SOCIO-PSYCHOLOGICAL STUDY OF HIV/AIDS PATIENTS ATTENDING S.N. MEDICAL COLLEGE, AGRA AND J.N. MEDICAL COLLEGE, ALIGARH

ABSTRACT

THESIS

SUBMITTED FOR THE AWARD OF THE DEGREE OF

Doctor of Philosophy

IN

SOCIOLOGY

BY

SEEMA KUMARI

Under the Supervision of

PROF. NOOR MOHAMMA
Chairman

DEPARTMENT OF SOCIOLOGY AND SOCIAL WORK
ALIGARH MUSLIM UNIVERSITY
ALIGARH-202 002 (INDIA)

2010
Acquired Immuno Deficiency Syndrome (AIDS) is recognized as the most fatal disease that humankind has ever faced. The epidemic was diagnosed first in 1981 and by the end of the year 5.7 million people across the globe were found to be afflicted by it. The disease is caused by the Human Immuno Deficiency virus (HIV), which breaks down the immune system of a body completely to combat infections. The virus remains dormant for 5 to 10 years before the onset of full blown AIDS which is always terminal. Today, AIDS is rapidly wiping out the hard-earned gains of human development in terms of regressing life expectancy, rising child mortality rates and killing the most productive and reproductive population in the prime of their youth. The economic impact of HIV/AIDS in terms of costs resulting from treatment and care of people living with HIV/AIDS (PWHA) is magnanimous.

With the rising spread of HIV/AIDS there has been a growing emphasis on understanding its epidemiology and manifestations. Various factors such as biological, socio-cultural, economic and psychological have broadly seen as causing the spread of the virus. Migration, prostitution, machismo behavior, low literacy level, prevalence of myths and misconceptions further aggravate the rapid spread of the disease. It is seen that the infection is rapidly spilling from populations with high-risk behavior to the general population and also from urban
to rural areas. Since there is no sure cure for the disease, its prevention becomes of paramount importance.

As of now, there are only four well-defined routes by which HIV is known to spread. These are through sexual intercourse with a HIV infected person, by exchange of infected blood and blood products as in transfusion, by sharing of contaminated needles/syringes and lastly transmission from an HIV infected mother to her child before, during or after childbirth. Although no culture and community is known to be immune to AIDS yet, certain populations are more vulnerable to the disease because of their high-risk behaviors.

There is a global reaction and response to HIV/AIDS advocating the importance of education, awareness generation and also for adopting ‘safe practices’ has connotations to safety in sexual acts and medical safety (against sharing of needles and syringes). Many millions know nothing or too little about the virus to protect themselves against it. Globally, low level of knowledge coupled with myths and misconceptions are driving the disease out of control. The spread of epidemic at large scale may damage the socio-cultural fabric of society. The study was designed to estimate the past trend of HIV/AIDS spread and to forecast the HIV/AIDS in India and U.P. The information about the patients was taken from the two district medical colleges that are S.N. Medical College, Agra and J.N. Medical College, Aligarh of Uttar Pradesh. In recent years, U.P like all other parts of the country has been facing a new menace to public health-HIV/AIDS. At present, the prevalence of this dreaded and incurable disease in the state is low, but
that how HIV began in all countries of the world where HIV prevalence is now at very high level. Although HIV prevalence is low here, it has made its presence felt in many districts of the state.

With a population of 166 million at the 2001 census approaching 188 million in 2007, U.P is India’s largest state in population and one of its fastest growing. While HIV prevalence is low at present, the National AIDS Control Organization (NACO) considers the state highly vulnerable. HIV spreads quietly in an unsuspecting population, as it has no immediate symptoms. Few infected people may suspect their condition so that they may, in turn, infect others.

**Uttar Pradesh’s Risk Factors of HIV/AIDS are as:-**

- High levels of Poverty
- Large presence of high-risk groups at targeted interventions
- Over 50,000 truckers on eight national highways
- Over 8,000 sex-workers
- A large migrant population
- Long, porous Indo-Nepal border
- Low, but rising, HIV/AIDS awareness among rural females
- Over 20% slum population in 69 cities and towns.

The study will explore the causative factors of HIV/AIDS along with socio-economic and psychological implications of disease on the patients, their families, and community as whole.
Objectives of the Study: Though the broad research objective of the present study was to throw light on the socio-psychological impact on HIV/AIDS patients attending in S.N.Medical College, Agra and J.N.Medical College, Aligarh, the specific objectives around which the present study was developed are:

- To explore the socio-economic background of the HIV/AIDS patients.
- To analyze and assess the HIV/AIDS prevalence rates among men and women.
- To examine the causative factors of HIV/AIDS.
- To study the role of family as an institution in the prevalence of HIV/AIDS.
- To assess the socio-psycho and economic implications of HIV/AIDS on the patients, patients families and community.
- To assess the mental agony of the HIV/AIDS patients.
- To analyze the patterns and trends of the HIV/AIDS prevalence rates in U.P.
- To evaluate the government’s efforts and strategies in combating the disease.
- To suggest the government for appropriate policy programme to address this issue in the light of the present study.

Research Procedure Followed: - Keeping in view the objectives of the study the diagnostic and descriptive research design was prepared and executed. The
various aspects of the research design pertained to the important demographic features of the universe/sample frame, sampling procedure, research tools, data administration procedures and other details. The present work has been designed from the diagnostic and descriptive perspectives to analyze the socio-psychological condition of HIV/AIDS patients. The present study is diagnostic in nature because it facilitates in exploring the real problem by identifying the real causes of the problem of HIV/AIDS patients. It is also descriptive in nature because it is a detailed account of HIV/AIDS and its affect on the society, family members and individuals psychologically, socially and economically.

Keeping in view the objectives of the study, the combined method of both quantitative and qualitative information was collected. A sample of 50 HIV/AIDS patients was selected from the S.N.Medical College, Agra and J.N.Medical College, Aligarh (25 patients from each medical colleges) out of the total HIV/AIDS patients registered in ART centers of these medical colleges during the years 2004 to 2008 for collecting information. These 50 HIV/AIDS patients were available and hence randomly selected for the purpose of the study. The structured interview schedule was to collect information from them. A part of this, 17 case studied have also been prepared to supplicate the quantitative information.
Findings:

The major findings of the research problem are as under:

- Data reveal that young males and females are vulnerable group and the potential future targets of HIV/AIDS and their average age is 31 years. The most of the patients fall in the age-group of 18 to 35 years (68% of Agra and 56% of Aligarh, Table No. 3.1).

- The HIV/AIDS prevalence rate is higher among the males (68% in Agra and 56% in Aligarh) than the females (see table 3.2).

- That the study reveals that the majority of the affected patients (68% in Agra and 72% in Aligarh) were illiterate (see table no. 3.3).

- That most of the HIV/AIDS patients were from poor families (48% in Agra and 36% in Aligarh). They are casual labourers (see table no. 3.4).

- It is also clear from the study that majority of the patients (64% of Agra and 72% of Aligarh) were from rural areas (see Table no 3.5).

- The study shows that most of the affected patients (80% in Agra and 64% in Aligarh) were married (see table no. 3.6).

- The study further explores that the causative factors of HIV/AIDS is unsafe sex with multiple partners (72% in Agra and 64% in Aligarh) (see Table no. 3.9).

- That the researcher explored that in most of the cases wives were found as a loyal partner of the infected husbands and family members can play
an important role to cope up with this dreadful disease (Case study no. 6 & 16).

- The socio-psycho and economic implications of HIV/AIDS it has been found that majority of the affected patients (Table No. 3.12) faces hated attitude from their neighbors, relative and indifferent behavior.

- That the study reveals that HIV/AIDS has not only had its psychological influence on the affected persons but family members including children, parents and other care-takers were also affected (Table No.3.14).

- While tracing the economic implications, the study illustrated that monthly income of all the respondents was badly affected after the diagnosis and disclosure of HIV positive status (36% of Agra and 28% of Aligarh, Table No. 3.13) reported a substantial decline in the income after diagnosis.

- To assess the mental agony of the HIV/AIDS patients, it was observed that (50% patients of Agra and 72% patients of Aligarh, 76% of Agra and 56% of Aligarh, 68% of Agra and 60% of Aligarh, 60% of Agra and 44% of Aligarh, 32% of Agra and 36% of Aligarh, 28% of Agra and 40% of Aligarh and 80% of Agra and 88% of Aligarh, Table No.3.16 and Table 3.17) suffered from anxiety, tension, depression, aggressiveness, regression, fixation and suicidal attempt.
Qualitative Analysis

The purpose of including case studies was not to give any statistical precision, but to give a feel about the life of the HIV/AIDS patients. Therefore, the case material is presented in a biographical form, which is quite revealing and self-explanatory. These individual case histories confirm our findings from quantitative analysis.

The conclusions one can draw from these cases are:-

- All the HIV/AIDS infected were from the working class, i.e. small laborers.
- Social rejection was considered as a big set-back to the patients.
- Majority of the patients never heard about the disease before it was diagnosed to them.
- Almost all the respondents belonged to a socially backward category of the society.
- Attitude of the educated people towards them was negative.
- Most of the respondents got the infection through unsafe sex with multiple partners.
- In most of the cases, wife was found as a loyal partner of the infected husbands.
- Most of the patients were economically poor as a result of which they were not able to purchase the casual medicine or consult a doctor.
- The doctor’s behavior towards these patients was not proper.
Hence, the most of the patients were distressed, feeling the sense of deprivation, lack of security and rejection.

**Findings of the Interviews with the Patients**

During the interviews, most respondents were found depressed, disappointed and in miserable conditions. They were regarding themselves as useless, ineffective and abandoned part of the society. Almost all the respondents were spending their lives desperately. Although most of the family members do not know the real status of the disease of patients but those who know they hated them. In-fact, all the respondents faces social, economic and psychological pressure.

The respondents were almost uneducated. They lacked information about health conditions and health care services. At the same time, they lacked the knowledge about this dreadful disease. They too had little knowledge about their rights and responsibilities in the context of HIV/AIDS. They do not know how to negotiate different situations concerning HIV/AIDS (whether to refuse unsafe and unwanted sex or not). They were not having a safe and supportive environment to express their feelings and emotions with. There was the loss of their family’s identity and affection. Besides, economic hardships and psycho-social distress were almost faced by all the respondents.

**Findings of the Discussion with Health Personals**

Some health-care providers were also interviewed to know their views about the spread of HIV/AIDS disease. The interview was conducted on two qualified
doctors’, two nursing staff, two laboratory staff and two blood bank staff from each ART Centre of S.N. Medical College, Agra and J.N. Medical College, Aligarh. It was observed that doctors and paramedical staff were not mentally prepared to handle HIV/AIDS patients. They were unwilling to treat them and were scare of them. Doctors and paramedical staffs were untrained and technically not fully trained to handle such patients. They were having fear in their mind while dealing with such patients in a proper manner.

Findings of the Families opinion of the Patients

No doubt, HIV/AIDS is a fatal disease but the stigma attached with this dreadful disease is more fatal than disease itself. Its implication destroys the intra-familial relationships resulting in hate and repulsion from ones’ own family members. The associated embarrassment, distrust, fear, blame and shame that the disease carries with itself result into irritating behavior of family members towards the patients. However, in some cases, only wife was considered as a most sincere and loyal to the patient from among the whole family.

Due to isolation and rejection faced by the patients from their family members and other members of their society, they were compelled to change their residences. The children of these patients were the most penalized members of the family who had to face a lot of psychological stress and strain from the surroundings. Their education was almost hindered; almost all the families of the patients suffered from economic crises very badly and at the same time, most of them were unable to meet their basic needs of life.
Suggestions:

The present study deals with the suggestions brought about for policy making and also with the programmatic actions based on the study’s principle, research findings and particularly on the choice available to the persons once they are diagnosed as HIV positive. It has been concluded that HIV/AIDS has and is adversely affecting the entire individual’s life and consequently the society.

For People Living with HIV/AIDS

- Provision of accurate and first-hand information about contraceptives, safe sex, risk of mother-to-child transmission, antiretroviral therapy, and the consequences of unsafe abortion are necessary for HIV positive women in order to plan about their pregnancy and childbearing.

- Increased accessibility of information to the pregnant women and couples planning for pregnancy regarding HIV/AIDS is needed. The preventive measures against mother-to-child transmission through breast feeding during neonatal period should be observed.

- To establish programs for the provision of accurate information about benefits and risks of disclosure that enable HIV positive persons to make informed choice regarding disclosing their HIV status.

For the General People

- Increased access of information related to safe sex, family planning, pregnancy and safe abortions as preventive measures for the general
population, including adolescents, the elderly and for people living with HIV/AIDS.

- Increased access to information on voluntary and confidential HIV testing and counseling for the general population should be made available.
- Undertaking innovative sex education programs and addressing gender issues among male and female adolescents and tied as well as married couples.

For Health care Providers

- Developing and implementing a firm policy regulation to ensure the confidentiality of HIV/AIDS patients among health care providers and other concerned staff as well.
- Provision of specialized training to medical and paramedical workforce in the treatment and care of HIV positive patients should be ensured.
- Provision of training programs to health workers for improving communicative skills (including body language) to increase awareness about the reproductive rights among the HIV positive persons will be an important strategy.

For work place

- Formulating regulations regarding the ethical treatment of HIV positive persons within business establishments (public and private sector) is recommended.
• Framing of policies regarding the provision of job security, employment benefits and post-retirement benefits to HIV positive persons in their lives as well as to care for their family members and other dependents after their death is advocated.

• Implementation of workplace policies for workers aimed at ensuring the confidentiality and right of HIV positive persons will be an encouraging step.

For the Government:-

• Formulation and implementation of legislation about preventive measures of HIV/AIDS and rights of HIV positive persons are advocated.

• Allocation and release of adequate funds for effective and comprehensive programmes against HIV/AIDS epidemic compatible to social and cultural demands are recommended.

• There is need to establish HIV/AIDS and IV Drug use task forces at federal and provincial levels.
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To Whom It May Concern

This is to certify that Miss. Seema Kumari has completed her doctoral thesis entitled “Socio- Psychological Study of HIV/AIDS Patients Attending S.N. Medical College, Agra and J. N. Medical College, Aligarh” under my supervision. This work is the original work of the researcher and is suitable for submission for the award of Ph.D. degree in Sociology.

(Prof. Noor Mohammad)
Supervisor

Residence : 4/1294-A, New Sir Syed Nagar, Aligarh-202002
Dedicated to

My SUPERVISOR
PROF. NOOR MOHAMMAD
&
THE SUFFERERS OF HIV/AIDS
ACKNOWLEDGMENTS

"In the name of God the most beneficent and merciful"

I bow in reverence to Almighty whose gracious blessing gave me required devotion for the completion of this work. I am grateful to God for bestowing on me the courage to carry out this research work.

When years of earnest research finally translate into a neatly written this, it is easy to take all the credit, and pat on self on the back for a gigantic task accomplished. The fact remains, however, that no work of such magnitude is possible without a whole network of support systems available to the research scholar. I consider myself both lucky and blessed to have been associated with people who went out of their way to lend me helping hand even before I asked for it. Though mere words are not sufficient, they are all I have to acknowledge, with deep gratitude, all the people whose names are mentioned here.

With immense pleasure and profound sense of gratitude, I take this opportunity to express my most sincere thanks to my supervisor Prof. Noor Mohammad, the Chairman, Department of Sociology & Social Work, A.M.U, Aligarh for his valuable guidance, constructive criticism, enlightening suggestion, congenial atmosphere and expert suggestions during the course of study, and of course, pain taking scrutiny at the later stage of work, all this with affection and kindness which helped me complete this onerous work. Because any doctoral work is conducted under the great pressure of time, resources and continuous supervision. The work can never reach to the logical conclusions unless the researcher is supported by friendly atmosphere and sharing moments. I feel very tempted in acknowledging that his knowledge, his insight and masterly control over the subject has left lasting impact on me and it will continue to influence
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From the core of my heart, I thank all my study participants for allowing me to tread and many a times intrude into their personal lives. Without their complete and honest involvement, this endeavour would not have been possible. I am indeed, indebted to them.

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Seema Kumari

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**List of Abbreviations**

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immuno Deficiency Syndrome</td>
</tr>
<tr>
<td>CDC</td>
<td>Centre for Disease Control and Prevention</td>
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<tr>
<td>CSW/s</td>
<td>Commercial Sex-Workers</td>
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<td>DMB</td>
<td>Department of Micro-biology</td>
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<td>EMS</td>
<td>Extramarital Sex</td>
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<td>HIV^-</td>
<td>HIV Negative</td>
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<td>HIV^+</td>
<td>HIV Positive</td>
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<tr>
<td>HIV</td>
<td>Human Immuno Deficiency Virus</td>
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<td>IDU</td>
<td>Injecting Drug User/s</td>
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<td>J.N.M.C</td>
<td>Jawaharlal Nehru Medical College</td>
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<tr>
<td>KABP</td>
<td>Knowledge, Attitude, Behavior &amp; Practices</td>
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<td>MTCT</td>
<td>Mother to Child Transmission</td>
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<td>NACO</td>
<td>National AIDS Control Organization</td>
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<td>NACP/s</td>
<td>National AIDS Control Programme/s</td>
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<td>PMS</td>
<td>Premarital Sex</td>
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<td>PLWHA</td>
<td>People Living With HIV/AIDS</td>
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<td>S.N.M.C</td>
<td>Sarojini Naidu Medical College</td>
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<td>STD</td>
<td>Sexually Transmitted Disease/s</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection/s</td>
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<tr>
<td>U.N</td>
<td>United Nations</td>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>UNDCP</td>
<td>United Nations International Drug Control Programme</td>
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<td>UNDP</td>
<td>United Nations development Fund</td>
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<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
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<td>UNFPA</td>
<td>United Nations Population Fund</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<td>USAID</td>
<td>United states Agency for International Development</td>
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<td>UTS</td>
<td>Union Territories</td>
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<td>WBC</td>
<td>White Blood Cells</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>ART</td>
<td>Antiretroviral Therapy</td>
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<td>Acronym</td>
<td>Description</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<td>AZT</td>
<td>Azidothymidine</td>
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<td>WB</td>
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<td>NGO/s</td>
<td>Non Government Organization/s</td>
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<td>UTA</td>
<td>Universities Talk AIDS</td>
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<td>SPPC</td>
<td>Strategic Plan for Prevention and Control</td>
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<tr>
<td>NAC</td>
<td>National AIDS Committee</td>
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<td>NACB</td>
<td>National AIDS Control Board</td>
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<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
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<td>Prevention Indicator</td>
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<tr>
<td>CBO/s</td>
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<td>IAVI</td>
<td>International AIDS Vaccine Initiative</td>
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<td>TRNS</td>
<td>Technical Resource Network</td>
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<td>CSM</td>
<td>Condom Social Marketing</td>
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<td>VD</td>
<td>Venereal Disease</td>
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<td>GRID</td>
<td>Gay Related Immune Disorder</td>
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<td>Lav</td>
<td>Lymphadenopathy Associated Virus</td>
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<tr>
<td>FDA</td>
<td>Food and Drug Administration</td>
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<tr>
<td>ANC</td>
<td>Antenatal Clinics</td>
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<td>Intra Venus Drug Users</td>
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<td>DNA</td>
<td>Deoxy-ribose nucleic acid</td>
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<td>RNA</td>
<td>Ribose nucleic acid</td>
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<td>RTIs</td>
<td>Reproductive Tract Infections</td>
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Chapter I
Introduction
CHAPTER I

INTRODUCTION

The unfolding epidemic a tale of courage as well as cowardice of compassion and bigotry of inspiration and redemption and despair" (Shift, 1987)

HIV/AIDS seems to pose an enormous challenge to human life and development; the repercussions of the epidemic are extreme, affecting all aspects of human society and organization. Over two-thirds of the world’s people living with HIV/AIDS are in India. In some communities a vicious cycle of deepening poverty and rising rates of infection is undermining past progress, in many regions of India more than a quarter of adults are living with HIV/AIDS.

Unlike most diseases HIV/AIDS also seems to affect the most economically productive sector of the population as well, healthy sexually active men and women of the world. The whole population of the world indeed because the epidemic is by no means confined to India. Globally, the epidemic is increasingly affecting younger people. Roughly half of all people living with HIV are aged 10 to 24 years (Webb, 2000). A question may arise as to what the meaning of HIV/AIDS is and its defining features?

1.1 What is HIV/AIDS?

Among the challenges of present era, Acquired immune deficiency syndrome (AIDS) is the leading enemy. This socio-medical problem has involved the whole globe breaking the boundaries of countries and continents. Electron microscopic virus of AIDS, called ‘Human Immune Deficiency Virus’ has already infected million of people and the incidence is increasing alarmingly in the world (Bryon, 1990). AIDS is not simply a medical problem but due to its associated
morbidity and mortality every aspect of individuals’ life is vulnerable to great damage (Morrison, 2002).

Human Immune deficiency virus (HIV) destroys the defense system of human body. As a result, even the minor least lethal ailments may prove fatal for infected person (walker et al, 1999). HIV infection may go unrecognized for many years as patients may remain symptom free for prolonged period. The initial symptom free state of the sufferer is called “Carrier state” as the person has AIDS virus in his/her blood and this is most dangerous phase in the disease process. Carriers, unknowingly and unintentionally, may transfer their virus to any healthy individual e.g. by donating blood.

A carrier of HIV may appear perfectly healthy and normal or one may suffer from minor negligible episodes of ill health, these minor episodes often go unrecognized except in high – risk population. Full blown AIDS is a late sequel of the disease process. Acquired Immune Deficiency syndrome (AIDS) as name explains is not a single disease but is a complex of many associated pathologies which are strongly associated with psychological and social disturbances. It may take on an average of seven to ten years for the development of full-blown AIDS. In spite of extensive medical research, there is no definite cure for AIDS yet. The available medication is just palliation to slow the speed of disease process and to improve the quality of life as much as possible.

The discovery of AIDS in early 1980’s and its global spread since then; have shaken the entire world (Gottlieb et al, 1981). Genetic detail of HIV indicates that it is probably more than a century old. HIV infected cases were less than 0.001% of the world population until the mid 1970’s. After 1970, the virus surged because of rapid social changes, African urbanization, globalization and flood of intravenous drug users in western country along with changing sexual practices accelerated the epidemic of HIV/AIDS in the world.

AIDS is characterized by the progressive loss of CD4 + helper/inducer cells are important subset of T.lymphocytes which perform vital function in the immune
system. AIDS is leading to serve immune suppression and constitutional disease, neurological complications, opportunistic infection and neoplasm that rarely occur in persons with intact healthy immune function (ACOG, 1992). Although the precise mechanism, leading to destruction of immune system has not been fully delineated, but abundant epidemiologic, virology and immunologic data support the conclusion that infection with the Human Immune Deficiency Virus (HIV) is the under lying cause of the AIDS.

HIV/AIDS has acquired the form of global epidemic. Responses to the HIV epidemic have increasingly focused global attention on dealing not only with the cause of the epidemic but also with its consequences of a development problem like the global AIDS epidemic has often been lacking in the past. However, keeping in view the spreading disaster of HIV, now the global strategy has changed towards dealing with the impact and consequences of a large number of infections, while at the same time trying to prevent or slow down the spread of this virus. As HIV is becoming a major cause of adult mortality in many countries, the effects of the epidemic are psychological, social, economic deterioration (World Bank. 1993a).

1.2 The Global Scenario of HIV/AIDS:

The latest statistics of the global HIV and AIDS were published by UNAIDS in November 2009, and refer to the end of 2008.

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<td>AIDS deaths in 2008</td>
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<td>Child AIDS deaths in 2008</td>
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More than 25 million people have died of AIDS since 1981.

Africa has over 14 million AIDS orphans.

At the end of 2008, women accounted for 50% of all adults living with HIV worldwide.

In developing and transitional countries, 9.5 million people are in immediate need of life-saving AIDS drugs; of these, only 4 million (42%) are receiving the drugs.

**Global trends**

![Graph showing the increase in people living with HIV from 1990 to 2008.](image)

**Fig.-1.1**

The number of people living with HIV has risen from around 8 million in 1990 to 33 million today, and is still growing. Around 67% of people living with HIV are in sub-Saharan Africa.
Table 1.2: Regional statistics for HIV & AIDS, end of 2008

<table>
<thead>
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<th>Region</th>
<th>Adults &amp; children living with HIV/AIDS</th>
<th>Adults &amp; children newly infected</th>
<th>Adult prevalence*</th>
<th>Deaths of adults &amp; children</th>
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<td>Sub-Saharan Africa</td>
<td>22.4 million</td>
<td>1.9 million</td>
<td>5.2%</td>
<td>1.4 million</td>
</tr>
<tr>
<td>North Africa &amp; Middle East</td>
<td>310,000</td>
<td>35,000</td>
<td>0.2%</td>
<td>20,000</td>
</tr>
<tr>
<td>South and South-East Asia</td>
<td>3.8 million</td>
<td>280,000</td>
<td>0.3%</td>
<td>270,000</td>
</tr>
<tr>
<td>East Asia</td>
<td>850,000</td>
<td>75,000</td>
<td>&lt;0.1%</td>
<td>59,000</td>
</tr>
<tr>
<td>Oceania</td>
<td>59,000</td>
<td>3900</td>
<td>0.3%</td>
<td>2,000</td>
</tr>
<tr>
<td>Latin America</td>
<td>2.0 million</td>
<td>170,000</td>
<td>0.6%</td>
<td>77,000</td>
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<tr>
<td>Caribbean</td>
<td>240,000</td>
<td>20,000</td>
<td>1.0%</td>
<td>12,000</td>
</tr>
<tr>
<td>Eastern Europe &amp; Central Asia</td>
<td>1.5 million</td>
<td>110,000</td>
<td>0.7%</td>
<td>87,000</td>
</tr>
<tr>
<td>North America</td>
<td>1.4 million</td>
<td>55,000</td>
<td>0.4%</td>
<td>25,000</td>
</tr>
<tr>
<td>Western &amp; Central Europe</td>
<td>850,000</td>
<td>30,000</td>
<td>0.3%</td>
<td>13,000</td>
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<tr>
<td>Global Total</td>
<td>33.4 million</td>
<td>2.7 million</td>
<td>0.8%</td>
<td>2.0 million</td>
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* Proportion of adults aged 15-49 who were living with HIV/AIDS

During 2008 more than two and a half million adults and children became infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS. By the end of the year, an estimated 33.4 million people worldwide were living with HIV/AIDS. The year also saw two million deaths from AIDS, despite recent improvements in access to antiretroviral treatment.

**Situation of HIV/AIDS in India/Uttar Pradesh**

India has a population of one billion, around half of whom are adults in the sexually active age group. The first AIDS case in India was detected in 1986, since then HIV infection has been reported in all states and union territories. The spread of HIV in India has been diverse, with much of India having a low rate of infection and the epidemic being most extreme in the southern half of the
country and in the far north – east. The highest HIV prevalence rates are found in Maharashtra, Andhra Pradesh and Karnataka in the South, and Manipur, Mizoram and Nagaland in the north – east (NACO, 2007).

Four southern states, (Andhra Pradesh, Maharashtra, Tamil Nadu and Karnataka) account for around 63% of all people living with HIV in India. (NACO, 2007).

In the southern states, HIV is primarily spread through heterosexual contacts, whereas infections are mainly found amongst injected drug users and sex workers in the north- east.

<table>
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<tr>
<th>People living with HIV/AIDS</th>
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<td>Adults (15 years or above) HIV Prevalence</td>
<td>0.3%</td>
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In India around 5.7 million people were living with HIV in India more than in any other country.

**HIV/AIDS in Uttar Pradesh (U.P):** - In recent years, U.P like all other parts of the country has been facing a new menace to public health-HIV/AIDS. At present, the prevalence of this dreaded and incurable disease in the state is low, but that how HIV began in all countries of the world where HIV prevalence is now at very high level. Although HIV prevalence is low here, it has made its presence felt in many districts of the state.

