CHAPTER - II

REVIEW OF LITERATURE
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Related literature helps one to recognize the problem in its various extents makes the study equivalent and suggests methods of research suitable to study the problem. It helps the researcher to discover the facts which had remained unexplored and critically scrutinize the results. It is only because of this reasons that an attempts has been herein to review and describe theories and relevant studies to provide a meaningful background to the present study.

This chapter is divided into two segments. The segment one is discusses in depth the social stigma theory by Ervin Goffman (1963). The second segment is a review of literature that is relevant to the understanding of AIDS stigma and discrimination experienced by people living with HIV/AIDS special focus on Women infected and affected with HIV/AIDS.

2.1 Theoretical frame work.

According to Goffman’s (1963) social Stigma and Discrimination theory, people stigmatize others because the others are different, and often label the others with undesirable characteristics that diminish their social status. I used the Goffman’s Social stigma theory as a lens of view for examining HIV-related stigma and discrimination. This theory shed light on the motive, why people stigmatize; why some PLWHA experience more stigma than others; why people hide their HIV status and the impacts it creates.

The term stigma is derived from the Greek language, and refers to a bodily mark that was stamped on the skin of criminals, slaves, or traitors as a way of identifying them. Herek (1990) observed that “the mark signified social ostracism, disgrace, shame or condemnation”. Hence, in the minds of the society, these persons were considered “polluted” and were avoided by the society (Goffman, 1963).

Erving Goffman (1963) in his book Stigma: Notes on the management of spoiled identity, Goffman defined stigma as “an attribute that is deeply discrediting”. He argued that “persons who possess certain characteristics are considered socially undesirable and acquire a “spoiled” identity”. Discredited persons are considered different from others and are therefore perceived to be “bad, dangerous or weak”. Consequently, they are “reduced in our minds from a whole and usual person to a
tainted one” (ibid). In fact, any person possessing a stigma is considered “not quite human” since the person deviates from what is perceived as ‘normal’ (Goffman, 1963). As Herek (1990) noted, the difference between social expectations and the reality is more apparent during social interactions when the individual’s attribute fails to meet social normative expectations. To illustrate the occurrence of this difference, he provided the example that persons living with HIV/AIDS may feel stigmatized and threat of discrimination in the group of HIV/AIDS negative persons but feel more comfortable in a social network with others who share similar stigma. These scenarios make the individuals to feel inferior and they may experience a sense of discrimination. Goffman (1963) referring to Riesman (1951) notes: “inferiority accounts for the danger he/she represents, sometimes rationalizing an animosity based on other differences, such as those of social class”.

Goffman (1963) argued that people who bear a stigma fall into two categories that of discredited and discreditable attributes, which the stigmatized individual has to contend with. Being discredited implies that the stigmatized individual assumes his differentness is known or is evident, while discreditable is where the person assumes that his/her stigma is not immediately perceived by those around him.

Goffman (1963) pointed out that stigmatized persons share similar beliefs with the rest of society and perceive themselves as normal “human beings”. However when they deviate from the normal expectations of the society and acquire a stigma, their expectations change because other people are not ready to make contact with them on “equal grounds”. Consequently, feelings of shame due to blame by others are gradually internalized magnifying the reality of who he/she ought to be. Goffman (1963) highlights how “shame becomes a central possibility, arising from the individual’s perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing”. Some people however hold on to personal identity beliefs that are expected of them and in turn consider others as not normal or the ones with the problem. Although this is outright denial of the reality, others confirm this reality by refusing to treat him/her with the respect deserved by normal persons, and instead accord him/her the treatment of a contaminated person, which the stigmatized embraces or denies (Goffman, 1963).
Goffman (1963) highlighted that stigma affects individuals and they respond accordingly, and given examples to show how stigmatized individuals try to change their situation by attempting to correct the deformity, by various means. Associating stigma were feelings of fear, insecurity, inferiority and anxiety, constantly being unsure of how the “normals” would identify and treat the person, and whether they would reject or accept the person.

