of pre and post test means Score of adjustment within family support score:

An effort was made to see whether adjustment could influence among family support categories due to intervention.

Table 8.10

Comparison of pre and post test means Score of adjustment within family support score

NGO Groups		N	PRE	Post
SOFOSH	Moderate family support	27	56	49.8
	Good family support	9	55	51.2
FPAI	Moderate family support	5	49.6	46.4
	Good family support	7	46.7	49
Deepgriha	Poor family support	1	49	56
	Moderate family support	1	39	33
	Good family support	2	41.5	48
Total Sample	**Poor family support**	**1**	**49**	**56**
	Moderately family support	**33**	**54.52**	**48.8**
	Good family support	**18**	**50.28**	**50**

Same as health, moderate family support show significant positive change (P value = 0.001) in adjustment. There is only one respondent from Deepgriha who shows poor family support. Moderate family support indicates partial acceptance of HIV infected persons in the family. This helps in keeping better morale of the respondents that leads to adaptability and changes and suggestions for better adjustment.

Comparison of pre and post test means score of adjustment within HIV background helping coping:

Moderate HIV background had better adjustment capacity during pre-intervention phase. However, intervention has played a role to bring equal score of adjustment among positive and moderate HIV background. Table 8.12 illustrates the same.

Table 8.11

Comparison of pre and post test means score of adjustment within HIV background helping coping

NGO Groups	HIV background helping coping	N	Total coping PRE	Total Coping Score post
SOFOSH	Poor HIV background helping coping	1	65	59
	Moderate HIV background helping coping	15	53.33	49.73
	Positive HIV background helping coping	20	57.1	50.15
FPAI	Poor HIV background helping coping	5	47.2	49.6
	Positive HIV background helping coping	7	48.43	46.7143
Deepgriha	Moderate HIV background helping coping	3	41.67	46
	Positive HIV background helping coping	1	46	47
Total Sample	Poor HIV background helping coping	**1**	**65**	**59**
	Moderate HIV background helping coping	**23**	**50.48**	**49.2**
	Positive HIV background helping coping	**28**	**54.54**	**49.2**

Table shows positive HIV background is helping coping. As a significant impact on changing pre intervention mean score of adjustment significantly (P value = 0.008). Positive HIV background includes higher age at detection, higher duration of diagnosis, and communication with partner regarding infection and following safer sex practices for precautions. All those factors have accelerated process of adjustment. Higher age has better adjustment due to maturity, the stage in the family life cycle, helps in better status and decision making process. Higher duration of diagnosis gives better coping and alternate ways to accept HIV, communication with the partner and infection to partner and self has helped better acceptance and reduced

guilt. This leads to their preparedness of following safer sex practices to avoid further deterioration of health.

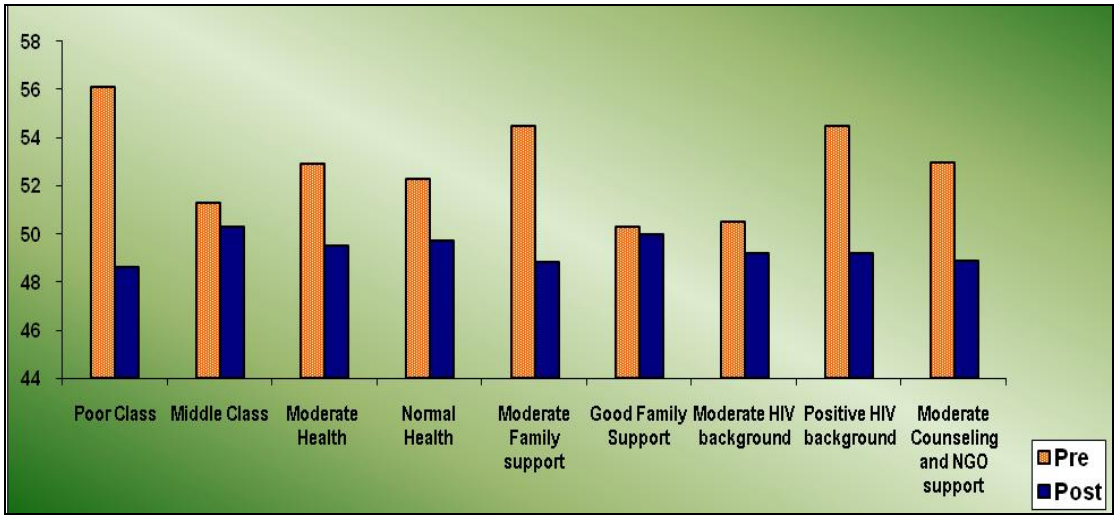
Table 8.12

Comparison of pre and post test means score of adjustment within Counseling and NGO support

During pre-intervention analysis, it was observed that moderate counseling and NGO support helps better adjustment. Following table shows the categories which have changed their adjustment score positively due to intervention.

NGO Groups	Counseling and NGO support	**N**	**Total coping PRE**	**Total Coping Score post**
SOFOSH	Poor counseling and NGO support (5-7)	4	59.75	50.75
	Moderate counseling and NGO support (8 to 11)	25	56.24	49.72
	Good counseling and NGO support (12-15)	7	51.71	51.7
FPAI	Moderate counseling and NGO support (8 to 11)	12	47.92	47.9
Deepgriha	Poor counseling and NGO support (5-7)	1	46	47
	Moderate counseling and NGO support (8 to 11)	2	44	44.5
	Good counseling and NGO support (12-15)	**1**	**37**	**49**
Total Sample	Poor counseling and NGO support (5-7)	**5**	**57**	**50**
	Moderate counseling and NGO support (8 to 11)	**39**	**53.05**	**48.9**
	Good counseling and NGO support (12-15)	**8**	**49.88**	**51.4**

Graph 8.5 Pre and post mean scores of adjustment within various scores



Consistently adjustment scores have shown significant change in various categories like socio-economic class, health, family support, HIV background and counseling and NGO support.

Counselling and NGO support includes pre-post and adherence counseling and NGO support includes supplementary nutrition, financial support, accommodation and membership in support group. It was reported that coping of respondents has improved after counseling. Significant change in adjustment is shown in moderate counseling and NGO support (P value = 0.01). Those respondents who had moderate counseling and NGO support, had received few inputs about HIV diagnosis, treatment, care and ART which enhanced the process of adjustment after intervention. This helped in reducing anxiety, stress, depression and fear about death.

8.4 Quality of Life

This term is used to evaluate the general well being of individuals and societies. It is used in the context of international development, health and politics. It is different from standard of living. Quality of Life indicators include wealth and employment, infrastructure, physical and mental health, education, recreation, leisure time and social belonging. It also indicates concepts like freedom, human rights, however, happiness is a subjective term and hard to measure. Happiness does not necessarily come from comfort and income. Quality of Life – Personal satisfaction with the cultural or intellectual conditions under which you live, a level of satisfaction

(Thomas J. Leonard 1998). The test of quality of life had 100 questions about financial stability, family life, career, health care, personal happiness and pleasure. For the present study only 50 questions were applicable. Table 8.3.1, 2, 3, 4, 5, 6 indicate pre and post comparison for quality of life.

Table 8.13

Pre- post score comparison for quality of life

Quality of life, happiness, satisfaction are relative concepts even for common man. These concepts respondents had never heard before. In the pre intervention phase, respondents had answered the questions in the test as per their understanding of the concepts, hence the scores are shown higher, however after intervention, as they realized the meaning of the concept, the score has gone down. This has resulted into negative changes in quality of life.

NGO Groups	**Mean Coping Scores**	
	PRE	**Post**
Maximum Score	49	49
SOFOSH (N=36)	45.4 $\pm$ 6.3	34 $\pm$ 7.7
FPAI (N=12)	48.6 $\pm$ 1.8	37.0 $\pm$ 6.8
Deepgruha (N=4)	48.5 $\pm$ 0.6	39.0 $\pm$ 6.4
Total Sample (N=52)	**46.4 $\pm$ 5.5**	**35.1 $\pm$ 7.5**
t=9.517,ns,df 51		

Quality of Life : Change in the quality of life is significant as shown in table 8.14. However, in all the socio-economic classes, the pre and post mean score of quality of life is seen decreasing. The test used during the study had many new concepts, which respondents did not know or they had never imagined about it.

Comparison of pre and post test means score of quality of life within Socio-economic score:

In the pre intervention phase quality of life was something very foreign concept .The respondents could never imagine giving time for oneself, children, praying, planning for money and spiritual health can improve quality of life. These concepts were explained in intervention phase.

Table 8.14

Comparison of pre and post test means score of quality of life within Socio-economic score

NGO Groups	Socioeconomic score	N	Total Quality of Life PRE	Total Quality of Life Post
SOFOSH	Poor	17	44.2	32.6
	Middle Class	19	46.4	35.3
FPAI	Poor	4	50.2	38.5
	Middle Class	7	47.7	36.5
	Higher Class	1	48	34
Deepgriha	Middle Class	3	48.3	37.3
	Higher Class	1	49	44
Total Sample	**Poor**	**21**	**45.3**	**33.7**
	Middle Class	**29**	**46.9**	**35.8**
	Higher Class	**2**	**39**	**9**

In poor and middle class in pre intervention phase quality of life scores were higher, however, in the post intervention phase it is reduced. Because respondents could not understand the meanings of concepts. In the posttest, after realizing it, their answers were different, that has reflected in the test results.

Comparison of pre and post test means score of quality of life within health score:

An effort was made to see whether quality of life is changed due to better health condition.

Table 8.15

Comparison of pre and post test means score of quality of life within health score

NGO Groups	Health Score	N	PRE	Post
SOFOSH	Poor health condition	2	48.5	37.5
	Moderate health condition	24	44.96	32.7
	Normal health condition	10	45.9	36.5
FPAI	Moderate health condition	9	48.56	38.5
	Normal health condition	3	48.67	32.3
Deepgriha	Moderate health condition	3	48.67	42
	Normal health condition	1	48	30
Total Sample	**Poor health condition**	**2**	**48.5**	**37.5**
	Moderate health condition	**36**	**46.17**	**34.9**
	Normal health condition	**14**	**46.64**	**35.1**

In moderate health condition and normal health condition in post intervention there is a decrease in quality of life. Effort was made to raise quality of life by inputs in communication, health, self care, relationships, and stress management, however, its effect is not seen, in short span of intervention phase.

Comparison of pre and post test means score of quality of life within family support score:

Quality of life can be changed in a better way if there is a support from family support.

Table 8.16

Comparison of pre and post test means score of quality of life within family support score

NGO Groups		N	PRE	Post
SOFOSH	Moderate family support	27	45.11	33.7
	Good family support	9	46.33	35
FPAI	Moderate family support	5	48.4	39.8
	Good family support	7	48.71	35
Deepgriha	Poor family support	1	48	39
	Moderate family support	1	48	30
	Good family support	2	49	43.5
Total Sample	**Poor family support**	**1**	**48**	**39**
	Moderate family support	**33**	**45.7**	**34.5**
	Good family support	**18**	**47.56**	**35.9**

The respondents realized various components of quality of life i.e. time management, financial management, stress management, communication within family, relationship with friends, boss and colleagues and seeking pleasure and happiness in doing small things for the family members, during intervention.

Comparison of pre and post test means score of quality of life within HIV background helping coping:

The test was very new for the respondents. Quality of life is a relative concept also. Following table shows whether quality of life has changed within categories of HIV background helping coping.

Table 8.17

Comparison of pre and post test means score of quality of life within HIV background helping coping

NGO Groups	HIV background helping coping	N	Pre test	Post test
SOFOSH	Poor HIV background helping coping	1	48	31
	Moderate HIV background helping coping	15	44	34.6
	Positive HIV background helping coping	20	46.35	33.8
FPAI	Poor HIV background helping coping	5	48.8	39.2
	Positive HIV background helping coping	7	48.43	35.4
Deepgriha	Moderate HIV background helping coping	3	48.33	37.3
	Positive HIV background helping coping	1	49	44
Total Sample	Poor HIV background helping coping	**1**	**48**	**31**
	Moderate HIV background helping coping	**23**	**45.61**	**35.9**
	Positive HIV background helping coping	**28**	**46.96**	**34.5**

Although the test results are significantly negative, one has to give rigorous inputs to improve quality of life. It would take time to incorporate changes in respondents' life style to improve the quality of life.

Comparison of pre and post test means score of quality of life within Counseling and NGO support:

An effort was made to see whether quality of life can be changed with counseling and NGO support.

