A Study on Stigma Management among HIV Positive People

Laveena D'Mello
Senior Leturer, Social Work Department
SIMS Mangalore.

Dr. Govindaraju B.M.
Dept of Sociology
Mangalore University, Karnataka.

ABSTRACT

Stigma means, calling and labelling a person to identify negatively. Call by different names to disgrace shame, guilt and feel low. Stigma is knowingly and unknowingly people's attitude towards others is to look down upon. Parker (2002) describe stigma as, it is a technique of social control, which identifies and use differences between groups of people to create social hierarchies and inequalities. The people those who are infected with Human Immuno-deficiency Virus and Acquired Immuno-Deficiency Syndrome (HIV/AIDS) are facing stigma from every dimensions from within themselves, from their spouse and relatives and from the society. There are various diseases that man can become the victim but the fear, denial, stigma and discrimination is common HIV epidemic. People consider them as they have committed immoral act, the behavior which is not accepted in the society. This is because HIV/AIDS is a life-threatening disease, related to sex behavior of the person, illegal relationship with prostitutes, drug use, etc. They are also causing infection to others.

Stigma is more to women than men due to gender discrimination, patriarchy system in the society and society's attitude by giving secondary status to women. More over most of the time it is women who were identified first and detected HIV positive. In this paper researcher had made an attempt with the objectives to examine the Management of Stigma among the HIV positive people, by suggesting the various measures for the infected to cope up with the situation and to live positive healthy life with the experience and suggestion of the victim of the diseases. Researcher has identified 25 samples, those between the age group of 21- 55 years by adopting field survey and case studies.

Key words: HIV/AIDS, Stigma and Discrimination, People living with HIV/AIDS (PLHA), Positive living.

I. Introduction:

In the olden days the incurables diseases are like leprosy, cholera and tuberculosis which are contagious disease and people those who are infected are kept in isolation and excluded from the main stream of the society. Human Immuno-deficiency Virus and Acquired Immuno-Deficiency Syndrome (HIV/AIDS) is one of this kind epidemic right from the time it was first discovered people have discriminated and kept away. People show their fear of acquiring the disease when they came to know the positive status of a person and want to keep distance as much as possible. It is clear the form of spreading or transmission of the disease is through any form of sex, blood transfusion, contaminated hypodermic needles, exchange between mother and baby during pregnancy, childbirth or breast feeding or other exposure to one of the above bodily flied only. Other than this in socializing with people, communicating with them, staying and interacting with them or using same utensils, children mingling with other children, playing together, going to school together and sitting in same bench, attending public functions pooja's rituals ceremonies, weddings, visiting them in hospital will not effect. The general notion of the people is HIV positive people will get infection due to their immoral behavior and people want to keep away from this infection themselves and their family.

Discrimination: It is an act of making a difference in treatment; favouring or punishing. And the discrimination is always negative feeling towards the HIV positive person. Stigma can lead to prejudice and active discrimination directed towards persons who are perceived to be or who are actually infected with HIV, and the social groups and persons with whom they are associated. Discrimination occurs when a distinction is made against a person that results in his or her being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group. Public and private services are for the general public, once they came to know the HIV status they deny for them. It is common in hospital setting and health care centers. They don't want to be associated with them or to take any risk in treating them. Even in the case of employers, they will find out various reasons to terminate them from employment. They put pressure on the positive people to leave the job because they are not able to do hard work, common absenteeism and other health problems. Positive people also have to face discrimination from their colleagues. If this situation they have to face in the society and at work place, the situation is not different in their home,

family and with relatives. Families and relatives may reject and put ban on their living, staying and accommodating with other negative family members at home. By discriminating they violate human rights of the individuals by the close family members itself.

Stigma: HIV/ AIDS-related stigma appear and one needs to understand how stigma in HIV/ AIDS interact with pre-existing Stigma and discrimination (S&D) associated with sexuality, gender, caste, and poverty and preexisting fears about contagion and disease. HIV/AIDS-related S&D are most closely related to sexual stigma. The HIV epidemic initially affected populations whose sexual practices or identities are different from the "norm" (sex workers, men who have sex with men). HIV/AIDS-related S&D has reinforced pre-existing sexual stigma associated with STIs, homosexuality, promiscuity, and prostitution. The belief that sex workers and homosexuals are to blame for the epidemic or that sex workers or homosexuals are the only group at risk of HIV is still common. MSM's and IDU's often deal with the dual stigma in relation to their HIV status and their sexual identity or their addiction respectively.