These uncertainties are explained by Goffman (1963), “thus in the stigmatized arises then sense of not knowing what the others present are ‘really’ thinking about him”. Consequently, the individual might expect to be discriminated against, which may affect his/her behavior, resulting in social withdrawal and other subsequent disadvantages (Mills, 2004).

Herek and Glunt (1988, cited in USAID, 2001) acknowledged that “the stigma attached to HIV/AIDS as illness is layered upon pre-existing stigma”, for example, social behaviours that contravene social norms, including ‘promiscuous’ people, such as gay men, commercial sex workers and women, in general” (Deacon, 2006).

Several researchers have used the social stigma lens in understanding the experiences of stigma and discrimination of PLWHA across the world. The findings from a wide range of literatures have confirmed that the majority of PLWHA experience various forms of stigma and discrimination in contexts of individual, family, community, institutional settings like hospital, work place and educational institutions. The findings from the literature further confirm that the belief that HIV/AIDS is contracted through immoral behaviour is often a factor that the majority of people use to treat PLWHA differently. In addition, misconceptions about HIV routes of transmission reinforce these misconceptions. The theoretical clarifications of stigma and discrimination described above have provided a body of knowledge that has strengthened the understanding of the primary concept of this study.

2.2: Literature Review.

The amount of literature available on HIV/AIDS-related stigma is substantial in evolution of HIV/AIDS stigma, policy-related and legal initiatives. However, much less material is available on programmatic solutions for HIV/AIDS stigma and discrimination.
2.2.1 Women living with HIV/AIDS.

In January 2002, U.N. Secretary General Kofi Annan for the first time announced that, women represented half of HIV positive individuals worldwide, and more than half in sub-Saharan Africa. HIV/AIDS had become a common epidemic in many African countries, moving from high-risk groups such as sex workers and injection drug users to the general population, largely because of persistent gender inequality in the society. He appealed to the international society towards implementation of effective HIV prevention programs to address the realities of women's lives.

The gender inequality and severe poverty is fatal to women in the world, especially in developing countries, which is creating risk factors for women with HIV. Women who have been infected with HIV find it difficult to share this vital information with their partner because of fear of hostility. The Kenian Population Council (2001) in their survey found that most of the respondent are HIV infected but they are failure to share or disclose their status to their partners because the fear of violence or abandonment.

The study of Human Rights Watch (HRW) 2004 at Philippine found that commercial sex workers are tested for HIV without their consent at government clinics, which is one of the major barrier for the commercial sex worker to access health and prevention services and to increase their risk of infection.

The study on gendered impact of HIV/AIDS conducted by United Nations Development Fund for Women (UNIFEM) in collaboration with Indian women’s organizations in the year 2000 found that majority of respondent had no knowledge about sex related issues prior to their marriages, they learned about HIV/AIDS only after they were infected. Several respondents shared that they had experienced physical, sexual, and mental violence, including suffering abuse and neglect by their husbands and in-laws. The respondent from Chennai shared their experiences of beatings, marital rape, forced sex, and mental torture by their partner or in-laws. The entire respondent are shared that they were “blame”, for their husbands infection. The respondent are also shared that in majority of the cases they receive support from natal family. Ironically, it was the family of the infected person that discriminated the most compared to other sections of society.
The study of NACO (2006) found that the HIV infection in India is no longer restricted to high risk population from urban to rural areas and high risk group to women who are mostly monogamous marriages. In India women are increasingly susceptible to HIV infection, as they account for around 2 million of the approximately 5.2 million estimated cases of PLWHA of these only 0.5% of the women are sex workers. Majority of the respondents reported that their families are quite supportive in spite of there being slight hesitation initially by a few (in the case of female’s family support from the natal family). However, the study report found gender disparity in the family support irrespective of whether the sample is from urban or rural area. While nearly 5.5% of female PLWHA have been asked to leave home after being tested positive, only 1.9% of the male PLWHA have been subjected to such treatment from the family.