Table 8.18

Comparison of pre and post test means score of quality of life within Counseling and NGO support

NGO Groups	Counseling and NGO support	N	PRE	POST
SOFOSH	Poor counseling and NGO support (5-7)	4	47.5	34.5
	Moderate counseling and NGO support (8 to 11)	25	45	33.96
	Good counseling and NGO support (12-15)	7	45.71	34.1
FPAI	Moderate counseling and NGO support (8 to 11)	12	48.58	37
Deepgriha	Poor counseling and NGO support (5-7)	1	49	44
	Moderate counseling and NGO support (8 to 11)	2	48	34.5
	Good counseling and NGO support (12-15)	**1**	**49**	**43**
Total Sample	Poor counseling and NGO support (5-7)	**5**	**47.8**	**36.4**
	Moderate counseling and NGO support (8 to 11)	**39**	**46.26**	**34.9**
	Good counseling and NGO support (12-15)	**8**	**46.12**	**35.25**

Not much difference was observed in quality of life.

Concept of quality of life was very unique and unknown to respondents. In the pre-intervention phrase, they perceived it in a different manner and have mechanically answered the questions in the test. In the post intervention phase after inputs being giving on how the quality of life can be improved was provided and then the

respondents realized its real meaning and have responded positively, that hereafter they would keep in mind to take joy in sharing small things with their dear ones.

Pre-post test comparison of means scores of motivation:

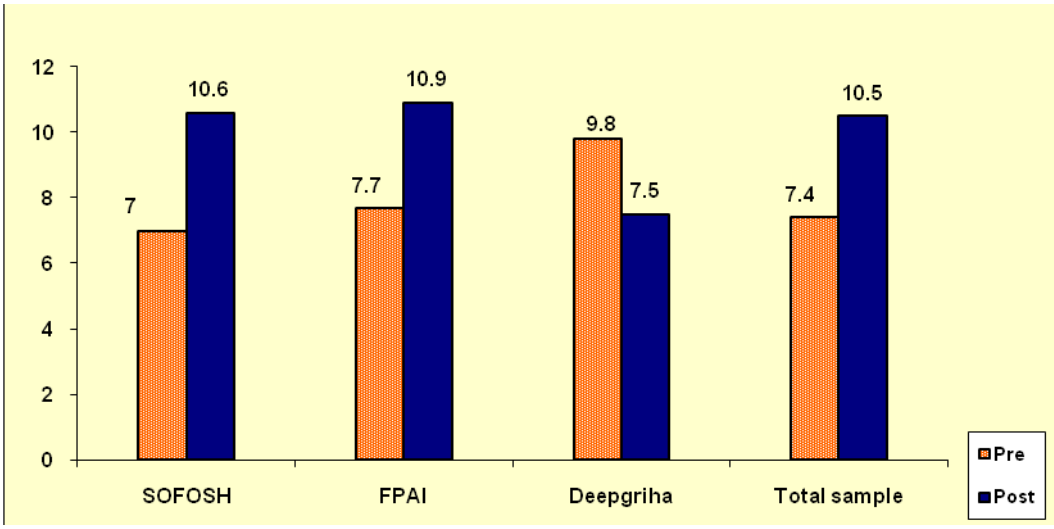
Motivation is an inner desire, consistent effort to achieve a goal at any cost. It would increase with innate capacity of individual, personality family environment. Personal demands from oneself, work environment and level of encouragement from others. The respondents had tremendous motivation to live life with HIV status. To take up their responsibilities at families and of children, intervention has positively helped them to raise motivation and alternative ways of problem solving.

Table 8.19

Pre-post test comparison of means scores of motivation

NGO Groups	**Mean Coping Scores**	
	Pre test	**Post test**
Maximum Score	32	32
SOFOSH (N=36)	7.0 ± 3.1	10.6 ± 3.9
FPAI (N=12)	7.7 ± 2.7	10.9 ± 4.6
Deepgruha (N=4)	9.8 ± 2.1	7.5 ± 4.4
Total Sample (N=52)	**7.4 ± 3.1**	**10.5 ± 4.1**
Paired T test		
T value	-4.487	
df	51	
sig. (2-tailed)	0.000	

Graph 8.6 NGO wise pre post comparison of mean scores of motivation



Except in Deepgriha all other NGOs respondents show increase in motivation.

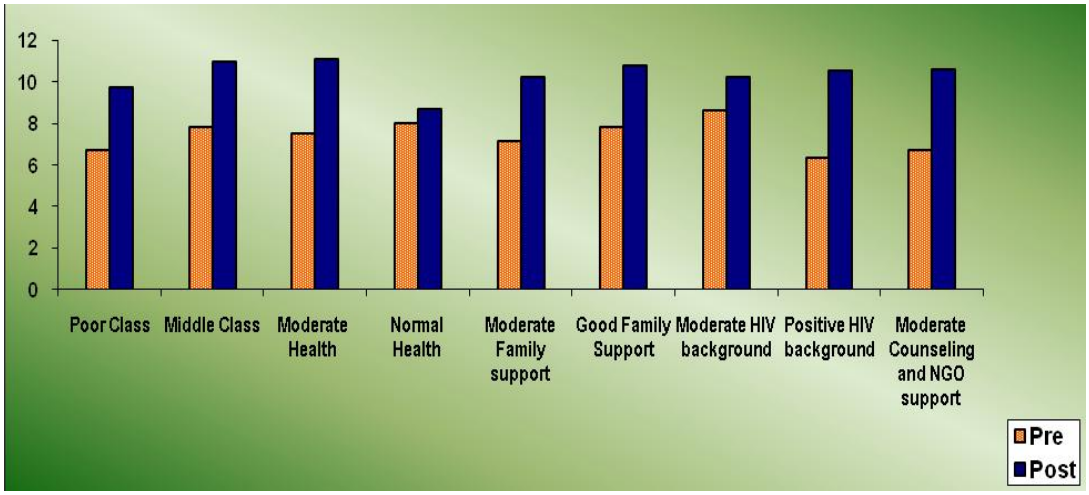
There is a significant increase in the motivation level of respondents. Motivation shows a highly significant positive change among the respondent (P value = 0). Intervention has definitely helped the respondents to accept the problem and to cope with it. This can be observed in the above table.

Table 8.20

Comparison of pre and post test means score of Motivation within Socio-economic score

NGO Groups	Socioeconomic score	N	PRE	POST
SOFOSH	Poor	17	6.18	9.59
	Middle Class	19	7.74	11.58
FPAI	Poor	4	8.75	10
	Middle Class	7	6.71	11
	Higher Class	1	10	14
Deepgriha	Middle Class	3	10.33	7
	Higher Class	1	8	9
Total Sample	**Poor**	**21**	**6.67**	**9.67**
	Middle Class	**29**	**7.76**	**10.97**
	Higher Class	**2**	**11.5**	**12.7**

Graph 8.7 Pre and post mean scores of motivation within various scores



Various scores indicate increase in the motivation.

Significant change in motivation is observed in poor and middle socio economic group. This is proved with respective P Value 0.004 and 0.005. Generally those who

have limited resources have better motivation as indicated in the table, respondents from poor and middle class were prepared to absorb inputs for motivation to live with HIV. These are the people who make all possible efforts or strive for betterment of themselves, and face the situation at any cost.

Comparison of pre and post test means score of motivation within Health score:

Health and motivation go hand in hand. It was assumed that as better health condition with positive inputs will improve motivation. Following table explains this.

Table 8.21

Comparison of pre and post test means score of motivation within Health score

NGO Groups	Health Score	N	PRE	Post
SOFOSH	Poor health condition	2	0	10.5
	Moderate health condition	24	6.92	11.08
	Normal health condition	10	8.6	9.6
FPAI	Moderate health condition	9	8.56	12.67
	Normal health condition	3	5	5.67
Deepgriha	Moderate health condition	3	9.33	7
	Normal health condition	1	11	9
Total Sample	**Poor health condition**	**2**	**0**	**10.5**
	Moderate health condition	**36**	**7.53**	**11.14**
	Normal health condition	**14**	**8**	**8.71**

Table indicates those who were in moderate health condition could think about their future plans about health and hence have improved their motivation (P value = 0) highly significant to prove the above statement. Although there is a wide difference of pre and post means score among those who have poor health condition, the sample number of the respondents is very low.

Comparison of pre and post test means score of Motivation within Family support score:

Family support keeps one motivated to do daily activities and extra efforts achievements. During study efforts was made to see if with inputs like improving communication, disclosure of HIV status, positive parenting, change can be seen in motivation. Table 8.23 shows those who had moderate and good family support, they have shown change in motivation. As there is someone for support, one finds motivation to live further.

Moderate Support p value = 0.008.

Good Support p value = 0.03.

Table 8.22

Comparison of pre and post test means score of Motivation within Family support score

NGO Groups		N	PRE	Post
SOFOSH	Moderate family support	27	6.59	10.41
	Good family support	9	8.22	11.33
FPAI	Moderate family support	5	9	9.6
	Good family support	7	6.71	11.86
Deepgriha	Poor family support	1	8	11
	Moderate family support	1	11	9
	Good family support	2	10	5
Total Sample	**Poor family support**	**1**	**8**	**11**
	Moderate family support	**33**	**7.09**	**10.24**
	Good family support	**18**	**7.83**	**10.83**

Comparison of pre and post test means score of motivation within HIV background helping coping:

Motivation and HIV background are associated in all the three categories motivation is shown better.

Table 8.23

Comparison of pre and post test means score of motivation within HIV background helping coping

NGO Groups	HIV background helping coping	N	PRE	POST
SOFOSH	Poor HIV background helping coping	1	8	15
	Moderate HIV background helping coping	15	8.4	108
	Positive HIV background helping coping	20	5.9	10.3
FPAI	Poor HIV background helping coping	5	8.2	10.4
	Positive HIV background helping coping	7	7.29	11.29
Deepgriha	Moderate HIV background helping coping	3	10.33	7
	Positive HIV background helping coping	1	8	9
Total Sample	Poor HIV background helping coping	**1**	**8**	**15**
	Moderate HIV background helping coping	**23**	**8.61**	**10.22**
	Positive HIV background helping coping	**28**	**6.32**	**10.5**

Change in pre and post motivation test is shown highly significant among those who have positive HIV background. (P value = 0). Coping is shown better, due to long duration and due to communication with partner about HIV diagnosis, safer sex practices which have helped in improving motivation.

Comparison of pre and post test means score of motivation within counseling and NGO support:

Intervention in the form of counseling helps in improving the motivation. Following table shows, that those who did not receive good counseling during pre-intervention, have shown good improvement in motivation.

Table 8.24

Comparison of pre and post test means score of Motivation within Counseling and NGO support

NGO Groups	Counseling and NGO support	N	PRE	POST
SOFOSH	Poor counseling and NGO support (5-7)	4	7	12.5
	Moderate counseling and NGO support (8 to 11)	25	6	10.44
	Good counseling and NGO support (12-15)	7	10.57	10.29
FPAI	Moderate counseling and NGO support (8 to 11)	12	7.67	10.92
Deepgriha	Poor counseling and NGO support (5-7)	1	8	9
	Moderate counseling and NGO support (8 to 11)	2	9.5	10
	Good counseling and NGO support (12-15)	**1**	**12**	**1**
Total Sample	Poor counseling and NGO support (5-7)	**5**	**7.2**	**11.8**
	Moderate counseling and NGO support (8 to 11)	**39**	**6.69**	**10.56**
	Good counseling and NGO support (12-15)	**8**	**10.75**	**9.12**

Highly significant positive change is observed (P = 0) in pre and post mean score of motivation, among those who have received moderate counseling and NGO support. Those who had basic counseling inputs, were better prepared to absorb inputs on motivation.

8.6 Personality Test :

Kundu Introversion Extroversions Inventory

The inventory developed by Dr. Ramnath Kundu, was used to assess the personality of the respondents. Purpose of the inventory is to obtain a reliable measure of introversion, extroversion dimension of adult behavior or to use it for diagnosis, selection and career guidance. It is developed according to Indian socio-cultural pattern. The test consists of 70 items with uneven number of response choices divided into 5 blocks – A, B, C, D, E. It is found that people, different in their likes, dislikes, personality and hobbies. Within this test, there are questions on these aspects. Questions indicate the personality type of the subject / respondent. There are no right or wrong answers to any questions. There are several options given from among which subject can pick up the most appropriate answer for them this test also was adapted. The scoring method is as under. Personality has biological factors, environmental and social factors and psychological factors. In the inventory the questions were asked. The Purpose of the inventory is to obtain a reliable measure of introversion –extroversion dimension of adult behavior or to use it for diagnosis, selection and career guidance. It is developed according to socio-cultural pattern. The number of items in each block and the corresponding number of response choices have been shown in enclosed manual Table 1, 2, 3, 4, 5, 6, 7 and 8 (See Appendix) .