With a population of 166 million at the 2001 census approaching 188 million in 2007, U.P is India’s largest state in population and one of its fastest growing. While HIV prevalence is low at present, the National AIDS Control Organization (NACO) considers the state highly vulnerable. HIV spreads quietly in an unsuspecting population, as it has no immediate symptoms. Few infected people may suspect their condition so that they may, in turn, infect others.

Part of U.P’s vulnerability lies in a population where illiteracy is still widespread despite improving educational levels. In 2001 census, 31% of males
and 58% of females were listed as illiterate. The state is also a major crossroads for commercial traffic, one way HIV is known to spread. With nearly 80% of its population living in rural areas, reaching people with essential HIV information is a difficult task. A low level of HIV prevalence presents both an opportunity and a danger. The opportunity to arrest its spread is here today, the danger is that its quiet nature will expand its devastation tomorrow.

**Uttar Pradesh’s Risk Factors**

- High levels of Poverty
- Large presence of high-risk groups at targeted interventions
- Over 50,000 truckers on eight national highways
- Over 8,000 sex-workers
- A large migrant population
- Long, porous Indo-Nepal border
- Low, but rising, HIV/AIDS awareness among rural females
- Over 20% slum population in 69 cities and towns.

The district-wise pattern of HIV infection provides a clear indication of how the disease is spreading. District level “hotspots” show that HIV moved throughout the state and suggest how it could expand in the future. The map (1.1) on this page shows the percentage of patients at sexually-transmitted disease (STD) clinics that tested positive for HIV infection. HIV typically begins among high-risk groups such as patients in STD clinics. When five percent or more of STD patients test positive for HIV, NACO considers an area to be moderate HIV prevalence. The map shows that HIV infection was found in STD clinics in nearly every district of Uttar Pradesh where patients were tested. This often signals the possible advance of HIV towards higher prevalence—moving quietly into the population as a whole.
The map (1.2) shows the percentage of pregnant women who tested positive for HIV infection at antenatal clinics (ANC). When one percent or more of the ANC women test positive for HIV and five percent or more of patients at STD clinics also test positive, then NACO considers the area to be of high HIV prevalence. Women at ANC clinics are considered to be of low-risk of HIV since they are assumed not to engage in high-risk sexual behaviour. As such, they provide an indication of the population as a whole.
These both maps suggest that HIV infection is higher in eastern Uttar Pradesh, possibly due to its higher migrant population, and is spreading westward.

In the above figure (1.2) we are able to understand the incensement of HIV/AIDS cases. The above table shows the record of last 17 years from 1992-2008. In the year 1992 there were 99 cases of HIV/AIDS but after the 15 years there were 9440 cases of HIV/AIDS. Through this record we can easily conclude that in spite of the governmental policies and programmes for awareness about the HIV/AIDS cases, this dreaded disease is increasing continuously. But in the year 2008 there are fewer cases of HIV/AIDS in comparison to 2007. But the battle against the HIV/AIDS is still going on but we can’t reach to any final conclusion.
1.3 Origin of HIV/AIDS: There are a number of perspectives. Some of the perspectives are being highlighted here:

**Theory 1: Old Human Disease:**

The first theory is that HIV has been around mankind for a very long period and has recently become more virulent. One possibility is that the virus comes from a small and isolated ethnic group, which had acquired immunity to it, so that it has rarely caused death. When it spread outside this group, and reached people who had no such immunity, it became a killer disease.

This theory states that diseases common in one part of the world, when carried to “virgin” territory have often proved a mortal danger to the newly exposed population. European diseases, such as measles and smallpox, virtually wiped out some North American Indians in the eighteenth and nineteenth centuries. This theory is important for a key reason. If this was the origin of HIV, then the isolated groups’ immunity might enable a vaccine to be developed to protect the rest of the world.

There are few completely isolated people left in the world, mainly in the rain forests of New Guinea, Amazon, and perhaps Central Africa. In fact we have in India the nearly extinct Great Andamanese, a tribe having only 35 members according to the 1991 census. Since one of the early locations of AIDS was Central Africa, much speculation was focused on this possibility. By its nature, this is a theory that is very difficult to disprove, but there is some evidence which argues against it (Renee, 1988).
Chapter - 1

Theory 2: Animal Disease:

The second theory is that HIV has existed for a long time as an animal disease, and has only recently managed to infect and trigger off epidemic in humans. There are other examples of diseases “crossing over” from an animal to mankind, and since a rather similar virus has been found in a species of monkey, this possibility has received considerable attention.

History has recorded many great human disease epidemics, which have been traced back to infectious organism carried by animals or insects. It is a fact, that domestic and wild animals can harbour germs which, can be passed on from person to person independent of the original animals source. Like the malaria parasite, in many cases the human host is essential to the life –cycle of the infective organism. It can also be that the human may be an accidental host, contracting the infection from an animal in rare or unusual circumstances, sometimes with the result that the ensuring disease is more severe in the human than it was in the original hosts.

Since AIDS is a sexually transmitted disease, the theory that is originated among monkeys has in some cases given rise to the idea that the original transmission from monkey to human was via sexual relationship. Recent molecular epidemiological data has indicated that HIV virus has evolved from the Pan troglodytes sub species of the chimpanzees. It was present in that species for centuries. It is remarkably similar to a virus known as Simian immuno deficiency which is endemic among monkeys. If the virus was present among the chimps and monkeys how did it enter the human beings?

The most likely explanation is found in the cultural practices of the in Central Africa. Chimpanzees have traditionally served as a source of
food to certain people in sub-Saharan Africa. A person may have been infected with the virus during the process of butchering the chimps; he may have had an open wound. The wound may have been contaminated by chimp's blood. Intermittently this type of contact would have occurred throughout the centuries.

The disease was introduced in United States probably through blood and it spread to other parts of the globe through migration of people as well as prevalent sexual practices of the Gays. The gay revolution of 1969 with high risk homosexual practices was one of the perfect settings for the spread of the infection (Thomas, 1995).

**Theory 3: Man-Made Virus:**

The third theory is that of a man-made virus, perhaps from a germ warfare laboratory. Unlike the first two, this is not a scientific theory posed in terms which are open to experimental confirmation. Rather it has been propagated like a campaign with different versions picked up and reported in various newspapers and magazines around the world.

The other theory is that it may be due to contaminated or mutated vaccines that were developed against polio virus. There are no accepted proofs for this theory. According to Renee Sabatier, like all conspiracy theories AIDS as germ warfare is impossible to disprove, but it does seem improbable. The first argument against it is that Genetic Engineering was not sufficiently advanced to developed such a man made virus at the time first appeared. The AIDS virus must have been in existence several years before 1980, when widespread cases of AIDS started to appear in US hospital. If one accepts the evidence for AIDS cases as early as 1959, it must have been in existence since the mid 1950s. Virologists are emphatic
that even if such a virus could be developed today, the science of genetic
engineering was not sufficiently advanced in the late 1970s, for this to be
possible.

The second argument is that a virus like HIV is not the sort of bug a
germs warfare laboratory would wish to develop. There is no point in
developing a virus as a weapon unless one’s own side can be protected
against it. The ideal germ warfare organism would be one that caused
disease very quickly that did not spread by itself but only infected those
deliberately infected with it, and for which there was vaccine to be used to
protect one’s own side. The HIV differs from this in every respect. Few if
any, virologists take seriously the theory that HIV is the result of a
scientific conspiracy. So far, there is no substantive evidence whatever that
this is where AIDS came from, while there are number of convincing
arguments that this origin is unlikely (Thomas, 1997).

Theory 4: Mutation Theory:-

Theories and counter arguments to find the origin of HIV/AIDS is
less important that to understand where HIV/AIDS is going. The fourth
theory is called the “mutation theory”. According to this theory, viruses are
continually changing and mutating into new strains. It is possible that a
mutation took place in a virus, which produced a new virus with the deadly
properties of HIV. As reported earlier, the first recorded cases for the
traces of HIV infection were from North America (1969), and Zaire
(1959). However it is possible that there were other cases of HIV/AIDS in
other countries of which we have no knowledge. With increased migration,
market economy, liberalization and expansion of global tourism industry,
lot of travel has taken place among people within and outside the country
since 1950s. This has increased interaction among people. Thus, it is easy
for disease to cross over from one person/community to another. It was believed that HIV was a virus that had undergone mutation or it was produced by recombination of the viral particles. Since the oldest sample was obtained from Africa, it was postulated that it began in Africa and then spread to rest of the world. This theory was not accepted. More sensitive tests showed that this theory was not acceptable. With all these theories to the background, the struggles to find a cure for HIV/AIDS continue globally (Randy, 1987).

Basically these four theories discussed above have been highlighted in various studies. My study is socio-psychological study of HIV/AIDS patients and it has been discussed by various studies conducted on HIV/AIDS so far. Hence the reviews of literature discussed accordingly and are being given here.

1.4 Empirical Evidence of Literature Review:

Although an HIV/AIDS epidemic is a relatively new phenomenon, substantial and committed efforts are needed to explore the epidemic of HIV/AIDS. But still, there are some studies and research work going on especially in the developing countries like India in Uttar Pradesh (Agra and Aligarh). Although in developed world, HIV/AIDS has been recognized as hot issue in the form of Plague of present time, but in countries of third world where current status of HIV/AIDS is of low prevalence high risk; this volcano is still covered with ice of ignorance.

Review of literature is an essential and preliminary step for any kind of research – be it social or scientific. It, allows a researcher to build theoretical as well as empirical foundations against the back drop of which the objectives of the study find adequate justification. It helps in limiting and designing research for the problem under study. It is a complete
misnomer to assume that after selecting a problem one should rush headlong into planning and carrying out the strategies for study before making a thorough survey of related literature. One must find and relate the area of enquiry with that of existing body of knowledge for purpose of theorization studies are not supposed to be reviewed merely in terms of summaries, but have to be critically appraised, assessed and evaluated.

In the light of the above arguments regarding the importance and inevitability of review of literature, it can be argued that a review of the subject under study is indispensable. Considering the fact that it helps in discerning a theoretical framework as well as in analyzing, interpreting the data in the present study.

Ratzan (1993) in his book AIDS: Effective Health Communication for the 90's, has laid out the framework for effective health communication through an effective campaign of prevention message and strategies that are targeted at those evidences which are in the greatest need. An important aspect that has been neglected involves those individuals with impaired communication ability. Often they are ignored and the effective communication is needed for those individuals. Education is vital for breaking the viscous circle of HIV spread as it has observed in the study that general population especially of rural areas is not well aware of the nature and severity of the HIV/AIDS epidemic. They in general think that this is the disease of foreigners and they are spared of this lethal disease because of their religious, moral and social norms and life-style. Effective communication has to be maintained for getting rid of this epidemic. Due to rapidly growing HIV infected population there is intense need of attention of educators, counselors, physicians and health, care providers as viewed Ratzan.
Edgar at el (1992) has mentioned in their essay, *AIDS: A communication perspective*; that individuals will take necessary actions for prevention only when

a) They are properly informed and

b) They feel motivated to respond to the information they possess.

The communicating about HIV/AIDS is a continuous process because slowing the information for only a fraction result is individuals falling back into their old ways of unsafe sex. Edgar stressed on prevention, health risk communication, health behavior, safe – sex; condoms and education for avoiding the lethal disease.

As is clear from the study there is very limited knowledge about HIV/AIDS in Indian society including with Aligarh and Agra in Uttar Pradesh, people have no concept of safe sex, and most of population does not use condoms those who use them only for avoiding pregnancy. There is a considerable high risk population in the society which is endangering the life of others associated people because of their ignorance and negligence about the disease.

Muir (1991) has addressed the issue of education and information of specific groups of individuals: general public homosexual and bisexual males, injection during users, adolescent and street youths, women, minorities and special needs groups. He focused on HIV prevention, particularly interventions involving education and information to the targeted groups. Among the at risk population; a special group is of women who sometimes directly and indirectly are vulnerable to HIV infection. AIDS as it affects women has only recently gained attention. In the United kingdom, the Scottish women and HIV/AIDS Network is the major group
that is trying to educate the young women in their teens, since 40 percent of the AIDS cases among women in the UK are belonged to age group of 15-29 years and this group is the most resistant to adopt safe sex guidelines and measures.

Judy Bury et al (1992) said that although women with AIDS are relatively not in large number, their needs are special, especially if they are pregnant. Education directed at those who are positive and at greatest risk of getting pregnant is extremely important and needs to be developed in such a way that the women will understand how important it is. The female constitute 49% of total population, and share a great risk of developing HIV/AIDS, as females are with added risk of un-education, social deprivation and discrimination.

The prevalence of HIV infection in Asia on the rise but for variety of reasons, the government and health care authorities of Asian countries have for several years, been underestimating the statistics and diverting attention away from this crisis.

Bonacci (1992) has examined the religious, cultural, social and economic reasons for the official suppression of the alarming data on HIV infection in Asia. He has discussed the religious and cultural barriers to some of the educational attempts including the religious prohibition against contraceptives and the cultural barriers in talking about safer sex techniques. This goes in comparison with study findings which show that religion is wrongly perceived regarding the issues of the contraceptive, safer sex and sex in general. To get through this supposed barrier is a critical problem for all of those working in the field of AIDS especially in the region where general public is not willing and hesitant to talk about such issue like AIDS publicly.
The relationship between sexually transmitted diseases, unsafe sex and AIDS has been established. McCauslin (1992) said that education about safe sex and awareness about STDs is lacking. There are very limited numbers of health care providers who are particularly interested in the treatment of STDs, more over the patients are reluctant in the treatment from authorized personal due to stigmas associated with STDs and AIDS.

Elizabeth (1995) said that it was estimated in 1995 that by the year 2000, ninety percent of all new infections will occur in developing countries.

HIV/AIDS affects each and every aspects of individual’s life. Weeks (1995) proposed an ethics of love founded on four principles: Care, responsibility, respect and knowledge in case HIV/AIDS, keeping a positive outlook has proven to be more beneficial than some drugs indicating the importance of social aspects in addressing the issue of HIV/AIDS.

Brien (1995) described the successes and positive strategies those living with HIV employ to promote survival and positive quality of life. What is needed is to give courage and stamina to those who are positive so that they can lead lives more productively and excitingly.

Gonzales (1996) said that HIV does not care whether a person is heterosexual, a homosexual, bisexual or celibate (having no sex at all). It does not see whether a person is black or white, male or female, young or old. It does not ask a person’s financial status, moral beliefs or career path. The fact is HIV simply invades any body. It can reproduce itself, and eventually kills. Gonzales said that AIDS has touched thousands of individuals, some unknown and some well known. It has touched artists,
athletes, scientists, writers, musicians, activists and doctors. It has been observed in the study that the sufferer of AIDS belonged to almost every field of life of every social status.

Among the routes of spread of HIV/AIDS, unsafe sex is one and transfusion of unscreened blood is another major route. Like Indian society U.P. (Agra and Aligarh) became infected with HIV through unsafe blood transfusion is still a major concern in most developing countries and states, even though the blood banks claim one in a million chance of infection since 1985. Jenner et al. (1995) has mentioned in their study that prior to 1985, it is estimated that some 25,000 American contracted HIV from blood transfusions with most of those being hemophiliacs. The researcher discussed liability of blood banks, hospitals, physicians and factor concentrate manufacturers for transmission of HIV. There are predicted to be many new blood-borne infectious diseases in the future, so having a safe blood is extremely important.

Roth (1998) said that the high risk population women are facing the increasingly serious threat of HIV/AIDS. According to Roth, females are the depressive segment of the community and having almost no rights to refuse unsafe sex in developing countries.

Gorna (1996) in his book “vamps, virgins and victims: how can women fight against AIDS”?, as focused on various burning issues like the epidemiology of AIDS and women, the psychosocial impacts of AIDS on women, the ways in which women’s sexualities are understood including economics of risk, sex for hire, marriage and sexual violence. All these issues are equally important as far as Indian society/U.P is concerned. It has been noted that women in Indian society/U.P (Agra and Aligarh) are the main target of discrimination and stigma associated with
AIDS. They are thought to be responsible for deeds of their male partner. They are being socially exploited by male dominant society. Even in marital sexual relationship they are not giving the courage to say "No".

Campbell (1999) emphasized many facts why women are so vulnerable to become HIV positive. Women do not have control over condom use, gender roles and gender power put women at risk because men are overpowering in developing societies like India and men's behaviour that is formed during adolescence increases women's risk for AIDS.

As far as males are concerned, they face the social stigma and discrimination mainly outside their homes, mostly at their working places. When a male is identified as HIV positive ended up in unemployment, economic instability and financial deprivation. Businesses and trade people still have to be re-educated in order to understand what it means to be infected with AIDS virus and HIV/AIDS prevention strategies.

Christie (1995) has emphasized that as AIDS moves to become a chronic disease, and as people become more comfortable working with those who are infected, the better off this world will be.

Prevention the spread of AIDS is one of the most formidable and important challenges humanity has ever faced. Opinion among health care professionals, laypersons, religious leaders and gay rights activists on how to deal with this problems, ranging from mandatory AIDS testing to sexual abstinence to the implementation of programs to make high risk behaviour safer. Leone (1997) said that responding to the control and prevention of AIDS especially in third world countries like India is very important.
Tulloch et al (1997) said that role of print and electronic media is very important in the prevention and control of HIV/AIDS. Television is a cultural product and it is through television that awareness can be created.

Jaccornord (1998) stated that how print media can play an important part in the prevention and control of HIV/AIDS. This is through television that awareness against HIV/AIDS can be effectively produced and raised in the society where literary rate is very low. In societies like India/U.P. (Agra and Aligarh) that print, electronic media can help to educate population, in the context of HIV/AIDS prevention. Interpersonal channels have been also proven successful to address the issue of HIV/AIDS.

HIV infection has brought about many changes in the psychological response over the last 15 years. From the start of the epidemic, efforts have been made to bring together the medical, psychological and social dimensions of HIV, in some ways providing a model for other medical diseases and for psychological interventions. Catulan, et al (1997) has looked into all areas of the psychological aspects of HIV infection and identified the psychological, social and economic implications of HIV/AIDS on individuals, community and nation.

Hunts (1998) said that death is always in the back of an individual’s mind when AIDS is mentioned. There is hope for more and more people who are HIV positive to live more. New drug treatments have extended life expectancy beyond what was ever thought to be not possible. Unfortunately, there are many for which the drug treatments are not as successful, resulting in premature death.
M. Rajamanickam (2006) makes a study of HIV/AIDS in context of psycho-social. He tracing the origin and spread of this deadliest disease across the world. He also critically analyses pre-and post-psyche of AIDS patients with special emphasis on faulty sexual exercise- co- marital sex swinging, sexual sadism, sexual masochism, pedophilia and homosexuality.

According to him, human sexual activity is not new in its function. It was on going on right from the time when man was born in this world. There were sex diseases like the venereal disease, (VD); syphilis and Gonorrhea. Millions of men died of these diseases and man was able to conquer these diseases by discovering suitable medicines and methods of treatment. This disease, the HIV/AIDS cannot be said as absolutely new in origin. The editor in his book talked about a very useful purpose among all sections of the people in our country about HIV/AIDS.

Catz et.al (2002) conducted a study on the psychological distress among minority and low-income women living with HIV. Greater anxiety and depression symptoms were associated with women who reported higher stress, using fewer active coping strategies and perceiving less social support.

Gil et.al (1998) studied psychological adjustment and suicidal ideation in patients with AIDS. The study examined the relationship between adjustment and psychosocial and medical variable in 91 HIV infected patients. In patients with a diagnosis of AIDS, the number of psychological symptoms and the satisfaction with the social support received were clear predicates of poor medical adjustment.
Grassi et.al (1999) conducted a study on illness behavior, emotional stress and psychosocial factors among symptomatic HIV infected patients. A self-report questionnaire was completed by 73 asymptomatic HIV+ outpatients. Psychological morbidity was associated with a pattern of illness behavior characterized by conviction of disease progression, irritability, dysphoria, psychological perception of illness and low denial level. Individual capacity to express emotions, adequate levels of social support and low level depression as well as clinical variables influenced more adaptive illness behavior. Psychological stress and low CD4+ cells count was the main predictors of the effective dimension of illness behavior.

Pozzi et.al (1999) examined the psychological discomfort and mental illness in patients with AIDS. It was found that female patients showed an increased prevalence of anxiety and depressive disorders.

Hackman et.al (2002) conducted a study on psychological symptoms, among 50 years of age and older patients living with HIV disease. 25% of respondents reported moderate or severe levels of depression. A hierarchical multiple regression analysis revealed that HIV infected older adults who endorsed more psychological symptoms also reported more HIV related life stressor burden less support from friends and reduced access to health care and social services due to AIDS related stigma.

Hayasi and Fukunishi (1997) examined what kinds of social support are related to mood states in a sample of 50 HIV+ patients without AIDS. In the early stage of HIV infection, HIV+ patients without AIDS may be prone to depressive symptoms. The depressive symptoms were not significantly related to lack of ordinary social support such as friends and
family but were significantly associated with dissatisfaction with HIV/AIDS related medical support.

**Mc Crough (1990)** conducted a study on assessing social support of people with AIDS. Results indicate that social support has a direct effect on health, buffers the effect of physical and emotional stress and mediates immune dysfunction. Although nurses frequently incorporate social support needs during patients’ assessment, it may not be specific or systematic. Assessment of social support for the person with AIDS is important because of the devastating psychosocial consequences of the disease.

The above literature reviews which highlight the socio and psychological behaviours of PLWHA. Here I am highlighting its implications on HIV/AIDS patients socially, economically and psychologically. Since my study is related to these three dimensions and I will follow these perspectives. This is being explained here how my study is different from other earlier studies.

1.5 **Implications of HIV/AIDS:**

The risk factors of HIV/AIDS and its mode of transmission are the principal determinants of its impact on society. HIV/AIDS affects the population in a number of ways. There will be increased morbidity and many of these people will be in their reproductive years. This could reduce fertility rates. The impact can be divided into three broad areas namely:

- Social Implications
- Economic Implications
- Psychological Implications
These implications are represented by the following diagram and my frame of research work is represented in the following way (Tri-Fold Implications of HIV/AIDS), as follows

**Fig. 1.3 Tri-Fold Implications of HIV/AIDS**
1.5.1 Social Implications

Stigma and discrimination is one of the basic problems that a person has to face after being identified as an HIV positive. The discrimination starts from the laboratory, and then doctors and other medical staff treat these persons as untouchables. This discrimination extends to family members and the among social sector.

The social implications of HIV infection will result from the illness and death of individuals and the consequent effect on the family, community and broader society. Obviously, it is also vital to observe who falls ill and dies in terms of their role in the family and community. The death of an adult male, who is an income earner, will affect the family’s access to resources. The people who fall ill and die are the parents and leaders in society, which means a generation of children, may grow up without the care and role models they would normally have. The death of an adult female may result in children receiving less care and females being taken out of school. A few attempts have been made to look at this at community level, but research is very limited.

There are no recent models for a community disaster of this magnitude and universality to help one predict the effects on morale and behavior to be expected from deaths of young adults, from urgent need to change sexual behavior in ways which threaten self-esteem, and from stress of living the threat of premature deaths (Piot, P., careal, M.). Societies at large will be affected and the forces behind behavior change will have to emerge from the society itself. Since this disease requires behavior modification at the personal level, the general incentive for the same would manifest from social custom and family attitudes. This approach is justified, given that the social milieu from where the HIV patient belongs plays an important role in his thought process, attitude and behavior. Health care establishments have to adopt strategies for change keeping in mind, the social customs and traditions. The responsibility of health care personnel is not only to develop heightened awareness of personal responsibility for stopping the spread of
AIDS but also of increasing public tolerance and understanding of those directly affected.

Patterns of family formations and sexual permissiveness vary widely from one country and one ethnic group to another. Moreover, as a result of acculturation, westernization, new economic networks, social mobility and population heterogeneity, cities contrast not only with rural areas but also with one-another, form traditional to most cosmopolitan.

As AIDS predominantly affects young adults’- people in their late twenties, thirties and forties- care taking responsibilities are often thrust upon the elderly parents in their sixties and seventies. In our culture, the usual adult role is assisting and caring for elderly parents. The necessity for this role reversal tends to create additional stress. The guilt in the situation is not only with the person who has tested seropositive but is also evident as parents blaming themselves for the situation, agonizing whether they played a role in their child’s homosexuality or sexual promiscuity. There is also an assumed natural order or life, and parents do not expect their children to die before them. The personality of an individual pre-determines how he or she will respond to illness. People who are independent and grasped initiatives before becoming ill continue to strive for independence afterward.

People with HIV/AIDS are forced to make many difficult psychological and social adjustments. They are faced to painful illness and treatment, possible loss of job and income, loss of independence and a reassessment of social and personal needs. Relationships change, some become strained, and others develop into deep, supportive, meaningful ties. It is essential that patients, families and friends avail themselves of the psychological and social support of the community (Lehman Virginia and Russell Noreen, 1998).

Never before, in the history of any disease, has the need to encourage and foster the co-operation and active participation of broad sectors of population been as evident as in the case of HIV/AIDS. Understanding human behavior in order to
modify it for the sake of health has become a global challenge (Carbello Manuel and Bayer Ronald, 1990).

1.5.2 Economic Implications:

At the household level the effects of HIV infection are obvious; the cost of medical care and related areas will increase. In addition, if the infected person is an adult, then production and income of the household will be reduced. It is not easy for a common person to get treatment of HIV/AIDS, it cost him/her a lot and if a person is the only earning hand, it is always difficult to survive. In addition, poverty pushes some women into risky behavior or dangerous situations. With no other options in sight; they may resort to sex work to feed their families.

The epidemic many also affect national economy through the illness and death of producers and the diversion of resources from savings to care. The impact of the epidemic will be felt first and worst with reference to GDP per capita and includes aspects such as longevity, standard of living, infant, child and maternal mortality and distribution of income.

HIV/AIDS has profound effects on individuals and the society. Several researchers have measured the social impact of HIV/AIDS at the individual, family and community levels in terms of socio-demographic indices, morbidity and mortality. The way the impact is measured helps in shaping the public response to the HIV/AIDS problem.

In the case of HIV/AIDS, there is no similar pressure to mount a strong public health campaign at an early stage because the disease remains invisible for many years. During this time, the infection has succeeded in spreading throughout the population. When action is finally launched, the epidemic has reached the AIDS stage and it is usually too late to avoid its economic and development impacts, as cited in this diagram below (figure 1.4). Through this figure we can easily understand how HIV/AIDS affect households and leading different aspects.
Many social and economic determinants such as poverty and societal marginalization render groups of individuals and their families susceptible and vulnerable to HIV infection. Dramatic economic change in India over the past several decades, for example, have left some households more exposed to the impact of HIV/AIDS than others. Female and elderly headed households are likewise least able to cope with the economic, labour and social losses arising from HIV/AIDS.

Table 1.3 illustrates the possible pathways of HIV/AIDS impact on families and communities. The first and greatest impact is at the level of individual and households. Whiteside (2002) rightly makes the observation that ‘macro economic impact takes longer to evolve and the scale and magnitude of macro-impact will depend on the scale and location of micro level impacts.

