

**Behaviour Change in Family and Community of HIV/AIDS Patients in ART Center**

**Meerut: A Sociological Study**

Dr. Arvind Sirohi\*

Prof. Alok Kumar\*\*

Dr. Deepandra\*\*\*

\*Assistant Professor, Department of Sociology, C.C.S. University, Meerut

\*\* Professor & Head Department of Sociology, C.C.S. University, Meerut

\*\*\*Assistant Professor, Department of Sociology, C.C.S. University, Meerut

---

**Abstract:** India has the world's fourth largest country suffering from AIDS. The Acquired Immuno Deficiency Syndrome Commonly known as AIDS is caused by Human Immuno Deficiency Virus (HIV), which completely breaks down the immune system of a body to combat infections, even the commonest ones. The social stigma and discrimination attached to HIV/AIDS that is present in all societies. There are several levels at which HIV/AIDS related discrimination, Stigmatization and denial is experienced and felt. Moreover, these include societal, community and cultural levels, economic barriers in addition to this the experience of individuals.

**Key Words: Health, Illness, Sick-Role, HIV/AIDS, Social Behavior, Family**

The concept of health, disease and treatment is as varied as culture. Health does not mean merely the absence of disease but complete adjustment of individual to external environment, both physical and social. Impact of environment on health and disease cannot be ignored. There are many beliefs and restrictions associated with health and welfare of the people which are strictly followed by them (Barua, 1998). The social science concepts such as socio-economic status and culture are used widely in health research is a measure of an individual's position in such stratification system. Culture is another concept commonly involved in health research. Research on the health effects of policy is also an important aspect of applied health research in the social science (Sundar, 2007: 131-141). This includes all the conditions in which men are born, live, work, procreate and die. Culture everywhere in India's patterns of social organization, designed to regulate a particular society, the members can understand the behaviour of most people and they may predict how an individual will react in a given society (Ibid: 200). World is a beautiful place and so is the experience of living in it. It would be tragic if this beautiful experience of living life is shortened by HIV/AIDS, when its prevention is within one's control, though not the cure. The Acquired Immuno Deficiency Syndrome Commonly known as AIDS is caused by Human Immuno Deficiency Virus (HIV), which completely breaks down the immune system of a body to combat infections, even the commonest ones. The infection in a HIV positive person remains dormant for about 5-10 years before the onset of full-blown AIDS, which is terminal (Sharma, 2012: 21). The disease is transmitted through blood, prenatal exchange, and sexual contact. (Satpathy. 01). According to the UNAIDS estimate there are about 2.5 million persons living with HIV in

south and southeast Asia, with India alone having 1.5 million. (ibid: 250). India has the world's fourth largest country suffering from AIDS. However, the estimated number of Human immunodeficiency virus (HIV) infections in India.

The social stigma and discrimination attached to HIV/AIDS that is present in all societies. There are several levels at which HIV/AIDS related discrimination, Stigmatization and denial is experienced and felt. Moreover, these include societal, community and cultural levels, economic barriers in addition to this the experience of individuals. (Mohd. Anwar, 2015). Ever since the detection of HIV millions of lives have been lost worldwide to AIDS, with a large number surviving the disease living a life of extreme penury, despair, squalor and hopelessness, often listed as a major health emergency. Besides taking lives, HIV/AIDS has separated families, Reduced life expectancy, destroyed and impoverished communities and, to a significant extent, undermined progress of the millennium development Goals. In India, it is said that the impact of HIV/AIDS felt at the individual and this could significantly influence the impact at the other levels and to that extent the most immediate response in impact alleviation interventions need to start with the affected individuals and their households (Falleiro, 2014: 02). In the late 80<sup>s</sup> of the 20<sup>th</sup> Century, there was a growing realization that if any response to HIV had to be successful, there had to be an active role of the HIV infected person, unlike many other diseases. The Acquired Immunodeficiency Syndrome (AIDS) is a collection of symptoms and infections resulting from the specific damage of immune system caused by the Human Immunodeficiency Virus (HIV). HIV affects mainly young people, being transmitted by sexual intercourse, sharing of needles and from the mother to fetus. The Indian epidemic, in fact, is believed to be one of the fastest growing HIV/AIDS epidemics in the world. AIDS is especially unfortunate because it attacks those who are at or just beginning, the prime of their lives (Nagendra, 2008). The epidemic is dramatically reducing life expectancy. HIV/AIDS had now spread extensively throughout the country (Dubey Manisha and Choubey Kailash, 2008). HIV/AIDS also affects household income, as families increase expenditure on medical care and adults become too sick to work (Kathy, 2004).