Scoring – The scoring key is prepared on the basis of judgment given by the psychiatrists, psychoanalyst and psychologists. The general order of scoring is such that high score indicates introversion i.e. negative response is indicative of introversion. But some of the items have been framed in such a way that negative response in these items would indicate extraversion. The different categories of responses are given different weights depending on the degree of introversion extroversion they measure.

How to Score : No scoring key is required. Count the tick (√) in each row in each block and enter the figure under the column T against the respective row. As per test proportion of maximum score

Method of scoring of personality test

Original Score Category	Proportion of higher limit to maximum limit	Categories modified according to proportion for current study	Category Name
Minimum 70 to 89	36.9	47 to 68.4	Extremely extravert
90 to 130	53.9	68.5 to 99.9	Slight to moderate - extrovert
131 to 171	70.9	100 to 131.3	Ambivert
172 to 199	82.5	131.4 to 153.6	Slight to moderate introvert
229 and above	Above 82.5	153.7 and above	Extremely introvert

Lower score of personality is desirable i.e. extrovert. However in the study the score shows that respondents have become introvert, after intervention also they are ambivert, hence there is no graphic presentation.

As the personality test was adapted for the study, the maximum score was 185 maximum score and minimum score was 47, in the original test scores were 70 minimum and 247 was maximum. Hence to suit the score to fit in the categories, proportion of the higher limit to the maximum score was considered, to make categories for the present data. The difference between the categories is as mentioned in the above table.

Pre-post test comparison of means scores of personality:

Personality development is a long process; the factors are heredity and environment. Environment includes family, school, relatives, friends, colleagues at work place etc. that influences the personality development process. The period of study was too short to have such an impact on making such changes in the personality.

Table 8.25

Pre-post test comparison of means scores of personality

NGO Groups	Mean Coping Scores	
	Pre test	**Post test**
Maximum Score	241	241
SOFOSH (N=36)	121.3 ± 15.1	125.2 ± 8.9
FPAI (N=12)	117.7 ± 10.0	120.7 ± 9.6
Deepgruha (N=4)	127.3 ± 3.4	126.3 ± 8.7
Total Sample (N=52)	**120.1 ± 13.6**	**124.3 ± 9.1**
Paired T test		
T value	-1.796	
Df	51	
sig. (2-tailed)	0.078	

The pre intervention mean score is 120.1 lies in the category of ambivert. This category has remained the same, even in the post intervention phase. The score analysis show a significant change among

Poor socio-economic group (P value = 0.03)

Moderate health condition (P value = 0.02)

Moderate family support (P value = 0.02)

Moderate counseling and NGO support (P value = 0.02)

However, all the mean scores lie in the same ambivert category; hence the results have no meaning as such. Score analysis for personality test is given from 8.27 to 8.31.

Comparison of pre and post test means score of personality within socio-economic score:

Making of the personality is a very long and complicated process, there was very little change observed in the post intervention phase. Respondents find it difficult to

disclose their HIV status as it is they are socialized in such a manner to keep family matters a secret due to stigma attached to certain disease conditions.

Table 8.26

Comparison of pre and post test means score of personality within socio-economic score

NGO Groups	Socioeconomic score	N	PRE	POST
SOFOSH	Poor	17	122	128.24
	Middle Class	19	120.74	122.53
FPAI	Poor	4	118.75	121.5
	Middle Class	7	115.71	119.14
	Higher Class	1	128	128
Deepgriha	Middle Class	3	127.67	123
	Higher Class	1	126	136
Total Sample	**Poor**	**21**	**121.38**	**126.95**
	Middle Class	**29**	**120.24**	**121.76**
	Higher Class	**2**	**127**	**132**

The above table shows that the respondents are in ambivert category, if we look at the score they have balanced their conditions, it shows neither they are introvert nor extrovert.

Table 8.27

Comparison of pre and post test means score of personality within health score

NGO Groups	Health Score	N	PRE	Post
SOFOSH	Poor health condition	2	135	124.5
	Moderate health condition	24	117.62	125.5
	Normal health condition	10	127.5	124.7
FPAI	Moderate health condition	9	119.44	120.67
	Normal health condition	3	112.67	120.67
Deepgriha	Moderate health condition	3	128.33	125
	Normal health condition	1	124	130
Total Sample	**Poor health condition**	**2**	**135**	**124.5**
	Moderate health condition	**36**	**118.97**	**124.25**
	Normal health condition	**14**	**124.07**	**124.21**

Table shows positive slight change introvert to ambivert.

Table No. 8.28, 8.29, 8.30 and 8.31 explain the respondents' ambivertness. They are still finding the ways of coping, few make a choice to withdraw from family, relatives, neighbourhood while few find new ways of dealing/coping as they interact with other patients.

Table 8.28

Comparison of pre and post mean score of personality within family support score

NGO Groups		N	PRE	Post
SOFOSH	Moderate family support	27	122.56	126.81
	Good family support	9	117.67	120.44
FPAI	Moderate family support	5	119	125
	Good family support	7	116.86	117.57
Deepgriha	Poor family support	1	127	123
	Moderate family support	1	124	130
	Good family support	2	129	126
Total Sample	**Poor family support**	**1**	**127**	**123**
	Moderate family support	**33**	**122.06**	**126.64**
	Good family support	**18**	**118.61**	**119.94**

Comparison of pre and post test means score of Personality within HIV background helping coping:

An effort was made to see the weather personality of the respondents get influence by different categories of HIV background helping coping.

Table 8.29

Comparison of pre and post test means score of personality within HIV background helping coping

NGO Groups	HIV background helping coping	N	Pre test	Post test
SOFOSH	Poor HIV background helping coping	1	110	126
	Moderate HIV background helping coping	15	120.2	127.73
	Positive HIV background helping coping	20	122.75	123.3
FPAI	Poor HIV background helping coping	5	115.8	119.6
	Positive HIV background helping coping	7	119.14	121.43
Deepgriha	Moderate HIV background helping coping	3	127.67	123
	Positive HIV background helping coping	1	126	136
Total Sample	Poor HIV background helping coping	**1**	**110**	**126**
	Moderate HIV background helping coping	**23**	**120.22**	**125.35**
	Positive HIV background helping coping	**28**	**121.96**	**123.29**

Table 8.30

Comparison of pretest and post mean score of personality within counseling and NGO support

NGO Groups	Counseling and NGO support	N	Pre test	Post test
SOFOSH	Poor counseling and NGO support (5-7)	4	122.5	118.75
	Moderate counseling and NGO support (8 to 11)	25	119.08	125.52
	Good counseling and NGO support (12-15)	7	128.71	127.86
FPAI	Moderate counseling and NGO support (8 to 11)	12	117.75	120.67
Deepgriha	Poor counseling and NGO support (5-7)	1	126	136
	Moderate counseling and NGO support (8 to 11)	2	125.5	126.5
	Good counseling and NGO support (12-15)	1	132	116
Total Sample	Poor counseling and NGO support (5-7)	5	123.2	122.2
	Moderate counseling and NGO support (8 to 11)	39	119	124.08
	Good counseling and NGO support (12-15)	8	129.12	126.38

8.7 *Summary:*

In the present study, in the pre-intervention phase, there were 191 respondents from different NGOs. They were interviewed and were given five tests. In puts orintervention was given in each NGO, with prior appointment or on the date of meetings. Respondents very well shared their emotions being HIV infected. They felt acceptance, while interview was going on and they doubted, whether investigator knew their HIV status. As they were experiencing stigma and discrimination, it gave them support, acceptance and a platform to ventilate their feelings. Some of the

concepts like quality of life and strengths or characteristics of their personality were new for them. However, their reaction was, that knowledge is so vast, knowledge about HIV, ART about quality of life, positive attitude; alternative ways of looking at reality was quite new from their perspective. It took 2, 3 meetings sessions and continuous follow up with social workers from NGOs, to organize intervention and post intervention sessions. Difficulties and problems about it are already given in chapter 3. However 52-55 respondents we could follow. The nature of test was time consuming, respondents had to catch the transport to their native place or had other pre occupations and hence few tests they could not complete. Out of 191, 52 completed all the test after intervention.

As regard to the post test, the score obtained after intervention, does not show any change. There are two possible reasons, i.e. coping is an individual strength, which exclusively depends on endurance capacity and prevalent circumstances. The circumstances may vary from time to time which affects the inner strength that is endurance capacity. The favorable conditions always help to think various alternatives to overcome difficulties. This capacity gets impetus through the past experience which is the part and parcel of the attitude. The entire process is very gradual and long term, to get the positive change in coping scores may take considerable time for expected outcome. Hence major change is not seen in coping mechanism and in personality also. Personality development is a long term process, which need inputs from many agencies. Hence the results are shown ambivert. Those who had good family support, their coping has slightly improved and intervention was an additional input which enhanced their morale (Table 8.1) . About adjustment test, capacity to adjust, has improved, especially among the poor socio-economic class. During the crisis, one needs to accept and adjust with the circumstances, respondents were in vulnerable situation, that they had to adjust with the circumstances and inputs on family, health, emotional aspect and communication has helped them. About quality of life, many concepts respondent did not know, hence the scores in the pre intervention session were found high, however after explaining about it in detail in post intervention phase, the answers were negative. Respondents had not experience any pleasure and happiness in their life, which was a very significant realization. This would help in future to design the strategy for intervention in terms of improving relationships, communication, making the life more meaningful by involving oneself

in small events which could be joyous for patients suffering HIV/AIDS. Motivation is an innate desire, consistent effort to achieve a goal at any cost. It can be raised by individual's natural capacity, personality and family environment. The respondents had motivation to live, as they had their responsibilities, but to live with enthusiasm and with positive mental outlook requires, some source of energy, inspiration and encouragement. After the post intervention, motivation of respondents had increased significantly. Respondents from poor and middle class show increase in motivation, similarly respondents within oderate and normal health condition show improvement motivation, similarly those who had moderate and good family support show increase in motivation. As regards personality, there was no change in personality characteristics after intervention, but respondents have shared, at least they were made aware of few characteristics which now can act as their strengths.

CHAPTER IX

SUMMARY, CONCLUSION AND SUGGESTION

9.0: Introduction

9.1: Summary of each chapter

9.1.1: Socio Economic background

9.1.2: Health status

9.1.3: Stigma and Support

9.1.4: Intervention

9.1.5: Impact of intervention

9.2: Testing of Hypothesis

9.3: Conclusions

9.4: Suggestions

9.5: Discussion

CHAPTER IX

SUMMARY, CONCLUSIONS AND SUGGESTIONS

9.0: Introduction:

In the present study various aspects related to coping with HIV by infected women are dealt with. It is a well-known fact, that health care in our country is not so well organized, in spite of the decentralized services. There are limitations on the part of the infrastructure, health care professionals, services and availability of diagnostic and treatment facilities. In spite of the National health programme to control various diseases, we have continued to have health problems in the form of epidemic of Malaria, Dengue, Chikungunia, gastroenteritis etc. In addition to this, HIV and other related opportunistic infections create pressure on government services. To control HIV / AIDS, since NFHS III, we have started providing ART at government hospitals; however, there is still a lot that can be done at government as well as at NGO level. The overall situation in NGOs, counseling services are provided, at present, post test and adherence counseling level. At government institutions, due to limitations of set up, many a times pre test counseling hardly is provided. At post test, patient brings report and counselors are expected to explain it to patients. We have poor follow up and health care by patients themselves, adherence counseling in its real sense does not take place. Patients are busy in their daily routine, they find it difficult to approach NGO or government institutions, due to their poor financial condition, it is not their priority to care for health. Hence, the study has made us reveal, that there are lot of components of coping that can be added to improve strength of women to live with HIV. Those women, who have motivation to live, their capacity to adapt and adjust, can be changed for better and their quality of life can be improved. The brief summary of all chapters is given below:

9.1: Summary of each chapter

Chapter 1 explains theory of HIV; its origin, modes of transmission, diagnosis and treatment. The nature of HIV is such that it has special implications that are stigma, uncertainty and threat to life, deterioration of health. Women receive infection from their partners. They suffer multiple problems being HIV positive like stigma,

isolation, guilt and depression which are difficult to cope. Coping mechanism concept is being explained with its components as coping, adjustment, quality of life, motivation & personality. The relationship of coping and social work intervention also has been discussed.

In the second chapter of literature review, earlier studies on intervention, motivation, coping with HIV, quality of life are being mentioned. Association of gender inequality and vulnerability of women to suffer HIV also has been studied. The association of intervention and developing coping mechanism was needed, hence the study was undertaken, to develop a module for intervention to work with HIV infected women.