Fig. 1.4 The impact of HIV/AIDS on development
### Impact of HIV/AIDS at the household levels

<table>
<thead>
<tr>
<th>Production and earnings</th>
<th>Investment and consumption</th>
<th>Household health and consumption</th>
<th>Psycho-Social costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced income</td>
<td>Medical costs</td>
<td>Health maintenance activities reduced</td>
<td>Loss of individual motivation</td>
</tr>
<tr>
<td>Reduced Productivity</td>
<td>Funeral costs</td>
<td>Loss of individual motivation</td>
<td>Grief of survivors</td>
</tr>
<tr>
<td>Reduced labour use of land</td>
<td>Legal fees loss of savings, change in consumption and investment</td>
<td>Loss of deceased poor health of survivors Dissolution of household</td>
<td></td>
</tr>
</tbody>
</table>

**Table 1.3 Source:** (Donahue, 1998)

### 1.5.3 Psychological Implications:

An HIV positive person has to go through intense mental pressure, after being identified as an infected person. One becomes easy victim of tension, fatigue and isolation which leads towards frustration and even to commit suicide. Widows in Agra and Aligarh (U.P.) are exceptionally disadvantaged, as culturally they tend to be regarded as having very low status in household. A woman whose husband has died in the first year of marriage may be regarded as particularly unlucky. Women widowed by HIV and AIDS are doubly marginalized as a result of stigma. They may be thrown out of their homes or sent back to their parent’s homes without their Istridhan (dowry or jewellery) in the abnormal state of mind. They are poorly equipped to counsel children in this way. Children become depressive and frightened all the time. Resultantly, they run away from schools and indulge in crimes and beggary. These psychic children become the spoiled kids of the community and usually involved in drug trafficking.
Children in HIV/AIDS affected household begin to suffer even before a parent or caregiver has died. Household income plummets, schooling is often interrupted and many children are forced to drop out either to care for a sick percent or to earn money. Depression and alienation are common. Another working phenomenon is the emergence of child headed household with parents gone, children have to take on the responsibility of earning money. Looking after younger siblings and running households. The threats and challenges these children face is compounded by the emotional trauma of losing parents and stigma, associated with the disease, which marks them out as a new class of untouchables. In figure 1.5 we can easily understand the problem of children and their families from which they are suffering and can suffer in their own future.

Fig. 1.5 Problems among children and families affected by HIV/AIDS
"Human kind can not bear very much reality" (Eliot, T.S.) and the reality of our situation is harsh. HIV/AIDS is one of the several problems simultaneously facing the developing world, which compete for community action. It is a mistake to view the AIDS pandemic as a purely medical phenomenon. AIDS is primarily a social phenomenon with urgent and consuming medical issues attached (Silverman, D., Perakyla A., Bore, R.).

1.6 Socio Psychological Aspects of HIV Infected Patients:

Common response to the diagnosis of HIV infection reflects stigma associated with drug abuse, sexual promiscuity and society’s preconceived fears. Familiar patient reactions are shock, withdrawal, despair, and acute high level anxiety, depressive reactions, and anger, guilt, avoidance and denial. These are usually expected in the context of a preconceived ‘death sentence’ and should perhaps be characterized as manifestations of ‘situational distress’ or ‘adjustment reactions’ (Winston, J.A., 1995). In the Indian context particularly, the HIV infected person strongly fears the social denial. Other major problems faced by HIV patients in India (Agra and Aligarh) are:

- Identity crisis,
- Denial of health care,
- Low self – esteem,
- Guilt feeling,
- Family disintegration (Gracious Thomas, 1994). Psychological disturbance seen in the period after the ‘bad news’ about HIV is delivered will reflect twin prominent faces of patient concern,
- Fear for the future and actual course of the disease, and
- Fear of the reaction of others.

Tables 1.4 and 1.5 depict the acute socio-psyche phenomenon associated with HIV infection and disease and common AIDS related patient anxieties.
Table 1.4: Acute Socio-Psycho Phenomena Associated with HIV infection and Disease.

**Shock**
- Of diagnosis and possible death
- Over loss of hopes for good news

**Fear and Anxiety**
- Uncertain prognosis and course of illness
- Of disfigurement and disability
- Effects of medication and treatment
- Of isolation and abandonment and social/sexual rejection
- Of infecting others and being infected by them
- Of lover’s ability to cope and their possible illness
- Of loss of cognitive, physical, social and work abilities

**Depression**
- Over inability to overcome the virus
- Over new and voluntary health/lifestyle restrictions
- At being ‘caught out’ and the uncertainty of the future

**Guilt**
- Over post ‘misdemeanours’ resulting in illness ‘punishment’
- Over possibility having infected other
- Over being homosexual or drug user

**Obsessive Disorders**
- Relentless searching for new diagnostic evidence on body
- Faddism over health and diet
- Preoccupation with death and decline and avoidance of new infections
Table 1.5: Common AIDS Related Patient Anxieties

- Prognosis in the short and the long term
- Infection risk to and from other people
- Social, occupational, domestic and sexual hostility and rejection
- Abandonment, isolation and physical pain
- Inability to alter circumstances
- How to maximize future health
- Ability of lover/family/partner to cope
- Availability of appropriate medical/dental treatment
- Being identified as homosexual/drug abuse/prostitute etc.
- Loss of privacy, confidentiality
- Future social and sexual unacceptability
- Declining ability to cope
- Loss of physical and financial independence

Each of these issues identified in Table 1.5 is significant for the pervasive distress they may create and in terms of their being manageable to some extent by sensitive and relevant provision of information and socio psycho- intervention. Despite the negative connotations of a definitive diagnosis of AIDS, patient’s reactions may always not be so gloomy. A number of patients, particularly those who have been chronically ill but not easily classifiable or manageable, may greet such news with an unexpected sense of relief: they have at least something concrete to fight.

Identification of HIV generates further complicating psychological issues that may take considerable time to adjust and to manage. These include the more nebulous issues of control and self-esteem. HIV undermines patient’s confidence in their ability to remain self determining in most spheres of life. Many also feel that their life is irrevocably focused on their infection/disease and its association
with death. Self-esteem is further undermined by social targeting and blame placing along with the physical effects of a serious ailment. Intensity of psychological distress and likelihood of the emergence of psychiatric disturbance is also significantly related to the stage of the infection. Those with AIDS related complexes may develop greater psychological morbidity than those who are asymptomatic and those with frank AIDS (Miller David, 1988).

The development of relationship dynamics in the development of patient distress is widely accepted. Patients for whom the constancy of the disease may lead to feelings of guilt, of being a burden or a bore, will often find themselves cast in the role of ‘protector’ of loved ones. They may attempt to submerge their own distress in order to shield loved ones from the necessary emotional or domestic role changes and in doing so, they may suffer greater emotional, psychological, psychiatric and even physical distress.

The social milieu from which the patients present is also of critical importance. If friends or loved ones have already developed AIDS or died, the patient fears may become intensified, leading to trauma. The socio-psycho problems are faced not only by the people with AIDS but also by their carers. One study has found that chronic intense care of people with AIDS results in conspicuous psychological disturbance, including depression, chronic anxiety and functional disruption (McKusick, L., Herdsman, W., Abrams, D., Coats, T., 1987).

Anxiety disorders may occur any time in the course of HIV disease and are most likely to become manifest at pivotal points in disease progression (Elliott, 1988). Most people with HIV respond adequately to the stress of living with the disease and are able to limit the impact of disease-related anxiety on their daily functioning and quality of life. They cope with medical problems, employment changes, family struggles, relationship difficulties, financial hardship, and the uncertainty of the disease process itself. In these circumstances, anxiety is often considered a normal psychological response to stress (American Psychological Association, 1999).
Anxiety is often part of a complex symptom picture that frequently includes concurrent mood disorders and psychoactive substance use disorders. Anxiety disorders are higher in the HIV clinical population as a whole than in the general population (Dewet et al., 1997; Rabkin et al., 1997; sewell et al., 2000).

Patients with HIV, like those with other chronic medical conditions, may experience the entire spectrum of anxiety disorders as defined by the DSM – IV (American Psychiatric Association, 1994) include:

- Anxiety disorder due to general medical conditions
- Adjustment disorders with anxious mood
- Generalized anxiety disorder
- Substance induced anxiety disorder
- Panic disorder with or without agoraphobia
- Specific and social phobia
- Obsessive – compulsive disorder
- Post traumatic stress disorder. Because treatment for the different disorders varies, accurate diagnosis is critical (Karasic and Dilley, 1998). Successful treatment depends on a through assessment of the patient’s presenting symptoms, preferred coping style, and repertoire of coping skills. As with many other psychiatric conditions, treatment of anxiety disorders frequently involves both medication and psycho-therapeutic intervention. Although anxiety in patients with HIV illness may be due to medical conditions or adverse medication side effects, it also frequently occurs at pivotal points in disease progression, such as being diagnosed with HIV, disclosing HIV status to significant others, starting/changing medication regimes, the onset of first or new HIV – related illnesses or opportunistic infections and HIV – related changes in physical functioning/ appearance and cognitive functioning.
1.7 Psychological Conditions before the Diagnosis of AIDS:

Human beings are always trying to improve their living standard. A high living standard is often confused with loose morals and harmful habits; carnal pleasure becomes the sole aim of life.

Psychological conditions of the HIV/AIDS patients before the diagnosis may be ascertained with the help of detailed case- histories. Normally, pleasure seeking behaviors are found in such histories. For this gain of pleasure, he or she does not think about what he or she is doing. This is mostly dependent upon the attitude towards sexual behavior, information about sexual models and availability of the sex partner. The pre-psyche state and post-psyche state of the HIV/AIDS patients easily understand through the diagram followed the fig. 1.6 (diagrammatic illustration of pre-and post-psyche of the HIV/AIDS patients.

There are some sexual behaviours or sexual exercises lead the problem of HIV/AIDS, called “Faulty Sexual Behavior”, as follows:-

(i) Co-marital sex swinging
(ii) Sexual sadism,
(iii) Sexual Masochism,
(iv) Pedophilia, and
(v) Homosexuality.

Co-Marital Sex – Swinging:

Co-marital sex is a type of extramarital sex. Now – a – days this has become a status symbol of some elite groups. In this type of the sexual exercise wives and husbands participate openly and jointly in extramarital encounter. Extramarital means something more than what is usual, or expected, especially of sexual relations, occurring outside of marriage. An activity in addition to what has been performed usually. In some metropolitan cities the change – wife phenomena is generally occurring. Hunt (1970) reported that 2% of his sample involved in swinging among them, the women proportion was high. Gilmartin (1975) assessed the psychology of this type of partners and reported that affluent and well
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Educated people of his sample have major motive to novelty in sexual practices. Therefore, co-marital sex swinging means to be ultrafashionable specially in seeking sexual pleasure, operating with full vigour. The persons who are engaged in this type of sexual pleasure are called swingers.

**Sexual Sadism:**

Sexual sadism is the major role player of the AIDS. About 10-13 percent reported AIDS cases were due to sadism or masochism. In sexual sadism an individual attains sexual gratification through inflicting pain on sex partners. Sadism may be expressed through physical acts such as whipping, slapping or biting or verbally through teasing and sarcasm. The Freudian point of view is that sadism may allow men to exercise power over the partner and thus unconsciously resuming that they are maintaining their sex organs as with exhibition and voyeurism. Freidians suggest that such type of people suffered with castration anxiety. Sometimes this sexual sadism becomes very high. In such cases the female is affected by injury, and if this injurious part is sex organ, but not easily perceived, then the HIV / AIDS virus is developed very smoothly.

**Sexual Masochism:**

Sexual masochism is different from sexual-sadism. In sexual masochism, an individual receives sexual gratification through receiving pain from sex partners. Masochists seek not only physical punishment, but also verbal assaults for being naughty. Tension, fear and anxiety are the basic prior conditions of this type of acting.

**Pedophilia:**

This is a type of sexual abnormality in the present times and t is often reported in newspapers that be opposite sex and way also be the same sex, that is practiced in many places. In this abnormal sexuality state, an adult desires and engages in sexual activity with a child, who is not fit for sexual union. The child preferred by the pedophilic may be mainly the opposite sex and also may be the same sex.
Psychological findings indicate that pedophilia may occur more often in individuals who find problems in adult sexual relationships. The average age of the pedophilics was found to be around 40 years (Carson et al, 1988). There are also cases of women pedophilia and are playing dominant roles.

All these four sexual abnormalities are the sexual activities which generally take place with the opposite sex. All these sexual activities may take place due to dissatisfaction and frustration caused in the sexual activity with the opposite sex.

Though homosexuality is classified as one of the sexual abnormalities, it is prevalent in the western society and it seems that it is receiving the constitutional sanction. It has been observed that homosexuality is one of the contributing phenomenons of the AIDS.

**Homosexuality:**

Now-a-days it has taken the form of trans-sexuality. Homosexual origin is a very controversial issue, but the person may desire for such function. This has some theoretical background. These theorists trace some prior conditions in these persons.

The behavioral theorist is of the view that homosexual is reinforced by the heterosexual satisfaction. If any unexpected fear is raised in the mind, the satisfaction in the reinforcement is reduced. For the tension reduction and gaining maximum sexual satisfaction they were attracted by the homosexuality. The psycho-analytic view is that homosexuals resolve their Oedipal and Electron complexes in a fashion different from the majority, in the case of males (Siegelman, 1974; Ibrahim, 11976).

1.8 **Post-Psyche of HIV/ AIDS Patients:**

AIDS patients have poor prognosis by their psychological effect. The major symptom of the AIDS patient is the cyclothymia. DSM-III-R categorized the different states in their AIDS patients’ psychological standard under three major categories on the basis of their severity level ass cyclothymia, dysthymia ‘hemia’ and adjustment disorder with depressed mood.
At the early stage of the AIDS, diagnosed patients suffered by cyclical mood alternation and depression. These symptoms known as cyclothymia (DSM-III-R). Klein, Depue & Slaters (1985-86) studies focused that these patients suffered with less pleasure in usual activities, low energy level, and feeling of inadequacy, decreased efficiency, productivity, talkativeness and cognitive sharpness, relative disinterest in sex, pessimistic, broading attitude. In this stage the patient avoids to meet his / her friends, relatives and even neighbors to a maximum level. Desire for isolation is found common in the patients.

The general reactions found in all AIDS patients (after acknowledging the HIV/ AIDS), showing in fig. 1.6.
Thus my study will focus on these three issues i.e., Social, Economic and Psychological dimensions in spreading of HIV/AIDS which have been discussed in quite detail in the preceding pages.
Chapter II
Research Methodology
CHAPTER II

RESEARCH METHODOLOGY

2.1 Introduction:

The current study is first ever study of its nature in India along with Uttar Pradesh. People are really hesitant to talk about such sensitive issue. The current study will prove a landmark towards the HIV/AIDS awareness creating enabling environment for HIV positive patients and psychological condition of HIV positive patients. This study will motivate the high risk behaviour people to get their tests done and develop the sense of care about themselves as well as about general community. The growing level of HIV/AIDS cases in India as well as in Uttar Pradesh (Aligarh & Agra) is of great concern for the country.

- It has been realized that demographic vulnerability young people are at higher risk for HIV/AIDS.
- Prevalence of hepatitis-B and hepatitis-C, in India along with Uttar Pradesh is one of the highest in the world. HIV another blood borne pathogen has almost similar modes of transmission.
- High risk sexual behaviors, such as sexual promiscuity, exchange of sex for money and homosexuality exist in the country. In some segments of population usage of condom for disease prevention is extremely low.
- Blood transfusion service both in public and private sector are still not hundred percent safe.
- There is irrational use of infected multiple uses of syringes and needles.
- HIV/AIDS is spreading at faster rates.

Keeping in view the above mentioned facts, an attempt has made to explore the prevalence, causes and consequence of the HIV/AIDS epidemic in India as well as in Uttar-Pradesh (Aligarh & Agra) with the following objectives.
2.2 Objectives of the Study:

- To explore the socio-economic background of the HIV/AIDS patients.
- To analyze and assess the HIV/AIDS prevalence rates among men and women.
- To examine the causative factors of HIV/AIDS.
- To study the role of family as an institution in the prevalence of HIV/AIDS.
- To assess the socio-psycho and economic implications of HIV/AIDS on the patients, patients families and community.
- To assess the mental agony of the HIV/AIDS patients.
- To analyze the patterns and trends of the HIV/AIDS prevalence rates in U.P.
- To evaluate the government’s efforts and strategies in combating the disease.
- To suggest the government for appropriate policy programme to address this issue in the light of the present study.

Since the problem is highly sensitive and touching behaviour aspects of the society. For conducting the study, both qualitative as well as quantitative methodologies were employed. This chapter describes the procedures and techniques used in both, qualitative and quantitative studies. No doubt, the most important and uphill task was to reach the HIV positive people and to take them in confidence as far as cultural values are concerned so ethical issues which were taken in care are described in this chapter. This chapter covers the sample selection, locale, variables and the study design inclusive of a few case studies.

2.3 Study Design:

To get the best result by utilizing scarce resources, both qualitative and quantitative studies were combined. There are several benefits of using integrate approaches in research to get the optimum result particularly in the sensitive case
studies where data availability, economic constraints and time frame really matter. For conducting the research work, several meetings were arranged for developing the patient’s confidence and preparing them to share their views.

The major factors to be taken into account were socio-psychological and economic implications. The focus was that how general community took those people and the attitude of different stakeholders towards patients and their families. The main cause of HIV/AIDS were discussed with PLWHA (People Living with HIV/AIDS) and tried to discuss the life pattern of those marginalized people was also tried to discuss.

A number of methods were used to collect data. These were questionnaire schedules, personal interviews with different personalities and affected household members’ community meetings and case studies.

2.4 Study Area:

The study was conducted in two districts medical colleges named as Agra (S.N. Medical College, Agra) and Aligarh (J.N. Medical College, Aligarh) of U.P, because I am a student of Aligarh Muslim University and it is quite easy for me to meet patients and their families and Agra is not so far from Aligarh that’s why I choose these two medical colleges. These both districts of U.P. are selected to investigate the influence of socio-psychological and economic impact of HIV/AIDS on society. The cultural values, socio-economic status and mode of living in both the districts of U.P are almost same. Religion and language which are the powerful forces influencing the lifestyle of people are almost same in both the districts of U.P.

Uttar Pradesh forms a major area of the Northern fertile plain or the Indo-Gangetic plain. This area is said to have been occupied by the group of people referred to as ‘Dasas’ by the Aryans. Their main occupation of these inhabitants was agriculture. Till BC 2000 the Aryans had not settled in this region. It was through conquest that the Aryans occupied this area and laid the foundations of a Hindu civilization. The regions of U.P was said to have been the ancient panchala
country. The great war of Mahabharata between the Kauravas and Pandavas was said to have been fought here. Besides the Kurus and Panchalas the Vatsas, the Kosis, Hosalas, Videhas etc. formed the early region of U.P. These areas were called Madhya desa.

Area of Uttar Pradesh- 294,441 sq. km.
Capital of Uttar Pradesh- Luck now
Languages- Hindi
Districts- 70
Population- 139, 112, 2877
Males- 73,745,994
Females- 65,014,423
Literacy- 41.71%

U.P. is bounded by Nepal on the North, Himachal Pradesh on the North-West, Haryana on the West, Rajasthan on the South-West, Madhya-Pradesh on the South and South-West and Bihar on the East, situated between 23°52’N and 31°28N latitudes and 77°3 and 84°39E longitudes, as shown in map below. This is the fourth largest state in the country (www.webindia123.com uttar history/history.htm)
AGRA:

Agra is situated on the banks of the river Yamuna, this little city of Agra is one of the major tourist destinations of the world due to the presence of many splendid Mughal-era buildings as Taj Mahal, Agra Fort and Fatehpur Sikri. UNESCO acclaims the three as the world heritage sites. These monuments are the heritage sites of our country. Agra is the third biggest city in Uttar Pradesh.
Agra is a city of the past filled with graveyards and stones. It is a vibrant centre of culture, Art and Religious philosophies. Agra is famous for handi-crafts products as leatherwork, footwear, brass wear, carpets, jewellery, zari and embroidery work.
Origin of name of Agra:

Agra was perhaps named after the Indian city where the great monument, Taj Mahal was located. Some say that city was named after the daughter of an official of the Rock Island Railroad.

In one of our most rewarded Hindu epic 'Mahabharata' refers to it as 'Agraban', part of Brij Bhoomi, the homeland of Lord Krishna. However, the earliest recorded history of Agra is that it was established by a local king in 1475. It grew into an important power centre under the Delhi Sultan Sikandar Lodi, who shifted his capital here from Delhi in 1504. Agra attained full glory in the Mughal period, from the time Babur captured it in 1526. Babur’s son the Emperor Akbar, who was a great Empire builder commissioned the Agra Fort in 1565 and the city grew around nucleus of the fort.

However, Agra is best known for the Taj Mahal, one of the seven wonders of the modern world. Emperor Shah Jahan built his exquisite, white marble mausoleum for his favorite Queen Mumtaz Mahal. Taj Mahal a world heritage declared by the UNESCO has always evoked varying emotions from wonders to ecstasy and has often inspired poetic vers. Over the centuries, it has become the symbol of undying love and flawless beauty.

The monument was commissioned in 1631 and took 20,000 artists and 22 years to complete. An entire township, Taj Ganj came up around the site. Here, artisans live and sell their wares of marble and stone inlay and replicas of the Taj. After the reign of the last great Mughal, Aurangzeb, Agra fell into the hands of the Jats and then the Marathas. In 1803, the British general lake captured the city. Once again, it secured its position of eminence as the capital of the Northwestern provinces.

After the sepoy Mutiny of 1857 the capital of the central province and its high court were moved to Allahabad. From the rule of the Jats to the early British period, Agra’s monuments were plundered and exquisitely crafted pieces were
transported away. The city fell into decline and disarray till modern times, when people rediscovered its historical importance and tremendous tourist potential.

**Demography of Agra:**

Agra had a population of 14,00,000 as per the census of 2001. About 53% of the population constitutes males and females constitute 47% of the population. The average literacy rate of Agra is 65%, which is higher than the National average of 63.5%. About 76% of the males and 53% of females are literate.

**Economy of Agra:**

The economy of Agra based on agriculture, small-scale industries and other trades. The major crops grown in the region are wheat, mustard, paddy, bajra, potato etc. The agriculture activities in the district come under joint director, whose head quarters are at Agra. Directly or indirectly, 40% of the total economy of Agra depends on industry. Over 7200 small scale industrial units are spread all over the district that are engaged in the production of leather goods, handi-crafts, zardozi, marble and stone carving and inlay work. Agra is also well known for delicious sweets as petha and snacks as dalmoth and gajak.

**Culture of Agra:**

Agra is an amalgamation of various cultures. The city is a mixture of both rustic and modern lifestyle. As Agra falls under the Brij region in U.P. The city is influenced by the Brij culture. People’s food habits, language and attires have influences from the Brij culture. The culture of Agra can be described an amalgamation of Brij culture and Mughal culture. We see that two different cultures come together to form the culture of Agra India. Men wear dhoti and kurta and women wear traditional sarees.

The festivals celebrated in Agra are Eid-ul-Fitr, Eid-ul-Adha, Muharram, Diwali, Holi, Taj Mahotsav etc. Agra is also popular for its Id Melas and colourful Tezias taken out on Muharram. Diwali, the festival of lights, is popularly celebrated here. The Taj Mahotsav festival is a culturally vibrant platform that brings together the finest Indian crafts and culture.
There are celebrations ranging from folk music, poetry classical dance performances, elephant and camel rides to games and a food festival. There are processions with decorated elephants, camels, drumbeaters, folk artists and master craftsmen. The Taj food festival is an experience to savor exotic cuisines and delicacies and Craft Mela exhibits exquisite crafts like marble inlays, wood, carvings, brass and metal ware, hand made carpets, the blue pottery, the chikan works, Banaras silk etc. Other festivals are common to other regions of the country (http://www.indianetzone.com/4/agra.htm/2/4/08).

S.N. Medical College Agra:

S.N. Medical College and Hospital, Agra is situated in the centre of city in a well-outlined campus, adjacent to main Mahatma Gandhi Road (M.G. Road). From three sides, campus is surrounded by residential and market area. College and hospital have separate blocks and buildings for different departments.

Today, this college has completed over 60 years of its useful existence dedicated to the cause of Medical Education and Research and in the service of suffering humanity being the college motto “LIVE TO SERVE”.

From this college, soon after the Medical Council of India and the General Medical Council of Great Britain recognized its inception. The first of M.B.B.S,
doctors passed out in the year 1944. The hospital attached to the Agra Medical School since 1854 known as the Thompson Hospital, with the elevation of Agra Medical School to S.N. Medical College, the Thompson Hospital was also rechristened as S.N. Hospital. (http://www.sunmcagra.in/infra.php).

S.N. Medical College and Hospital, Agra provides tertiary level specialized health care services not only to people of urban and rural areas from Agra but also to the patients approaching from surrounding states of Rajasthan, Madhya Pradesh and adjacent districts of Mathura, Firozabad, Etawah, Jhansi & Bharatpur.

**Available Land Area:**

S.N. Medical College & Hospital situated in a total area of 24.49 acres with Emergency Department at the main road and other departments within the campus. The college campus is surrounded on one side by District women Hospital (known as Lady Lyoll Hospital) with an area of 15 acres and adjacent to the main entrance of the college there is Tuberculosis Demonstration and training centre.

Available infrastructure in the institute can be best described under the following major headings:

- College infrastructure
- Hospital infrastructure

S.N. Medical College, Agra, named after the first lady governess of U.P. poetess and freedom fighter, Bharat Kokila Smt. Sarojini Naidu situated in the city of the Taj Mahal. It is one of the first three Medical Schools of the country. For Agra Medical School, the year 1939 was a year of achievement. With a view to meet, the growing demands for qualified doctors in the united provinces. The status of Agra Medical School upgraded to that of a full-fledged Medical College affiliated to the Agra University for the award of M.B.B.S. degree.
In the S.N. Medical College of Agra, this four year (2004-2008) reported cases of HIV/AIDS show that in the year 2007 the highest percentages of HIV/AIDS cases are 152. Though in the year 2008 there are reductions in the cases i.e. 136, but this data clearly shows that there is increasing no. of cases of HIV/AIDS in the city of Agra.

In U.P, 1100 children are HIV+. In Agra there are only 22 children HIV+ which are registered in hospital. There is an incensement of HIV+ children day by day and there is no any doctor who is specialist in the treatment. In S.N. Medical College of Agra 315 HIV+ are getting treatment in which 293 are adult and 22 are children. In adult 60% are male, 39% female and 8% homo. In children 77% are boys and 23% are girls.

**History of Aligarh:**

Aligarh is a city in Aligarh district in the northern Indian state of U.P. The city is located about 90 miles southeast of New-Delhi. It is the administrative
headquarters of Aligarh district, and has a population of half a million. It is mostly known as a university town where the famous Aligarh Muslim University is located.

It is known till the 18th century by the earlier name of kol. After the British occupation of Aligarh district was formed in 1804.

Both Akbar and Jahangir visited kol on hunting expeditions; Jahangir clearly mentions the forest of kol, where he killed wolves. From the study of the place names of the district, it appears that the district was once fairly well covered by forest, thickets and grooves. The early history of the district, indeed down the 12th century A.D. is obscure.

Kol or Koli was the earliest name of the city and Aligarh was the name of the fort nearby. Kol covered not only the city but also the entire district, though its geographical limits kept changing from time to time. The origin of the name of kol is obscure. In some ancient texts, kol has been referred to in the sense of a tribe or caste, name of a place or mountain and name of a sage or demon. During the time of Ibrahim Lodhi, when Muhammad, son of Umar was the governor of kol, he built a fort at kol and named the city after his own name as Muhammadgarh in 1524-25, and Sabit Khan who was the governor of this region during the time of Farrukh Siyar and Muhammad Shah, rebuilt the fort and named the town after his own name Sabitgarh. After the occupation of kol by the Jats in 1775, it was renamed Ramgarh and finally, when a Shia commander, Najaf Khan, captures kol, he gave it its present name of Aligarh. Aligarh Fort (also called Aligarh Qila), as it stands today was built by French engineers under the control of French officers Benoit de Boigne and Perron.