The paper Gender and HIV/AIDS by Turmen, T. (2003) outlines the biological, social and cultural factors that put women and adolescent girls at risk of HIV infection in compare to men. Violence against women or the threat of violence often increases women's vulnerability to HIV/AIDS. An analysis of the impact of gender on HIV/AIDS demonstrates the importance of integrating gender into HIV programming and finding ways to strengthen women by implementing policies and programs that increase their access to education and information. Women’s empowerment is vital to overturn the epidemic.

The commission on HIV/AIDS and Governance in Africa (CHGA-2004) found that African women and girls experience creates vulnerability to infection through a number of paths, majority of the women are economically dependent on the men in their family, be it their father or their husband and therefore also depend on the men’s goodwill for their up keep and livelihood. Women have less access to productive assets like land and credit, women’s rights are generally not respected and women enjoy least protection against abuse and exploitation. Women and girls are not much educated, which contributes to lower social status and poor ability to capitalize the available information’s. Social constructions of masculinity and femininity render women powerless to resists their husband’s or parents demands for unprotected sex. These and other gender dynamics underpin the spread of HIV in Africa and lead to the present feminization of the epidemic.
Research conducted by UNDP Prevention of Trafficking and HIV/AIDS among Women and Girls (TAHA) revealed that young people aged 15 to 24 now make up more than one quarter of the 38 million people living with HIV/AIDS. More than half of the 5 million new infections of HIV/AIDS in 2003 were among people under the age of 25 and the reasons are typically beyond their control. While in Asia, Eastern Europe and Latin America, young men constitute the majority of young people who are HIV-positive, sixty-two per cent of the 15- to 24-year-old livings with HIV/AIDS globally are female.

The global scenario shows that girls and young women remain far more vulnerable to HIV infection than young men, the girls and young women account for 60 per cent of all HIV positive young people (UNICEF, 2011). In addition to their innate biological susceptibility, social norms prevent them from accessing sexual advances, negotiating safe sex, disapproving the partner’s unfaithfulness, having sex with - or being married off to - older men, sex in exchange for money or goods due to poverty, and being abused. Worldwide, gender inequities continue to affect women’s decision-making and risk-taking behaviour as well as vulnerability to HIV infection, which is often beyond a woman’s individual control (UN, 2009). Ninety-five per cent of people living with HIV are in the developing world where poverty, poor sanitation, lack of access to health services, and low status of women contribute to the continuing spread of the infection.

2.2.2: Women and HIV/AIDS - Knowledge, Attitude, Behaviours and Practice (KABP).

The lack of proper awareness and knowledge regarding HIV/AIDS may leave a large number of women vulnerable to contract the HIV/AIDS. Accurate knowledge and awareness about HIV/AIDS is very important for the prevention and control of HIV/AIDS. Keeping this in mind, the studies discussed in this section primarily focus on the knowledge, attitude, behaviour and understanding of prevention (KABP) regarding HIV/AIDS infections among women.

Since HIV and AIDS emerged over 30 years ago, the percentage of HIV-positive people women has drastically increased globally. The ‘feminization’ of the HIV epidemic has resulted women more vulnerable than men living with HIV.
The study of Balk and Lahiri, (1997) conducted on awareness and knowledge of HIV/AIDS in the states of Maharashtra, West Bengal, Tamil Nadu, and ten other less populous states found that only one in six women had heard of HIV/AIDS. Among the respondent knowledge about transmission and prevention of HIV/AIDS is very poor. The study also revealed that, poorly educated, and poor women are the least likely to be AIDS-aware and if aware, have the poorest understanding of the syndrome. However in spite of low levels of awareness and knowledge, the study found strong positive association between AIDS awareness and knowledge and condom use.