The third chapter explains the research design, the universe, sampling procedure, size of the sample, tools of data collection. The detailed discussion about tool and psychological tests are given,the pre and post phases of intervention also are discussed with the chapterisation and limitations of the study.

Chapter four onwards major observations are discussed.

9.1.1: Socio economic background:

The socio economic condition plays a significant role in quality of life. This includes age, education, occupation, family composition etc. Age was a crucial role so far as the effect and reaction of HIV is concerned. About 3/4th (Three fourth) of the respondents were in the productive age group, when they were diagnosed HIV. This affects on their health, capacity to earn and the span of life to live with HIV. Most of the respondents were doing unskilled jobs, which influences on their financial condition, to the extent that the income was hardly sufficient to fulfill basic needs. Out of 191 respondents 101 were widows, this shows, they hardly had any support from families. As women realize the HIV diagnosis of husbands, they experienced shock, threat to life and marital relationship. As this diagnosis was revealed to other family members they reacted with haterate and women experienced stigma, loss of support and isolation. Majority of the respondents were yellow BPL card holders, having no share in the property of the family.

9.1.2: Health status

Another crucial aspect of the study was health. Women's health is a very delicate and multifaceted issue in Indian situation. This is linked with women's status in society. It begins with limited opportunities to women to get education, no choice of mate, decision to marry and the number of children. However, the study shows, women hardly could get education up to primary level; about half of the respondents were married below the legal age of marriage. This has serious implications, like early sexual exposure, early pregnancy, early child birth and chances of HIV infection in the absence of condom usage. Women had 2-3 children as their dependents after being HIV infected; women had no control over the decision to have a baby.

The next chapter four discusses health status and problems of women. Those are female feticide, abuse, violence, harassment. Multiple roles of women and inaccessibility restrict them from health seeking behavior. Majority of the respondents were seeking medical help from government hospitals. About three fourth ($3/4^{th}$) of them were on anti-retroviral therapy and hence their CD4 count was at the expected level. They hardly had suffered any opportunistic infections; this shows their effort to care for their health. Very few respondents reported to have HIV transmission to their children. Women reported that HIV infection of their spouses was not disclosed to them till spouse suffered repeatedly opportunistic infection and experienced deterioration of health.

9.1.3: Stigma and support:

HIV is a stigmatized disease, due to one of its modes of transmission, that is multi partner unprotected sexual contact. This puts the sufferer to vulnerability about perceptions regarding character and habits. Chapter six discusses reaction of respondents and their family members after being diagnosed as HIV. They experienced shame, loss of self-esteem, loneliness and threat to life. Majority of the women reported communication gap between spouses and strained relationship. During this critical period, women have been supported by their natal families. In spite of their critical situation, they have managed to face the reality with great courage and strength. It was reported that due to awareness, scientific studies and efforts, comparatively stigma has been reduced. This was experienced while the women lost their spouses and they were performing last rites. Even while admitting

the children in the school or at the time of accepting any of employment, women could manage to keep their HIV status confidential. This indicates that gradually awareness is increasing in society and support is extended.

9.1.4: Intervention:

Chapter on intervention discusses meaning, method, tools of social work intervention and its effect on coping with critical situation. Assessment of pre intervention is given, positive HIV background supportive coping mean indicated lowest scores for coping. Test on adjustment, showed positive change.

In the intervention or second phase of the study, intervention on following aspects was given in the form of individual and group counseling in all NGO's.

- Health care
- Money management
- Stress management
- Management of emotions, especially anger
- Spirituality
- Developing positive attitude
- Improving communication with family
- Disclosure of HIV to children
- Parenting
- Time management

9.1.5: Impact of intervention

Chapter eight discusses impact of intervention. In the pre intervention phase, 191 respondents were interviewed. Intervention was given on the above mentioned aspects. An effort was made to meet to maximum number of respondents, however due to several problems we could meet 52 respondents till the end. Respondents shared their emotions, they felt acceptance while investigator was interacting with them. As they were experiencing stigma, they felt lot of support and encouragement to ventilate their emotions. Some of the concepts like quality of life, positive attitude and alternative ways of looking at reality were quite new for them. As regard to the post test the scores obtained does not show much difference in coping and quality of life test. There is reason that coping is an individual strength which exclusively

depends on endurance capacity and prevalent circumstances. The circumstances may vary from time to time which affects the inner strength which depends on endurance capacity. The favorite conditions always help to think various alternatives to overcome difficulties. This capacity gets impetus through the past experience which is the part and parcel of the attitude. The entire process is very gradual and long term, hence to get the positive change in coping scores may take considerable time for expected outcome. Personality development is long term process which needs inputs from many agencies; therefore the results of personality test are shown as ambivert. However those who had good family support, their coping has slightly improved and intervention was an additional input which enhanced respondent's morale e.g. (Table 8.1). About adjustment test after intervention shows, capacity to adjust has improved especially among poor socio economic class. During the crisis, one needs to accept and adjust with the circumstances, respondents were in vulnerable situation, hence they had to adjust with circumstances input from family relationship and communication, emotion, and health have helped them.

9.2: Testing of hypothesis:

In this section hypothesis testing was carried out. A point is to be mentioned here that, considering the nature of subject, there are several areas which are overlapping to each other. However an attempt is made to test the hypothesis in terms of qualitative as well as quantitative data.

- **Hypotheses 1- -Stronger the coping mechanism, lesser the implication of HIV.**

To test this hypothesis psychological implications of HIV infection among the women were studied along with assessing the level of coping mechanism among the among the HIV infected women. It was found that respondents encountered large number of the difficulties in day to day life. The range of difficulties varies from communication within family to the social relations in the society. At every stage, respondent faced the prominent problems.

a). Financial crisis due to heavy expenses on treatment.(Table 6.15)

b). Unskilled occupation, hence limited resources of income. e.g. (Table 4.6)

c). Stigmatization by the family members doubting about extra marital relationship. e.g. (Stigma Table 6.10, 6.12, 6.13)

d). Deteriorating physical condition, hence no earning capacity, leading towards more dependency on relatives. (Table 5.2)

e). Constant threat to the life. (Diagnosis of HIV Table 6.1)

Like these, respondents have faced several problems in spite of these problems almost all respondents had succeeded to overcome these problems at different stages as indicated (Table 7.1 coping).

On this basis, it can be stated that though there are several limitations in tracing the roots of coping mechanism it could be revealed from the data that, the women had less implications of HIV who have strong power to struggle and fight with the prevailing condition, that is strong coping mechanism.

In brief it is to say that, though the data does not support strongly to prove this hypothesis, there are several indications which come across during the investigation. (chapter- 6, Parvati's case) among the women had stronger coping mechanism faced the lesser implications of HIV, therefore hypothesis no. 1 is partially proved.

Table 9.1

Pretest and post test comparison of mean scores of coping

NGO Groups	**Mean coping scores**	
	Pre	**Post**
Maximum Score	70	70
SOFOSH (N=36)	38.08 ± 7.2	38.4 ± 7.4
FPAI (N=12)	41.6 ± 8.1	37.8 ± 5.5
Deepgriha (N=4)	33.2 ± 5.3	40.5 ± 6.6
Total Sample (N=52)	**38.46 ± 7.5**	**38.5 ± 6.9**
Paired T test		
T value	-0.052	
Df	51	
sig. (2-tailed)	0.959	

The pre and post test score are almost equal. Coping is an individual strength, which exclusively depends on endurance capacity and prevalent circumstances. The circumstances may vary from time to time which affects the inner strength that is endurance capacity. This capacity controls and governs the behavioral output in an expected way. The favorable conditions always help to think various alternatives to overcome day to day difficulties. This capacity gets impetus through the past experiences which are a part and parcel of the attitude; it is one of the more influencing elements of coping strength. The entire process is very gradual and long term, to get the positive change in coping score, may take considerable time for expected outcome.

From the data it can be concluded that, respondents who had favorable health conditions and better socio economic condition could cope well with HIV crisis.

Table 9.2

Coping mechanism

comparison of mean scores of pre and post test of coping

NGO Groups	Socioeconomic score	N	PRE	Post
SOFOSH	Poor	17	39.47	37.8
	Middle Class	19	36.84	39.1
FPAI	Poor	4	44.5	39.75
	Middle Class	7	39.29	37.9
	Higher Class	1	46	30
Deepgriha	Middle Class	3	31.33	39.3
	Higher Class	1	39	44
Total	**Poor**	**21**	**40.43**	**38.1**
Total	**Middle Class**	**29**	**36.86**	**38.8**
Total	**Higher Class**	**2**	**37**	**43**

Table shows, coping has slightly improved, while there was normal health condition. If intervention is given more intensively, it can give positive results. As respondents

had normal health, they experienced lesser implications of HIV. However more research is required to prove it statistically.

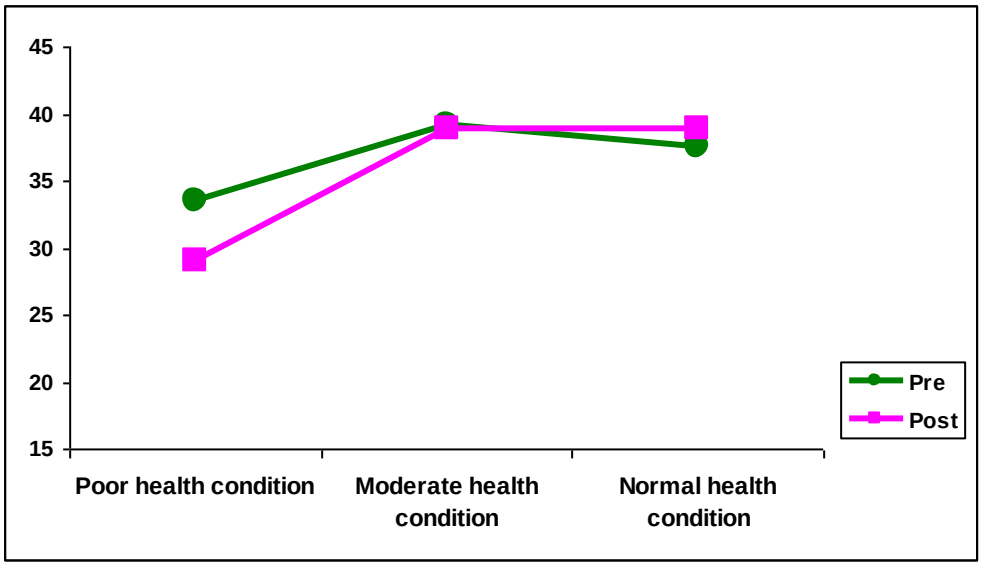
- **Hypothesis II- Secondary status of women leads to vulnerability to infection and it further aggravates the problems related to HIV.**

Hypothesis number II, women are always neglected. They have secondary status. They have no control over major decisions about their life, like age of marriage, choice of mate, number of children to be born, use of contraceptives, continuation of job after marriage etc. In case of HIV, heterosexual transmission is the most common route of infection to women. While women are diagnosed of HIV, family friends, neighborhood point out doubt about woman's character. Woman cannot insist on condom usage for preventing pregnancy as well as sexually transmitted infections (STI) including HIV. In our society, we hardly give any sex education and population education to girls prior to marriage. All these circumstances lead to vulnerability of women to receive HIV infection and it adds the problems like stigma, health deterioration, repeated hospitalization, striving for care of oneself and family members.

- **Hypothesis III-There is close association of health status and coping mechanism.**

There might be close association between health status and coping mechanism (T= -1.0, P= 0.3). In continuation of the above discussion the hypothesis number 3 is about the health status of women and their coping mechanism. Health has several angles; health can be maintained if there are resources. Health problems of HIV lead to doubt about the character of the infected person. Due to stigmatized disease like HIV, there is a threat to health everyday due to deteriorating CD4 count and opportunistic infection. Everyday women have to face several problems throughout the life. Their natural strength gets deteriorated to fight with infections, to strive for livelihood, to care themselves and children, these results in to deterioration of coping mechanism.