Establishment of Aligarh Muslim University (1875):

In 1875, Sir Syed Ahmad Khan founded the Muhammadan Anglo Oriental College in Aligarh and patterned the college after Oxford and Cambridge Universities that he had visited on a trip to England. This later became Aligarh Muslim University in 1920.
Economics:

The city is an agricultural trade centre. The processing of agricultural products and manufacturing are also important. It is particularly famous for locks
and brass castings (sculptures). In 1870, Johnson & Co. was the first English locks firm to be set up in Aligarh. In 1890, the Johnson & Co. initiated the manual production of locks on a small scale here. There is a thermal power station 15km away from the city. It is called Harduaganj, but it is referred as Kasimpur Power House.

Demography:

According to the census of 2001, the total population of Aligarh district was 2,990,338 persons. In which male population was 1,607,222 and female population was 1,383,166. The sex ratio according to the census of 2001 of Aligarh district was 861. The density of population was 798 persons per sq.km in 2001. The literacy in the district was 44.9 percent. Males are more literate than females being 259.9 percent, 426.8 percent respectively. The land owing and cultivation castes of the district are Brahmins and Jats.

Aligarh district can rightly be called a rural district. It has only 25.15% urban population. The whole of population of the district lives in twelve blocks in which there are 1,749 villages and twenty townships among which Aligarh is the district headquarters and chief urban center. Aligarh district reflects its picture of backwardness characterized by high density of population, illiteracy, crunch of financial resources, technological backwardness and very high dependence on agriculture and small fragmental agriculture holidays, resulting in low productivity, widespread unemployment and under unemployment (A..Mani, 1976: xiii-xv).

J.N. Medical College, Aligarh:

J.N.M.C. situated in the premises of Aligarh Muslim University, Aligarh. Aligarh is situated at a distance of 130 km, South East of Delhi on Delhi-Calcutta Railway and Grand Trunk Road route. The latitude is 27 degree 54 minute north and longitude is 78 degree 5 minute east.
Chapter-2

Fig.-2.3 (J.N. Medical College, Aligarh)

The J.N.M.C. is one of the constituent colleges of the Aligarh Muslim University, faculty of Medicine. Although, the image of its creation was initiated since the days of MAO College but it was started in year 1962 when the Indian Medical Council recognised its MBBS degree. The institute of ophthalmology of this university has been in existence since 1952 and has already established a name for it. The college has an attached hospital of 1000 beds in the Institute of ophthalmology at the Gandhi Eye Hospital. The main College building, the Hospital, the Residential Hostel (Hadi Hasan Hall and S.N.Halls) for students and the residences for the staff (Medical Colony) are located in one campus. The special feature of this college is that it is one of the few medical colleges in this country entirely under the university administration and has a close link with other disciplines of the university. The medical college is situated about 4 km from the Aligarh Railway Station.

Fig.-2.4 (Source:-UPSACS)

In the above figure of J.N.Medical College of Aligarh, annually reported (2004-2008) HIV/AIDS cases shows that how HIV/AIDS spread and increased year wise as in year 2008, 71 cases were recorded in J. N. Medical College of Aligarh, apart from other medical colleges and private institutions in Aligarh.

2.5 Research Design:-

Sociologically research designs are mainly classified into four categories i.e., exploratory or formative, descriptive, diagnostic and experimental. All the four types are having their own merits and demerits, but all have their relevance under particular situations depending upon the subject and nature of the research. Exploratory research design tries to find out something new or unknown dimensions, the descriptive design aims at giving a detailed account of somewhat a less known matter. The diagnostic design aims at a real diagnosis or unfolding of the problem and the experimental design finds out the cause effect relationships
between the variables. However, the categorization is never absolute and very often any two or more amongst, these four types of designs work in close association of one-another because of the socio-cultural complications and behavioural variations in sociological probing. The present work has been designed from the diagnostic and descriptive perspectives to analyze the socio-psychological study of HIV/AIDS patients. My present study is diagnostic in nature because it facilitates in exploring the real problem by identifying the real causes of the problem of HIV/AIDS patients. It is also descriptive in nature because it is a detailed account of HIV/AIDS and its affect on the society, family members and individuals psychologically, socially and economically.

2.6 Universe of the study:

U.P like all other parts of the country has been facing a new menace to public health-HIV/AIDS. U.P is India’s largest state in population and one of its fastest growing. While HIV prevalence is low at present, the National AIDS Control Organization (NACO) considers the state highly vulnerable. In U.P from 1992 to 2008 there are 33322 HIV positive patients are living in which most of them are from socially and economically poor background. They are illiterate and not aware about HIV/AIDS. In Agra from 2004 to 2008, there are 530 HIV positive patients attending in S.N. Medical College in which most of them are from reproductive age group. Where as in Aligarh from 2004 to 2008, there are 261 HIV positive patients attending in J.N. Medical College. They also from the reproductive age-groups, and are also from various social categories.

2.7 Sample Selection: -

Social sciences make use of several types of sampling methods depending upon the nature of the problem and situation of the field. A simple random method is used if the universe is homogenous and a stratified sample method is used if it is heterogeneous. Similarly, there are other methods which are used in different situations. U.P is the most populous state of India with much special diversity. In the present study, area sampling along with the purposive sampling has been done
because of the specific need of the study. These sampling methods have helped in selection of the respondents with desired characteristics. In the present study 50 HIV/AIDS patients were selected. Out of 50 patients 25 from S.N.Medical College, Agra and 25 from J.N.Medical College, Aligarh, have been selected. These 50 HIV/AIDS patients have been studied extensively by the help of the structured interview schedule. Intensive case histories of 17 patients suffering from HIV/AIDS have also been prepared to reach definite conclusion about the causes and consequences of the problem because sometime statistical analysis fail to reveal the facts of the problem. These case-studies are presented not only to elaborate and substantiate the statistical evidence but also to present human dimensions which statistical tests fail to explain. The purpose of including case studies is also to give a feel about the life-world of these HIV/AIDS patients.

During the preparation of the case study, the researcher also observed each of the HIV/AIDS patients deeply by watching their activities, observing their behaviour pattern etc. the researcher has several sittings with HIV/AIDS patients in order to win over their confidence to extract the facts. The researcher succeed in it.

2.8 Research Tools:

Every research design calls for a specific research tool meant for collection of data. There are a good number of such tools available for sociological findings such as interview schedule, questionnaire, case study, Content Analysis, observations and focused group interview etc. Both qualitative and quantitative data is required for an in-depth study and a research tool is opted as per the requirement of the research. However, no absolute categorization is possible between qualitative and quantitative data.

The present work calls for both qualitative and quantitative data because of the intermingling dimensions of the problem. Two- types of research tools have been mainly used for the collection of data-one, Interview-Schedule, and case
study method. Besides, observation and secondary data source have also been used, as and when required, in order to authenticate the information.

The researcher developed her own tool as per the objectives of her study. The tool was pre-tested by a pilot study. Later on this was used on the HIV/AIDS patients attending ART centres of S.N.Medical College, Agra and J.N.Medical College, Aligarh. The interview-schedule has been used to collect detailed information about HIV/AIDS Patients.

Moreover, the case study method has been used to get details of the specific and typical personal experience of the carrier, to crystallize the qualitative aspects of the problem. Case studies have been developed proportionately after selecting potential respondents according to their response during structured interview.

2.9 Data Processing and Analysis:

After completing the investigation and recording the interviews, the processing of the data was initiated. First of all, the interview schedule was checked and edited. Errors and omissions in recording the answers were located. It was found that there were a few of minor nature which were corrected.

For the quantitative analysis of 50 respondents... the data was codified. A separate code was assigned to each of the questions and each of the responses and feeded to the computer. Coded data was categorized with the categorizing plan prepared for the purpose. However, the responses of the open-ended questions were separately analysed. Percentages of the responses were calculated and inferences drawn.

The aim of presenting the illustrations of some of the cases was not to give any statistical precision, but to give a feel about the life of the HIV/AIDS patients. Therefore, the case-material is presented in a biographical form, which is quite revealing and self-explanatory. A gist of the interviews of the HIV/AIDS patients is also presented in the same form. The interviews of the patients were carefully listened and a summary of each of the case was prepared. Certain portions were deleted which were not found relevant to the present area of inquiry.
Chapter III
Analysis and Interpretation of Data
CHAPTER III

ANALYSIS AND INTERPRETATION OF DATA

(A). Analysis of Quantitative Data

3.1 Introduction

The HIV epidemic and its associated socio-psychological and economic consequences are relatively new phenomenon and have, so far, not been serious consideration given in development planning by most of the affected countries. HIV/AIDS is silently becoming a major cause of adult mortality in many countries. The rapid but hidden spread of the epidemic is affecting the suffering societies psychologically, socially, and economically. These impacts are personal, community related, social and national and state simultaneously.

3.2 Demographic characteristics of Respondents

3.2.1 Age

Agra and Aligarh are populous districts of Uttar Pradesh and Uttar Pradesh is the most populous state of India, reflects that most of the affected were lying in the peak age of their earning. Sixty eight percent (68%), of this population was falling in the range of (18-35) years age-group, twenty eight percent (28%), of this population was falling in the range of (36-50) year’s age-group, four percent (4%) of this population was falling in the range of (51& above) year’s age group in Agra.

Where as in Aligarh, fifty six percent (56%), of this population was falling in the range of (18-35) year’s age group, twenty eight percent (28%), of this population was falling in the range of (36-50) year’s age-group and sixteen percent (16%), of this population was falling in the range of (51 & above) year’s age-group.

The table 3.1 shows that the mostly patients are from the reproductive age-group whose average age is 31 years.
So in both the places of study i.e. Agra and Aligarh the concentration of the HIV/AIDS patients in the age group when they are sexually active. From the information collected, it is clear that their average age is 31 years. They get this fatal virus due to unawareness and unconsciousness about the consequences of the disease. Because, this virus takes 3 months for incubation so, after 3 to 9 years, the signs and symptoms appear among the patients and they live for 1-3 years after developing AIDS (GOI, 2003). At the same time, their behavioral change in the teen ages needs to be focused too. “Over 5.2 million people in south Asia are estimated to be infected with HIV/AIDS at the end of 2003 of this, up to one quarter are aged under 25 years” (Rasheed, 2004). It is very much evident from the data that young population is at more risk. But a very large proportion of those at the risk of HIV infection in South Asian Countries are drug injectors, sex workers and their clients, and homosexual who are in their teens or early twenties (MAP, 2004). In Manipur state of India, over 40 percent of the males who injected drugs included in the surveillance system in 2002 were under the age of 25. In Katmandu Valley (Nepal), where injecting drugs is a long established practice, some 44 percent of new injectors were under 25 years.

Table: 3.1

<table>
<thead>
<tr>
<th>Age</th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>18-35</td>
<td>17</td>
<td>68%</td>
<td>14</td>
<td>56%</td>
</tr>
<tr>
<td>36-50</td>
<td>7</td>
<td>28%</td>
<td>7</td>
<td>28%</td>
</tr>
<tr>
<td>51 &amp; above</td>
<td>1</td>
<td>4%</td>
<td>4</td>
<td>16%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

3.2.2 Gender Distribution

Bury at el (1992) quoted the study conducted in U.K., “The Scottish women and HIV/AIDS Network is the major group that is trying to educate the

63
young women in their teens, since 40 percent of the AIDS cases among women in the UK are in the 15-29 age group with the rapid increase of HIV infection among women.

Table 3.2
Gender wise distribution of the respondents

<table>
<thead>
<tr>
<th>Age</th>
<th>Agra</th>
<th>Aligarh</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
<td>68%</td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
<td>32%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

If we compare Agra and Aligarh in the case of gender, we will find more males are suffering from HIV/AIDS in Agra than Aligarh because Agra is a big city and this is a tourist place where more tourists and migrant workers are coming in search of jobs and recreation.

India is one of very few countries in the world where female population is less than the male. Agra and Aligarh are the districts of Uttar Pradesh where female population is also less than the male population.

HIV/AIDS is more common among males as well as females. Females are playing a role of vector. In data analysis it is very much obvious that 68 percent were males and 32% were females in Agra and 56 percent were males and 44 percent were females in Aligarh.

3.2.3 Educational Status

A study from 32 countries found that women with post-primary education were five times more likely than illiterate women to know facts about HIV/AIDS (Vander moortela and Dalamonica, 2000). In Zambia, during the 1990s, HIV Infection rates fell by almost half among educated women but showed little decline for women with no formal schooling (UNICFF, 2004). In order to know the impact of education on the spread of HIV/AIDS, the researcher also explored
about the educational background of the respondents. The following Table No. 3.3 shows the educational status of the respondents:

Table 3.3

Distribution of the respondents regarding literacy

<table>
<thead>
<tr>
<th>Age</th>
<th>Agra</th>
<th>Aligarh</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Illiterate</td>
<td>15</td>
<td>60%</td>
</tr>
<tr>
<td>Literate</td>
<td>10</td>
<td>40%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 July to 2009 February)

No doubt, education is the key to an effective response to HIV/AIDS.

Table 3.3 reveals that 60% were illiterate, and 40% were literate in Agra and 72% were illiterate, and 28% were literate in Aligarh. In India (as in all other developing countries), the definition of literacy is: “Any person who can write and read a paragraph in any local language is considered as literate.”

If we compare these two districts in the context of education, we will find that there is more literacy in Agra than Aligarh, because Agra is more developed than Aligarh.
Fig.-3.1 Education wise comparison
So, the literate people are also quite unaware about the penalty of getting HIV/AIDS. According to some studies, all over the world, 150 million children were currently enrolled in schools and drop out before completing primary school and at least two third of them were girls (world Bank, 2002). It is really a hard luck that till date, HIV/AIDS has never been specific of the curriculum of “Medical Education” and therefore it is needless to talk about or have discussion over such a sensitive issue in general education.

3.2.4 Occupation of the Respondents

National AIDS Control Program, Delhi, and State AIDS Control Program, Lucknow reminded that more than 70 percent of all confirmed cases of HIV/AIDS are deported workers from metropolitan cities while many of the women HIV/AIDS sufferers happen to be those who fall prey of this due to their husbands. Women and men working as sex-workers are particularly vulnerable to HIV transmission. A representative of Jagruti, India, an organization working with sex workers said, “If a woman could not feed herself why would she worry about a disease that might kill her in ten year’s time? If a client offers to pay twice as much for sex without a condom, the need for money might overtake everything.” Rushing (1995) said, “The risk of young girls contracting HIV/AIDS is higher than that of adults, and especially for those girls entering the sex industry.” The importance of the prevention of sexually transmitted diseases generally in the fight against HIV/AIDS increases when it is realized that the presence of a sexually transmitted disease raises the chances of having the AIDS infection by more than 300 percent.

Most of the respondents belonged to very depressed and marginalized communities. As table 3.4 reflects, 48 percent of the total respondents were laborers in Agra and 36% of the total respondents were laborers in Aligarh. They had very poor socio-economic background. 24 percent of the total respondents were housewife in Agra and 44% of the total respondents were housewife in Aligarh. 12 percents out of all respondents were students in Agra, whereas 8
percent of all respondents were students in Aligarh; 8 percent of all respondents (all females) were indulged in sex-working with a high risk behavior in Agra, where as 0% is in Aligarh; 8 percent respondents doing job in Agra where as it is found 0% in Aligarh. 12% of the total respondent involved in farming (as a farmer) in Aligarh whereas 0% in Agra. While in both places there was not any respondent who was involved in as a shopkeeper.

Table 3.4

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Agra</th>
<th></th>
<th>Agra</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Service</td>
<td>2</td>
<td>8%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Laborer</td>
<td>12</td>
<td>48%</td>
<td>9</td>
<td>36%</td>
</tr>
<tr>
<td>Shopkeeper</td>
<td>0</td>
<td>0%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Farmer</td>
<td>0</td>
<td>0%</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Sex-worker</td>
<td>2</td>
<td>8%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>House wife</td>
<td>6</td>
<td>24%</td>
<td>11</td>
<td>44%</td>
</tr>
<tr>
<td>Student</td>
<td>3</td>
<td>12%</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

While comparison Agra and Aligarh in terms of profession, we found that there are some patients involved in government services in Agra but in Aligarh mostly patients are involved in agriculture and laborers.

3.2.5 Residence of the respondents

The number of reported HIV infections and AIDS cases has been steadily rising in Agra and Aligarh in U.P, and affects all geographical regions of the country. Poverty, illiteracy, politics, social repression, exploitation, crime and unemployment are the casual problems of rural areas.

68
Table 3.5
Locality wise distribution of the respondents

<table>
<thead>
<tr>
<th>Locality</th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Rural</td>
<td>16</td>
<td>64%</td>
<td>18</td>
<td>72%</td>
</tr>
<tr>
<td>Urban</td>
<td>9</td>
<td>36%</td>
<td>7</td>
<td>28%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source: field survey from 2008 June to 2009 March)

Table 3.5 reveals that 64 percent of the respondents were residing in the rural areas of Agra and 72 percent of the respondents were residing in the rural areas of Aligarh. Whereas 36 percent were the dwellers of urban areas in Agra, but in Aligarh, 28 percent were the dwellers of urban areas. In rural areas, intra-familial relationships, religious institutions and values are strong enough, yet in urban areas, the mobility of people especially from metropolitan cities makes the place more vulnerable for HIV/AIDS. The key factor for high prevalence of HIV/AIDS in rural areas is that the, “high risk behavior people feel more protected in congested areas and purely urban as well as purely rural areas going to shrink for them”. In rural areas, high risk behavior people can prolong their activities like sex-working, injecting drug and drug trafficking more confidently.

Comparing demographically the rural areas of two districts under study, we find that there are much people living in rural areas of Aligarh than that of Agra.

3.2.6. Marital Status of the Respondents

In India, “Marriage is actually women’s primary risk factor” (Krishnan, 2004). On Colombia’s Atlantic Coast, 25 percent of all HIV cases were among women, about 50 percent of them were either married or in a stable relationship. In yet another study, at a health clinic in Pune (India), it has been found that out of 400 women, 93 percent of them were married, 25 percent had sexually transmitted
infection (STIs) and 14 percent were HIV positive. Ninety one percent have never had sex with anyone than their husbands (WHO, 2004).

Table 3.6

Marital status of the respondents

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Agra</th>
<th>Aligarh</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Married</td>
<td>20</td>
<td>80%</td>
</tr>
<tr>
<td>Unmarried</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Divorce</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Widow</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 July to 2009 February)

Table 3.6 reflects that 80% of all the respondents were married, 12 percent of respondents were unmarried and only 8 percent of respondents were widowed in Agra, Whereas, in Aligarh 64 percent of all the respondents were married, 24 percent of respondents were unmarried, 8 percent were widowed and a very few number of respondents (4 percent) were divorcee. It shows that disease is more common among married respondents.

As shown in figure 3.2 comparatively, in Agra there are much more reported cases of HIV/AIDS victims (who are married) than in Aligarh.
3.3. General characteristics of the Respondents

3.3.1. Smoking Habits among the Respondents

The data, basically, reflects the chances of people who may shift themselves in future towards drug addiction through cigarettes primarily and switch over their status toward injecting drug users laterally. So, the sharing of needles among injecting drug users is very precarious behavior, which becomes a cause of so many communicable diseases as HIV/AIDS.
Table 3.7  
Percentage Distribution of Smokers

<table>
<thead>
<tr>
<th></th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Smokers</td>
<td>17</td>
<td>68%</td>
<td>15</td>
<td>60%</td>
</tr>
<tr>
<td>Non-Smokers</td>
<td>8</td>
<td>32%</td>
<td>10</td>
<td>40%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 July to 2009 February)

The question was asked to all the respondents; overall sixty eight percent respondents were smokers as shown in the table 3.7. Thirty two percent of the respondents were non-smokers in Agra, whereas, in Aligarh sixty percent of the respondents were smokers and forty percent of the respondents were non-smokers.

If we compare Agra and Aligarh in terms of smoking, we will find that there is not very much difference in the distribution of smokers in two districts as is evident from the table above.

3.4. Medical Examination of the HIV/AIDS Patients

3.4.1. Mode of diagnosis of HIV/AIDS status of respondents

Table 3.8

Mode of diagnosing of the HIV/AIDS

<table>
<thead>
<tr>
<th>Source</th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Accidentally Discovered</td>
<td>5</td>
<td>20%</td>
<td>11</td>
<td>44%</td>
</tr>
<tr>
<td>Doctor Diagnosed</td>
<td>20</td>
<td>80%</td>
<td>14</td>
<td>56%</td>
</tr>
<tr>
<td>Overall</td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

General question was asked to the respondents about their diagnosis regarding HIV/AIDS. There were two possibilities, either a sick person was
diagnosed during his treatment with the help of signs and symptoms or he/she got any accident, blood screening and deported on sero-positive status on annual checkup. Table 3.8 points out that 20 percent of the respondents in Agra and 44 percent of the respondents in Aligarh were quite unaware of their sero-positive status. They come to know about disease suddenly and accidentally. But eighty percent of the respondents in Agra and 44 percent of the respondents in Aligarh were diagnosed as HIV positive after laboratory test on the recommendation of doctors.

3.5. Main source of HIV/AIDS

When questions were asked to conclude their views about the sources of HIV/AIDS, most of the respondents declared more than one source.

Table 3.9

Mode of Transmission of the Respondents

<table>
<thead>
<tr>
<th>Main Source</th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Multiple Sex partners</td>
<td>18</td>
<td>72%</td>
<td>16</td>
<td>64%</td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td>4</td>
<td>16%</td>
<td>9</td>
<td>36%</td>
</tr>
<tr>
<td>Use drugs with same needle</td>
<td>3</td>
<td>12%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>25</strong></td>
<td><strong>100%</strong></td>
<td><strong>25</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

Table 3.9 shows that 72 percent respondents were multiple sex partner as a main source, 16 percents respondents were blood transfusion as a main source and 12 percent respondents were use and sharing of needles as a main source of HIV infection in Agra and 64 percent respondents were multiple sex partner as a main source, 36 percent respondents were blood transfusion as a main source of HIV infection in Aligarh.

Comparatively in Agra, more cases are from multiple sex partners, but in Aligarh there are more cases from blood transfusions and there is not any case
reported in J.N. Medical College, Aligarh from drugs but in S.N. Medical College, Agra, there are few cases reported from drugs. We can easily understand through the figure below.

![Comparison wise Transmission of the Respondents](image)

**Fig. 3.3 Comparison wise Transmission of the Respondents**

3.6. Social Implications

Social implications of HIV/AIDS are perhaps serious, most threatening and hurdle to human development. As the roots of epidemics penetrate deeply among individuals, families, communities and nations, they have to face deaths on a scale which is not acceptable in modern era. In situations where quick social change is already posing shocks to traditional family and social structures, these costs might be enormous affecting gender roles, fertility, household patterns and perhaps offsetting many of the achievements made in these areas in the near past. A particularly concerned and insight-full analysis of effects which are challenged by the epidemics is given by Reid et al (1993). She explains, “five sets of
relationships, or ‘social contrasts’ which might be addressed if communities and nations are to survive for quality life”.

These are the relationship between

- men and women
- Individuals and communities
- Communities and government
- The infected and the uninfected
- The present generation and the next

In each of these relationships power imbalance, lack of trust, faith and confidence and failure to handle problems equally and honestly contribute to the rapid spread of this dangerous epidemic. Along with these entire problems and pressure, confusion and complications within these relationships will be amplified and stretched to breaking point by the HIV prevalence rates and widespread presence of the virus.

3.6.1. Family Structure of the Respondents

People who marry have in fact two families. One is the “family of orientation”, the family in which one grows up, consisting of oneself and one’s parents and siblings. The other is the “family of procreation”, the family that one establishes through marriage, consisting of oneself and one’s partner and siblings (Thio, 1996). In India (U.P., Agra & Aligarh), “Joint family” bindings are very strong and more generally recognized as popular mode of living. HIV/AIDS patients are stigmatized by the general community and they become badly rejected even by their own families. No one wants to get paralyzed due to the problems of someone else. They mostly live alone, isolated and family does not accept them as a part.
Table 3.10

Percentage distribution of respondents who live with joint family

<table>
<thead>
<tr>
<th>Family System</th>
<th>Agra</th>
<th>Aligarh</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
</tr>
<tr>
<td>Nuclear</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Joint</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>Overall</td>
<td>25</td>
<td>25</td>
</tr>
</tbody>
</table>

(Source: field survey from 2008 June to 2009 March)

Table 3.10 indicates that 44 percent in Agra and 40 percent in Aligarh of the respondents were living at their own. Thus some (a very few) respondents were having no accommodation and they kept on sleeping on the paved path. Ultimately, these marginalized people use to live very miserable and isolated life. 56 percent of the respondents in Agra and 60 percent of respondents in Aligarh were living in joint family system.

If we compare both districts in terms of family system, we found that majority of families in Agra are of nuclear type, but in Aligarh mostly patients’ have joint type of families.

3.6.2. Status of respondent’s family regarding HIV/AIDS

The common situation where a man has become infected from outside, and puts his wife at the risk of these silent infections, creates severe tensions and stresses within the families. A very few women insisted their spouse to use condoms while having sex. Failing to do so keeps the wife inking about the risk of her husband being infected by the epidemic and thereby threatening not only her life but also threatens the survival of the children and the family as a whole.

Everyone was well aware that how a wife has the right to comment upon her husband’s sexual behavior. This is an important but difficult to answer for many cultures including Agra and Aligarh set-up. In the male dominating society, how far men re-evaluate their own values and needs with respect to sexual
behavior and attitude in the form of threats to their sexual partners (wives in most of the cases in Indian set-up), children and families? Should they all evaluate the risk their infection produces? Many infected people remains unaware of their HIV positive status, because testing system are far from being available every where. When detected, the short and long-term social and cultural effects are generally disastrous for them and their families.

Due to possible social problems, infected people often tend not to inform their spouses or regular sexual/emotional partners. In other cases, people are not concerned with HIV/AIDS infection due to more pressing concerns associated with their “under-privileged” and “socio-economic” situation. As far people are economically and socially at superior positions, they tend to regard themselves as “immune” from the disease because of their socio-economic status. Many of those with professions that involve frequent mobility do not assume their responsibility towards occasional sexual partners. Thus the HIV/AIDS epidemic and prostitution are highly concentrated. In table 3.11 reveals that how much family members had this dreadful disease.
Table 3.11

Percentage of respondent’s family member had HIV/AIDS

<table>
<thead>
<tr>
<th>Locality</th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Overall from All</td>
<td>9</td>
<td>36%</td>
<td>7</td>
<td>28%</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>16</td>
<td>64%</td>
<td>18</td>
<td>72%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:--field survey from 2008 June to 2009 March)

There were 36 percent of the respondents whose family members were affected in Agra and in Aligarh 28 percent of the respondents whose family members were affected. It is noticeable that most of the respondents in this category were coupled and they got transmission of virus from each other innocently. It was all happened just due to lack of information and illiteracy among the respondents.