Vijay Grover and Abhik Ghosh (et al. 2003) studied the knowledge at adolescents about different methods of transmission and prevention of HIV/AIDS. U.V. Somayajula (2004) studied the sexual behavior and knowledge about mode of transmission and prevention of AIDS in fishermen. Leena Abraham (2005) attempts to explore the awareness of sexuality and sexual behavior among urban, unmarried, college-going young men and women come from low income families. Kathy Attawel (2004) studied severe impact on economic growth. HIV/AIDS also affects household income, as families increase expenditure on medical care and adults became too sick to work. Fredric Bourdier (1998) studied the emergence of HIV/AIDS in India. K.G. Santhya and Shrieen Jejeebhoy (2007) studied the links of early marriage and HIV prevention among young women in India.

The other sociologists (Saha, 1997; Bourdier, 1998; Gollub, 2006; Nag, 2002; Narasimhan, 2007; Jejeebhoy, 2007; Prata, 2006; Cruz, 2005; Raath, 2005; Jacob, 2007;)

studied various aspects of HIV/AIDS like development and history of epidemic, early marriage and HIV in India, prevention of AIDS, AIDS and female sex workers, HIV and education, patterns of health seeking behaviour, sexual behaviour and AIDS etc. The main AIDS work in India has focused chiefly on preventive measures using 'information, education, communication and strategies, with youth being targeted as a group vulnerable to the HIV infection. But there is no study which focuses on HIV/AIDS and its impact on individuals, family and community and coping strategies adopted by its patients. So, there is need to conduct such type of study particularly at ART center Meerut.

### **Objectives of the Study**

In the light of the above-mentioned framework, following questions are specifically proposed:

1. What are the behavioral changes in the family of HIV/AIDS infected patients?
2. What are the behavioral changes in the community of HIV/AIDS infected patients?
3. What are the coping strategies adopted by HIV/AIDS infected patients to overcome the problem?

The first question takes note on the behavioral changes in the family of HIV/AIDS infected patients in terms of shared of his HIV status with their spouse, with family members and their changes in behaviour and any type of stigma and discrimination faced by them. The first reaction of family and spouse and the kind of change in their behaviour.

The second question takes note on the behavioral changes in the community of HIV/AIDS infected patients in terms of shared of their HIV status with their non- family members and change in their behavior of non-family members and social status of their family in their community.

The third question takes not on the coping strategies adopted by HIV/ AIDS infected patents in terms of participation in other side like and daily routine of life the discrimination from family side, who really support you to overcome the problem.

### **ART Centre of S.V.B.P Medical Hospital, Meerut City**

The field work of the present study was done in Sardar Vallabh Bhai Patel Medical Hospital, Meerut. (S.V.B.P.), which is situated in the Meerut City on the Meerut–Lucknow Highway. The S.V.B.P. Medical Hospital has an ART (Anti-Retroviral Treatment) Centre. This Art Centre was found here at 8<sup>th</sup> December 2005 and it is funded by UPSACS (Uttar Pradesh State AIDS Control Society). The all matters of any HIV/AIDS patient is totally confidential. Nobody can get any type of knowledge about patient from this ART Centre.

### **Technique of Data Collection**

The information from the respondents have been collected by using the schedule/interview guide in the quantitative phase of data collection. The interview

schedule/guide contains both close-ended and open-ended questions. The observation technique has also used.

### Methods of Data Analysis

Data collected with the help of interview schedule guide technique from HIV/AIDS patients was analyzed quantitatively by using SPSS (Statistical Package for Social Science Data Analysis). Simple statistical techniques are also associations and co-relations was looked into to indicate the degree of relationship between socio-economic profiles and impact of HIV/AIDS.

### Perspectives/Approaches

To observe the HIV/AIDS Patient in ART center Meerut implementation and utilization at grass root level, interactional perspective has been used for the present study to analyze the impact of HIV/AIDS on the patients and the relationship of their family and community. To know the gaps and relevance of the study regarding social structure, structure-functional and international approach has been useful to conduct the study. Thus, the present study has made the use of structure-functional approach to observe the socio-economic background of the respondent and its relation with the impact on the society.