9.1 Pre post mean score comparison between health status and coping mechanism

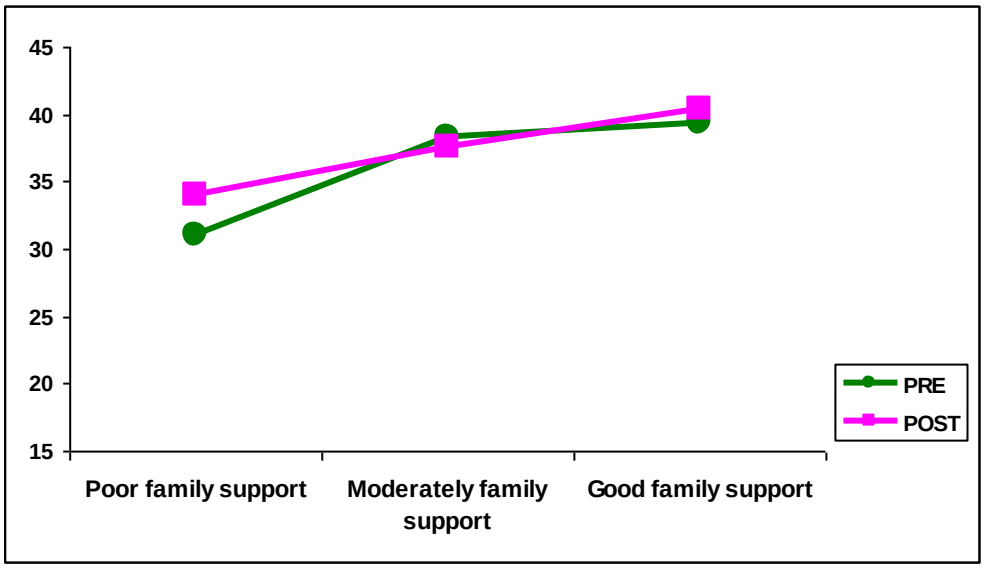


Above graph indicates slight improvement in the post intervention phase in normal health condition.

- **Hypothesis IV- There is a negative relationship between the support system and coping mechanism**

During critical period everyone needs support to face the situation. This support could be emotional support, financial support, support for maintaining health (medical care) and family support to care for someone. Support was assessed and it was found that respondents had the only support from families in terms of emotional support, for caring and sharing emotions. Though women required financial support, they hardly had resources. They chose to stay with their parents and as much as possible, took up some jobs which did not require more skills, as there was no regular income to support the family. They needed counseling to live with HIV, however as there was no support, they developed friendships with fellow patients of HIV and are facing the crisis. It could be said, if there is no support, coping mechanisms can be developed.

9.2 Pre post mean score comparison between family support and coping mechanism



Above graph indicates that poor family support might play a role in improving coping mechanism, however there is not adequate evidence to draw any conclusion.

- **Hypothesis V- There is large deficit in services required and services available.**

To face the crisis of HIV one needs support and various services . While respondents are suffering with HIV, they need counseling, guidance about nutrition and maintaining health, intervention about handling stress, mental health problems. Respondents did express, their problems like accepting the HIV, communicating about it with families, information about the side effects of Anti-retroviral therapy, taking small jobs, dealing with normal and infected children. However, it was found that respondents presently can avail the HIV testing and counseling facilities. There is a need to have comprehensive, holistic care centres for patients. Those need to be well equipped with trained counselors and necessary network of supportive services.

- **Hypothesis VI- Social work intervention at individual and group level can strengthen coping mechanisms leading to overcome various prevalent social problems.**

To test this hypothesis, study was carried out in three phases. In the intervention phase, respondents were addressed in group counseling sessions, for management of

stress, handling emotions, maintaining health, health of the family, parenting and disclosure of the HIV. It was found in the post intervention phase, components of coping like motivation and adjustment capacity has improved. Quality of life has not shown any significant change. Quality of life has several facets; very few were touched upon, like enjoying small things in life with family members and communicating with them. It helped in creating positive attitude towards life. Personality development being long and gradual process has shown changes, however women expressed they have become stronger while coping with HIV in the absence of any support. Individually women spoke with the investigator, about their feelings of acceptance, encouragement, appreciation for living and coping with HIV. Some of the respondents were referred for child's placement at institution, to get membership in support group and to seek legal advice. Hence it can be said, social work intervention helps in strengthening the coping mechanisms.

9.3 Conclusions:

To conclude it could be said that coping is an ability which is developed during personality development process.

So far as respondents are concerned, the kind of social milieu in which they live , they are taught to believe , that there are many situations, events on which human beings have no control. Some of us accept it as a 'karma' which helps to accept critical situations in life. Respondents also have responded with the same attitude, Being women and living in lower socio economic strata, they keep on adjusting with the circumstances as they are more conscious about their roles and responsibilities, hence there was very little difference in coping ability as such after intervention.

- Coping and motivation are interlinked, in spite of the fact of having contracted HIV, the respondents were motivated and intervention has helped them to live happily with HIV.

  In our society, majority of the people are observed to be contented, they do not have many aspirations and neither have resources. Respondent's demands were very realistic; they were concerned about their children's future, and make them to self-reliant.
- Respondents were vulnerable to receive HIV infection. They could not insist on condom use. They were not disclosed HIV status of husbands, it is only

after husband developed opportunistic infections, they realized about HIV, by then they already had contracted HIV. Women expressed that, they feel depressed, anxious and guilty; hence they need guidance and support by trained counselors.

- Adjustment test has shown change after intervention. We live in a society, where adequacy of resources is absent. This leads to adapt to the situation, we generally do not complain about reality. While respondents were diagnosed with HIV, they adjusted with it and did not take resort of drinking, smoking or consulting quacks. They have adjusted with the situation by adopting measures like prayer, visiting to religious places and interacting with family members.
- Quality of life was a new concept for the respondents. Their quality of life was observed to be poor as, HIV virus attacks the body, their overall interest in life gets reduced and however during intervention respondents appreciated suggestions to raise quality of life by enjoying small events, things in life.
- Personality development is a long term process; there was limitation to intervene for bringing out positive changes in the personality. However respondents could think about alternate ways of coping with the situation.
- Therefore it can be said, that intensive, holistic intervention in the form of counseling certainly helps to live with HIV in a qualitative manner. For this, counselors need to be trained holistic care and counseling module in all school of social work.
- Respondents need supportive services like supplementary nutrition, institutional care, and sponsorship for children, legal assistance and income generating activities.

9.4 Suggestions:

In our society, we observe gender inequality; girl child is denied even the freedom to enter into this world. She is denied freedom of choice of career, choice of mate and not given reproductive rights. In spite of the universal education and right to education a drop out of girls from school is observed to be high. Marriage has been perceived ultimate goal of girl, woman's life, hence they are neither given proper education nor are provided with vocational skills. During any critical situation girls/

women are left with no support. Based on these observations, suggestions are given at,

1. **At beneficiary level**
    a) Girls, women should be given sexuality and HIV/AIDS education.
    b) Women be empowered with vocational skills
    c) Efforts should be made to popularize and practice gender equality
    d) More support group activities be organized
2. **At Government and NGO level:**

    Since 1986, Government and NGO's are making lot of efforts for treatment and care of HIV infected persons. However, looking at the infrastructure for health and development in our country, we need to create lot of support at different sectors and paramedical services level also. Laboratory facilities, counseling services can be improved. Based on these observations following are the suggestions -

    a) Government should recruit more trained counselors to provide/enhance coping ability of HIV infected women.
    b) The module prepared by the rsearcher should be encouraged for intervention to enhance coping mechanisms.
    c) Refresher training programmes be organized for counselors
    d) Inter-sectoral planning need to be done, as HIV is related to poverty, unemployment, migration and urbanization issue.
    e) Affordable, approachable and accessible health care be provided to the poorest of the poor.
3. **At policy level:**

    To combat with any national health problem, the country has to have policy, budget, personnel and infrastructure. Budget for health in our country is inadequate. HIV/AIDS have been one of the millennium development goals and an important agenda. However as stated earlier, it has to have resources to fulfill the goal or agenda. Based on these observations following are the suggestions-

    a) Anti-Retro Viral therapy of first and second line be made available for patient care;
    b) Income generating activity for HIV infected women be taken up for support;

c) Care homes for infected women and children be started;
d) Research activity be encouraged to combat with HIV;
e) Efforts to be made for attitudinal change in people about stigma and discrimination through awareness programmes.

At the end, I would like to suggest more intensive research be done to see the impact of intervention and further social work education should make changes in curriculum to teach coping skills through counseling. HIV/AIDS should be taught at bachelor's level, master's level and students should be well-equipped with the training inputs on counseling.

Training should comprise following points

a. HIV/AIDs causes and effects
b. Diagnostic test
c. Pre test Post test counseling
d. Psychosocial implication of HIV
e. Treatment methods and adherence counseling
f. Working with family
g. Comprehensive module to strengthen coping mechanism
h. Holistic care

9.5: Discussion:

Investigator has been working in the field of counseling and teaching since a long time. The patients mostly belong to lower socio economic group; the most common mode of transmission is heterosexual, multipartner, and unprotected sex. This group generally migrates for want of employment in the absence of education and vocational skills. Many times this youth group migrates in urban areas without families. In the absence of sex-sexuality education and absence of healthy recreational facilities they tend to get into high risk behavior. This leads to HIV infection. While the person gets infected, he is pressurized to get married without disclosing his HIV status. On the other hand women in our society are forced to marry after the age of 17-18 years. There is no channel to understand the male partner's habits or risk behavior. It is only realized when either spouse falls sick, or gets pregnant and attends antenatal clinics. Such women are diagnosed at government ICTCS. It was thought to conduct the study

at the time of diagnosis to assess the coping, however due to administrative constraints and confidentiality issue study was conducted with the help of NGO's.

Defining the psychological term 'coping' was a major problem. Initially, with the help of literature and discussions with experts in the field it was decided to use the psychological tests, those test were adapted and then translated. However, respondents found the psychological concept like coping, adjustment, quality of life etc. very difficult. It took a very long time to interpret the objectives of the study, phases and significance of intervention. In the first phase i.e. pre intervention 191 respondents participated in the study, by the time inputs were given, they attended individual and group counseling, found it useful, however till the third phase of intervention 52 respondents could be pursued. Pretest and post intervention results were further computed with scores and then the results are presented.

All the five components of coping mechanisms are independent concepts and long term processes, which are developed during socialization process. An effort was made to strengthen coping mechanism. For this, module was developed, which included guidance on management of time, stress, money and emotions. Input on maintaining communication with family also was provided. However it is realized that, changes in personality and quality of life cannot be brought within a very short span of time. Respondents were from lower socio economic group and from slum areas, some of them attended NGO's OPD's to receive few supplementary services. They could not come for study purpose as they were not provided with any travelling allowance. Researcher had the time constraint, to finish her work within a stipulated period. Hence, I feel more rigorous study can be done with intervention module to strengthen coping mechanisms.

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APPENDIX I –Interview Schedule

Social work intervention to assess and strengthen the coping mechanisms of women infected of HIV/AIDS

1.00 Identification Data :

1.01 Name :

1.02 Age :

1.03 Address:

1.04 Education:

1.05 Occupation: Primary Secondary

1.06 Family occupation: What does your husband do?

1.07 Total income of the family:

1.08 No. of dependents on you in the family:

1.09 Do you possess a BPL ration card?

1/10 Marital status/ Married/ deserted/ widow, legally separated, remarried, divorced:

1.11 When did you get married?

1.12 No. of children:

Sex of child	0-6 years	7-18 years	18-24 years
Male			
Female			

1.13 Are you a resident of Pune or migrated from elsewhere?

1.14 Year of residence in the city:

1.15 No. of close relatives residing with you:

No. of Males	**No. of Females**
Father Father in-law Brother Brother in-law	Mother Sister Mother in-law Sister in-law

1.16 Nature of relationship with native place:

1.17 Frequency of visits to native place:

1.18 Family assets and share:

	Yes/No	**Your share(%)**
Bank Balance		
House		
Land plot		
Insurance/Policy		
Ornaments		

1.19 Share in property:

Husband	Self	Other relatives

2.0 Health, Nutrition, Illness

2.01 How is your health presently?

a. Weight b. Height c. BMI d. Hb

2.02 At what age did you get married

a. 17 b. 18 c. 19

2.03 What was your age at the time of first delivery?

a. 18 b. 19 c. 20

1.22 Major development in family in last 3 years

1.21 Perception about adequacy of income: adequate/ inadequate

1.22 Major development in family in last 3 years

1.23 Have you ever thought of remarriage?

1.24 Did you experience (vulnerability) sexual harassment?

1.25 Major differences in the family:

2.04 First pregnancy after marriage:

2.05 Total no. of pregnancies?

2.06 Total no. of children?

a. 1 b. 2 c. 3

2.07 Is there any major illness during last 1 year?

2.08 Is there any prolonged illness during last year?

2.09 Are all your children healthy / normal?

2.10 What is the spacing between two children?

2.11 Which contraceptives did you use?

2.12 Who referred you for testing HIV?

a. Doctor b. Husband c. Health Worker d. Others

2.13 When was HIV detected?

2.14 When you were referred for HIV test?

a. First pregnancy b. Second Pregnancy c. Frequent health complaints seen

2.15 Where were you diagnosed?

a. ICTC b. Hospital

2.16 Age at the time of detection

2.17 Number of children at the time of detection

a. 1 b. 2

2.18 Did you receive pretest counseling?

2.19 Are you suffering from any opportunistic infection?

a. Yes b. No

2.20 How much is your CD4 count at present?

2.21 Which method of healing did you try?

a. Traditional b. Scientific

2.22 Since how long your partner was infected?

a. Since 2 years b. 5 years c. 10 years

2.23 How do you take care of yourself?

Aspect	No.	Question	Yes	No
Preventive	1	Avoiding outside food		
	2	Avoiding outside water		

	3	Avoiding crowded places		
	4	Avoiding sex		
	5	Washing hands		
	6	Taking bath regularly		
	7	Restrict from chewing tobacco		
	8	Taking care during menstruation		
	9	Care in case of injury		
	10	Cutting nails regularly		
	11	Wash clothes separately with disinfectant		
Curative	12	Taking medicines regularly		
	13	Take guidance for opportunistic infections		
Promotive	14	Exercise regularly, Yoga		
	15	Regular medical check-ups		

2.24 Give information about morbid condition:

Back ache, knee trouble, feeling sad, feeling aneamic, getting numb fingers, dry skin

2.25 Complaint about menstruation:

Irregular, frequent, prolonged, painful, excessive bleeding, excessive fatigue, white discharge.