3.6.3. Family Attitude towards Respondents

No doubt, attitude of the various segments of people play a vital role in the smooth living of HIV positive people. Fig.1.3 in chapter 1 is the reflection of the tri-dimensional relationship i.e. social, psychological and economic factors, which are inter-related and inter-dependent and have great impact on the victimized people. Only optimistic attitude and normal behavior can prove to be ‘life blood’ for the HIV/AIDS people.
Table 3.12
Attitude towards respondents after diagnosis of HIV/AIDS

Agra

<table>
<thead>
<tr>
<th>Category</th>
<th>Sympathetic</th>
<th>Just Normal</th>
<th>Harsh/hated</th>
<th>Indifferent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Neighbors</td>
<td>5</td>
<td>20%</td>
<td>5</td>
<td>20%</td>
</tr>
<tr>
<td>Family members</td>
<td>6</td>
<td>24%</td>
<td>7</td>
<td>28%</td>
</tr>
<tr>
<td>Relatives</td>
<td>0</td>
<td>0%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Friends</td>
<td>8</td>
<td>32%</td>
<td>4</td>
<td>16%</td>
</tr>
<tr>
<td>Community members</td>
<td>3</td>
<td>12%</td>
<td>1</td>
<td>4%</td>
</tr>
</tbody>
</table>

Aligarh

<table>
<thead>
<tr>
<th>Category</th>
<th>Sympathetic</th>
<th>Just Normal</th>
<th>Harsh/hated</th>
<th>Indifferent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Neighbors</td>
<td>4</td>
<td>16%</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Family members</td>
<td>8</td>
<td>32%</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Relatives</td>
<td>3</td>
<td>12%</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Friends</td>
<td>7</td>
<td>28%</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Community members</td>
<td>4</td>
<td>16%</td>
<td>5</td>
<td>20%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

Table 3.12 indicates five variables on the basis of which attitude of different segments were analyzed towards patients.

**Neighbors**

Very rubbing and harsh attitude was observed by 44.0% of the respondents from their neighbors in Agra and 40.0% in Aligarh. 20.0% of the respondents of Agra and 16.0% of the respondent of Aligarh were those who got sympathetic...
attitude from their neighbors after being diagnosed as HIV positive, who were unfamiliar about the consequences of this disease. There were 20.0% respondents of Agra and 12.0% respondents of Aligarh who observed that their neighbors were just taking HIV/AIDS as a normal disease like cancer or tuberculosis. While discussing the dealings of neighborhood, 16.0% of the respondents of Agra and 32.0% of the respondents of Aligarh, which is more than the Agra, felt the reasonable difference between the behavior and dealings before and after declaration of their sero-positive status.

**Family Members**

According to walker (1991), how a family copes with any illness, including HIV depends on both the nature of the family organization and the belief systems that govern the family’s response to illness. The impact on the family also varies with their ethnicity, religion, race and social class, family’s developmental level, and the family’s relationship with the treatment providers (Rait, et al, 1997).

HIV/AIDS is not only a single medical disorder but its associated stigma adds in the complexity of AIDS. The shame, blame, fear, distrust, disgust and dangers that surround these issues and the problems of discussing them in present-day cultures, are major hurdles facing family of PLWHA today. The point which makes it even worse is that there are very few channels in our present societies through which they can be tackled and faced.

Table 3.12 divulges that 24.0% respondents of Agra and 32.0% respondents of Aligarh got sympathies from their families. Mostly, in the society of Agra and Aligarh, in-fact in Indian society, “mother and wife” prove to be the most sincere and caring for their patients. But they used to face lot of criticism and social pressure from the community. The UN secretary General’s report on South Africa revealed that two-thirds of care-givers in the household surveyed were females, with almost a quarter of them over the age 60 (UN Secretary General, 2004).

About 36.0% of the respondents of Agra and again 36.0% of the respondents of Aligarh were gloomy to express that they faced hateful and harsh
activities from their family members after diagnoses. About 12.0% of the respondents of Agra and 24.0% of the respondents of Aligarh were of the view that they felt apparent difference among the family members. Many of the respondents from the both districts were complaining that their brothers left their home or compelled the patient to leave home. About 28.0% of the respondents of Agra and just 8.0% of the respondents of Aligarh shared that their family did not know the severity of HIV/AIDS, so the family members deal them normally.

Relatives

The behavior and interaction of relatives was remarkably changed. 52.0% of the respondents of Agra and 20.0% of the respondents of Aligarh were found angry on the response of their relatives. They even denied to see them. About 48.0% of the respondents of Agra and 32.0% of the respondents of Aligarh exposed the fact that their relatives did not even accept them. 12.0% of the respondents of Aligarh declared that they got sympathies from their relatives. They were mostly from marginalized community and STIs (Sexual Transmitted Infections) were very common among the relatives of the respondents of this group. About 8.0% of the respondents considered their relatives are normal in attitude towards them.

Friends

All the respondents unanimously had the same view point that their friends were changed in either ways optimistically as well as pessimistically. But there were very few respondents who said that his friend’s behavior was as normal as before, after declaration of his/her HIV positive status. About 36% of respondents of Agra were of view point that their friends showed hateful behavior because of the fear, that PLWHA may disclose the name of their company of friends. They were all involved in the deviant behavior. About 32% of the respondents of Agra told that their friends became more sympathetic with them. They have very limited friend as they were the rejected people of society. Over 16% of the respondent of Agra said that their friends were just normal after diagnosis of this status, and the
same 16% of the respondents of Agra were of the view that their friends just have changed. They said, "When they had enough money with them, they were having a lot of friends". Now they are deprived and helpless, no one was ready to have any relation with them.

Whereas, 40% of the respondents of Aligarh were of the view that their friends have just changed, 28% of the respondents told that their friends became more sympathetic with them. About 20% of respondents were of the view that their friends showed a deviation from them because of the fear, that PLWHA may disclose the name of their company of friends, over 12% of the respondents told that their friends were just normal.

Community Members

60% of the respondents of Agra and 44% of the respondents of Aligarh were depressed that no one was ready to have any interaction with the locality they belong. They felt that community people just pointed out their HIV sero-positive status among the general public. 24% of the respondents of Agra, and 20% of the respondents of Aligarh said that there was an adequate behavior of the general community with them. People from their locality were not even bothering to say "Hello, Namste, Salaam, or whatever". Most of the respondents were assuming themselves as a symbol of rejection and isolation. Over 4% of the respondents of Agra and 20% of the respondents of Aligarh told that people were feeling just normal. They belong to poor socio-economic class of the society, quite unknown about the disease. Over 12% of the respondents of Agra and 16% of the respondents of Aligarh replied the question about the behavior of community people that they were sympathetic and considering them as casual patients.

If we compare Agra and Aligarh in the context of attitudes towards respondents after diagnosis of HIV/AIDS, we found that in Aligarh neighbors are more sympathetic than Agra. Comparatively in Agra people are just normal than Aligarh. They do not want to show any emotion towards HIV+ people. But when compared in terms of ignorance, people in Agra are more ruthless and they hate
HIV/AIDS persons than the people in Aligarh who have more indifferent behavior.

3.6.3 Change of the Residence:-

Due to social pressure, it is very hard to face the community by the HIV positive people. PLWHA are considered rejected and isolated people of the society. Many of the HIV positive people are compelled to change their residence due to negative response of the neighborhood.

| Table 3.13 |
| Percentage of respondents who changed their residence after HIV/AIDS |

<table>
<thead>
<tr>
<th>Sex</th>
<th>Agra</th>
<th>Aligarh</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
<td>32%</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>16%</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>13</td>
<td>52%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:-field survey from 2008 June to 2009 March)

Regarding the change of residence, overall 48% of the respondents of Agra and 60% of the respondents of Aligarh were compelled to change their residential place due to unbelievable peer and community pressure. Everyone was trying to pull them out of their locality and people even tried to take the help of the residents of the neighboring localities for this purpose. About 16% of the respondents of Agra and 28% of the respondents of Aligarh who changed their place were females and 32% of the respondents of Agra and Aligarh were from male segment. Females were more wretched and depressed that they were considering themselves “the evil of the society”.

If we compare respondents who changed their residence after HIV/AIDS then it clear that the patients who changed their residence were little more in Aligarh in comparison to Agra.
3.7 Psychological Implications

Stigma and discrimination associated with HIV/AIDS have disastrous psychological and emotional impacts. Strong social rejection, blame of doing something very unethical, breaking the trust and faith, dishonesty, feeling guilty and ashamed, disgusting attitude of loved one's, avoidance by the companions, isolation and so on are the total output of this stigma and discrimination. All these factors affect the psychology of the affected persons in such a way that whole the personality of a person is changed all together.

In some cases, due to self-stigma, the persons with HIV/AIDS are isolated which destroy their personal and community ties resulting in deep emotional shock (Welbourn, 1995). The person is surrounded by deep feeling of guilt and anxiety as a result of which he/she thinks about suicidal attempts.

In less severe cases there is an intense hopelessness towards every aspect of life. The whole picture of life turns black in case of infected person. He thinks negative about everything. This not only affects the particular person but the associated family members especially children and friends are also encircling by his wave of helplessness.

3.7.1 Impact on School going children

Many children suffer multiple losses (of father, mother, siblings, grandparents, uncles, aunts and other relatives). In addition, they may lose friends, familiar surroundings, schooling, hope for future, and their remaining childhood. The impact of HIV and AIDS on a child starts well before the death of a parent or caretaker. Children living in household where a member is HIV positive are at risk of other infectious diseases. He or she may have to care for ill and dying family members and face the trauma of the death of their loving ones. Their distress amplified by the stigma is often associated with HIV/AIDS.

Table 3.14, reveals the psychological implications on school going children of HIV positive patients. Caring for children noted changes in their behavior during parental illness. Caretakers noted that children become worried, sad and
that they try to help more at home and stop playing so as to take care of their parents.

Table: 3.14

Psychological impact of the society on the respondent’s school going children

Agra

<table>
<thead>
<tr>
<th>Category</th>
<th>Sympathetic</th>
<th>Just Normal</th>
<th>Harsh/hated</th>
<th>Indifferent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Teachers</td>
<td>4</td>
<td>18.1%</td>
<td>2</td>
<td>9.09%</td>
</tr>
<tr>
<td>Friends</td>
<td>8</td>
<td>36.3%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Relatives</td>
<td>2</td>
<td>9.09%</td>
<td>8</td>
<td>36.3%</td>
</tr>
<tr>
<td>Family members</td>
<td>6</td>
<td>27.2%</td>
<td>3</td>
<td>13.6%</td>
</tr>
<tr>
<td>Community members</td>
<td>3</td>
<td>13.6%</td>
<td>4</td>
<td>18.1%</td>
</tr>
</tbody>
</table>

Aligarh

<table>
<thead>
<tr>
<th>Category</th>
<th>Sympathetic</th>
<th>Just Normal</th>
<th>Harsh/hated</th>
<th>Indifferent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Teachers</td>
<td>5</td>
<td>26.3%</td>
<td>6</td>
<td>31.5%</td>
</tr>
<tr>
<td>Friends</td>
<td>4</td>
<td>21%</td>
<td>3</td>
<td>15.7%</td>
</tr>
<tr>
<td>Relatives</td>
<td>3</td>
<td>15.7%</td>
<td>5</td>
<td>26.3%</td>
</tr>
<tr>
<td>Family members</td>
<td>5</td>
<td>26.3%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Community members</td>
<td>8</td>
<td>42%</td>
<td>1</td>
<td>5.2%</td>
</tr>
</tbody>
</table>

(Source: field survey from 2008 June to 2009 March)

There are 5 different stake holders of the society. On the basis of their significance, implications were measured on the school going children.
Teachers

Teachers are really the back-bone of any society. But one should not forget that they are human beings too. 54.5% of the respondents of Agra and 26.3% of the respondents of Aligarh said that teachers were considering their kids as a part of stigma. During classes, teachers tried to point out the children of patients (Malaney, 2000). Children were feeling quite disgraced and humiliated. These children are seen as a neglected part of their society through the teachers. 18.1% of the respondents of Agra and 15.7% of the respondents of Aligarh were of the view that the teacher’s behavior towards their children was entirely different. Teachers were having fear that these children might be the carrier of HIV and they might transfer it to others. They remained at an arm’s length from them. 18.1% of the respondents of Agra and 26.3% of the respondents of Aligarh said that teachers were feeling pity for children and reflecting their sympathies, whereas 9.0% of the respondents of Agra and 31.5% of the respondents of Aligarh were of the view that behavior of teachers was just normal because they were not told about the parents’ status of disease. Those poor disheartened kids could not complete even primary education because of de-motivation and economic burden.

HIV/AIDS affected children & their families

- **Child born to HIV parent**
  - 0 year
  - Risk of HIV infection at birth
  - High risk of infection, abuse, malnutrition, loss of schooling, healthcare high work loads

- **Child care for sick parents**
  - 10 years
  - Trauma of caring of sick & dying parent

- **Parent death, child is orphaned**
  - 16 years
  - Orphaned placed or with guardian

Fig. 3.4
Parents were also unable to pay very meager amount of fee of school what to talk of good schools. Globally, 115 million children do not attend primary school, and 57% of them are girls. According to some studies, 150 million children currently enrolled in school will drop out before completing primary school and at least two thirds will be girls (Filmer and pritchett, 1999).

Friends

Friends of the PLWHA’S children were innocent and really had no knowledge about the HIV/AIDS. Those who showed indifferent behavior were due to poor information from their parents and teachers. Table 3.14 reveals that 40.9% of the respondents of Agra and 42.1% of the respondents of Aligarh are of the view that the friends and kids of their schools were very harsh towards them and they hated us. These kids or children were avoided by their friends. 22.7% of the respondents of Agra and 21% of the respondents of Aligarh were of the view that the friends of their kids were reserved due to their parents’ and teachers’ indication, 36.3% of the respondents of Agra and 21% of the respondents of Aligarh discussed about the emotionality and empathetic behavior shown towards their kids and just 15.7% of the respondents only from Aligarh were of the view that the friends of their kids up to the school level were found to be normal.

Relatives:

The behavior of relatives with the kids was same as it was towards their parents. They even did not want to see them and feel that these kids would be burden after the death of their patients. They were having pessimistic attitude towards the victimized family. According to the table 3.14, there were 45.4% of the respondents of Agra and 31.5% of the respondents of Aligarh who believed that their relatives hated their children. 36.3% of the respondents of Agra and 26.3% of the respondents of Aligarh informed that their relatives are normal and behaving with their kids as usual due to unawareness of their HIV positive status. 9.0% of the respondents of Agra and 26.3% of the respondents of Aligarh were complaining about the negative behavior of their relatives. 9.0% of the
respondents of Agra and 15.7% of the respondents of Aligarh were optimistic and said that their relatives had concern with their kids and were positive towards them.

**Family Members:**

The behavior of the family for the children of HIV positive was not as normal as it should be. Stigmatization, discrimination and social isolation, dropping out of school, moving away from friends, and bearing an increased workload in the home all increased the stress and trauma that accompanied the death of a parent (Foster et al, 1997). According to the table 3.14, 27.2% of the respondents of Agra and 42% of the respondents of Aligarh were observing that family members (uncles of patients’ children) were not allowing their kids to play and even talk to the patients’ children. They might be doing this as a precautionary measure for their own children but respondents were sensing that they have negative attitude towards their kids. 27.2% of the respondents of Agra and 26.3% of the respondents of Aligarh were of the view that their relatives were having sympathetic behavior towards children. They were feeling pity on the fate of their children. 31.8% of the respondents of Agra and 31.5% of the respondents of Aligarh were of the opinion that the dealings of family with their children were entirely different as compared to their previous behavior. Such type of behavior increases the chance of suffering from inferiority complex under such distrust atmosphere. Only 13.6% of the respondents of Agra were of the opinion that their family members are just normal to their children.

**Community Members**

Fear, worries, observing and caring for ill parents in pain, stigmatization, hospital visits, shattered hope and eventual loss are all experienced by children affected by HIV/AIDS at various times over several years. Along with these, it is observed by 40% of the respondent of Agra and 36.8% of the respondents of Aligarh, according to table 3.14 that the people from the community always raised their fingers on them and their children. They were of the view that their children
are more neglected and punished by the unethical behavior of the community members. 27.2% of the respondents of Agra and 15.7% of the respondents of Aligarh were of the view that there was indifferent behavior of the community towards their children. Children were not in the position to play in the streets due to strong community rejection. Ultimately, Children were quite depressed and lethargic regarding the fearful and tense atmosphere prevailing around them. To 18.1% of the respondents of Agra and 5.26% of the respondents of Aligarh, community members were normal at least with their children. This is because that these community members were not aware of the implications of HIV/AIDS. 13.6% of the respondents of Agra and 42% of the respondents of Aligarh were of the view that the children got sympathetic behavior from community members.

While comparing it in the context of psychological impact of society on the respondent’s school-going children, we found that there are a good number of persons having sympathetic response in Aligarh than Agra and when compared it in terms of harshness, we found that in Agra people are more harsher than the people in Aligarh.

### 3.7.2 Psychological State of Mind of the Respondents

Families may experience a range of emotional reactions including fear of contagious, anticipatory grief, shame and helplessness, which create disruptions and problems in their life and personal relationships.

#### Table: 3.15

Percentage of respondent’s families shocked after the declaration of HIV/AIDS

<table>
<thead>
<tr>
<th>Sex</th>
<th>Agra</th>
<th></th>
<th></th>
<th></th>
<th>Aligarh</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td></td>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17</td>
<td>68%</td>
<td></td>
<td></td>
<td>14</td>
<td>56%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
<td>32%</td>
<td></td>
<td></td>
<td>11</td>
<td>44%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
<td></td>
<td></td>
<td>25</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Source:- field survey from 2008 June to 2009 March)
According to table 3.15, 100% of the respondents from both districts (Agra & Aligarh) disclosed that their families felt distressed after the diagnosis of their status as HIV positive. Individuals affected by HIV may be influenced by psychosocial stresses common to other chronic or life threatening illnesses, such as cancer or heart disease. But families of the patients along with them were quite uncomfortable, agonizing, hurting and painful due to social, peers’ and employers’ reactions as well.

3.7.3 Psychological States of Mind of the Respondents

Depression results from abnormal functioning of the brain. Depression is a major contributor to fatigue in patients with HIV/AIDS. Feelings of hopelessness, pessimism, feelings of guilt, worthlessness and helplessness, etc. are the major symptoms of depression and anxiety. One in three persons with HIV may suffer from depression and anxiety (Bing et al, 2002). In order to ascertain these facts, the researcher interviewed the respondents and their responses are shown in the following table No. 3.16

Table 3.16
Percentage of respondent's mental agony

<table>
<thead>
<tr>
<th>Type</th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>13</td>
<td>52%</td>
<td>12</td>
<td>48%</td>
<td>25</td>
</tr>
<tr>
<td>Tension</td>
<td>19</td>
<td>76%</td>
<td>6</td>
<td>24%</td>
<td>25</td>
</tr>
<tr>
<td>Depression</td>
<td>17</td>
<td>68%</td>
<td>8</td>
<td>32%</td>
<td>25</td>
</tr>
<tr>
<td>Aggression</td>
<td>15</td>
<td>60%</td>
<td>10</td>
<td>40%</td>
<td>25</td>
</tr>
<tr>
<td>Regression</td>
<td>8</td>
<td>32%</td>
<td>17</td>
<td>68%</td>
<td>25</td>
</tr>
<tr>
<td>Fixation</td>
<td>7</td>
<td>28%</td>
<td>18</td>
<td>72%</td>
<td>25</td>
</tr>
<tr>
<td>Suicide</td>
<td>20</td>
<td>80%</td>
<td>5</td>
<td>20%</td>
<td>25</td>
</tr>
</tbody>
</table>
While explaining the different terms regarding the psychological states of mind of the respondents, they expressed their views as reflected in the table 3.16. In the table 3.16, it is apparent that 80% respondents of Agra and 88% respondents of Aligarh who were really depressed and attempted suicide. In fact, ignorance about HIV/AIDS means that people are frightened and that frightened people do not behave normally. 76% respondents of Agra and 56% respondents of Aligarh were found with hypertension. Due to irritating behavior of the community, PLWHA become hypertensive and reflect ridiculous behavior. There were 68% respondents of Agra and 80% respondents of Aligarh who were really in the phase of depression. There were 52% respondents of Agra and 72% respondents of Aligarh who were very much anxious about their future life and curious about the status of their disease. There were 60% respondents of Agra and 44% respondents of Aligarh whose behavior was aggressive. Aggression is the outcome of a person's attempt to accomplish something that he or she is not capable of achieving and aggressive people may keep on abusing without any logic (Flippo, 1987). There were 32% respondents of Agra, and 36% respondents of Aligarh who were in the regression state of mind and resorted to show immature behavior.
Those respondents were involved in unreasonable complaining and crying for help to relieve some frustration. There were 28% respondents of Agra and 40% respondents of Aligarh who were behaving in fixation segments; fixation means redundancy of some practices without any realistic significance in fixation stage. PLWHA kept on doing the same activity again and again impractically.

3.7.4 Psychological Impact of HIV/AIDS on Respondent’s Children

According to Mckelvy (1995), children with HIV positive parents may feel helplessness, abandoned, resentment, sadness, anxiety and anger. They may take parental roles in their early ages as their parents suffer from this social stigma. If the family is not conscious about their HIV status, these children may lack confidence and other psychological sources of support that help them in the grooming of their future. Children may struggle to come to the terms with information about their parents that was disclosed along with HIV status.

From the table No. 3.17 below, a high percentage of about 72% respondents of Agra and 52% respondents of Aligarh affected persons narrate that their children are actually cut-off from main stream of society, that create the sense of isolation in them.

**Tables 3.17**

<table>
<thead>
<tr>
<th>Impacts</th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>N/A</th>
<th>%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental retardation</td>
<td>13</td>
<td>52%</td>
<td>9</td>
<td>36%</td>
<td>3</td>
<td>12%</td>
<td>25</td>
</tr>
<tr>
<td>Inferiority complex</td>
<td>17</td>
<td>68%</td>
<td>5</td>
<td>20%</td>
<td>3</td>
<td>12%</td>
<td>25</td>
</tr>
<tr>
<td>Isolation</td>
<td>18</td>
<td>72%</td>
<td>4</td>
<td>16%</td>
<td>3</td>
<td>12%</td>
<td>25</td>
</tr>
<tr>
<td>Sense of deprivation</td>
<td>12</td>
<td>48%</td>
<td>10</td>
<td>40%</td>
<td>3</td>
<td>12%</td>
<td>25</td>
</tr>
<tr>
<td>Insecurity/ Unprotected</td>
<td>15</td>
<td>60%</td>
<td>7</td>
<td>28%</td>
<td>3</td>
<td>12%</td>
<td>25</td>
</tr>
</tbody>
</table>

N/A Stands for not applicable
Table 3.1: Impacts studied among Agra and Aligarh

<table>
<thead>
<tr>
<th>Impacts</th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>N/A</th>
<th>%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental retardation</td>
<td>12</td>
<td>48%</td>
<td>7</td>
<td>28%</td>
<td>6</td>
<td>24%</td>
<td>25</td>
</tr>
<tr>
<td>Inferiority complex</td>
<td>15</td>
<td>60%</td>
<td>4</td>
<td>16%</td>
<td>6</td>
<td>24%</td>
<td>25</td>
</tr>
<tr>
<td>Isolation</td>
<td>13</td>
<td>52%</td>
<td>6</td>
<td>24%</td>
<td>6</td>
<td>24%</td>
<td>25</td>
</tr>
<tr>
<td>Sense of deprivation</td>
<td>10</td>
<td>40%</td>
<td>9</td>
<td>36%</td>
<td>6</td>
<td>24%</td>
<td>25</td>
</tr>
<tr>
<td>Insecurity/ Unprotected</td>
<td>17</td>
<td>68%</td>
<td>2</td>
<td>85</td>
<td>6</td>
<td>24%</td>
<td>25</td>
</tr>
</tbody>
</table>

N/A-Stands for not applicable

(Source:- field survey from 2008 June to 2009 March)

When they lack their company, they tend to follow the evil practices like drug abuse, burgling and violence. They are always down in every aspect of life and are never being considered as part of the normal society. 68% respondents of Agra and 60% respondents of Aligarh said that they felt poor about their children who feel deprived and feel inferiority complex in every sphere of life. 60% respondents of Agra and 68% respondents of Aligarh felt that their children are insecure. They assumed that their children were shelter-less and direction-less in each matter of their life. It is very much clear since 52% respondents of Agra and 48% respondents of Aligarh were very poignant to express that their children got mental retardation and they were having irrational fear and sense of phobia. 48% respondents of Agra and 40% respondents of Aligarh said that they felt very disgusted since their children feel deprived of the basic necessities of their life.

3.8. Awareness about HIV/AIDS

Proper awareness is the only way to fight against HIV/AIDS, due to religious bindings and cultural implications; it is an uphill task to create awareness among youth especially about their unsafe sexual behavior. Most of the people are still unaware about the causative factor of HIV/AIDS and are becoming easy victim of this fatal disease.
Table 3.18

Percentage of respondents awareness about HIV/AIDS

<table>
<thead>
<tr>
<th>Awareness about HIV/AIDS</th>
<th>Agra</th>
<th></th>
<th>Aligarh</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
<td>56%</td>
<td>9</td>
<td>36%</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>44%</td>
<td>16</td>
<td>64%</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100%</td>
<td>25</td>
<td>100%</td>
</tr>
</tbody>
</table>

(Source:- field survey from 2008 June to 2009 March)

Table 3.18 shows that 56% respondents of Agra and 36% respondents of Aligarh were aware about the HIV/AIDS but do not take precautionary steps as they do not know the consequences of this dreaded disease, whereas 44% respondents of Agra and 64% respondents of Aligarh do not have any knowledge about HIV/AIDS. This shows that there is a lack of knowledge about the HIV/AIDS disease because they are educationally backward. We can easily understand through this figure.

Fig. 3.5 Awareness about HIV/AIDS
The above table clearly shows that the patients in Agra were more aware than the patients in Aligarh, because in Agra people are very mobile and patients’ attitude towards knowing about HIV/AIDS is good compared to those in Aligarh. In Aligarh, patients are less conservative; they do not want to talk openly about their problem related with Sexually Transmitted Diseases (STDs).

3.8. Source of Awareness about HIV/AIDS

Media is really playing an important role in creating awareness among the community. A great attention is required to select the media according to the target community. Language of the message should be simple, easy and very common in the general public as expressed by the respondents.

Table 3.19
Source of awareness about HIV/AIDS Respondents

<table>
<thead>
<tr>
<th>Media</th>
<th>Yes</th>
<th>Percent (%)</th>
<th>No</th>
<th>Percent (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agra</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>News paper</td>
<td>6</td>
<td>24%</td>
<td>19</td>
<td>76%</td>
<td>25</td>
</tr>
<tr>
<td>Radio</td>
<td>7</td>
<td>28%</td>
<td>18</td>
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<tr>
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(Source: field survey from 2008 June to 2009 March)

Table 3.19 indicates that 64% of the respondents of Agra and 76% of the respondents of Aligarh knew about HIV/AIDS through television. 56% of the
respondents of Agra and 64% of the respondents of Aligarh said that printed material was the main source of information about HIV/AIDS. There was encouraging response from 64% of Agra and 76% of Aligarh while 56% respondents of Agra and 64% respondents of Aligarh got awareness about this fatal disease from television and printed material. 28% respondents of Agra and 60% respondents of Aligarh were of the view that Radio was playing a very important role in spreading the knowledge about HIV/AIDS. 36% respondents of Agra and 32% respondents of Aligarh said that friends were the main source of information about HIV/AIDS. 24% respondents of Agra and 28% respondents of Aligarh view that newspaper is the main source of information about HIV/AIDS and just 20% of the respondents of Agra and 12% of the respondents of Aligarh got information from other sources.

3.8.1 Awareness about Condom

Table 3.20

<table>
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<th>Awareness About Condom</th>
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(Source:-field survey from 2008 June to 2009 March)

Table 3.20 reflects that 48% of the respondents of Agra and 28% of the respondents of Aligarh knew about condom and its proper use. A large number of respondents indicate that they do not have knowledge about condom. Thus from it, we can conclude that the HIV/AIDS patients from Agra and Aligarh were aware about this disease but Agra (56%) patients were more aware than the patients from Aligarh (36%). The source of information about HIV/AIDS disease was mainly from media. The electronic media was more important source than other sources.
of information. These patients stated that despite of being knowledgeable about this disease, they did not take any precaution to save themselves from the HIV/AIDS.