The study of Pallikadavath (et. al. 2004) conducted in rural Maharashtra revealed that men are liable for HIV infection among their partners as men are indulge in high risk sexual activities with Commercial Sex worker. Though the respondents are aware about correct knowledge of HIV transmission but misconception is still exist. HIV positive Men and women tested for HIV reported inadequate counselling and sought treatment from traditional healers as well as professionals. Condition of the widow’s are very pathetic, they faced severe stigma and social isolation and forced to return to their natal houses. The study suggested the need to assure access to supportive care and means of preventing opportunistic infection that overcome gender and societal constraints to reach rural women, children and the poor.

Another study conducted by Health Vision and Research (2005) analyzed the knowledge, attitudes, beliefs and practices among people living with HIV/AIDS (PLWHA) in the West Bengal (India). The study found that PLWHA are lack of sufficient knowledge about STD and associated symptoms. There were issues of negative attitudes. Majority PLWHAs reported that they are indulged in sex with their spouses only. The study suggested for involvement of PLWHA in planning and implementing the HIV/AIDS prevention programmes.

The study of Naik (et al. 2005) on the knowledge, attitude, and practices regarding sexuality, HIV/AIDS and other STDs amongst tribal communities living in the southern region of Karnataka (India) found very low level of knowledge, awareness and information about HIV/AIDS. High prevalence of behavioural risk factors, people ignorance, and insufficient health infrastructure facilities contributed to the spread of HIV/AIDS. The study suggested the formulation of effective, culture
sensitive and appropriate intervention programs to combat the spread of HIV/AIDS among the tribal population.

A cross-sectional community-based study was conducted by R. Hemalatha, R. Hari Kumar, K. Venkaiah, K. Srinivasan & G.N.V. Brahman (2010) among female sex workers (FSW) in eight districts of Andhra Pradesh, India. Key risk behaviours and STIs related to the spread of HIV were assessed. The socio-demographic data revealed that about 70% of the FSWs were illiterates, almost 50% were married and 41% of the FSWs reported that sex work as the sole source of income. Majority of the respondents are aware about HIV/AIDS and 99% believed that HIV/AIDS cannot be prevented. Logistic regression analysis found considerably lesser community care units with high client volume, not carrying condom and could not use condom in past 1 month due to various reasons such as client’s refusal.

The study on Psycho-Social Problems of Women Living with HIV/AIDS and its Impact on their Families in Andhra Pradesh, India conducted by K. Kalpana, Saraswati Raju Iyer (2013) highlighted that “The global experiences and recent studies reveal that the HIV/AIDS is a life-threatening disease, irrespective of age, gender, cast, creed, colour and race and therefore people react to it in strong ways”. Without proper knowledge about HIV/AIDS, several innocent people are victimised specially conditions of the women are pathetic, they are “blame for this deadly diseases in the family. HIV positive women are experienced of stigma and discrimination instead of care and support from their family and community. HIV/AIDS related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at persons, especially women living with HIV and AIDS. Subsequently the stigma and discrimination are being shunned by family, peers and the wider community, poor treatment in healthcare and education settings, an denial of human rights, psychological stress, depression and a negative effect on humanity and society as a whole with respect to inter and intra family responses. The study recommended that it is urgently needed to focus on these areas for appropriate approach to combat and reduce the stigma and discrimination and empower the victims of HIV/AIDS to lead respectful life without social stigma and discrimination.