2.26 What is the source of information of ART?

a. Doctor b. Counsellor c. Relatives

d. Media e. (a+b+c)

2.27 Has the doctor and counselor explained to you about ART?

a. Yes b. No

2.28 Does ART have any side-effects on you?

Headache, Giddiness, nausea, sleeplessness, depression, restlessness, vomiting

2.29 Do you find any difficulty in adhering instructions of counselor?

a. Yes b. No c. Frequently d. Rarely

2.30 Do you feel you are competent to overcome these difficulties?

a. Yes b. No

2.31 Is there any senior person to help you in this regard? If yes, nature of help.

a. Yes b. No

2.32 Are your friends or relatives helping you? If yes, nature of help.

a. Yes b. No

2.33 Do you visit the doctor regularly?

a. Yes b. No

2.34 Why do you feel the need to visit doctor regularly?

2.35 Have you received adherence counseling?

a. Yes b. No

2.36 Have you followed the instructions by the counselors? If yes, do you find it is beneficial?

2.37 Are you satisfied with counseling?

a. Yes b. No

2.38 Are you a member of support group? In what way does it help you?

2.39 Are you a vegetarian or a non-vegetarian?

2.40 What is your dietary pattern?

Meal	Time	Items/ ingredients
Breakfast		
Lunch		
Tea-time		
Dinner		
Other snacks		

2.41 Since your illness have you changed your food habits?

2.42 How do you take care of your nutrition?

2.43 Do you wash vegetables before cutting?

2.44 Do you fast? If yes, mention frequency:

a. Yes b. No

a. Once a week b. Twice a week

3.0 Stigma and social support:

3.01 What was your reaction after you were referred to ICTC?

a. Concerned about health b. Felt like avoiding doctor
c. Felt anxious c. Guilty d. Depressed

3.02 Reaction after diagnosis?

a. Loss of self esteem b. Anger c. Loneliness
d. Stigma e. Depression

3.03 Was your partner infected?

b. Yes b. No

3.04 When did your partner talk to you about his infection?

a. Immediately b. After opportunistic infection

c. After he developed severe symptoms

3.05 How was your relationship during this period with your partner?

c. Satisfactory b. Not satisfactory

3.06 What precaution you have taken during this period?

d. Safer sex practices b. Did not take any precaution

c. Forced not to take precaution

3.07 Were you pressurized to undergo pregnancy after knowing HIV status? If yes who pressurized?

e. Yes b. No

3.08 Do you have any doubts about sex behavior of your partner?

f. Yes b. No

3. 09 If yes, how have you reacted? What was his counter reaction?

3.10 Did you have a feeling of insecurity?

3.11 Was there any mutual understanding about this?

3.12 Are your children infected?

g. Yes b. No

3.13 What was the reaction of family members?

Relations	Reactions			Have you experienced			
Father-in-law				Less contact	Less dialog	Social b	Doubts about character
Mother-in-law							
Brother-in-law							
Sister-in-law							
Father							
Mother							
Brother							
Sister							

3.14 Did you experience stigma in case of:

a. Less visits to in-laws place b. Less visits to parents

c. Less visits to neighbors d. Less visits to friends

e. Interactions were few, attending less social functions

f. No help in emergencies, difficulties.

3.15 What was your reaction?

a. Anger b. Anxiety c. Depression d. Felt embarrassed

e. None of them, calm acceptance.

3.16 Did you face any difficulties in life so far?

a. Yes b. No

3.17 What type?

a. Health	yes	no	b. Economic	yes	no
c. Relationships	yes	no	d. Family	yes	no
e. Psychological	yes	no			

3.18 Whom do you approach at times of difficulties?

b. Parents b. in-laws, colleagues, friends, professionals:

3.19 With whom do you share your feelings, happiness, sorrow? Parents, friends, in-laws, colleagues, spouse.

3.20 Where did you get guidance-counseling?

3.21 Did you receive pretest counseling?

3.22 Did you receive post test counseling?

3.23 Did you receive adherence counseling?

3.24 Being a young woman/widow, do you have any problems/troubles?

3.25 How is attitude of society towards you?

a. Excellent-better b. Okay-can manage c. Negative attitude.

3.26 Did you experience feeling of rejection by family?

a. Yes b. No

3.27 Did you experience discrimination at your work place?

a. Yes b. No

3.28 Did you have any difficulty in admitting your children in school?

a. Yes b. No

3.29 In what way do you feel your coping has improved after counseling?

3.30 State your experience of funeral of your husband.

3.31 How does self-help group provide you support?

a. Health care b. Morale boosting c. Care of children

d. Financial support

3.32 Who gives you support, when you are anxious /sad / depressed?

a. Husband b. Parents c. In-Laws d. Brothers

e. Children

3.33 Who takes care of you, when you are irritated?

a. Husband b. Parents c. In-Laws d. Brothers

e. Children

3.34 When you are in difficult situation who helps you? may take risk and help you?

a. Husband b. Parents c. In-Laws d. Brothers

e. Children

3.35 Who loves you unconditionally?

a. Husband b. Parents c. In-Laws d. Brothers

e. Children

3.36 Who will be more happy, if you prosper and do well?

a. Husband b. Parents c. In-Laws d. Brothers

e. Children

3.37 On whom can you depend for assistance / help?

a. Husband b. Parents c. In-Laws d. Brothers

e. Children

3.38 Did your relatives meet you recently or you met them?

a. Yes b. No

APPENDIX II – Psychological Tests

I- ADJUSTMENT INVENTORY

1.	My parents never blame my personality	True / False
2	I don't have mother so I am unhappy	True / False
3	If I want to speak in-front of the small group of (4-5) persons I can talk without any problem	True / False
4	I can talk frankly about my problems with my parents.	True / False
5	I cannot mix-up with people.	True / False
6	I am always anxious about some or the other problems.	True / False
7	I am capable of solving my difficulties.	True / False
8	I don't have new, latest thing in my house.	True / False
9	I feel hesitant to offer snacks to others during Picnic	True / False
10	I can not stay away from my family	True / False
11	I generally don't get dissuaded easily from my work /task.	True / False
12	My parents cannot understand me.	True / False
13	I feel intimacy / love about everyone in my family.	True / False
14	I feel I am successful in my life	True / False
15	I don't feel marriage is an unnecessary burden.	True / False
16	People in my neighborhood take me along with for recreational activities.	True / False
17	I am worried about happiness in married life.	True / False
18	I enjoy doing difficult tasks than easy one.	True / False

19	I have to bear troubles / problems due to adverse situation in family.	True / False
20	I cannot tolerate other's opinions and beliefs / perception.	True / False
21	I don't have any difficulty in controlling my sexual desire.	True / False
22	I am anxious / worried about the health of my parents.	True / False
23	Sometimes I feel emotionally disturbed in absence of any feelings	True / False
24	I don't get disturbed easily.	True / False
25	I take quick decisions.	True / False
26	My parents are always confused.	True / False
27	If there is a quarrel in friends I make efforts to intervene.	True / False
28	There are continuous complaints, cribbing at home.	True / False
29	I always get a sound sleep.	True / False
30	Sometimes I feel like rebelling against seniors.	True / False
31	I feel like crying very easily.	True / False
32	I rarely have a headache.	True / False
33	I am sufficiently appreciated for my work.	True / False
34	I don't hesitate to ask anything to elders.	True / False
35	In a competition there is success or failure.	True / False
36	I feel I have a chronic sickness or inadequacy.	True / False
37	Financial problems at home make me unhappy.	True / False
38	I rarely feel that I will be attacked.	True / False
39	I feel sad /guilty for a long-time if I hurt someone.	True / False

40	I feel like running away from home.	True / False
41	Many times I feel that my parents cannot understand me.	True / False
42	I am doubtful that somebody is conspiring against me.	True / False
43	I am frequently cheerful.	True / False
44	I never had suicidal thoughts.	True / False
45	I don't envy prosperity of others.	True / False
46	My feelings are easily hurt.	True / False
47	I am care less.	True / False
48	I feel suffocated in college environment / atmosphere.	True / False
49	I cannot learn quickly.	True / False
50	I do not have doubts about my capability to succeed.	True / False
51	I do not like social restrictions.	True / False
52	I do not like to do job.	True / False
53	I like educational programmes in college.	True / False
54	I am distracted while teachers are teaching.	True / False
55	I frequently face difficulties in communicating because I fall short of appropriate words	True / False
56	I am fearful during exams and competitions.	True / False
57	I don't remain absent at school at present.	True / False
58	I feel sad if I am not able to complete a planned task.	True / False
59	My methods of studying are appropriate.	True / False
60	I change friends frequently.	True / False

61	I am scared about love, romance and marriage.	True / False
62	I believe I am superior than others.	True / False
63	I take a lead / initiative in social work.	True / False
64	It is not my nature to worry on feel distressed over minor issues	True / False
65	I avoid introducing others in social functions.	True / False
66	I feel satisfied about my health.	True / False
67	I feel nausea very often.	True / False
68	I need more money to take care of my health.	True / False
69	I have a heart trouble.	True / False
70	I have sound sleep at night.	True / False
71	I feel depressed very often	True / False
72	I have sometimes loose motions.	True / False
73	I do not require to take much care about my health.	True / False
74	Sometimes I feel helpless.	True / False
75	I do not have any serious illness.	True / False
76	I get nutritious diet.	True / False
77	Sometimes I feel giddy.	True / False
78	I get cold very often.	True / False
79	Sometimes I have difficulty in breathing.	True / False
80	I periodically see dreadful dreams.	True / False
81	I feel self-pity about my self	True / False

II-COPING CHECKLIST

1	You go over the problem again and again in your mind, to try to understand it.	Yes / No
2	Accept it since nothing can be done.	Yes / No
3	Talk to a family member who can do something concrete about th problem.	Yes / No
4	Get away from the things for a while, take a rest or a vacation.	Yes / No
5	Compare yourself with others and feel that you are better off.	Yes / No
6	Wish that you can change what has happened.	Yes / No
7	Seek reassurance and emotional support from family members.	Yes / No
8	Try to make yourself feel better by taking drugs. (Mood elevating	Yes / No
9	Visits places of worship, go on a pilgrimage.	Yes / No
10	Go on shopping spree.	Yes / No
11	Engage in various physical exercise.	Yes / No
12	Anticipate probable outcomes and mentally rehearse them.	Yes / No
13	Console yourself that things are not all that bad and could be wor	Yes / No
14	Try your luck at games of chance (Races, Lottery, Cards)	Yes / No
15	Seek reassurance and support from friends.	Yes / No
16	Retreat to a quite, favorite spot to think things over.	Yes / No
17	Try to make yourself feel better by having a drink or two (alcohol	Yes / No
18	Accept the next best thing top what you wanted	Yes / No
19	Think about fantastic or unreal things to make you feel better.	Yes / No