(B). CASE STUDIES

3.9 Introduction:

This is based on the interview of the clients, family members, peer-group and the health care providers. The facts collected as stated by them and also observed by the researcher are presented in the form of case studies here. The case study given here are in the biographical form. In order to maintain confidentiality, their names have been changed but other information’s are fact-based. These case studies are analytical and inferences have been drawn accordingly.

3.10 Findings of the Qualitative Study:

There were 50 HIV positive patients, in which 25 in S.N. Medical College, Agra and 25 in J.N. Medical College, Aligarh separately, including 12 males and 8 females in S.N. Medical College, Agra and 14 males and 6 females in J.N. Medical College, Aligarh who were interviewed in depth after creating complete enabling environment of love, care and privacy. In-depth interview of each patient was conducted by the researcher.

CASE STUDY CONDUCTED IN AGRA:

CASE-1:

Profile-Mr. 001 (real name has been changed), 26 years of age, a young victim of HIV/AIDS. He is working in an NGO working for the welfare of HIV/AIDS patients in Agra.

How he infected:

Mr. 001 has cheerful personality with an attractive smiling face. When he was asked how he was infected with HIV, he started telling his story in a very low voice and subdued way showing signs of sorrow and pains in his face. According to him, he was engaged with the automobile spare parts business at Shah Ganj,
Agra. He had his own shop. One unfortunate day, he was unloading the goods from a truck carrying the waste of hospital, like used syringes, lincon etc. He slipped and fell on that heap of syringes and got multiple pricks all over his body. Following this event, he developed fever for quite a few days and was cured completely, but at that time, he was totally unaware of his future destination.

About the diagnoses of his sero-positive state, Mr. 001 told that like every young Muslim he is very keen to go to Saudi Arabia to perform Hajj. For this purpose in 2004, he underwent a screening process at Agra. The result of his screening report was shocking, as he was suspected to be HIV positive and this suspicion was confirmed with certain other diagnostic tests later on conducted on him.

Feeling after Diagnosis:

What was the response of his family and friends when they came to know about his HIV status? Mr.001 replied that “this news was a shock not only for me but also for my family. Neither me nor my family were ready to accept this fact that I am HIV positive. Friends and relatives as they know me were not ready to accept this fact.

After this he noticed a marked change in the family attitude towards me. Being youngest of four brothers and sisters, I was very dear to my family members. Though they were scared with me.

Effects or Implications:

There were some immediate effects of this bad news on Mr. 001. He narrated that he left his spare, parts business, as he became hopeless and dejected with his life. He also developing a feeling he may be rejected by including his near and dear ones. In real sense he even some of friends stopped talking to him for fear of the disease as they may also be affected.

When Mr. 001 came to know about his HIV positive status, he announced the cancelled of his engagement. The only reason Mr. 001 knew about his strange
decision was that his fiancé was very dear to him and he did not want to hurt his loved ones, as he was very clear about his future life.

**Society’s Attitude:**

Mr. 001 was also very annoyed with the behaviour of health care providers including doctor, nurses and paramedical staff. He told that in the beginning when he was very sick with almost no immunity, he was admitted in S.N. Medical College, Agra. He became suspicious and scared of the visitors that they are simply coming to see me as a HIV/AIDS patient, but are avoiding close contact with me. He was in miserable condition and was crying for help but nobody was paying attention. Recalling this, Mr. 001 said that those were worst days of my life. He was about to die when Allah helped him and gave him new light of hope in his life. Some one working with an NGO rescued him on time and helped me for proper treatment and car almost near normal life. Now he has started working for the welfare of the people living with HIV/AIDS by associating with an NGO.

Mr. 001 said that PLWHA only need a little more care and attention a loving attitude, a caring behaviour of their loved ones. This is the only life saving “drug” in the form of love, which can add few more beautiful and comfortable moments in the life of the PLWHA. ([Source: interview with the Sufferer](#)).

**CASE 2:**

Mr. 002 is Twenty- two -year- old and a rickshaw puller is an unmarried boy. He is five feet and three inches tall. His native village is in Bihar and he came to Agra when he was ten years old. He keeps himself fairly well dressed as compare to other rickshaw pullers. Mr. 002 always wears a shirt and pant. He never wears a ‘lungi’ or a ‘kurta’ like many others in the same occupation. His hair is well oiled and neatly combed always.

Mr. 002’s father died when he was a child of 2 years still an infant. He had only his mother and an elder brother. Though the family had a small piece of land on which some cash crop was grown, his brother did not show interest and soon had to part ways. This was not the end of the family’s woes. 002’s upper right arm
was mildly paralyzed due to polio which he suffered while he was only five years old. His mother tried several traditional methods of treatment with only a marginal improvement in his status. When Mr. 002 was ten years old and studying in class fifth, his mother sent him to Agra to stay with a relative so that he could get good education in the city. But very soon, the promise of helping 002 to get good education was breached by the so-called relative and 002 was left to fend for himself. Mr. 002 tried very hard to find some work for himself so that he could earn for his survival. After many efforts, 002 was finally able to get work as a washer boy at a fruit-juice shop. Although he toiled hard and washed glasses from morning till night yet, he was not able to send some money to his mother back home in the village.

The hope of getting some good work took Mr. 002 to Delhi. There he managed to get the work of a waiter in a small hotel. He worked as waiter for two years and during these two years he had premarital sex with a commercial sex worker in one of the brothels in Delhi. Mr. 002 told that he developed a liking for this girl and used to visit her once a week. He used to pay Rs. 100-150 per visit. The girl revealed about her past to 002. She told him that she had come from Bengal to Delhi in search of a job. Once a “Baba” (spiritual guru) met her on the Delhi station and gave her a “ladoo” (traditional Indian sweets) laced with some drug. After eating it, the girl lost her senses and the “Baba” raped her. Thereafter, she was sold to one of the brothel in Delhi.

Mr.002 said that he was in love with this sex worker because of her looks and wanted to marry her. He asked her to run away from the brothel with him but she refused, as she was afraid of running away from the brothel.

As he was rejected by the girl, he was a broken man and decided to return to Agra and started looking for a job, but was not successful in getting one. With no money in hand he started living on the pavement of the M.G Road in the Rajamandi. There he came in contact with a few rickshaw pullers who too were living on the same pavement. One of them became a friend of 002 and offered him
help by getting him a rickshaw on rent. Mr.002 started pulling the rickshaw but this was not easy for him because of his partially paralyzed arm. Mr.002 says that he feels very tired soon and can not pull the rickshaw for long durations.

In spite of his poor financial status, 002 visits the brothels frequently to satisfy sexual urge at the brothels. He treats some of these women as his steady partners.

Mr.002 does not have access to a T.V. or a radio, as rickshaw is all that he has. He is also not fond of reading a newspaper. He says that he has not seen/heard any AIDS awareness massage but he knows that AIDS is dreadful disease. On being asked as to what causes AIDS 002 promptly replied, “people having sex with commercial sex workers only get AIDS.” Although 002 too had sex with commercial sex workers but he did not perceive himself to be at risk. Mr. 002 justifies saying that “I have had sexual relations only with three particular sex workers whom I know well. Moreover all these girls have been healthy looking and do not show signs of any illness as such.” Mr.002 admits that although he has indulged in different types of sexual practices including anal and oral sex and that he has never used a condom. According to him, condom acts as barrier and kills the pleasure.

Mr.002 knows about STD and has suffered in the past. He said he took treatment from a nearby doctor for his ailment. 002 had very low level of awareness regarding HIV/AIDS and thought that AIDS could be cured. He also believed that a person with HIV/AIDS could live a normal life as lived by other normal person.

However, the post-intervention period saw the dispelling of some of the crucial misconceptions. For example, Mr. 002 now perceives himself to be at risk of HIV/AIDS due to his indulgence in unprotected sex with sex workers in contrast to his notion prior to the intervention. He now knows that HIV/AIDS is not something, which immediately shows signs of itself. He is regretting for his ignorance and his past indulgence for pleasure.
Mr.002 is still thinks that use of a condom provides less enjoyment and he shows reluctance to use the same. He was being mobilized to have a safe sex by using condom in future. *(Source: - Direct interview with the patient).*

**CASE 3:**

Mr. 003, a middle-aged man of 45 years, who is HIV positive, narrated his story that he worked in Delhi for about 6-7 years. During his stay, he earned a lot and sent the whole money to his family in Agra. He said, “I was away from my family for quite a long time. I started visiting sex-worker in order to satisfy my sexual urge. Mr. 003 said, “This was a natural need and instinct of human, so I was helpless. I probably got infected by HIV through unsafe sex.” His general health deteriorated rapidly when he was diagnosed to be HIV positive. He returned to his home to have full family care and love. Mr. 003 was very sad to tell his loved ones for whom he had spent golden days of his life away from his home working hard. When he needed them in such critical period of his life, his family members turned their faces and were very cold towards him. There was such a strong rejection and repulsion of hate from his family especially his wife that he did not want to live any more. His wife did not tolerate him for even a single day and she left his home with her kids saying that from now on. “She had no relation with him and he should not dare to contact her again.”

Although Mr. 003 was being treated with ARV drugs now a days but his condition was miserable. He was having no hope for his life. He was more deprived of the love and affection. More over he got no financial support on permanent basis, so his prognosis was not very bright. *(Source:-Through interaction with the patient).*

**CASE 4:**

Case 4 is related to Agra who reported in S.N.Medical, for treatment. I came in contact with the patient in Gynaecology Deptt. Where she was refused for certain test. Case 4 a young lady of 25 years and was very beautiful. She was smiling while waiting for someone. I greeted her by saying Namaste and enquired
about her health; she also greeted me and told me that she is waiting for the
doctor. I also wished to doctor who was with her. On my enquiry, the doctor told
me about her health condition. Then I started informally talking to Mrs. 004 about
her background, family life and her relations with the husband. She narrated that
she was married 6 months before. Her husband was not satisfied with her as she
was having some problem in her personal part. She was having ‘Vulval’ growth.
In the beginning before marriage it was aggravated and she was divorced. As she
started thinking for remarriage, she went for medical check-up. On that day she
came for this check-up

Although, the story of patient appeared vague, on examination by
gynaecologist, the growth was diagnosed provisionally to be viral warts. A minor
surgery was planned, and her biopsy of warts was taken and specimen was sent for
his to pathological test. At the same time, her two blood samples were taken and
subjected to HIV screening at two different authentic laboratories.

According to gynaecologist, vulval warts were many in number and
complete cure was not possible in one sitting. Therefore, it was postponed till next
session after two weeks. Meanwhile, her biopsy report was available and diagnosis
was confirmed to be HIV positive. Mrs. 004 residential address was incorrect
which she had given on admission forms as she wanted to hide her identity.

After her release from the hospital, she disappeared and never came for further
treatment. I tried to contact her on the address given by her, but the address was
not correct. It seems that her act was knowingly done just to hide her identity.

What is her present status, nobody knows probably she might be
transmitting the death silently to so many. There is a strong suspicion that she may
belong to red light area adjacent to S.N. Medical College, but this is just a
supposition. According to interview, “the warty growth gives a clue towards
unsafe sexual behaviour of the affected person. Mrs. 004 might have concealed
certain information out of fear or shame.” *(Source:-Through the direct
interaction with the sufferer).*
CASE 5:

Forty years old, Mrs. 005 earns a livelihood by working as a commercial sex-worker in one of the brothels in Agra. She is five feet and three inches tall and the contours of her body clearly depict her middle age. She has two daughters and a son who live in her husband’s native village in Agra district with one of her distant relatives.

Mrs. 005 qualities to be a true representative of an uneducated woman braving poverty, exploitation and injustice. She nostalgically remembers her childhood years when she used to live happily in Agra with her mother. She never went to School, as she was needed to look after her mother. Time passed by and she entered into her teens. She fell in love with a neighbour and slowly and steadily, their relationship turned into physical intimacy. Because of the fear of her mother, she eloped with her love one day. She stayed with him sometime and then after being exploited by the lover she was sold to one of the brothels. With nowhere to go and no one to complain, she accepted her fate and started practicing sex-work in order to survive. Now it has been a long years since she took to full-fledged sex-trade.

She says that there have been many ups and down in her life during all these long years. While practicing sex-work she again fell in love with one of her clients. The client too had a liking for her and finally one day he proposed to marry her. She was very happy as she too dreamt of having a happily married life with a home and children of her own. By then, she was on the verge of entering middle age and did not have many customers thus the brothel owner did not create any fuss in allowing her leave the brothel with her would-be husband.

In the preceding few months her so-called married life was filled with joy and happiness although she says that the man never married her openly in public. Over the next few years, she had three children born in her questionable wedlock. As time passed by, things started taking a turn for the worse. The attitude of her husband towards her started showing many signs of ill-treatment. Frequent
arguments started turning into fights and one day during one of those heated fights her husband beat her up, abused her and threatened to leave her back at the brothel. She with deep anguish and sadness verbalizes what her husband said, "Tuzh Jaise dhandha Karne wali ki jagah kothar par hi hota hai" meaning "whores like you only deserve to live in a brothel." She was humiliated and equally infuriated at the unjust behaviour of her husband towards her. She realized that all the years that she had put into her marriage with this man and all the time that she had given for bringing up her three children from this man had just gone in vain.

So perturbed was she with the feeling of worthlessness of her life that she herself returned to the brothel she said good-bye to. But now she was well in her middle age and thus, earning by sex work too was not easy or lucrative for her. Yet with no other skills or options on hand, she held on to her old profession.

As of now, she is not able to get more than two-three clients for herself per-day. She laments, “sab grahak choti-choti ladki mangte hai”, meaning “Every customer wants a young girl.” Thus, she is frequently seen sitting near the stairs of the brothel and trying to help fellow sex-workers who are young in age by fixing up customers for them. If the deal strikes, she gets a share of 10-20 percent from her fellow sex-workers for helping them find a client. She is addicted to chewing pan and tobacco. She says she feels good after eating them. She is a doting mother and has not told about her occupation to her children in order to avoid a feeling of low self-esteem amongst them as well to protect them from social discrimination. She some how manages to send money to her relative in the village so that her children are able to go to school and get educated. She hopefully says, “Main chahti hoon ki Mere Bacche is Dhande Mein Na pare. Wo padh Likh kar Kuch Aur Karen”, meaning I do not want my children to enter into this trade. I wish they get educated and do something else”. She visits her children once in every one to two years. She sometimes feels sad as she has no contact with her mother at all and does not even know if she is alive or dead. Slowly and steadily one day she feels something and go to near a hospital in S.N. Medical College, Agra because
she heard about HIV/AIDS as before. As she knows about HIV/AIDS, she honestly admits that she is not a position to insist for condom usage to all of her clients and she was only aware about the sexual mode of HIV transmission and prevention. Most of the time she prevails on her client to use condom before sex. The fear of losing her clients due to insistence for condom usage hinders her from having consistent condom usage with all of them. When asked if she suffered from any sexual transmitted disease, she firmly replied in negative. She said she never had any such disease because she always kept herself clean. But with a little bit of probing, she agreed that she sometimes suffered from the problem of itching in genital areas for which she applies medicated cream to get relief. She believes that the problem of itching is quite common in other women too, and that it is caused because of excessive heat in the body. But suddenly this problem takes a very big problem in her genital parts. She registered in December 2006 of microbiology dept. in S.N. Medical College Agra. Rapid and Elisa tests were done and reports were in favour of HIV-positive, which was expected. She gave another symptom like fever and feels very laziness and tied ness. She accepted that as far as the range of indulgence in unsafe practices is concerned and she agrees without much inhibition that due to the insistence of certain client and because of her economic need to do, she has at times practiced unprotected intercourse.

When she heard that she is HIV/positive, and then said “ye to Hona Hi Tha. Jis Dhandhe mein hoon us Dhande Mein ye Koi Buri Aur Bahut Bari Baat Nahi hai, Ab Main sirf Apne Bachcho ke liye Pareshan Hoon ki Ab Unka Kya Hoga. Ab to Mera time gaya,” meaning this is to be happened. This is not a big news or shameless news in which type of profession I am, I am just fear about my children that what would happened with them”.

After diagnosis, she is taking medicine properly but she wants to die as soon as possible. She plainly defends her complacent attitude by telling, “Ab Kya farak parta hai, jo hai so hai” meaning. Now how does it matter, whatever has to happen will happen? (Source: - Direct interview with the sufferer).
Case-6

Mr. 006 is a forty two (42) year old man and has whitish complexion. He has grey hair and wrinkle on his face. He is plain looking and has very reserved nature. The pressure of life, it seems, has sobered his sense of dressing up. His appearance is very neat and soothing.

Mr. 006 is an educated married man. He lives in Agra and he has two children, one is male child and other is female child. His wife is also literate and a good homemaker. He was a computer operator and he was earning well. He is a religious person and believes in God very much. He tries to offer five times pray to God. Mr. 006 was a simple man who lived happily with his wife and children and other family members. His family is joint type of family.

Days passed by and one day, he had suffering from stomach ache and went for a routine check-up in near by hospital, then after he admitted in S.N. Medical College. Agra and some tests are required. All tests did properly and consciously. One test was in Microbiology department of S.N. Medical College and that test was for HIV, then he diagnosed as a HIV positive. He was unsure about his histories. When I asked during my field visit about his histories, he looked very shameful. But when I ask repeatedly with very politly he said, yes a three or four months ago, I made a relationship with a commercial sex worker in Agra, under the peer-influence. He said the situation in which duration he made a mistake, “when I made physical relationship with a commercial sex-worker that time my wife had some problem and I can not make relationship with her”. This type of feelings, I shared with my friends and one day they came near me and said, lets go somewhere for enjoying and passing time. I was ready for this and my friends said, now you do not worry. Today, we will take you out for some pleasure and enjoyment.

Then they took me to a brothel. I was surprised and questioned,” why we are coming for here?” They smiled and say you leave aside your problems and worries. This time, is for pleasure and enjoyment only, do not think any thing. You
just amagazing this and enjoy it. Today we all are enjoying. After that, Mr.006 and his all friends had sex with commercial sex-workers and after gratifying themselves, they came back from the brothel.

After this pleasurable incidence a gap of some period, he was feeling unhealthy and always tied. When he went a doctor and shared all the things. Then he diagnosed as HIV-positive through Rapid test and Elisa test and registered in S.N. Medical College in December 2007.

He heard about his own status, got very depressed and frustrated. He was not able to think anything like what was wrong and what was right. When I asked to him during my interview about this situation and problem he stated that “Jab mane suna to mere ankhon ke samne andhera chha gaya, aisa laga ki meri sari dunia ujar gayi, aur main Barbad ho gaya, ab main kya karunga” meaning when I heard about this disease. I shocked and I feel I lost the world and I spoiled; now what I will do?”

Due to depression and frustration, he does not work properly. He always thinks negatively and his mind is diverted all the times. He does not want to say anything with others. He has a rigid type of personality. He loosed his confidence.

For this, he does not want to talk any body and does not want to meet anyone. He always refused for visit and participating in any activities. During the interview, he was pleasant but seems confused by some direct questioning. His mood is very depressed, and his affect was blunted but mood-congment.

His office members came to know about his disease he was ignored by them and finally he was out of his job. His office mates did not gave positive response and do not have any attachment and humanity towards him. When he lost his job, after that he and his family member suffering financial problem.

His wife is supportive and trying to have a good mood and always encouraging. Mr., 006 feels very guilty and thinks about suicide and two or three times, he has been tried to attempt a suicide.
At present, he connected a network of HIV/AIDS in Agra and earns some money through network project and training of PLWHA. *(Source-Through interaction with patient and patient's family members).*

**Case 7 & 8**

Mr. 007 and Mrs. 008, a couple acquired HIV/AIDS on their way to life innocently. When the couple was interviewed Mr. 007 was 35 years old and belonged to a Taj ganj locality in Agra. He said that he belonged to a poor family with two brothers and two sisters.

He had a poor and illiterate family background that has further suppressed his financial and social status Mr. 007 had a small ‘dhaba’, which was the only source of income for the family.

Mr. 007 acquired this lethal infection from his partner Mrs. 008 to whom he had married after a long struggle. This was the first marriage of Mr. 007 while second marriage of her wife. About his life partner, Mr. 007 told that Mrs. 008 was also from the same village. Mrs. 008 was formally married to an army man named, Mr. X, under social and emotional pressure. Her husband went to one place to another place without his wife; there he had unsafe sexual relations with multiple sex-workers to fulfill his natural desire and to compensate his homesickness. When Mr. X turned back home, he transferred that infection to his poor wife without telling his HIV status to her, this transmission was doubt, through sexual route.

After few years, he died because of complications of AIDS. After death of Mr. X, Mrs. 008 was diagnosed to be HIV positive four years ago since the death of her first husband, 008 had to pass through a real crucial time. She was the target of social rejection and hate, as everybody in the village knew her HIV status. Meanwhile, Mr. 007 was attracted towards 008, and in spite of knowing her HIV status, he proposed, as she was reluctant. But on continuous and persistent request, she explained her HIV status to 007 and possible future consequences.
Mr. 007 said, “I am ready to bear all the consequences, I ensured you about my support and care, I know it is not your fault, I do not want you to face the pain of this problem alone, I want to share the pain”. He further said,” I am human being, a human being must help other human being in the needy hour. I think this is the right time to save humanity”.

He expressed these views emotionally, he knew that he had received HIV from his wife, but she was innocent and that was not her fault. She also innocently and unknowingly got the virus from her ex-husband who did not care and inform her. She sacrificed for her married life and became victim of HIV/AIDS. Now why should she suffer alone a dark future he sacrificed for her and they were leading a happy life.

Mr. 007 told,” His immediate family members reacted negatively in the beginning but with the passage of time, things improved and now they were really supporting and caring them.”

Regarding their friends, Mr. 007 explained that, “When his friends came to know about their HIV status they started hating and ignoring them. That was really very painful and they were very upset about their attitude. We locked ourselves at home, as social rejection was very difficult to bear. Then one of our friend who himself was HIV positive, visited them and encouraged them to face the realities of life. His personal example was in front of them. After-ward, they started convincing their friends about the fact that HIV/AIDS does not spread by greeting, meeting and taking care of PLWHA. As a result of all these efforts, now all the friends were our supporting hands. About ‘Mrs. 008’ HIV status, she told, “it is more than 4 years now when she was infected with HIV. During the last few months, she was permanently suffering from fever, diarrhoea and cough. Her CD4 level was checked which turned out to be 281 only. Very minor ailments were proving very serious for her, so she started taking Antiretroviral (ARV) drugs. Since Mrs. 008 was using ARV, now she was not only healthy but was active in other family affairs”.

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Seeing the interest, honesty and confidence, one of their sincere friend helped Mr. 007 to restart his own ‘dhaba’. Due to that rehabilitation step, now Mr. 007 and his wife were very happy and contented with their life. In their special message couple said, “PLHWA should take courage and came out because AIDS is not a sin but a disease like so many other diseases. Still there are many ways to coop up with life’s ups and downs. They need to advocate ‘for rights and needs. Let’s get together for the noble cause.” (Source: - Direct interaction with the sufferer).

CASE STUDY CONDUCTED IN ALIGARH

Case-9

Mr. 009 is a thirty-two year (32) old man. He is a native of a village in Aligarh Dist. in Uttar-Pradesh. He is about five feet and five inches tall and well built. Mr. 009 is usually seen wearing a printed shirt and a dark coloured pant. He mostly sports a pleasant smile and is willing to talk and be friendly. He has been married for the last thirty years and his wife 28 years old. He has a joint family along with his wife and three married children, live together is their native village. The family owns a piece of land, which is cultivated in order to run the household expenditure since the income earned from agriculture is not enough, he had to search for some other work, since childhood he was found of driving and thus, came to Bombay and learnt how to drive a truck and other things very earlier. He got a driving license and started working as a truck driver for a transport agency in Bombay. The truck is owned by the owners of the transport agency while Mr. 009 is paid a monthly salary of Rs. 6,000.

Mr. 009 has to stay away from his home for most of the time due to the nature of his job. Sometimes, when he has to transport goods on a long route he is separated from his family for up to six months or so. On an average, Mr. 009 remains away from his family for 2 to 3 months at a stretch. Sometimes Mr. 009’s family has to face crucial problems while he is away from home.

Besides his family, Mr. 009 too faces living problems because of the nature of his work. For most of the time, while 009 is in Bombay waited for a tour to be
fixed up by his transport agency he has to park his truck in the parking lot of the Bombay railway station. The parking lot serves as a waiting place for most of the truck drivers. He laments that sometimes when a suitable tour is not fixed up then he has to wait endlessly in his truck in the parking lot itself. Besides coping up with long and timing waiting hours during pick summers and chilly winters, he has also to put with a major lack of basic amenities such as adequate shelter and toilet facilities near by.

He says that driving a truck is not easy task. It needs a lot of stamina and alertness on the part of the driver. He further convinces, “I have to remain awake mostly at nights because driving trucks for the purpose of transporting goods is allowed only during night hours. Most of the time when other people are sleeping, drivers are on the steering wheel driving alertly”. He quickly adds, “It is very important to transport goods carefully at the place of destination. If there is a little bit of carelessness on the part of the driver leading to an accident then he may not only lose his job but his life too”.

Mr. 009 has been on the job of driving a truck for the last eight years. He points out—“it has been a long time and during all these years I have experienced and learn many new things-some good ones and some bad too. Apart from smoking bidi, I occasionally drink liquor once or twice in a week. On an average, I usually spend Rs.40 per day for buying cigarettes and sometimes tobacco too. But on days when I buy a liquor bottle for myself, I have to part with Rs. 80 to 100”. Mr. 009 honestly admits that he had pre-marital sex with four local women of his native village. But he is quick enough to justify his acts by saying that such relations are quite normal and acceptable as “love/attachment” during youth. He admits, “I never used any precaution (i.e. condom) while indulging in such acts. I did not feel the need to do so because I knew all my sexual partners well by face. I believed that since all my sexual partners were good looking without showing signs of any disease thus, they were healthy and could not pass on any infection to me”. Mr. 009 also says that he always thought condom acted as a barrier in
deriving sexual pleasure. Thus after marriage he put the entire responsibility of using a contraceptive (pill) on his wife.

Mr. 009 shyly admits, “Since I have to stay away from my wife for long periods, visiting commercial sex-workers once a while has become a need for me like many other truck drivers”.

He reports that at the insistence of some sex workers he sometimes used a condom while having sex with them but the fact remains that consistent condom usage has not been practiced and several unprotected sexual transactions have already taken place. Mr. 009 has been visiting around three to four different sex workers every month.

Although Mr. 009 earns only Rs. 4500 per month yet, he spends around Rs. 1500 on his addictions for cigarettes and liquor and Rs. 300 per month for indulging in extra-marital sex with commercial sex workers. Still, he says he does not mind spending so much on himself as he needs to relieve himself of stress and strain.

Mr. 009 has sometimes in the past suffered from STD as concluded by the symptoms reported by him. But he calls the problem of STD as “garmi ki bimari” meaning a disease caused by excessive heat in the body. He casually says that these problems are common occurrences and are cured on their own. Thus, he has never felt the need to go to a doctor for treatment purposes. Further, even during the episodes of being infected with a STD, Mr. 009 has not used a condom, as he is unaware of the fact that sexually transmitted diseases are highly contagious. He also reported to have suffered from a STD in the six months prior to the pre-intervention period of the study.

As far as his knowledge regarding HIV/AIDS is concerned, Mr. 009 says that prior to the intervention he knew about AIDS as a disease as he had seen an AIDS awareness message being displayed on a public train in Mumbai. But, he humbly admits that he was not able to understand the contents of the massage. He could only understand that AIDS was a diseases primarily caused by having sex with
commercial sex workers and because of needles used for injecting purposes. Other vital aspects of the disease such as HIV transmission modes, symptoms of the disease were not understood by him. He strongly believes that men and women should not have sexual freedom like men because he feels women are the weaker sex.