Gender Related Stigma: HIV/AIDS related S&D are also linked to gender-related stigma. The impact of HIV/AIDS-related S&D on women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to education, information and services. 82% of the HIV transmission occurs in heterosexual transmission in women where they have monogamous relationships with their husband. 67% of the first detection is husbands when they are symptomatic and treating in the Hospital. And after their status is confirmed the doctors ask their family members to go for HIV test and they found positive. In cases the first detection was done in women when she faces some health complication, they are the one who blamed for bringing illness to the family first. Men are likely to be 'excused' for their behaviour that resulted in their infection, whereas women are not. They have considered as curse to get all problems in the family.

HIV/AIDS Scenario: Within the South and South-East Asia Region, an estimated 7.4 million are people living with HIV/AIDS (PLHA) (as of December 2005). This region ranks second in HIV prevalence, after sub-Saharan Africa, and accounts for about 20% of new annual HIV infections globally. The epidemic in India is varied, with areas of generalized epidemic in the South and North-east, and with pockets of concentrated epidemics and highly vulnerable regions with low-levels of HIV infection. Half of HIV patients in Asia live in India and is way ahead of China in disease burden. Seven Asian countries report an estimated 100,000 or more people living with HIV in 2009. India tops the list followed by China, Thailand, Indonesia, Malaysia, Myanmar and Vietnam, through the highest prevalence rate,

one per cent, was observed only in Thailand. In Asia, the rate of HIV transmission appears to be slowing down. The estimated 3,60,000 people who were newly infected with HIV in Asia in 2010 were considerably fewer than the 4,50,000 estimated for 2001. (The Hindu, December 1, 2011).

In India, the Human Immuno Deficiency Virus/ Acquired Immuno Deficiency Syndrome (HIV/AIDS) epidemic is nearly three decades old. India reported its first known case of AIDS to the world health organization on 1986. It would be easy to underestimate the challenge of HIV/AIDS in India. India has a large population and population density, low literacy levels and consequently low levels of awareness, and HIV/AIDS is one of the most challenging public health problems ever faced by the country (UNPAN, 2003) At the end of 2004, 5.3 million Indians were estimated to be infected with HIV. A hundred and eleven districts in the country are classified as high HIV prevalence districts. Transmission of HIV is predominantly through the sexual route (86%). Other routes include injecting drug use (IDU) (2.4%), vertical transmission from mother to child (3.6%) and transfusion of blood and blood products (2%), and others (6%) as of July 2005. (UNAIDS and World Health Organization, 2005). Recently, the Indian Government stated that it was 2.5 million people affected by HIV in India (NACO 2007).

In Karnataka - a diverse state in the southwest of India - has a population of around 53 million. In Karnataka the average HIV prevalence at antenatal clinics has exceeded 1% in all recent years. Among the general population, 0.69% was found to be infected in 2005-2006. Districts with the highest prevalence tend to be located in and around Bangalore in the southern part of the state, or in northern Karnataka's "devadasi belt". Devadasi women are a group of women who have historically been dedicated to the service of Gods these days, this has evolved into sanctioned prostitution, and as a result many women from this part of the country are supplied to the sex trade in big cities such as Mumbai. The average HIV prevalence among female sex workers in Karnataka was 8.64% in 2006, and 19.20% of men who have sex with men were found to be infected.

The district of Dakshina Kannada in state of Karnataka is not exceptional from the above mentioned facts and figures, with regard to the socio-economic status of HIV/AIDS. This district is not exceptional and also does not require much specific introduction in the case of education, health and trade and commerce in the state itself. As far as HIV/AIDS data is concerned the patients in Dakshina Kannada and the number is exceeding day by day. As per the District Aids Prevention and Controlling Unit (DAPCU) in Dakshina Kannada from the

year 2007 to 2011 is concerned the total positive cases in Dakshina Kannada district is 5,322, where in 3,440 are males and 1,882 are females. Out of them, 25 case samples were selected in the form of case studies. The respondents are between the age group of 21-55 years. The main objectives of this study are the Management of Stigma among the HIV positive people and to cope up with the situation and to live positive healthy life with the experience and suggestion by positive people.