The study on HIV-related knowledge, attitudes, perceived benefits, and risks of HIV testing among pregnant women in rural Southern India conducted by Rogers,
A., Meundi, A., Amma, A., Rao, A., Shetty, P., Antony, J., Shetty, A. K. (2006). The survey was carried out among the pregnant women attending rural antenatal clinic in Southern India. The study found the rising prevalence of HIV among pregnant women in rural India is of great concern. The study revealed that majority of the respondents (94%) had heard of HIV among this respondents 60% of them had relatively good knowledge about risk factors for HIV transmission. However, 48% did not know about the "means to prevent mother-to-child HIV transmission. Majority of women did not perceive themselves at risk for HIV and only 57% had been tested for HIV. Though, 85% of women expressed their willingness for test, but most of the respondents were worried about confidentiality and disclosure of HIV status because of fear of negative reactions from their husbands, parents, and community. The study strongly recommended for strengthening of the VCT and PMTCT services, urgent attention must be focused on education, development of innovative culturally appropriate interventions that empower women to make decisions about HIV testing, partner counselling, and addressing stigma and discriminatory attitudes toward people living with HIV/AIDS.

2.2.3: Impact of HIV/AIDS in respect of Scio-Economic life of Women.

Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is a massive development challenge of global proportions facing human societies. The impact of the HIV/AIDS epidemic on both national development and household economies has compounded a whole range of challenges surrounding poverty and inequality. Louwenson and Whiteside have summarised the devastating implications of HIV/AIDS for poverty reduction in a paper prepared for the United Nations Development Programme (UNDP) 2001: “The devastation caused by HIV/AIDS is unique because it is depriving families, communities and entire nations of their young and most productive people. The epidemic is deepening poverty, reversing human development achievements, worsening gender inequalities, crumble the ability of governments to maintain essential services, reducing labour productivity and supply, and putting a brake on economic growth. The worsening conditions in turn make people and households even more at risk of, or vulnerable to, the epidemic, and sabotages global and national efforts to improve access to treatment
and care. This cycle must be broken to ensure a sustainable solution to the HIV/AIDS crisis”.

HIV/AIDS impacts households on social and economic levels. At social level, the infected or affected households have to deal with issues around stigmatization, social exclusion and breakdown of family structure and social support networks. Women are overburdened with care and support roles. When any earning member of the household become terminally ill and eventually dies due to HIV/AIDS-related illnesses, surviving members are severely affected the rest of the family members have to manage medical costs and funeral expenses and forced to wage earning activities to support their family, thus HIV/AIDS can directly contribute to poverty.

The ILO study on Socio-Economic Impact of HIV/AIDS on people living with HIV/AIDS and their families” (2001) conducted in four states Delhi, Maharashtra, Manipur and Tamil Nadu through the networks of people living with HIV/AIDS. The study reveals that the mean age of women at the time of HIV testing was 24.4 years as compared to 28.03 years in the case of men. This means women are getting infected at a very young age; majority of the women respondent, (90%) got the infection from their husbands. So, marriage is a route of transmission of HIV for women.

The study also found that around 47.5% women respondents were widows and mean age of these women respondents are 30.1 years, which indicate the serious concern that women are increasingly becoming widowed at a very young age due to HIV/AIDS. The women respondents are experienced bad treatment by husband and in-laws, doubts being raised on their chastity and being blamed for their husband’s illness. In most of the cases women are thrown out by the in-laws family after death of their husband, women from HIV infected /affected are over burden of care and support have to handle regular household chores as well.

The on Socio-Economic Impact of HIV/AIDS deaths on households in India and coping strategies conducted by S.K. Singh (2003) documented that a significant negative impact on the economy of households where an active had died due to HIV/AIDS is clearly evident from the present study. Households with HIV/AIDS deaths had reported reduced savings during the reference period of reduced expenditures on consumer durables and had sold assets in order to raise or supplement income. On the social front they had experienced discriminations and a few of them
had to send their children away to distant relatives, and withdraw children from school. This study clearly points out towards a need of a comprehensive response to HIV/AIDS which includes efforts to reduce stigma & discrimination at all levels.