The range of unsafe practices followed by Mr. 009 vary from practicing unprotected sex with four local women in his village as well as commercial sex workers in cities to sharing of shaving blades with his fellow truck drivers. Mr. 009 says that he has been frequently injected for various medical reasons but he does not know whether new needles were used for the purpose.

After the intervention Mr. 009 reported that some major changes had set into his life. He knew about all the four HIV transmission modes as well as the procedure and availability of HIV testing facilities. Mr. 009 also realized that knowing a woman by face is no guarantee of safety in matter of sex. Using a condom is a safeguard that he knows now.

Although he has planned to give up the practice of having extra-marital sex with commercial sex workers and thus, has not visited a sex worker for quite sometime now. He said that if ever he visited a sex worker in future he would surely used a condom. Mr. 009 now does not share shaving blades with his friends any more as he knows that it may be risky. A major change was also observed in the attitude of Mr. 009 towards people living with HIV/AIDS. For instance, prior to the intervention he was not sure if he would continue to live with his wife in case she got infected with HIV, while in the post-intervention period Mr. 009 confidently said that he would live with as well as take care of his wife if she ever got infected with the virus. This change in attitude reflects a positive shift in favour of people living with HIV/AIDS. (Source: - interview with the sufferer).

Case:-10

Mr. 010, 23 years old, is a charming and smart young man coming from a rich family; he is quite well-dressed. Currently he is pursuing B. com from
Aligarh. He is the only child of his parents therefore, he has not told them about his being HIV-positive.

He lives here without his parents and along with friends. There is no any boundations in his life for what I am doing and not. One day he and his friends planned for visiting Delhi for enjoyment. Then he and his all friends visit Delhi. They already talked about pleasure and were in very happy mood in Delhi. All were young and in very enjoyable mood. All friends insisted to Mr.010 that sex is a very pleasureful and if you make this possible for one time then you automatically want this always. You will fill just like a heaven. There is no any beauty in this world to compare this.

Mr. 010 agreed for this relationship with commercial sex-workers after convincing by their friends. This happened three or four times end after some duration he filled some inner problems. He striked his own work because, he was educated and had knowledge regarding this, he immediately went in J.N. Medical college for testing HIV. Then he found HIV positive and this news was very shocking for him.

He was infected with the virus through a commercial sex-worker. Even though he was educated and had knowledge about the disease, he still did not take the necessary precautions and is thus suffering the consequences. He afraid of informing anyone about his disease because he dreads being rejected and ridiculed by society and specially his family members and relatives.

He is severely depressed and dejected. His disillusionment with society is very prominent when one, who knows about his condition, meets him and asks about his opinion of the people around him. He used to be a lively person, enjoying life and taking it as it came. But since the time he has learned about himself being infected he has lost interest in life and all the material things this world has to offer. (Source: - Interview with the sufferer).
Case: - 11

Mr. 011 was a middle-aged man who faced discrimination, social rejection and mental torture due to his HIV positive status for the last more than one decade.

Narrating his story he told, "He was diagnosed to be HIV positive when he was in Delhi. There he was working as a labour in a factory. Doctor performed his confirmatory blood tests, and he was diagnosed to be HIV positive. He further said, "When his status was disclosed. People ostracized him. He was hated”.

Recalling the behaviour and attitude of his family and friends while back home to Aligarh, Mr. 011 told, "I was afraid of being terminated as a member of that family. Though I never wanted to hurt my family members. But when I was deported back to Aligarh only my wife there to receive me with open arms when I saw the behaviour of my friends and community members, I was thinking, it would be better to die than spoil the lives of my family members. I felt isolated and alone. It was a horrible experience.”

He further added that no body was ready to talk to him or even took at him. He often felt seriously sick and when he was taken to hospital most educated class of society, doctors and nurses, were reluctant to treat him. They behaved badly with him. They even cursed him and every body wanted to see him once as it he was a monument. He did not want to recall even those painful days when he was thrown into hell. It was fortunate, that his wife and children are HIV negative. They were the biggest support to him.

Mr. 011 kept on struggling for PLWHA. He had worked very hard for the last some years to create awareness about HIV. He associated with an organization, which is working in Aligarh for PLWHA. He was contented with his efforts.

He said that he was thankful to God, for giving him the courage and ability to help those poor victims who got this infection. He said that HIV positive people are still hiding themselves. They should come forward because sickness is not a sin. They have to live a positive and meaningful life. Doctors and medical staff
need to be trained properly. Medical institutes must include special feature of HIV/AIDS treatment in training program and Government should strictly check.” *(Source: - Direct interview with the sufferer).*

**Case:-12**

Mrs. 012 a 37 years old well-groomed and maintained woman, resident of Iglas (a block in Aligarh) having three kids, got affected with this disease due to her husband. She was diagnosed HIV positive two years back. She was an educated lady who had got complete information about the disease but her husband kept her in dark and did not inform her about the disease. She got affected in innocence and due to the blind trust that women have in their husbands. Her husband was a business man. He was goldsmith and was often visiting Delhi in connection with his business. He was heterosexual and often visited brothels to satisfy his sexual urge. During this journey he started feeling week and noticed various health problems. He consulted doctors but of no use. He was advised to go for ELISA test which he reluctantly got it done. The test tested him positive. Despite of the fact known to him only he continued to have sex with his wife. The unfortunate women was infected by her trusted husband either due to utter carelessness or just to satisfy his lust without bother for his wife life and health.

After she was diagnosed positive, she said that the attitude of relatives’ friends and community was very pessimistic. It was difficult to tolerate it. She added that time was more painful than disease and she was compelled by the social pressure to shift her residence.

Despite the fact that both husband and wife were HIV positive, their kids are HIV negative. She was getting ARV’s but she was appealing to Gov. of Uttar Pradesh that the HIV/AIDS patients name should be kept secret/confidential and the violators be punished severely. *(Source: - Direct interview with the patient).*

**Case: - 13**

Mr. 013, a middle-aged poor man who was a victim of HIV/ AIDS. He was a shopkeeper by profession. When he was asked how he got HIV infection, he was
not very sure about it. To him, in 2005 he consulted a local quack (who claims himself to be a doctor) for flu and fever. Mr. 013 was given an intravenous injection for his fever as per routine of that “doctor”. After 24 hours of this injection, he developed severe jaundice. Again, the same “doctor” treated jaundice and during the treatment, many injections and intravenous infusion were given to him. After few months, he was found to be hepatitis-C positive. His hepatitis status passed through phases of remission and relapses and every time he took treatment from the same, self assumed doctor. According to Mr. 013, repeated use of un-sterilized syringes and pricks by infected needles was the source of transmission of HIV/AIDS to him and probably he was right to say so.

Answering the question how was he was diagnosed to be HIV positive? Mr. 013 said that over a period of time he started feeling quite lethargic and general weakness. He got his different blood tests done and was found to be HIV positive.

Narrating his family life as an HIV positive person, Mr. 013 told that he was living a very happy and satisfied family life. He was father of two sons. His wife was a very cooperative lady and she became even more loving and caring since Mr. 013 is diagnosed to be HIV positive.

When Mr. 013 was inquired about the HIV status of his family members he told that his wife and both sons were tested for HIV/AIDS and by the grace of God they were found negative.

Describing the attitude of his friends and neighbourhood Mr. 013 told that most of his friends did not know about his HIV status and those who knew the disease show different behaviour. He was more hurt from the educated community and according to him; the educated persons behave more rudely as compared to uneducated poor fellows.

Mr. 013 was a shopkeeper by profession. To him his business situation fluctuated with fluctuations in status of his health. He earned a reasonable amount when his general health was good and his family suffered an economic crisis, when he was not feeling well in general.
At present, Mr. 013 was taking ARV drugs and his present CD4 level has improved a lot as he was still on drugs. These drugs were provided to him by ART centre in J.N. Medical College, Aligarh.

Giving his conclusive message, Mr. 013 said that awareness regarding HIV/AIDS really is the need of the time. For this purpose, main target should be educational institutes where students should be told all facts and figures about HIV/ AIDS so that worsening condition of HIV/ AIDS and PLWHA could be given a powerful support. Moreover, he said that PLWHA should be encouraged to discuss problems with general population and the fear of rejection and curse from their fellows, family and friends is needed to be eliminated so that PLWHA could spend their remaining life in peace. (*Source-Direct Interaction with the Sufferer*).

**Case:-14**

Mr. 014, 29 years old man, a resident of Jamalpur, Aligarh, is an unmarried. He is five feet and four inches tall. He keeps himself fairly well dressed. He always wears a jeans and shirt. His hair is well oiled and neatly combed always. He is illiterate and never went school.

In his family, he has mother, father, two younger brothers and a younger sister. His father worked as a labourer and there was always shortage of money. One day Mr. 014 connected to an entertaining party who worked in Aligarh. He was attached with this entertaining party for the last five years. The main purpose of this party was to providing entertainment on various occasions like dancing on marriages and sometimes providing sexual facilities as well. In his entertaining party both male and female members worked and they are closely in-touch with each other. Mr. 014 was a senior member of his party. He had sexual relationship with his female members working in this entertaining party for fulfil his own sexual desire. For them this was not a big issue to have a sex with anyone because their profession allowed such type of activities and no will bother about that matter.
Mr. 014 was detected very accidentally on the death of his young colleague (partner) by liver cirrhosis. She was a commercial sex-worker, Mr. 014, being a good companion, went to hospital for blood donation. His screening report was surprising for all, he was HIV positive.

Mr. 014 told it was really very odd time while doctors declared his status as HIV positive. Everybody considered him as a dangerous person and reflected a lot of hate and rejection. He said, “He realized his entire mistakes and was repenting on all his activities and feeling regret. He further said, “God, might forgive the person but people never give the chance of forgiveness”.

Mr. 014 was living in a very miserable condition. He was isolated and completely depressed. Now he was dependent on old parents who were having no interaction previously due to his company and activities. Other than parents, his family members just hated him and they had no relation with him. He declared himself a spoiled member of his family. His state of mind was not completely sound and seemed as a psychic patient.

He was repeatedly saying, “Love your life and never indulge in evil practices which led towards hell.” But he got the real point after a very long time while the things were beyond his limits. (Source- Direct interaction with the sufferer).

Case:-15

Mr. 015, 32 years old man, who was living with his wife and the only daughter. His native place is Aligarh and he looks good. He has a great personality. Mr. 005 is not very much educated but he can write and read. In his family only his wife and daughter lived. His parents had died and no any other brother and sister. His family was too small and lived happily.

Mr. 015 was working in a cafe (restaurant). When I asked him during my field survey when he came in ART centre in J.N.Medical college, Aligarh, he did not want to tell anything about himself. But after convincing him he was ready to share about his past activities. He said that he had multipartner unsafe sex in the
red light area which is continuing. When he realised some problems in his private parts he came medical college for the treatment of STI (Sexually Transmitted Infections) a two years back, after that he was diagnosed as a HIV positive. He was not expecting this but it was happened. When he knew about status, he first of all examined his daughter and wife through medical check-ups and other tests. Thanks to God, they were negative. But since the day he was declared an HIV-positive patient, Mr. 015 was subjected to blame, anger, and bitterness from all the sides of his life. Even his wife left the home along-with their only child.

He initially decided not to disclose his HIV-status for the fear of rejection from the colleagues' side. But due to sudden rise in the intensity of the disease, he was compelled to take off from his work from time to time and finally he disclosed the truth to his colleagues. When he disclosed his HIV-status to his colleagues, they refused to sit with him in the café and after a few days the cafeteria in-charge was pressurized to make separate arrangements for him in regard to the use of crockery and other utensils for the purpose of eating food. Eventually, Mr. 015 was eliminated from his job by claiming that he was unfit.

Mr. 015, while answering the question about the possible cause of infection, said that human beings are an easy victim to mistakes. He was repenting on having multiple sex partners in the red light area. Basically, he visited a hospital for his problem of STI (Sexually Transmitted Infection) three years back. After being thoroughly checked HIV-positive factor was spotted out. He was not expecting this. Now he was alone and spending days in desperate condition. He was continuously pronouncing the proverb: “Breach of confidentiality remained one of the key concerns of PLWHA”. (Source: - Interview with the sufferer).

Case:-16

Mr. 016, a 38 years old man, got HIV-infection while he was in Bombay. He was basically a labourer by profession. Once in Bombay, due to some ailments, he consulted doctor who suggested him to go for blood tests. When the reports of his blood test came, the health personals in Bombay arranged an isolated bed for
him in the hospital. He was very much anxious and worried about the situation and was continuously thinking what wrong had happened to him since the doctors did not tell him the truth in the first instance. On his continuous request, the doctor disclosed the truth of his being HIV-positive. Mr. 016 said that this news was as astonishing moment for him and for everybody else there. After that, he came to Aligarh. This was not only a psychological trauma for him but he also suffered huge financial loss in Bombay, he uttered sadly.

About the attitude and reaction of his family, Mr. 016 told, “I was not willing to come back to Aligarh as I was too much worried about the response of my family. I never wanted to hurt my family, which included his mother, brothers, sisters and above all my wife and kids”. While talking to his wife on phone from Bombay and telling her his future plans, she had always insisted him to come back home to Aligarh. In-fact his wife had acted as a huge support and source of motivation for him. On his arrival to Aligarh, his wife along-with his mother stepped to receive him. He said that “Such was the spirit and faith of his life partner towards him”. However, the response of other family members and my friends as well was different. Among his four brothers, one brother along-with the patient with his wife and children had left home since rest of the family members showed a deviation from the relationship with him. Mr. 016 said that most of his friends were not aware of his HIV-status. They knew him as if he was a patient of T.B. Mr. 016 is jobless now-a-day. At present he was taking on ARV drugs. He was unable to speak fluently which was a disability due to his severe tension and mental stress. However, as per his statement, he was feeling much better than he was earlier and this was the result of psychological, medical and spiritual support that he received from his wife.

Mr. 016’s wife is a beautician by profession who had her own beauty saloon. She is HIV negative and is very careful in handling her clients.
Earlier, narrated Mr. 016, he had to depend on barber for his shave, but now he was trying to learn how to shave. Soon he would be expert in making his shave himself.

He said that one should hate HIV/AIDS but not the sufferers. He held that there is a need of change in the attitude of people towards the HIV-positive patients, since, he added, “Only love and care can cure”. *(Source-Direct interview with the sufferer).*

**Case:-17**

Mrs. 017 is a 32 years old woman who is living with her husband and four children in a village, in Aligarh. Her husband was a businessperson and he was doing his work in Jalandhar. He was caught up by the HIV through a commercial sex-worker. He was insisted by his friends to enter into the sexual activities in order to gain pleasure out of it. Her wife got infected due to her husband. After some time, Mrs. 017’s husband suffered from diarrhoea and fever. Tests were conducted, however, there was no threat detected out of the result of tests. In the meantime, his wife also went for medical check-up and while blood tests were conducted, she was diagnosed HIV-positive. Mrs. 017 had no prior psychiatric or substance abuse history. Being mother to four children aged between 7 and 1/5, Mrs. 017 narrated the story of her life filled with depression and anxiety; she was worried about the future of her children. Her younger baby who was only one and a half year old also suffered from HIV-positive.

She veiled her truth of being an HIV-positive patient for the fear of being hated and socially rejected by her family and community since she had heard of the remarks about people suffering from HIV/AIDS.

She refused and rejected all the opportunities that came in her way thereby isolating herself. At the same time, appalling thoughts always came in her mind including attempts to suicide. Her sleep was disturbed. She kept on awakening till late night due to anxiety and sweat-strokes. She was having crying spells and due to her fatigue, she was no longer able to do any kind of work; she felt scared of
food eating, lost her weight, suffered from continuous fever and diarrhoea. She expressed her belief that her death is certain. (Source: -Through interaction with sufferer).

3.11 Summary of in-depth interviews of patients

Through all the Case histories cited above, the major findings are as follows:-

- All the infected respondents belong to an economically backward section of society.
- Most of the infected respondents are illiterate.
- Majority of infected respondents are unaware of the disease.
- More than half of the respondents got this infection through illegal sexual behaviour or unsafe sex.
- Along with the ARV drugs, family love, care and support proved to be a vital factor in their survival.
- Social rejection is considered to be the biggest stigma for the patients.
- Negative attitude of the educated people towards the patient is also a great factor to aggravate this disease.
- Doctors who were treating them were also not sympathetic towards and were avoiding them.
- These patients are looked-down upon by other patients who were visiting the medical college for treatment. It was unethical to expose them to others.
- Wife in most cases prove to be the loyal partner of the patients while other relatives left them when they needed the care and love of the family.
- Most of the patients suffered from intense deprivation, lack of security and protection
3.12 Discussion with health-care providers

As it is quite obvious that HIV/AIDS infection is not a simple disease but it is compounded with many other diseases based on the weak immune system. Therefore, the infected person may not die of HIV/AIDS but may lose his life due to complications of infections. Although the physicians of different specialties are involved in the care of these patients but general physicians and gynaecologists are two main concerned specialties who deal with the HIV/AIDS patients in general and for specific gynaecological and obstetric concerns of female patients. The views of some of health care workers who deal with these patients were also enlisted during the course of investigation which is stated as under:

**Laboratory staff:** Being the important part of health care system laboratory staffs of two major hospitals of Agra and Aligarh were interviewed about HIV/AIDS positive patients visiting these hospitals and services provided to them. They opined in the following way:

According to both hospitals staff, “Accidental exposure to HIV patients is an important and serious issue in health care settings. Health care workers are not only concerned about acquiring the infection but also what others will think of them if they are exposed to such infection. They fear that it will destroy their families and limit their career opportunities. This fear is obviously due to associations of this dreaded disease with abnormal sexual relations and addiction.”

They further explained that while handling the body secretions of patients and often they do not know the sero-status of the patients, so they are at greatest risk of being infected. In addition, if God forbid, any of them get this infection, nobody will believe that they are innocent. Everybody will be suspicious about their characters. This whole picture may endanger their job without considering their hard work and talent.

Considering all these, consequences without any benefit most of laboratories refuse to help HIV positive patients. They added that staff should be ensured about their own safety and security.
**Nursing staff:** - Nursing staff is directly involved in the care of HIV positive patients along with doctors. They are sometimes for them even more closely than doctors. When asked a dedicated staff nurse in a busy S.N. Medical College, Agra about HIV positive patients and their nursing care, she said like all other diseases, sometime, HIV/AIDS patients come for treatment only when complications arise and there is very little hope to save their lives. Probably, this delay in getting treatment in the every stage is due to stigma associated with HIV/AIDS.

They are often ignoring HIV positive patients because they feel unsafe and may be infected by these patients and in cycle their family members may also affected through us as we can carry this disease to our houses. Why should we put them and their loved once in danger as this is incurable disease.

She added that she also does not want to disclose the seropositive status of HIV patients on the top of their files and on their bedside but it is done keeping in mind the safety of other patients and working staff. Nurse takes care of all sorts of deadly serious and infectious patients day and night but she does not feel herself willing to the extend that she can take better care of HIV positive patients. Basically, like all other members of society she is afraid of the dreaded nature of disease and not the diseased patients.

**Blood Bank staff:** - Transmission of HIV/AIDS, through blood as well as blood products, is a known route. Blood banks along with staff, both in private and government sectors are involved in this route indirectly. To know about the possible role of blood bank staff, one was interviewed, working as blood bank technician. To him since the implementation of safe blood transmission service in the government hospitals, the chances of blood borne transmission of HIV has reduced to a considerable extent, but still they are not 100 percent sure of that the blood which we are providing in emergency situation is safe. In emergency situations, we have no time for screening and blood is immediately needed to save the life of the patient. In such situations, sometimes, even cross matching of blood group is not waited.
About the concerned of blood bank staff, he said, they are also at constant risk of acquiring the infection, as they have to prick the donor. While preparing the donors, they can also get pricked of by the same needle with which they have pricked the donors, and if donors turn out to be HIV positive, after screening where do they stand? Technician during his talk criticized the certain commercial blood banks, which endanger the life of patients for money and provide the blood taken from high-risk donors like intravenous drug users and addicts. He insisted that Government should use electronic and print media for proper awareness about safety of donation of blood so that all misconceptions about blood donations can be removed from society. Only in this way, blood transfusion will be 100% safe and transmission of HIV/ AIDS and other fatal infections can be effectively checked.

3.13 Summary findings:-

The disease is spreading at an alarming speed and is taking shape of epidemic. HIV/AIDS is a major health challenge of present era and health care providers are related to this epidemic in a number of ways. Almost each and every member of health care system including doctors, nurses, laboratory staff, blood bank staff in one way or other are involved in the care and treatment of HIV/AIDS infected patients. Due to this mandatory relationship, both partners’ namely health care recipients and providers face certain problems due to stigmas associated with the HIV/ AIDS.

Still doctors are feeling great fear and threat while dealing the patients. Efforts should be made to create enabling environment for the health care providers to handle the HIV/AIDS patients in ethical ways.

3.14 Peer group Discussion:-

Mr. Manoj is a good friend of a HIV positive patient. He is presently working as coordinator for PLWHA activities. He was frightened initially of AIDS and tried to remain away from the patients affected with this disease. After awareness, all his fear had disappeared. Now he is working for PLWHA. He
stressed, “Awareness campaigns should be launched at macro level.” Manoj said that, “PLWHA really deserve love, care and affection, “He further gave his message to Government that,” there should be proper words in the hospitals like other disease. He said, “PLWHA are human like normal people.”

3.15 Patient’s family views:

Mrs. Meena Devi wife of HIV/ AIDS patient has two sons and two daughters. Her husband died about 2 year ago. After her husband death, she passed through very tough time, her survival was difficult, and support of family was her main priority. At present, she is working in Agra. While giving her message, she shared different experiences and said, “Patients should disclose themselves and take care if they got some injury. They must have separate shaving kit and properly disposable the blades after shave,” She faced a lot of problem from her family during the life of her husband and even after the death. She is spending very isolated and depressed life. Her relatives assume her HIV/AIDS patient while she is HIV negative.

3.16 Main Findings of the study:

Gender inequality, which increases a women’s vulnerability to HIV/AIDS, is what puts them at unjustifiable risk. Sexual, social, economic and political inequality has made women the new prime targets of infection.

There is quite non-availability of treatment centre.

Non-availability of “ARV drugs” (antiretroviral) is also big problem which leads towards more opportunistic diseases.

- High-risk sexual behavior among affected partner for transmitting the HIV virus is very common.
- HIV / AIDS education within the family is almost non-existent.
- Non- Availability of VCT (vaccination, counselling & Treatment) centers for general population, family and HIV position persons.
• Due to discriminatory attitude of medical and Para- medical staff at government hospitals, people avoid sharing their health problem.
• Diagnostic and prognostic tests of HIV/AIDS are very expensive.
• Lack of awareness among general public regarding HIV/AIDS.
• Faith-based organizations have an integral role to play in the battle against HIV/AIDS.
• HIV/AIDS patients and their families do not have safe and supportive environment.
• ABC (Abstain from sex, be faithful and condomize), approach is insufficient to a certain extent; there must be some other policies as well to face this incurable challenge.
Chapter IV
Conclusion & Suggestions
CHAPTER IV

CONCLUSIONS AND SUGGESTIONS

HIV/AIDS seems to pose an enormous challenge to human life and development; the repercussions of the epidemic are extreme, affecting all aspects of human society and organization. Over two-thirds of the world’s people living with HIV/AIDS are in India. In some communities a vicious cycle of deepening poverty and rising rates of infection is undermining past progress, in many regions of India more than a quarter of adults are living with HIV/AIDS.

Unlike most diseases HIV/AIDS also seems to affect the most economically productive sector of the population as well, healthy sexually active men and women of the world. The whole population of the world indeed because the epidemic is by no means confined to India. Globally, the epidemic is increasingly affection younger people.

Among the challenges of present era. Acquired immune deficiency syndrome (AIDS) is the leading enemy. This socio-medical problem has involved the whole globe breaking the boundaries of countries and continents. Electron microscopic virus of AIDS, called ‘Human Immune Deficiency Virus’ has already infected million of people and the incidence is increasing alarmingly in the world (Bryon, 1990). AIDS is not simply a medical problem but due to its associated morbidity and mortality every aspect of individuals’ life is vulnerable to great damage (Morrison, 2002).

Acquired Immuno deficiency syndrome is not a single disease but a set of diseases. Hence, it is named as a “syndrome”. With a view to understand the reason for fatality of this syndrome, it is important to understand he immune system of a human body.
HIV/AIDS has acquired the form of global epidemic. Responses to the HIV epidemic have increasingly focused global attention on dealing not only with the cause of the epidemic but also with its consequences of a development problem like the global AIDS epidemic has often been lacking in the past. However, keeping in view the spreading disaster of HIV, now the global strategy has changed towards dealing with the impact and consequences of a large number of infections, while at the same time trying to prevent or slow down the spread of this virus. As HIV is becoming a major cause of adult mortality in many countries, the effects of the epidemic are psychological, social, economic deterioration (World Bank. 1993a).

There are four known ways of HIV transmission in our body. They are-

1. By having unprotected sexual contact with a HIV positive partner.
2. By using HIV contaminated needles and syringes for injecting purposes.
3. By transfusion with HIV infected blood.
4. And lastly mother to child transmission, i.e., a HIV positive mother can pass on the infection to her child before, during or after child birth.”

Following this we can conclude that, fifty HIV/AIDS patients, twenty five from Agra S.N. Medical College and twenty five from Aligarh J.N. Medical College were interviewed by using a structured questionnaire. Most of the patients were suffering from lethal infection, falling in the age group of 18 to 35 years (68% of Agra and 56% of Aligarh) which is the most productive age of an individual from all aspects. As far as gender issue is concerned, it is obvious from the study that HIV/AIDS in males is higher (68% in Agra and 56% in Aligarh) as compared to females (32% in Agra and 44% in Aligarh).

The study reveals that majority of the affected respondents (60% in Agra and 72% in Aligarh) are illiterate. Some of the respondents acquired their primary level of education (40% in Agra, 28% in Aligarh). Most of the respondents are from very depressed or marginalized communities. 48% respondents of Agra and 36% respondents of Aligarh are laborers and this profession includes house-mates,
which are of house wife which was 24% in Agra and 44% in Aligarh. Service holders, shopkeepers, farmers, sex-workers and students share the smallest percentage (8%, 0%, 0% 18% and 12% respectively in Agra where as 0%, 0% 12%, 0% and 8% respectively in Aligarh). It is apparent from the survey that 64% of respondents of Agra and 72% of respondents of Aligarh are from the rural areas. In Agra 36% respondents are from the urban area whereas in Aligarh it is only 28%. The study shows that most of the affected people (80% in Agra and 64% in Aligarh) are married; 12% in Agra and 24% in Aligarh are unmarried; 8% from each (Agra & Aligarh) districts were widows and only 4% from Aligarh are divorcee.

In connection with the health condition of the respondents, the researcher comes to know that they are catch HIV/AIDS incidentally. The data show that, 20% from Agra and 44% from Aligarh were diagnosed incidentally and they were quite unfamiliar about their sero-positive status before it was diagnosed. Remaining respondents were diagnosed on the recommendations of health care providers. The study shows that 68% in Agra and 60% in Aligarh are smokers and 32% of Agra and 40% of Aligarh are non-smokers. The study further explored that probable mode of transmission of HIV/AIDS was sexual contacts with multiple partners (72% of Agra and 64% of Aligarh), 16% of Agra and 36% of Aligarh were affected due to blood-transfusion and 12% respondents of Agra fall prey of this disease due to the use of un-sterilized needles and irrational use of injections. Almost all the respondents agreed the fact that there are multiple sources of the transmission of HIV/AIDS. Turning towards the second implication of HIV/AIDS, 56% respondents of Agra and 60% respondents of Aligarh are from the joint family while 44% respondents of Agra and 40% respondents of Aligarh are from the nuclear family.