II. Management of Stigma

HIV/AIDS stigma and discrimination has three dimensions. They are stigma from within or by self, stigma from family members and from neibhours and larger community. Perceptions and experiences of HIV/AIDS Stigma is a social construction which has significant effects on the life experiences of the persons infected with the HIV. In this study, the Management of Stigma among the HIV positive people, to cope up with the situation and to live positive healthy life with the experience and suggestion of the victim of the diseases

Self management: HIV/AIDS will lead to face stigma within self. Internalized stigma based on strong feelings of guilt, shame, fear of death and depression. These feelings are shaped by fear of stigma and this fear is based an HIV/AIDS persons initial interaction with the members, their culture, traditions, norms, and values in the society. They think and anticipate the discriminating behavior of the partner, children, and daughter- in laws, sibling, parents, family members etc. The internal stigma or stigma from self is the feelings of the individual, emotions, the psychological and social reactions to hide their status from others and they do maximum efforts to keep it confidential.

The management of stigma can be according to Mr. S. 42 years and Mrs. S. 37 years old, stays in rural area, both the partners are positive with two negative children. They are staying in the joint family and kept their status secret. Mrs. S commented saying "I get irritated and angry often. I want to keep my status secret. I won't feel any discrimination in family because nobody knows my status. There is no difference in attitude, treatment and stigma about HIV status since my status is kept confidential." She also said, "I don't know till when I can keep it secret? My worries are if my parents come to know my status, what will be the consequences that I have to face? Where I will be? How long I can hide mine and husband's disease and taking tablets hiding from them? If they see the tablets what reply to give? All these questions will come to my mind often and with this tension life moves on". She is also worried about the purity and pollution "what image I will have in family and in society?" She is suffering from stigma within herself. She is trying hard to balance her life by taking care of

husband's health, her health, children's future, handling family matters and in maintain secrecy of the status in the family, neibhour hood, friends, and at work place in the society. Keeping the status secret is one of the management of stigma. But fear will be always exist thinking how long they can keep the status secret?

Though, such respondents are successful in hiding their HIV/AIDS status, they continuously experienced a fear of being exposed. Thus, they still experienced a kind of "Internal" or "Felt stigma" as they worried tremendously about how the family and others would react towards them if confidentiality breaches.

Managing stigma within the family: Families are the major sources of providing care during an affliction of disease among its members. They also define an individual's social identity and participation in society. The families may provide HIV care and moral support and thus jointly shouldering the burden of the killing disease not because they protect the positive people but to save their family prestige. Some families were ashamed and they came forward to take care of the negative dependents especially children who are negative and wanted to put the positive family members in the care and support centre. Some were supportive and some sympathized and some even disowned their HIV infected members. Female members got sympathy from the family members because they knew that they are the victims of the disease and disease is transmitted from their husband. In some cases, females were unwelcome at their in-laws and force to go to their mother's house. The mode of transmission of disease also plays major role in accepting.

The case reports of Mrs. H, positive lady got HIV through her husband, says "in my house only core members like children, daughter-in laws, and one son in law knows my status. The younger daughter told her husband before marriage about my status and he did not have any objection. He accepted me very well when my daughter delivered I had taken care of child and I go often to their house. There is no stigma from any one". Regarding stigma, she says "My family knows it but there is no stigma from anybody. There is no experience of stigma within family; all are respecting me. They have treated HIV as any other disease. My family tries hard to keep the status secret. And they have warned all the members not to reveal the status and keep it high confidence". It is clear, that family member manages to keep the status confident for their safety to avoid stigma.

Managing Stigma by disclosing the status in the Community: Most of the time HIV positive people's perception is that there is no need to tell people about their HIV status,

when they come to knew definitely people will not accept it. When the person develop some physical symptoms and admit in the hospital on regular basis and they observe the physical symptoms with deteriorating status, people will make guesses about the affliction of the disease but positive people will not admit their positive state in the community. Some people voluntarily disclose their status in the community, in NGO and with support group when they analyze, breeching confidentiality will more benefiting than keeping it confidential.