20	Try to look on the bright side of things.	Yes / No
21	Attend Bhajan groups.	Yes / No
22	Go for long walks.	Yes / No
23	Blame your fate, sometimes you just have bad luck.	Yes / No
24	Make yourself feel better by smoking.	Yes / No
25	Wear a lucky charm or amulet.	Yes / No
26	Talk to a friend\ who can do something about the problem.	Yes / No
27	Pray to God.	Yes / No
28	Make light of the situation /refuse to get too serious about it.	Yes / No
29	Listen to music for comfort.	Yes / No
30	Come up with a couple of different solutions to the problem	Yes / No
31	Try to forget about the whole thing.	Yes / No
32	Avoid being with people; seek complete isolation.	Yes / No
33	Consult a faith healer. Faith healer	Yes / No
34	Swallow analgesics or minor tranquilizers, not on medical advice	Yes / No
35	Refuse to believe that it happened.	Yes / No
36	Attend religious / philosophical discourses and talks.	Yes / No
37	Start Yoga / Meditation; practice Yoga / Meditation.	Yes / No
38	Hope a Miracle will happen.	Yes / No
39	Consult an astrologer.	Yes / No
40	Help others in trouble or distress.	Yes / No

41	Feel that time will remedy things; the only thing to do is wait.	Yes / No
42	Write letters to significant others.	Yes / No
43	Prepare yourself for the worst to come.	Yes / No
44	Pace up and down thinking about the problem.	Yes / No
45	Turn to work/studies to take your mind off things.	Yes / No
46	Seek sexual comfort.	Yes / No
47	Find a purpose or meaning in your suffering.	Yes / No
48	Spend time in the company of children.	Yes / No
49	View the future as bleak and hopeless.	Yes / No
50	Write short stories, poetry, etc.	Yes / No
51	Blame yourself.	Yes / No
52	You know what has to be done so your double your efforts and try harder to make things work.	Yes / No
53	Analyze the problem and solve it bit by bit.	Yes / No
54	Make a plan of action and follow it.	Yes / No
55	Read popular guide books for answers to your problem.	Yes / No
56	Draw on your past experience of similar situations.	Yes / No
57	Take up or indulge in a hobby (music, art, etc.)	Yes / No
58	Sleep more than usual to avoid the problem.	Yes / No
59	Read novels, magazines, etc. much more than usual.	Yes / No
60	Try to feel better by eating / nibbling.	Yes / No
61	Keep your feelings to yourself.	Yes / No

62	Make special offerings or perform special Pujas	Yes / No
63	Become a member of a group, club or organization, or if already a member, attend to group activities.	Yes / No
64	See more movies that usual.	Yes / No
65	Seek Professional help and do as they recommend.	Yes / No
66	Read books on philosophy or religion.	Yes / No
67	Compare yourself with others and feel that you are worse off.	Yes / No
68	Feel that other people are responsible for what has happened.	Yes / No
69	Take a big chance or do something very risky.	Yes / No
70	Write to “question-answer” columns in various magazines.	Yes / No

III-Quality of Life

Instructions:

Circle Y (for Yes) or N (for No) for each of these 100 questions. Then, add up the number of Yes' and score yourself using the scoring key below.

1.	**Family Relationships**	
Y -	N 1.	I am both pleased and content with my spouse / partner, or happy being single.
Y -	N 2.	I am close to my parent(s), alive or not. There is nothing in the way; nothing between us,
Y -	N 3.	I have a circle of friends who I have a blast with, without effort.
Y -	N 4.	I have a best friend and treat him/her extremely well.
Y -	N 5.	I am very close to my children. There is nothing in the way; nothing between us.
Y -	N 6.	I enjoy my family / extended family; we have worked through any dysfunction / past problems.
Y -	N 7.	I am part of a professional network that stimulates me intellectually and emotionally.
Y -	N 8.	I get along well with my neighbors.
Y -	N 9.	I have at least 20 friends and colleagues who live outside of my country of residence.
Y -	N 10.	I am loved by the people who mean the most to me.
2.	**Career / Business**	
Y -	N 11.	My work / career is both fulfilling and nourishing to me; I am not

		drained.
Y -	N 12.	I am highly regarded for my expertise by my manager, clients and / or colleagues.
Y -	N 13.	I am on a positive career path that leads to increased opportunities and raises.
Y -	N 14.	I work in the right industry or field; it has a bright future.
Y -	N 15.	I look forward to going to work virtually every day.
Y -	N 16.	My work is not my life, but it is a rich part of my life.
Y -	N 17.	I work with the right people.
Y -	N 18.	My work environment brings out the very best of me because it is to stimulating and / or supportive.
Y -	N 19.	At the end of the day, I have as much energy as I did when I started the day; I am not drained.
Y -	N 20.	The work I do helps to meet my intellectual, social and / or emotional needs.
3.	**Money / Finances**	
Y -	N 21.	I have at least a year's living expenses in the bank or money market fund.
Y -	N 22.	I am on a financial independence track or am already there.
Y -	N 23.	I don't have to work at financial success; money seems to find me with very little effort or pushing.
Y -	N 24.	I have no financial stress of any kind in my life.
Y -	N 25.	I invest at least 10 % of my income / earnings in my ability to increase / expand that income.

Y -	N 26.	I do not carry credit card debt; I do not overspend.
Y -	N 27.	When I buy something, I buy the best possible quality.
Y -	N 28.	I don't lose sleep over my investments.
Y -	N 29.	I am financially knowledgeable – I know how money is made and lost.
Y -	N 30.	I make money because I add enough value to the people who need what I have.
4.	**Joy / Delight**	
Y -	N 31.	I spend my leisure time totally enjoying my interests; I am never bored.
Y -	N 32.	Weekends (or other days off) are a joy for me.
Y -	N 33.	I have designed the perfect way to spend the last hour of my day.
Y -	N 34.	I look forward to getting up virtually every morning.
Y -	N 35.	I am very, very happy.
Y -	N 36.	I have designed – and am living – the perfect lifestyle for me right now.
Y -	N 37.	I have at least an hour a day that is exclusively for me and I spend it in a chosen way.
Y -	N 38.	I am able to stay present during the day; I don't lose myself to stress or adrenaline.
Y -	N 39.	I easily take delight in the littlest things.
Y -	N 40.	My home brings me joy every time I walk inside.
5.	**Effectiveness / Efficiency**	
Y -	N 41.	I don't spend time with anyone who bugs me or who is using me.

Y -	N 42.	I have more than enough energy and vitality to get me through the day; I don't start dragging.
Y -	N 43.	I have no problem asking for exactly what I want, from anyone.
Y -	N 44.	I have all of the right tools, equipment, computers, software and peripherals that I need to work well.
Y -	N 45.	Whatever can be automated, is automated.
Y -	N 46.	Whatever can be delegated, is delegated.
Y -	N 47.	I reply to all emails as I read them; I don't maintain an inventory of unanswered emails.
Y -	N 48.	I don't put things off; when it occurs to me, I do it, handle it, or have it done.
Y -	N 49.	I know what my goals are and I am eagerly and effectively making them a reality.
Y -	N 50.	I don't do errands.
6.	**Personal Foundation / Self-Responsibility**	
Y -	N 51.	I love my home; its location, style, furnishings, light, feeling and décor.
Y -	N 52.	My boundaries are strong enough that people respect me, my needs and what I want.
Y -	N 53.	I tolerate very, very little; I'm just not willing to.
Y -	N 54.	I don't see a cloud on my future's horizon; it looks clear to me.
Y -	N 55.	My wants have been satiated; there is little I want.
Y -	N 56.	My personal needs have been satisfied; I am not driven or motivated by unmet needs.

Y -	N 57.	There is nothing I am dreading or avoiding.
Y -	N 58.	My personal values are clear and my life is oriented around them.
Y -	N 59.	I have resolved the stresses and key issues of my upbringing and past events.
Y -	N 60.	I don't have a lot of unfinished projects, business or hanging items; I am caught up.
7.	**Personal Development / Personal Evolution**	
Y -	N 61.	I could die this afternoon with no regrets.
Y -	N 62.	I am living my life, not the life that someone else designed for me or expected of me.
Y -	N 63.	There is nothing that I am not facing head-on; nothing that I am putting up dealing with.
Y -	N 64.	I attract success, I don't have to strive for it or chase it.
Y -	N 65.	I have more than enough natural motivation, inspiration and synergy in my life; I am not stuck.
Y -	N 66.	I am evolving, not just improving or evolving, because I continually experiment.
Y -	N 67.	I have progressed beyond the notion of beliefs.
Y -	N 68.	I am at that place in life where I initiate and cause events, not wait for others or events to do so.
Y -	N 69.	I have learned to take the path of least resistance as I accomplish my goals.
Y -	N 70.	I am beyond striving for success; I simply enjoy my life and focus on what I fulfills me.

8.	**Self-Care / Well-Being**	
Y -	N 71.	I take at least 4 vacations a year.
Y -	N 72.	Life is easy; I have virtually no problems or unresolved matters affecting me.
Y -	N 73.	My teeth and gums look great and are in top condition.
Y -	N 74.	I have more than enough time during my day.
Y -	N 75.	I eat food for sustenance and pleasure, not for emotional comfort.
Y -	N 76.	I am not abusing my body with too much alcohol, television, caffeine or drugs.
Y -	N 77.	Whatever health problems I have, I am receiving proper, effective care for them.
Y -	N 78.	My body is in great shape.
Y -	N 79.	I reduce stress daily by meditating, taking a long bath, exercising, walking, etc.
Y -	N 80.	There is nothing I am doing that is messing up my mind or heart.
9.	Happiness	
Y -	N 81.	_____
Y -	N 82.	_____
Y -	N 83.	_____
Y -	N 84.	_____
Y -	N 85.	_____
Y -	N 86.	_____

Y -	N 87.	_____
Y -	N 88.	_____
Y -	N 89.	_____
Y -	N 90.	_____
10	Pleasure	
Please write down the 10 things that give you're the greatest pleasure, whether you currently do these things in your life or not.		
Y -	N 91.	_____
Y -	N 92.	_____
Y -	N 93.	_____
Y -	N 94.	_____
Y -	N 95.	_____
Y -	N 96.	_____
Y -	N 97.	_____
Y -	N 98.	_____
Y -	N 98.	_____
Y -	N 100	_____

_____ Number of Y's

_____ Number of N's

---------- 100 maximum

IV-Motivation Test

2. Consumable Booklet of A C M T

1.	**What I want most in my life is…….**		
	(A)	to get an ideal home life.	☐
	(B)	To be a popular man in the society	☐
	(C)	to do something requiring efforts	☐
2.	**I would like to solve……**		
	(A)	those problems which will give new experiences.	☐
	(B)	the socio-economic problems of my country.	☐
	(C)	very difficult puzzles and quizzes.	☐
3	**I am happiest when …….**		
	(A)	making others happy.	☐
	(B)	I become the centre of other's attention.	☐
	(C)	successful in my work.	☐
4	**I often strongly think of ……**		
	(A)	being one respected political leader.	☐
	(B)	being a famous social leader.	☐
	(C)	accomplishing something great.	☐

5	**My aim of life is……..**		
	(A)	to make a long record of successful achievements.	☐
	(B)	to attain high status in society.	☐
	(C)	to serve the nation.	☐
6.	**I like to praise those who…….**		
	(A)	have earned a name of repute in their own field.	☐
	(B)	have some principles in life.	☐
	(C)	have devoted themselves in the service of mankind.	☐
7.	**I want to know…….**		
	(A)	how I can be successful to whatever I undertake.	☐
	(B)	the honest means of accumulating wealth.	☐
	(C)	the easiest way of achieving the World Peace.	☐
8.	**Before starting a difficult task…….**		
	(A)	I would plan to work out its details.	☐
	(B)	I would think about the difficulties that may come in the way.	☐
	(C)	I would invite suggestions from others.	☐
9.	**It is my nature to ……..**		
	(A)	do things for my friends.	☐

	(B)	undertake tasks which require great skills.	☐
	(C)	keep things neat and clean.	☐
10.	**I wish I could always be ……**		
	(A)	eager in successfully doing difficult jobs.	☐
	(B)	eager to be sympathetic to sick and poor people.	☐
	(C)	eager to visit new places, see new persons and get new things.	☐
11.	**I feel upset when…….**		
	(A)	I am blamed by my own people.	☐
	(B)	I am neglected.	☐
	(C)	I fail to reach my desired goal.	☐
12.	**I want to accomplish the task…….**		
	(A)	in a neat and clean fashion.	☐
	(B)	to do it more better than others.	☐
	(C)	to finish it before the time fixed.	☐
13.	**I like to ……..**		
	(A)	read fictions and do courageous works.	☐
	(B)	think of my future.	☐
	(C)	visit different places of the world.	☐

14.	**I usually think…….**		
	(A)	that I should get honour and respect like a leader.	☐
	(B)	that I should perform something great and unique.	☐
	(C)	that I should help and look after the sick and injured.	☐
15.	**I like to be……..**		
	(A)	very systematic and orderly in the work I undertake.	☐
	(B)	very faithful and sincere to my friends and colleagues.	☐
	(C)	best in my performances and assignments.	☐
16.	**I like that ……**		
	(A)	I may earn money.	☐
	(B)	I may do most important work.	☐
	(C)	I may become the master of myself.	☐
17.	**I am always……..**		
	(A)	ready to fight for the noble and reasonable cause.	☐
	(B)	ready to enhance and develop my ability.	☐
	(C)	prepared to remove casteism and other social evils.	☐
18.	**I am sure that during next five years……**		