Symbolic Interactionist perspective is concerned with how people see and understand the social world. They believe that man can create and develop new symbolic environments and communities that nurture the sick, develop their skill and motivated their increased participation in the social scene. For example, some people explain disease by blaming it on those who are ill e.g. Victims of HIV/AIDS is blamed for promiscuous sexual conduct or intravenous drug use. In this case the social definition of the illness is directly related with social stigma.

### Findings

#### Behaviour Change in Family and Community

1. **Time Taken by Respondent to Disclose the HIV Status with others-** The large number 76(38.00%) of the respondents have disclosed their status with someone on just the day as they came to know about their status positive while the small number 24 (12.00%) of the respondents disclosed their status just after few months.
2. **With Whom you Share the Result-** The majority 113(56.50%) of the respondents have shared their status with their spouse while a small number 11(05.50%) of the respondents have shared their status with their family members. So, it can be said that spouse is much more reliable than other.
3. **First Reaction as Respondent Share their Status-** The majority 127(63.50%) of the respondent's family members gets shocked as their first reaction while a very few number 07(03.50%) of the respondent's family reaction was other.

4. **Stigma and Discrimination Faced by the Respondent in the Family-** All most all 189(94.50%) of the respondents face any stigma or discrimination within their family while a very few 11(05.50%) of the respondents does never feel same.
5. **HIV Status Shared with Their Spouse-** The large majority (84%) of the respondents shared their status with their spouse while a very few (04%) of the respondents have not shared their status with their spouse.
6. **Change in Behaviour of the Spouse-** The large majority (82%) of the respondents have some change in behaviour after sharing their status with their spouses and the very few number (04%) of the respondents have no changes in behaviour of the spouse of the respondent.
7. **Kind of Change in Behaviour-** The large majority (81.71%) of the respondents stated that their spouse starts discrimination as in change in behaviour while a very few (04.87%) of the respondent's spouse often had quarrels.
8. **HIV Status Shared with their Family Members-** All most all (96%) of the respondents have shared their status with their family members and the very few number (04%) of the respondents have not shared their status with their family members.
9. **Shared With-** The large number (34%) of the respondents have shared their status with any two members in their family and a very few (04%) of the respondents have not shared their status with anyone of the family member.
10. **Kind of Change in Behaviour-** The large majority (91%) of the respondents feels change in their family member's behaviour and the small number (09%) of the respondents feels belong to that there is no change in the behaviour of the family members.
11. **Nature of Change-** The large majority (81.30%) of the respondents have start discrimination while a very few (04.40%) of the respondents left their home.
12. **HIV Status Shared with Non-family Member-** More than half (56%) of the respondents have not shared their status with their non-family members and the less than half number (44%) of the respondents have shared their status with their non-family members.
13. **HIV Status Shared With-** The (58) number of the respondents have shared their status with their friends, while small number (22) of the respondents have shared their status with their relatives. Here it appears that friends are more reliable then relatives.
14. **Immediate Reaction of Non-family Members-** The large number 67(33.50%) of the respondent's immediate reaction was shock and small number 33(16.50%) of the respondents has avoided the respondent as they came to know about the positive status.



15. **Change of Non-family Members-** The majority (58%) of the respondents feels some change in the behaviour of non-family members and the small number (42%) of the respondents feels no change in the behaviour of their non-family members.
16. **Kind of Change in the Behaviour-** The half (51.74%) of the respondent's non-family members often had quarrels with them, while a very few number (3.45%) of the respondents have left the home.
17. **Someone with HIV/AIDS in the Relationship-** The majority (63%) of the respondents know someone with HIV/AIDS and the small number (37%) of the respondents do not know someone having HIV/AIDS in their relations.
18. **Patients Social Status in Family-** The majority (64%) of the respondents informed that their social status worse in their family while small no. (36%) of the respondents have informed that the improvement of social status is as such as in their family after having HIV/AIDS.
19. **Patient Social Status in Community-** The large majority (64%) of the respondents reported that their social status has worse in community while small number (36%) of the respondents reported that their social status in their community is as such as before their illness.
20. **Working Conditions-** The majority (76%) of the respondents reported the worse in their working conditions because he/she becomes too weak to work and the small number (24%) of the respondents reported that their working conditions is as such as before their illness.
21. **Financial Condition-** The large majority (81%) of the respondents report some to worse in their financial conditions because he/she becomes too weak to work and the small number (19%) of the respondents belong to as such in their financial conditions.
22. **Social Solidarity and Unity within Family-** The large majority (90%) of the respondents feels worse in the social solidarity and unity with in family and the small number (10%) of the respondents reported to as such of the social solidarity and unity within family.
23. **Social Status of Patients Family in Their Community-** The large majority (57%) of the respondents reported some to worse on social status of family in community and the small number (43%) of the respondents reported that there is no change in social status of their family within their community.
24. **Child Also Infected With HIV-** The majority (54%) of the respondents reported that they had no child while the small number (02%) of the respondents reported that their children are not infected with this disease.
25. **Child in Future-** The majority (57%) of the respondent's response they do not want a child in future and the very small number (03%) of the respondents want any child in future.