The field survey reveals that, Mrs. U expressed that "after our marriage, both our families were very happy especially when they got the news of Pregnancy. My happiness regarding pregnancy shattered in the Hospital. In the hospital they did my blood test and they told me that I am HIV positive. It was a great shock for me. I did not have any options but only to forgive my husband. Doctor asked my husband to go for HIV test and he too was Positive. Since our marriage is arranged by both the family, my husband's family knew our family background. So nobody told anything to me but cursing their son for giving the disease. My husband admitted his mistake with me and with his parents too. Within three years he died with cancer. I was young and had a small negative child. I did not wanted to be burden on the family. I used to visit the councilor and was the member of the support group where I got to know one person who also was young and HIV positive. We got registered our marriage and now we are living together in our own house." Mrs U able to manage her life by disclosing her status in the society and joining positive members group, where she got her life mate and she says if I keep my status secret the disadvantages are more than disclosing.

Managing stigma by Migration: Managing Stigma in the Community is not so easy**.** The values and belief system of the community decides the reactions of its members towards the AIDS infected person. Thus the Communities can be critical areas of stigma and discrimination for HIV infected individuals. Mrs. J. explained, "I am responsible, for the discrimination and stigma from the society. I never thought there will be so much discrimination in the society and their attitude towards me and my family. I was ignored about HIV and did not know the savior consequence of breaching confidentiality, I told my neighbours that I am positive and I didn't know how that news spread everywhere. This made me to undergo stigma from every one. Then one good neighbor of mine suggested me to visit care and support centre. We sold our property for very low prize and we shifted our house near to the care and support centre. We were able to get job in the centre. Day time we work for the centre and we come back to our house in the evening. I got financial and

psychological support from them". Mrs. J used the strategy to manage stigma from the community by shifting her house or migrating from one place to other.

III. Positive Living with HIV

HIV positive individuals often have emotions to cope up in life and to face the day to day life challenges. They have emotions like fear, grief, depression, denial, anger, anxiety etc. If the person is diagnosed as HIV positive, it does not mean death or the end of life. They have to live positively with the disease and not to lose hopes. Positive living or living positively with HIV/AIDS is a term used to describe leading normal, non risky life while following preventive and supportive measures to live, to control the infections caused by HIV. It also includes positive living is to prevent the spread of HIV to another person including the life partner or other person by control the spread of virus, infected to non infected person. To meet the physical, emotional, social and economic needs of PLHA, positive living should be governed by the following dimensions;

Hope: Hope is a powerful weapon for HIV-positive people. But many people lack this weapon. Hope is a belief in a positive outcome related to the events and circumstances in one's life. Hope is considered to be an important factor in positive living, it helps PLHA to live positively rather than wait to die. However women live longer because they are attached with their children. Many of the positive people wanted to live long, settle the family matters at the earliest, give education for their children and career for the grown up children, settle and get them marry before they die. Some even want to get share from their parents, fight for the property rights so that after their death the children are financially secure. For their positive children parents wants them to put in the care and support centre at least they have hope after their death, centre will take care of their children. Hope describes many qualities of long term plans which they want to achieve. Normally general public will take more time to plan for themselves and for their children's future, but positive people wanted to settle these issues at the earliest. The positive living is possible only when there is hope.

Selective Discloser: Positive living requires that there should be an environment of openness wherein a person with HIV can normalize and disclose that he is HIV positive, and can also have comfortable discussions about HIV. Generally people need companion to discuss their problems, aims, visions, joys and sorrows because man is a social animal. But positive living means to share their sorrows and worries, concerns and to get support. And there should be a helping hand and the person to listen to other. But in HIV too openness or discloser helps in

reducing the sorrows and discomfort. This helps to deal with internal HIV/AIDS phobia. PLHA are often much happier in their relationships when their HIV status is known to their partner. Disclosure is needed with only limited people like the spouse, children, counselor, Doctors and with support group. This will definitely reduces the burden and HIV people can live with positive outlook in life.