The study reveals that 44% and 52% of respondents of Agra and 40% and 48% of respondents of Aligarh faced harsh/hated attitude from their neighbors and relatives. The behavior of relatives (48% of respondents of Agra and 32% of
respondents of Aligarh) was indifferent and at the same time, friends (16% of Agra and 40% of Aligarh) of the patients too remained indifferent. 60% of respondents of Agra and 44% of respondents of Aligarh were forced to change their residential places after they were diagnosed HIV positive status and thus they faced strong social rejection and discrimination.

So far as the psychological implications of HIV/AIDS are concerned, the study reveals that HIV/AIDS has not only had its psychological influence on the affected persons but the family members including children, parents and other care-takers were also affected equally. They all, including the patient itself, suffered (more or less) from the stigma and discrimination. The school-going children of HIV-positive persons faced harsh and abhorrent behavior from their teachers (54.5% in Agra, 26.3% in Aligarh), their friends (40.9% in Agra, 42.1% in Aligarh), their relatives (45.4% in Agra, 31.5% in Aligarh), some suffered due to their family members (27.2% in Agra, 42% in Aligarh) while other faced the cruelty of community members (40% in Agra, 36.8 in Aligarh). The school going children of HIV positive persons faced sympathetic or empathetic behavior from their teachers (18.1% in Agra, 26.3% in Aligarh), from their friends (36.3% in Agra, 21% in Aligarh), from their relatives (9.09% in Agra 21% in Aligarh), from their own family members (27.2% in Agra, 26.3% in Aligarh), and from the community members (13.6% in Agra, 42% in Aligarh). They were sympathized by their teachers (9.0% in Agra, 31.5% in Aligarh), their friends (only 15.7% in Aligarh), their relatives (36.3% in Agra, 26.3% in Aligarh), their family members (13.6% in Agra only), their community members (18.1% Agra, 5.26% in Aligarh). However, some of the children of HIV-positive faced indifferent/adverse behavior from their teachers (18.1% in Agra, 15.7% in Aligarh), from their friends (22.7% in Agra, 21% in Aligarh), from their relatives (9.0% in Agra, 26.3% in Aligarh), from their family members (31.8% in Agra, 31.5% in Aligarh) and from community members (27.2% in Agra, 15.7% in from Aligarh) as well.
The families of all the respondents (100 percent) from both Agra and Aligarh were shocked to hear the news of their loved ones who were diagnosed HIV positive status. The children of most of the respondents were shocked and suffered from inferiority complex, isolation, sense of deprivation, insecurity and felt unsafe.

In regard to the psychological status of respondents, it is observed that 52% patients of Agra and 72% patients of Aligarh suffer from severe anxiety, 76% patients of Agra and 56% patients of Aligarh suffered from tension, 68% of Agra and 60% of Aligarh are depressed, 60% of Agra and 44% of Aligarh turned aggressive, 32% of Agra and 36% of Aligarh suffered from regression, 28% patients of Agra and 40% patients of Aligarh resembled fixation and 80% patients of Agra and 88% patients of Aligarh resembled the sign of committing suicide. All these psychological impacts were enough to bring changes in their personality and behavior.

While tracing the economic implications of HIV/AIDS on society, the study illustrated that monthly income of all the respondents is badly affected after the diagnosis and disclosure of HIV positive status. Most of the respondents from both rural areas (36% of the respondents of Agra and 28% of the respondents of Aligarh) as well as urban areas reported a substantial decline in the income after diagnosis. HIV/AIDS appeared as a cause of unemployment in 100% cases irrespective of localities where they were residing in (rural or urban). All the respondents were unsatisfied regarding the facilities provided by the government to PLWHA. The major problem was faced by the respondents living in rural areas.

As regards the general awareness about this dreadful disease, television was the main source (64% in Agra and 76% in Aligarh), followed by printed media (56% in Agra and 64% in Aligarh), Radio (28% in Agra and 60% in Aligarh) and at the same time, friends and other relatives were considered as fourth large source of disseminating the information about this disease (36% in Agra and 32% in
Aligarh), fifth and the last source of information was newspaper (24% in Agra and 28% in Aligarh).

So far as the knowledge about HIV/AIDS was concerned, 56% respondents of Agra and 36% respondents of Aligarh had the knowledge of HIV/AIDS and only 48% respondents of Agra and 28% respondents of Aligarh had the knowledge of condoms.

Health sector is neither adequately equipped nor ideally trained to provide health care facilities to HIV positive patients and is quite expensive. Blood transfusion services are though claimed to be safe but there are still loopholes in the so called safe blood transfusion. There are no more facilities for psychiatric and psychological support of the diseased and their depressed family members. Stigma, discrimination and social rejection are common in the society.

Unemployment and economic deprivation created serious problems for HIV-positive persons. Standards of social, moral and ethical values are set below than normal expectation for PLWHA and their families.

There is lack of awareness about HIV/AIDS and the use of condoms. People do not have much information in this area.

Media is although working against HIV/AIDS but its role is not as effective as it could be. The study establishes that the use of electronic gadgets, especially audio-visual sources, in the dissemination of information can prove more helpful in creating awareness about HIV/AIDS. Probably, the government is doing little to deal with this problem. This may create to chaotic condition in a society.

**Scope and Limitation of the Present Study:**

This study provides relevant information regarding the severity of the HIV/AIDS disease throughout the globe including India. The information regarding the HIV/AIDS in Agra (S.N. Medical College) and Aligarh (J.N. Medical College) is very useful for not only further study in this area but also in the better understanding of the particular target group.
This study can be used as a base for further researches. In this study the data was used according the requirements as mentioned in the objectives of this study. A multi-data-bank is available for further research. This research is an original one person study. There can be no doubt about the authenticity of this work. A survey was properly conducted through questionnaires and other appropriate research tools to enhance the usefulness of the research manifold. Simple statistics (in percentages) have been used to illustrate the data to prove the researcher’s hypotheses. This makes the study interesting, reader friendly and easy to understand.

Though there is a lot of scope yet limitations are also present as no study can be flawless. Inadvertently, errors must have slipped into the content analysis or even in the survey. Some amount of bias is also inherent in any study. Presence of artifacts cannot be denied altogether. The researcher has tried her level best to keep the study free of errors and biases.

**Inherent disadvantages of survey research may also be present in this study:**

- Variables cannot be manipulated as in laboratory research. Without control over the independent variables, the researcher cannot be sure of the relationship between the dependent and the independent variables.
- The proper use of questions and the vocabulary used in the questionnaires can have biasing effect on survey results.
- A survey is largely dependent on sampling technique.
- The study is confined to Agra (S.N. Medical College) and Aligarh (J.N. Medical College) only.
- The study is limited to the 50 samples (25 each district Medical college) only.
- The study is limited only to some proportion of the HIV/AIDS patients.
- Interview could not be transcribed on tape.
It is the humble submission of present researcher that the future studies in the field will be free from the limitations acknowledged by her. However, within all these limitations, this study has tried its best to do justice with the selected objectives of the study. Thanks to the numerous constraints, yet in-spite of the considerable pains taken, some parts of this work could not be properly framed as the researcher desired it to be. It is expected that despite its imperfections, it will prove a useful tool for successive researchers. This study can be considered as a small leap towards the great goal of understanding the human society with all its distinctions and challenges and making the world a place to live in.

**Suggestions and Recommendations:**

This section deals with the suggestions brought about for policy making and also with the programmatic actions based on the study’s principle, research findings and particularly on the choice available to the persons once they are diagnosed as HIV positive. It has been concluded that HIV/AIDS has and is adversely affecting the entire individual’s life and consequently the society.

**For People Living with HIV/AIDS**

- Provision of accurate and first-hand information about contraceptives, safe sex, risk of mother-to-child transmission, antiretroviral therapy, and the consequences of unsafe abortion are necessary for HIV positive women in order to plan about their pregnancy and childbearing.

- Increased accessibility of information to the pregnant women and couples planning for pregnancy regarding HIV/AIDS is needed. The preventive measures against mother-to-child transmission through breast feeding during neonatal period should be observed.

- To establish programs for the provision of accurate information about benefits and risks of disclosure that enable HIV positive persons to make informed choice regarding disclosing their HIV status.

- Services for STDs (Sexually Transmitted Diseases) and HIV/AIDS should be widely available and accessible.
• The social insurance policy for HIV-positive persons should be made available to meet their medicinal costs. This is very important as HIV positive people face multidimensional problems including unemployment, rejection and stigma. After declaration of their positive status, patients are surrounded by unhealthy and unwanted environment.

• Health service policies and programs need to be designed in order to provide the equal standard of care and service to all the clients irrespective of their HIV status. For overcoming the financial problems, there should be a proper planning to bear the expenses of their treatment.

• There should be a comprehensive policy for HIV/AIDS patients to continue their jobs. If it is really impossible, there must be an alternative arrangement for avoiding economic crisis.

• There is a need to increase the availability and accessibility of special AIDS care clinics for HIV positive persons with well-equipped and well-versed health care providers who should be specially trained to take care of such patients.

• To establish conducive arrangements or accessible maternal and family counseling services for the betterment of HIV positive persons.

• There is a need to organize training for HIV supporting groups, AIDS service organization, and other health-care providers to give accurate, comprehensive, and up-to-date information regarding the treatment of this lethal disease.

• Arrangements of strong and informative mass media campaign for care and treatment of HIV positive persons should be advocated.

• Provision of safe powdered milk to new born and scholarship to school going children of HIV/positive persons to facilitate their education is vitally important.
Chapter -4

• Provision of medical care and psycho-social support to the concerned individuals and their families on the issues relating to the protection of identity, relocation to safe place if so required, provision of friendly environment and logistic arrangement should be ensured.

• Creation of awareness among HIV positive persons about the availability of voluntary counseling and testing (VCT) will be of paramount importance.

• To educate and create awareness about legal rights of marginalized so as to empower them to seek justice and legal protection, for example women be made aware of their legal rights of inheritance, matrimonial home and maintenance will be an important step addressing the issue of HIV/AIDS.

For the General People

• Increased access of information related to safe sex, family planning, pregnancy and safe abortions as preventive measures for the general population, including adolescents, the elderly and for people living with HIV/AIDS.

• Increased access to information on voluntary and confidential HIV testing and counseling for the general population should be made available.

• Undertaking innovative sex education programs and addressing gender issues among male and female adolescents and tied as well as married couples.

• Provision of intensive education campaign programs for families, communities, schools, workplaces, health service providers and the media personnel so as to have clear understanding of HIV/AIDS which can reduce stigmatization, discrimination, and cases of abandonment.

• To raise community awareness and acceptance of HIV positive persons as well as their family members is essentially needed.

• Conducting intensive education campaigns towards the use of condoms and the image of condoms as a sign of “caring” should be advocated.
• Addressing myths and misconceptions related with HIV/AIDS to reduce fear and anxiety among general public.

• There is need to provide correct and factual evidence based information about HIV/AIDS to general people which is of key significance.

• There is need to change social barriers and create a conducive environment for women so that they can negotiate for safe-sex practices and say “No” to un-safe sex.

• Ensure protection of sexual and other health-related rights to all HIV positive persons.

**For Health care Providers**

• Developing and implementing a firm policy regulation to ensure the confidentiality of HIV/AIDS patients among health care providers and other concerned staff as well.

• Provision of specialized training to medical and paramedical workforce in the treatment and care of HIV positive patients should be ensured.

• Provision of training programs to health workers for improving communicative skills (including body language) to increase awareness about the reproductive rights among the HIV positive persons will be an important strategy.

• Provision of training in pre-test counseling, specialized psychological and psychiatric support should be encouraged.

• Developing and implementing a policy for ethical and safe blood transfusion besides the careful disposal of hospital waste is advocated.

**For work place**

• Formulating regulations regarding the ethical treatment of HIV positive persons within business establishments (public and private sector) is recommended.
• Framing of policies regarding the provision of job security, employment benefits and post-retirement benefits to HIV positive persons in their lives as well as to care for their family members and other dependents after their death is advocated.

• Implementation of workplace policies for workers aimed at ensuring the confidentiality and right of HIV positive persons will be an encouraging step.

For the Mass Media

• Promotion of mass media programs in national as well as local languages so as to broadcast the knowledge of HIV/AIDS, rights of HIV positive persons, preventive measures and change of behavior is essentially needed.

• Use of print as well as electronic media extensively for the promotion of PLWHA support groups is advocated.

• A well-designed strategy should be developed for media sensitization regarding all aspects of HIV/AIDS. Mass Media needs to take keen concern towards the rights of HIV positive patients. There should be a strict instruction to the media people for maintaining the anonymity and confidentiality of HIV/AIDS patients.

• Provision of guidelines to media so that the identity of the concerned HIV positive individual is not disclosed in media reports without his/her consent is very important.

• The practices related to re-use and disposal of needles and syringes must be properly studied and appropriate measures should be recommended to check misuse.

For the Government:

• Formulation and implementation of legislation about preventive measures of HIV/AIDS and rights of HIV positive persons are advocated.
• Allocation and release of adequate funds for effective and comprehensive programmes against HIV/AIDS epidemic compatible to social and cultural demands are recommended.

• There is need to establish HIV/AIDS and IV Drug use task forces at federal and provincial levels.

• There should be a well-structured framework for HIV/AIDS patients. The span of work, duty roaster and working procedure should be chalked out with the consent of health-care providers.

• The members of task forces should be kept alert and well prepared to manage the situation in the areas which are more vulnerable to the HIV/AIDS. There should be the advanced use of sources of communication among them and higher authorities.

• Availability of comprehensive drug treatment and rehabilitation services at district level should be ensured.

• Standard protocols should be developed to ensure that the voluntary counseling and testing (VCT) services meet the specifications.

• Government should be committed to tackle the stigma and discrimination associated with HIV/AIDS at the highest level due to the involvement of the leadership of our country and thereby ensuring the political will of this leadership.

• Screening of blood and blood products should be made cheap and reliable at all hospital blood banks.

• Education regarding HIV/AIDS should be made a compulsory course at the undergraduate level through university system of education.

• There is a need for the development of authentic texts (print, audio & video) on HIV/AIDS in vernacular.

• HIV/AIDS education should be incorporated in the curriculum of the medical & nursing schools.
Religious instructions must be introduced into school curricula at all levels on the issue of safe sex and HIV/AIDS.

Implementation of psycho-educational programmes due to the need of a radical change urgently required in the socialization process with the aim of putting an end to gender-based differentiation, which continues to be the main cause of most HIV infections world-wide. Socio-cultural norms that advocate equal rights and responsibilities of both men and women especially in the matters related to sex and sexuality and the use of condom needs to be formulated and implemented at the earliest.

There should be review of laws related to prostitution. Many advanced countries legally recognize prostitution as a work and have ensured certain basic rights of the commercial sex-workers. For instance, in Philippines sex-workers are registered and screened every 2 weeks for the presence of STD with the aim of treating these infections and thereby decreasing the spread of HIV (UNAIDS/WHO, Dec., 1999). Similarly, in Rwanda girls engaged in sex work have their HIV test result certificates with them and their partners can ask to have a look at them (Buysse, et al., 1996). But in our country including Agra and Aligarh (U.P) districts, we are still far behind in accepting and ensuring even the basic rights of commercial sex-workers. In order to curb the further spread of HIV, we need to review the laws related to prostitution, which are, by and large, oppressive for commercial sex-workers and hinder their ability to protect themselves from HIV. Emphasis and efforts should be focused on granting certain basic rights to the commercial sex-workers. For example, the right to negotiate for sex with clients can prove to be a major milestone in preventing many new infections.

Development, distribution and marketing of effective female condoms at affordable prices should be stressed on a priority basis. Female condoms
can truly be a viable means of giving women the right to practice safe sex as and when they desire.

**Suggestion for Future Studies.**

In future studies, other implications of HIV/AIDS on society like religious, political and impacts on health care system specifically should be evaluated in details. Moreover, further studies are needed to identify age and gender related implications of HIV/AIDS. For example, the study of HIV positive men and women in order to understand their sexual and reproductive decisions, sexual behavior, choices and needs as well as gender differences, which is of great importance besides other similarities. This study will also provide important information for HIV/AIDS Services organizations and policy makers to develop the better set up for patients and their families.

*Advance studies should target all aspects of discrimination and stigmas associated with HIV/AIDS and affected people. Studies should be conducted to search for better ways to tackle all associated stigmas with HIV/AIDS. Supplementary studies should be conducted to develop appropriate and innovative educational programs on safe sexual practices, reproductive rights of women and to raise the awareness and acceptance of HIV/AIDS patients in all spheres of society. All those factors which expose a person to high risk of getting HIV/AIDS infection should be explored in future studies.*

Further research studies should be planned to conduct an in-depth investigation in order to cope up with the mechanism and survival strategies that HIV positive men and women employ to facilitate child and family survival. Further research studies should also be conducted to disclose the factors that encourage and sustain stigma and discrimination in society.

*More over, what are the various ways and means of HIV/AIDS associated stigma that has an impact on those living with the virus? How does HIV/AIDS stigma affects those involved in providing care, support and other services to PLWHA (e.g., family members, doctors, nurses, social counselors, NGO workers*
and activists, community workers, researchers, media persons etc)? How does HIV/AIDS stigma differentially impact the marginalized groups in society (women sex-workers, MSM, IDUs, eunuchs)? All these questions should be answered in future studies. Such studies as well as others should use a participatory approach and involve HIV positive persons in all stages of the research process. Intensive training services for the care-takers of HIV positive patients and HIV/AIDS counseling should be an important part of future studies.

In addition several research projects should be conducted with the following objectives:-

- To develop appropriate, innovative education programs on sexuality and contraception for different target groups, such as the general population, youth and people living with HIV/AIDS,
- To develop gender socialization program,
- To empower women and make them more aware about their sexual and reproductive rights,
- To improve respect for women’s reproductive rights and their access to reproductive services,
- To minimize social, psychological and economic implications of HIV/AIDS,
- To raise community and family members awareness and acceptance of HIV positive persons,
- To make people aware of the use of condom as a care oriented action, which not only helps in preventing people from being caught up by the dreadful diseases but to manage gaps between off-springs.
Glossary
GLOSSARY

Some terms and concepts used by me after observance of the HIV/AIDS patients as follows:

**Antibodies**: Substance produced by white blood cells in response to antigens. They fight of bacteria, viruses and others organisms which attack our bodies and cause disease. In the case of HIV, antibodies produced by the body are not effective in neutralizing the virus.

**Antigen**: Any substance that the body regards as foreign and against which it produces an antibody. Viruses, bacteria and fungi are regarded by the body as antigens.

**Bidi**: A bidi is a, often flavored, Indian cigarette made of tobacco rapped in a tenden leaf and secured with colored thread at one end. Tobacco content in bidies is 10-20% and, unlike regular cigarettes, bidies do not contain added chemicals but deliver more nicotine, carbon monoxide, and tar than conventional cigarettes. Like all tobacco products, use can cause cancers

**Denial**: A person infected with HIV refuses to accept the fact that he/she is infected with HIV. Not accepting one’s HIV status because of stigmatization.

**Dhaba**: Dhabas were characterized by mud structures and cots to sit upon (called ‘chaarpai’ in Hindi) while eating. A wooden plank would be placed across the width of the cot on which to place the dishes and customers squatted on the cot while eating. With time, the cots were replaced by tables. The food is typically inexpensive and has a ‘home made’ feel to it.
**Elisa Test:** The standard screening test for HIV is a blood test known as the *enzyme immunoassay (EIA)* or *ELISA* for short. This HIV testing requires a small sample of blood from the person being tested. Typically, the test requires two visits; one to receive pretest counseling and have your blood drawn and the second to receive HIV testing results, post-test counseling and medical referrals for HIV care if the results are positive.

**HIV incubation period:** Human Immune Deficiency Virus. The time between infection with a disease causing organism and the onset of the visible signs and symptoms of the disease.

**Kaposi’s sarcoma:** A rare cancer- a tumor of the walls of blood vessels. It also affects the living of internal organs.

**Ostracization:** To exclude a person from society or refuse to associate with other family members, relatives, neighbors, etc.

**PWAS:** Persons with AIDS.

**Rapid Test:** This type of HIV testing makes it possible for the patient to get pre-test and post-test counseling, their test results, and any medical referrals they may need all in one visit and in a very short amount of time. Let's learn more about rapid.

**Retrovirus:** Retroviruses are a class of viruses characterized by their ability to convert RNA to DNA during replication in the host cell. Unusual, recently identified group of viruses, including HIV, which reproduces in a different way from most other viruses.

**RNA:** Ribonucleic Acid. Genetic material inside a cell.

**Sero-positivity:** Synonymous with antibody positivity.

**Western Blot test:** Vital antigens are layered on to a nitro cellulose paper. Patient’s serum is placed at one end of the strip. The paper is changed
with electricity for 24 hours. Antibodies move along the paper and interact with the antigens. Depending upon the molecular size the antigen-antibody complexes move to different areas. These patterns are compared with the standard pattern produced by the HIV. To declare the test, as positive antigen-antibody reactions should occur at all the three regions i.e. gag, pol, and are regions.

**Window period:** Once the virus enters the body, it starts to multiply. During this process the test does not detect the virus. The patient is highly infectious. After six to eight weeks the body produces antibodies. The tests become positive. This period when the patient has the infection and the test is negative is known as the “window period”. Similar situation may occur in a terminally ill patient, when his body can not produce antibodies. The test will be negative while the patient will have the infection. The test turns out negative because it takes six weeks for the antibodies to form. In the terminal stages the immune system may be destroyed so that there are no antibodies produced by the body.
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Appendix
Dear Respondent,

I am a student of Sociology & Social work in Aligarh Muslim University, Aligarh. This survey is being conducted as part of my Ph.D Programme. The information provided in this questionnaire will only be used for research purpose and will not be disclosed to anybody for any other purpose.

Your frank responses to the questions will be highly appreciated.

Thanking you for your co-operation.

Yours sincerely,

(Seema Kumari)

Questionnaire No.: 
Place of Survey: 
Date of Survey: 

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QUESTIONNAIRE

TOPIC- SOCIO-PSYCHOLOGICAL STUDY OF HIV/AIDS PATIENTS ATTENDING J.N.MEDICAL COLLEGE, ALIGARH AND S.N.MEDICAL COLLEGE, AGRA

Interview Schedule

City: ------------------ Locality: ---------------------

Date of Interview: ---------------------

Demographic Profile

Name---

1. Age----- (A) 18—35yrs. [ ] (B) 35—50yrs. [ ]
(C) 50yrs. And Above [ ]

2. Gender: [ ] Male [ ] Female

3. Religion--- (A) Hindu [ ] (B) Muslim [ ]
(C) Christian [ ] (D) Sikh [ ]
(E) Any Other [ ]

4. Place of Residence: Urban [ ] Rural [ ]

Q.5 Educational Qualification-----
(A) Illiterate [ ] (B) Literate [ ]
(C) Educated [ ] (D) Highly Educated [ ]

Q.6 Marital Status-----
(A) Married [ ] (B) Unmarried
(C) Divorcee [ ] (D) Widow

If married, number of children a) Male ------- b) Female -------

Their ages -------------------------------

Number of dependents: ---------------------
Q.7 Occupation----

(A) Service  (B) Agriculture
(C) Labor    (D) Housewife
(E) Other

Q.8 Income (Per Month In Rupees)
Enter the Figure in the Corresponding Boxes

9. Visited Overseas: Yes  No

If yes, how many times

Duration of Stay

10. Do you smoke? Yes  No

Frequently  Now & then  When need desired

If yes, how often in a day how many cigarettes

11. Do you use any drug? Yes  No

If yes, please mention the name of drug:

a) Drug for Sedation b) Drug for TB.

b) Drug for STD d) Any other

12. Do you think you are suffering from?

Anxiety  Hypertension  Depression  
Aggression Regression Fixation Resignation

13. Route of drug use

i) Oral

By cigarette by sneezing by inhaling
ii) If injectable then:

Through IM [ ] Through IV [ ]

If IV which vein mostly do you use for injection ----------------------------

Do you use drug in the company, with same needle/syringe? Yes [ ] No [ ]

If yes, how? Often [ ] Frequently [ ] Now & then [ ]

14. **Do you have any major surgery?** Yes [ ] No [ ]

If yes, please mention the name of surgery: --------------------------------

15. **Did you have blood transfusion? If yes, please mention the source of blood donation:**

   Relatives [ ] Friends [ ]
   Purchased from professional [ ] Free blood bank [ ]

   Were the hospital/place of surgery well-equipped for testing/screening of blood before transfusion? Yes [ ] No [ ]

   Did the doctor tested/screened the blood before transfusion?

   Yes [ ] No [ ]

16. **Have you ever visited dentist**

   If yes?

   a) Examined by qualified dentist Yes [ ] No [ ]

   If no, who

   b) Examined ------------------------------------------

17. **Do you shave?** Yes [ ] No [ ]

   If yes, who make your shave? Yourself [ ] Barber [ ]

18. **Do you have multiple sex partners?** Yes [ ] No [ ]

   If yes, How many: -----------------------------------
Do you use condoms during sex

Yes ☐  No ☐

If yes, who told you? ---------------------------------

If no, please explain: ---------------------------------

SOCIAL

19. Do you live in joint family system?  Yes ☐  No ☐

How many brothers and sisters you have? Brothers --------- Sisters  ---------

Has any member of your family are HIV+ve  Yes ☐  No ☐

If yes, how it is diagnosed

Accidentally discovered ☐  Doctor Diagnosed ☐

20. What was the attitude after diagnosis of HIV/AIDS?

<table>
<thead>
<tr>
<th>S/No</th>
<th>Category</th>
<th>(1) Sympathetic</th>
<th>(2) Just Normal</th>
<th>(3) Harsh/Hated</th>
<th>(4) Indifferent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Neighbors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Family Members</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>General Friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Community members</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

21. Have you changed your residence?  Yes ☐  No ☐

If yes, please mention the reason: ---------------------------------

22. What was the impact on your school going children? How you can describe the treatment of following with your children?
PSYCHOLOGICAL

23. How many members of your family deeply shocked after the declaration of HIV/AIDS ————?

24. What was the impact on children?

   Inferiority Complex

   Isolation

   Sense of deprivation

   Lack of security & protection

ECONOMY

25. Did HIV/AIDS impact on your earning adversely?

   Yes □  No □

   If yes, how much ————

26. How increase in much expenditure is on treatment of the opportunistic disease ————

27. How will you describe the impact of HIV/AIDS on Socio-Psychological and Economic Life?

<table>
<thead>
<tr>
<th>Social life</th>
<th>Interaction with family members Participation in family functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Earning</td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>Tension Anxiety Stress</td>
</tr>
</tbody>
</table>
27. Do you think that HIV/AIDS is a cause of unemployment of other family members as well?
   Yes [ ] No [ ]

29. Dependability after death of persons/head of family
   Yes [ ] No [ ]

Q.30 After Getting Infected What Is Your Attitude Towards Society?
   (A) Positive [ ] (B) Negative [ ]
   (C) Neutral [ ] (D) Afraid [ ]

31. The issue of AIDS is a very stressful experience for you.
   (A) Yes [ ] (B) No [ ]

GOVT. EFFORTS

32. Are there enough facilities provided to PLWHA by Government?
   Yes [ ] No [ ]

33. Are you already aware of the disease before the present incident?
   Yes [ ] No [ ]
   If yes, by which source you get awareness
   Newspapers
   Radio
   Television
   Any others

34. Are you any awareness regarding condom?
   Yes [ ] No [ ]
35. Is there any help line or any toll free number for HIV/AIDS awareness?
Yes [ ] No [ ]

36. What health care facilities are provided by the Government at work place?
Casual tests
Monthly tests
Biannual tests
Annual tests

Thank you for your co-operation.