This comprehensive study on the socioeconomic impact of HIV and AIDS was sponsored by the UNDP and NACO and was undertaken by the NCAER from October, 2004 to May, 2005. The study is based on a survey of 2,068 HIV and 6,224 non-HIV households spread over rural and urban areas of six states with high prevalence of HIV in India – Andhra Pradesh, Tamil Nadu, Karnataka, Maharashtra, Nagaland and Manipur. The impact of HIV and AIDS has been detailed for a cross-section of issues such as household income, savings, consumption as well as education, health, gender and levels of stigma and discrimination. Case studies and focus group discussions (FGDs) were also conducted to supplement the findings of the survey. While the case studies helped in capturing problems like stigma and discrimination, the FGDs were useful in confirming quantitative findings and further analysing data from the household survey. The study reveals that HIV affected households are more likely to report loss of income, increased expenditure (especially medical expenses), lower savings and higher borrowings and liquidation of assets. The children of HIV households report higher dropout rates and absenteeism due to the ill health of their parents. By demonstrating the wide-ranging negative consequences of HIV on the household, the report underscores the need to respond urgently to the negative impact generated by HIV-AIDS in India.

In Vietnam, a country with a low HIV/AIDS prevalence level, a study on the impact of HIV/AIDS on household vulnerability and poverty collected information from 125 households with 129 HIV/AIDS-infected individuals in four provinces (United Nations Development Programme [UNDP], 2005). Findings demonstrated that, in households with an HIV/AIDS-infected person, the total health care expenditure was 13 times higher than that of the average household. According to this study, coping strategies such as borrowing money and selling of assets, adopted by households, were more often —struggling strategies(UNDP, 2005). Such strategies are likely to disadvantage the households into the future as they may find it difficult to recover (financially) because of lingering debts or failure to replace sold assets.
The study conducted by Ramamani Sundar (2005) on household Impact of HIV/AIDS on the Education of Children in the high prevalence states of India. The survey results indicate that the presence of a HIV/AIDS affected individual in a household does affect the children’s schooling. Though the enrolment of children in school is affected only to some extent, continuation of schooling seems a greater problem for these children. Schooling of children belonging to HIV households is discontinued, mainly because they are ‘required to perform domestic chores/participate in paid work/take care of younger sibling’. These are reported as important reasons for drop out in the case of 50% of the boys and 78% of the girls in Andhra Pradesh and for 75% of the boys and 50% of the girls who had discontinued their schooling in Karnataka.

The study conducted by Malik, A. K. (et al 2008) on Socio economic consequences of HIV / AIDS in Bangalore district reveals that, along with affected persons, non infected family members and significant others are suffering emotionally, economically socially and physically from the illness and death of persons with AIDS.

The study on Psycho-social impact and quality of life of people living with HIV/AIDS in South India conducted by Thilakavathi Subramaniana, M.D. (et al 2009). The study examines psycho-social impact of HIV and quality of life of 646 HIV-infected persons from a major government sexually transmitted disease (STD) clinic in South India. In this cross-sectional study, data was collected using interview schedule and scales. Nearly 70% had problems in parenting their children after acquiring the infection. Most (88%) of the respondents reported that usually they seeks help from their family members, relatives or close friends at the time of their illness. Among the four categories of stigma, most of them (96%) reported perceived stigma whereas actual stigma was mentioned by only 33%. All four categories of stigma were experienced on a higher proportion by females than males. Each type of stigma was significantly associated with each domain of quality of life of the respondents (pB0.005). Respondents who reported of actual stigma (33%) had significantly good quality of life in their physical domain (49%), psychological domain (48%) and environmental domain (44%). Multivariate analysis showed that gender and marital status had significant association with quality of life. The findings
of the study underscore the need for enabling environment through “human force” to uplift their social status and to have a better quality of life.