	(A)	I will be earning lot of monies.	☐
	(B)	I will be an expert in my field.	☐
	(C)	I will be independent.	☐
19.	**I want that …….**		
	(A)	my institution may be more democratic.	☐
	(B)	the environment of my town be more peaceful and healthy.	☐
	(C)	the environment of my house may allow me to study more and more	☐
20.	**I like things which …….**		
	(A)	may make me rich and more possessing.	☐
	(B)	may make me to get respect that of a leader.	☐
	(C)	may be achieved by others with great difficulty.	☐
21.	**I get satisfaction most in ……..**		
	(A)	remaining in the company of famous and popular persons.	☐
	(B)	doing the most difficult tasks.	☐
	(C)	testing others and to give guidance to them.	☐
22.	**I give preference to ……**		
	(A)	difficult tasks over simple and easy tasks.	☐
	(B)	remain in the company of elderly and experienced persons.	☐

	(C)	get encouragement from my friends and others.	☐
23.	**I genuinely believe that for me …..**		
	(A)	liberal and kind to my friends at all times.	☐
	(B)	sympathetic to sick and poor people.	☐
	(C)	successful in doing difficult works.	☐
24.	**I wish that I may be…….**		
	(A)	liberal and kind to my friends at all times.	☐
	(B)	sympathetic to sick and poor people	☐
	(C)	successful in doing difficult works	☐
25.	**I am most happy when I ……**		
	(A)	get a chance to enjoy with others by wits and humour.	☐
	(B)	get honour and respect after performing difficult tasks successfully	☐
	(C)	get the chance to get a high position.	☐
26.	**I feel …….**		
	(A)	upset when I am not getting success in the examinations despite of hard work.	☐
	(B)	sad at the death of somebody near and dear to me.	☐
	(C)	enraged when some of my friends do not get justice.	☐

27.	**In general I may be described as a …….**		
	(A)	tolerable person	☐
	(B)	humble and polite person	☐
	(C)	optimistic person	☐
28.	**I sincerely wish……..**		
	(A)	to be a most wealthy person	☐
	(B)	to be a happy and most fortunate person	☐
	(C)	that I may attain the high achievements in a surprising manner.	☐
29.	**While working in a group I wish that …….**		
	(A)	I may perform the best work than others.	☐
	(B)	I may be the leader of the group.	☐
	(C)	I may do the work in the most systematic way.	☐
30.	**I consider myself better than others who…….**		
	(A)	are unsocial by nature.	☐
	(B)	do not feel the responsibility.	☐
	(C)	do not fix and aim of life and do not work to get it.	☐
31.	**I get pleasure in……**		

	(A)	the company of children	☐
	(B)	solving difficult problems.	☐
	(C)	living with jovial people.	☐
32.	**I believe……..**		
	(A)	love is more better than justice.	☐
	(B)	my future depends on some special achievements.	☐
	(C)	it is better to be sincere and faithful than to be popular.	☐
33.	**Generally, I ……**		
	(A)	Critically analyse other's decisions.	☐
	(B)	am polite in behavior.	☐
	(C)	do the work till it is completed successfully.	☐
34.	**In most of the social situations, I ……..**		
	(A)	try to be traditional.	☐
	(B)	try to become a bit able to do work in accordance with the social traditions.	☐
	(C)	try to attract and get other's attention by my work.	☐
35.	**I like to …….**		
	(A)	become a big authority in some business or work.	☐
	(B)	do my activities in a systematic way.	☐

	(C)	make friendly sympathetic behavior with sad people.	☐
36.	**My real wish ……..**		
	(A)	is to get the highly paid work.	☐
	(B)	is to enjoy the bliss of happy married life.	☐
	(C)	is to attain reputable attainments.	☐
37.	**I want that I should become so able that …….**		
	(A)	I may use such words the meaning of which nobody should be able to understand.	☐
	(B)	I may be able to do better work than others.	☐
	(C)	I may forgive him who wants to harm me.	☐
38.	**I……**		
	(A)	may try my level best to become a big person in my field.	☐
	(B)	may try to remain firm in following the truth.	☐
	(C)	may try to help the helpless people to the best of my capacity.	☐
39.	**Generally, I wish that ……**		
	(A)	I may be a worshipper of God.	☐
	(B)	I may serve the poor without caring for any return.	☐
	(C)	I may get additional success in some work.	☐

40.	**I avoid……..**		
	(A)	such persons who are pleasure-seekers only and are without responsibility.	☐
	(B)	those situations which are not competitive.	☐
	(C)	those persons who are mentally illusioned and unsystematic.	☐
41.	**I want that others may think about me as …….**		
	(A)	laborious person.	☐
	(B)	very good natured person.	☐
	(C)	very intelligent and capable person.	☐
42.	**I feel very good when ……..**		
	(A)	I relate my personal experiences to others.	☐
	(B)	I am told to make others to understanding something.	☐
	(C)	I have to do any difficult work.	☐
43.	**I always ……**		
	(A)	do the activities in my own systematic way.	☐
	(B)	try to please everybody with my behavior.	☐
	(C)	try to do my work in the best possible way.	☐

44.	**I evaluate my ability by saying ……**		
	(A)	my teachers are partial and side others.	☐
	(B)	Whatever the grade has been given to me is related with labour I have put it.	☐
	(C)	the grade given to me is less than the labour I have put in.	☐
45.	**I am …….**		
	(A)	morally a correct person.	☐
	(B)	determined to get my high goal in life.	☐
	(C)	tolerable to those persons who try to hit me.	☐
46.	**I am full of anxiety for …..**		
	(A)	knowing my deficiencies so that I may remove them.	☐
	(B)	doing more important work.	☐
	(C)	becoming the centre of attraction in the group.	☐
47.	**I bear out the pain because …….**		
	(A)	nobody should feel painful feelings given by me.	☐
	(B)	I may escape from other's allegations.	☐
	(C)	I may remove difficulties and get first class success.	☐
48.	**I am ……**		
	(A)	courageous, but would avoid unnecessary dangers and risks.	☐

	(B)	quite punctual and never late for work, school and appointments.	☐
	(C)	quite neat and organized in what I do.	☐
49.	**I am of the opinion that for pleasure and happiness one must……**		
	(A)	get the basic amenities of life.	☐
	(B)	enrich the records one's achievements.	☐
	(C)	support charities.	☐
50.	**In whatever work I undertake**		
	(A)	I like to do very best.	☐
	(B)	I like to assume full responsibility for it.	☐
	(C)	I like to make advance plans.	☐

V-Personality Test

Block A

1.	How is your personality?	
	1.	Flexible
	2.	Dominating
	3.	Aggressive
	4.	Submissive
	5.	Confident
2.	Which of the following four type of pictures (cinema) do you like to enjoy most ?	
	1.	Picture of battle
	2.	Picture of a comedy
	3.	Picture of grim tragedy
	4.	Picture of natural disaster
3.	To which one of the following four types of persons do majority of your friends belong ?	
	1.	Persons who love to spend money very much .
	2.	Persons who love to spend money but adjust it according to their earning.
	3.	Persons who love to spend money but do spend where social prestige is involved.
	4.	Persons who love to save money very much.
4.	N.A.	
5.	Which one of the following four types of persons do you like most to have with you in a social gathering ?	

	1.	Those who would initiate the spirit of laughing and talking in the function.
	2.	Those who would not initiate but join others in laughing and talking to make the function lively.
	3.	Those who would laugh and talk only to keep friendly terms with others.
	4.	Those who would always prefer to be silent and observe others' activities.
6.	Which one of the following four types of persons do you like most to have as your friends.	
	1.	Persons who will never do anything without planning.
	2.	Persons who will do planning in most of the occasions.
	3.	Persons who will never like to plan before doing a thing.
	4.	Persons who will do planning only on rare occasions.
7.	Which one of the following four types of persons do you like to have as your friends ?	
	1.	Those who usually feel happy.
	2.	Those who feel happy most of the time.
	3.	Those who feel happy occasionally.
	4.	Those who do not feel happy usually.
8.	Do you take help from people ?	
	1.	Yes
	2.	No
9	Do you like people who criticize you ?	
	1.	Yes
	2.	No

10.	If you don’t do work in a thoughtful manner do you get restless.	
	1.	Yes
	2.	No
11.	Which type of tasks do you like ?	
	1.	Delicate work
	2.	General
	3.	Untidy
	4.	Other

Block B

12.	Do you always think about yourself ?	
	1.	Yes
	2.	No
13.	Before accepting new ideas, do you think about it ?	
	1.	Yes
	2.	No
14.	Can you talk, communicate with a stronger ?	
	1.	Yes
	2.	No
15.	Do you work persistently though you do not get success ?	
	1.	Yes
	2.	No

16.	Can you face criticism of others ?	
	1.	Yes
	2.	No
17.	Do you take care while taking any decision ?	
	1.	Yes
	2.	No
18.	Do you feel planning is necessary ?	
	1.	Yes
	2.	No
19.	Do you believe in people ?	
	1.	Yes
	2.	No
20.	Do you take leadership in social activities ?	
	1.	Yes
	2.	No
21.	Should there be limited relatives and friends ?	
	1.	Yes
	2.	No
22.	Do you take care of your things ?	
	1.	Yes
	2.	No
23.	Do you take initiative in making friendship ?	

	1.	Yes
	2.	No
24.	Do you take care for avoiding unfortunate events ?	
	1.	Yes
	2.	No
25.	Do you think all alone about problem till it is solved ?	
	1.	Yes
	2.	No
26.	Do you like to plan for future ?	
	1.	Yes
	2.	No
27.	Do you like to change your routine ?	
	1.	Yes
	2.	No
28.	Do you think about motivation and thought ?	
	1.	Yes
	2.	No

Block C

29.	N.A.	
30.	Do you like to work alone or in group ?	
	1.	Alone

	2.	In group
31.	**N.A.**	
32.	**N.A.**	
33.	Do you face the difficulties or avoid them ?	
	1.	Face it
	2.	Avoid it
34.	Where do get strength to face difficulties ?	
	1.	
	2.	
	3.	
	4.	
35.	Do you agree that rituals can solve problems ?	
	1.	Yes
	2.	No
36.	Do you prefer to keep quiet or argue ?	
	1.	Yes
	2.	No
37.	Do you face difficulties while taking any decision ?	
	1.	Yes
	2.	No
38.	Can you take decisions independently ?	
	1.	Yes

	2.	No
39.	How do you like to do your tasks	
	1.	Fast
	2.	After thinking
40.	Which is your ordinal position ?	
	1.	1.
	2.	2.
	3.	3.
41.	Do you take responsibility of siblings ?	
	1.	Yes
	2.	No
42.	From where have you learnt sense of responsibility ?	
	1.	Yes
	2.	No

Block D

43.	Presently which responsibility do you hold ?	
	1.	
	2.	
	3.	
44.	Are you independent ?	
	1.	Yes

	2.	No
45.	Do you hide few things of your life from others ?	
	1.	Yes
	2.	No
46.	If you make mistakes do you restless ?	
	1.	Yes
	2.	No
47.	Do you believe in being positive, making efforts ?	
	1.	Yes
	2.	No
48.	N.A.	
49.	If people are aggressive with you, do you feel sorry ?	
	1.	Yes
	2.	No
50.	N.A.	
51.	Do you hesitate in asking loan from others ?	
	1.	Yes
	2.	No
52.	N.A.	
53.	N.A.	
54.	N.A.	

55.	Do you value motivation and emotions of others ?	
	1.	Yes
	2.	No
56.	When you are stressed with emotions what do you do ?	
	1.	Share with others
	2.	Tolerate it
	3.	Seek help from others

Block E

57.	How do you respect, value yourself.	
	1.	
	2	
	3	
	4	
58	**N.A.**	
59	**N.A.**	
60	**N.A.**	
61	**N.A.**	
62	**N.A.**	
63	**N.A.**	
64.	How is your will power ?	

	1.	
	2.	
65.	What efforts you make to raise will power, strength ?	
	1.	Yes
	2.	No
66.	Do you express your emotions ? After expressing does it help in strengthening will power ?	
67.	Are you worried about future ?	
	1.	Yes
	2.	No
68.	N.A.	
69.	Are you optimistic ?	
	1.	Yes
	2.	No
70.	Do you have control over your anger ?	
	1.	Yes
	2.	No