Acceptance: Long term denial as lot of effect on health and this as to be discouraged. Knowing and accepting one's HIV status helps to reduce stigma related to HIV. Many have lost their life, opted to end their life by doing suicides, deserted the family, family members rejected them, after the death of the husbands practically thrown out of the house, accepted only negative children and positive children with parents were sent to care and support center etc. Knowing and accepting one's status enables a more informed planning for the future.

Respect the rights: Respecting the rights are important component of positive living keeping in view the dignity of HIV infected persons. Society should treat men, women and children living with HIV/AIDS with respect and compassion. People living with HIV have the right to live life fully with respect and dignity regardless of sexual orientation. They have the right to work, get medical facilities, treatment, re-marry and to own property. People should treat them as normal and not to segregate from the society.

Live with purpose: Most of the people lose their purpose of life after diagnosed as HIV positive, so living positively is very important to find out one's purpose of life. Positive people instead of blaming on fate live with courage and to face life challenges boldly. The statements like problems comes after marriage, no charm in life, God's curse, cannot achieve anything in life, we are burden on others, cursing the spouse etc will makes life without objectives. HIV positives need assistance to realize a sense of purpose and meaning, work with limited capacities, taking rest and nutritious food and to start ART on time to prolong the life span. Good and healthy nutrition can help to delay the progression from HIV to AIDS. Nutritional care and support are important along with living positively.

Spirituality: Positive living is impossible unless people's spiritual side is addressed. Spirituality is an important to get strength to cope with a chronic illness such as HIV related diseases. Spirituality has both a religious and an existential component that share the concept of meaning in life, hope, self transcendence and rituals. Spirituality will help in coping up with physiological and psychological challenges of the illness. Many infected people see HIV

as a curse from God due to religious belief. This feeling has to be reduced and to seek the God's blessing to live positively and to get strength to fight with the disease and challenges.

IV. Conclusion

The lives of people living with HIV can be definitely changed by positive way with interventions. HIV/AIDS people should be encouraged physically, socially and spiritually so that they can live long. HIV/AIDS persons should be encouraged to lead a life with positive outlook. Counseling and psychological support will help to cope up with the situation. Widow's should be supported by helping them financially to get education for their children, scholar ship for continuing their education, widow pension, insurances, donations from the NGO, assistance by providing care and support for the needy. People should lead an independent life by keep a positive outlook in life, have plans, projects and dreams, first they should love themselves, maintain good harmony with the people around, active social life, reduce tension by keeping themselves busy, taking good food and enough sleep and to go for regular check-up , good contact with support group, councilor and doctor. It is advisable to be well-informed about scientific advances in HIV/AIDS and about new local resources available for the positive people.

References

1. Refresher training modules for ICTC counselors, published by National AIDS Control Organization.
2. Sharma Savita, (2006); "*HIV/AIDS and You"*, A P H Publications Corporation, New Delhi.
3. Solomon, S. & Buck, J. (2003): Stopping HIV before it begins: Issues faced by women in India. Nature Immunol, 4: 719 - 21.
4. Sujatha D. Sai, "Women and HIV/AIDS", Associate Professor, Sri Venkateshwara University, Tirupati, Tamil Nadu, Social welfare issn 0037-8038 Vol.58 No 9 December 2011.
5. Varma Sudhir, (2010) '*Gender, HIV and Social Work'*, Rawat Publication, Jaipur.
6. UNAIDS/ UNFPA/UNIFEM (2005): "Women and HIV AIDS: Confronting the Crisis", A Joint Report
7. UNESCO (2001): A Cultural Approach to HIV/AIDS Prevention and Care.
8. UNGASS, (2010): United Nations General Assembly Special Session, Report.

9. UNICEF, (2005); 'Accelerating the Momentum in the Fight Against HIV/AIDs in South Asia, overview paper United Nations Children's Fund, (UNICEF) Regional Office for South Asia, Nepal.
10. Wolitski, R. J., Henny, K. D., Lyles, C. M., Purcell, D.W., Carey, J. W., Crepaz, N., et al. (2006). Evolution of HIV/AIDS prevention programs—United States, 1981-2006 [Electronic version]. *MMWR, 55*, 597-603