### Coping Strategies Adopted by the Patient to Overcome the Problem

- 1. Coping Strategies-** All most all of the respondents 198(96.50%) felt stigma and discrimination from family side while a very few of the respondents 07(3.50%) does not feel the same. The large majority (91.00%) of the respondents is engaged with any time of physical exercise while a small number 18(9.00%) of the respondent do not engage with any type of physical exercise. The all of the respondents reported that counselling given by the counsellor is very helpful to overcome the problem. The majority 142(71.0%) of the respondents reported that religion is really helpful in coping while small number 58(29.0%) of the respondents founds that religion is not helpful in coping. the majority 138(69.0%) of the respondents founds close contact helpful in coping while small number 62(31.00%) of the respondents does not support the same. The large majority 156(78.00%) of the respondents founds friends helping in their coping while small number 44(22.00%) of the respondents does not founds same. The large number 132(66.00%) of the respondents stated that life partner is very helpful in coping while small number 68 (34.00%) of the respondent were not supporting in coping with this disease. All of the respondents reported that they never write or sign any document that declare that HIV status positive. It is important to know that people diagnosed with HIV/AIDS require not only clinical care but also need profound social, emotional and behaviour adjustments in their family life, sexual and social relation, at work place as well as an understanding of spiritual needs and legal and civil right counselling helps infected people make decisions about their life, to cope effectively with stress and to improve family and community relationship as well as quality of life. It also provides support to the families as well as loved ones of HIV positive members in a more supportive manner.
- 2. Visit to Doctor-** The large number 103(51.50) of the respondents visit the doctors regularly and gets treatment and small number 20(10.00%) of the respondents visit doctors sometime.
- 3. Doctors Support in Coping-** The majority 107(53.50%) of the respondents reported that doctor helps him a lot while the small number 31(15.50%) of the respondents find no help in coping with the disease.
- 4. Participation in Other Side-** The large majority 166 out of 200 the respondents participate in religious activities and small number 40 out of 200 the respondents participate in other side like. The above finding also suggest that majority of the respondent pass their time by participating, social gathering, function, religious activities and meeting. Here it appears that they have no hesitation with their family and community they are adjusting in their routine life of their society.
- 5. Daily Routine Life-** The majority 166 out of 200 the respondents engage themselves in religious activities and the small number 36 out of 200 the respondents spent time with friends and neighbors.

6. **Effect of Counselling-** The all of the respondents (100%) gets moral support from counselling that is given by doctors and counsellors at this ART Centre.
7. **Relative Who Supports-** The large number 114 out of 200 the respondents reported that their spouse is much supportive then other relatives while a small number 24 out of 200 the respondents reported that their mother-in-law is much more supportive than others relatives.

## REFERENCES

Barua, Indira and Phukan, Roopa

1998: “Socio-Religious Aspect of Health Among Sonowal Kachari”, **The Eastern Anthropologist**, Vol. 51, No. 4, pp: 351-362

Bindra, Anju

2010: **HIV/AIDS Health Care and Human Right**, Manglam Publication, Delhi

Fallerio, S.P.

2014: **Economic Impact of HIV/AIDS on Household**, Sage Publication, New Delhi

Hasan, K.A.

1979: **Medical Sociology of Rural India**, Sachin Publications, Ajmer

Mohd. Anwar and Haris Sultan

2015: “Socio-cultural Constraints for HIV/AIDS Patients”, **Indian Journal of Health and Well-being**, Vol. 6., No. 12, pp: 1183-1188

Satpathy., G.C.

2003: **Prevention of HIV/AIDS and Drug Abuse**, Isha Books, Delhi

Srivastava, R.K.

2011: **Public Health System in India**, DPS Publishing House, New Delhi

Sundar, I. and Manickavasagam, B.

2007: **Medical Sociology**, Sarup and Sons, New Delhi

Varma, Sudhir

2010: **Gender, HIV and Social Work**, Rawat Publication, Jaipur