A cross-sectional descriptive study on socioeconomic consequences of HIV/AIDS within the family was conducted by Taraphdar, P. (et al 2011) among patients admitted and attending integrated counseling and testing centre (ICTC) of School of Tropical Medicine, Kolkata. The study found that HIV/AIDS can lead to poverty affecting particularly women infected /affected with HIV/AIDS and can repeal the socioeconomic development of any country. Due to prolonged duration and severity of HIV/AIDS, majority of the indoor patients reported loss of job, declined family income, augmented expenditure for care seeking, and faced greater economic consequences, reflected by selling valuable assets like house, land etc. The skill workers lose their job because of illness (86.8%), disclosure of their HIV/AIDS status (13.2%). Valuable assets were sold to meet the hospital expenses for own illness and to meet the expenditure for partners illness, in the case of ICTC patients. In majority of the cases due to severe economic consequences PLWHA are forced to leave their high school education. HIV/AIDS status was known to other family members in case of 84.8% respondents from indoor patients, among them 15.4% experienced rejection by family members. In case of married women indoor patients whose in-laws were aware of their HIV/AIDS status they were blamed for spouse's illness, and had strained relation with in-laws and spouse, respectively. The study further revealed that Intensive behavior change communication and provision of care and support are required to curb AIDS-related stigma, discrimination, and to maintain physical, mental, and social wellbeing of people living with HIV/AIDS.

Furthermore, due to the rising spread of HIV/AIDS, India has witnessed many women becoming widows at a very young age. Since more men are dying of the disease than women, more women are faced with the burden of financially supporting the family. According to the International Labor Organization, Indian widows are as young as twenty years old. This is a relatively young age for single women to bear any financial responsibilities. When a husband dies due to HIV, young widows are forced to care for children and loved ones, without any other form of financial support. Such inconvenience is a severe economic challenge because young female widows are required to be independent after being finally dependent on their husband.
for years. In India, husbands serve as the primary bread winner and often encourage the spouse to be a housewife during the early years of marriage. However, after the death of a husband, the family witnesses a loss in income, which places a severe economic burden on young widows.

HIV/AIDS has emerged as a serious public health issue across the world, affecting the well-being of many men, women, and children and it is highly prevalent in India, which is the third-largest nation with a high rate of HIV, the virus has had negative social and economic implications for women. Economically, the virus places a financial burden on Indian women due to the high cost of medication and treatment. Furthermore, the spread of HIV/AIDS hinders women’s ability to be caregivers and homemakers, vital economic roles that Indian women value and cherish and places them in a vulnerable position. Unable to attend school or achieve economic stability, many HIV-infected women are forced to enter in commercial sex work, thereby spreading the disease to clients and worse to children through parent-to-child transmission. Socially, it has caused women to suffer from unethical stigma and discrimination, forcing them to live in isolation and endure brutal violence.

2.2.4: Stigma and Discrimination: situation of women infected and affected with HIV/AIDS.

Life for HIV infected women is never easy; they manifest profound physical and psychological consequences. Women bear a ‘triple jeopardy’ impact of HIV/AIDS, “as person infected with HIV, as mothers of child, and as carer of partners, parents or orphans with AIDS”. Women living with HIV/AIDS (WLWA) are at particularly high risk of living a painful, shameful life of exclusion. Several Women have been discarded from their family, friends and partners, thousands have lost their lives and thousands have been deprived to respectful life. Since it was first identified, HIV/AIDS has been linked with ‘sexual misbehavior’ and ‘promiscuity’ contributing to the high level of stigma and discrimination associated with it. Women are often even more susceptible to the stigma associated with HIV/AIDS and are frequently referred to as ‘vectors’ of diseased’. Discrimination of women living with HIV/AIDS, leads to discouragement from seeking essential medical and psychological care they need during the illness. HIV stigma and discrimination in women is associated with rejection from family, community, society, feelings of
uncertainty and loss, low self esteem, fear, anxiety, depression and even suicidal ideation.

The study on HIV/AIDS related discrimination, stigma and denial in India conducted by Bharat. S., (1999) found that most of the PLWHA are experienced stigma and discrimination from the health care providers once after their HIV detection in hospitals. Many PLWHA’s reported disparity in treatment, sudden changes in treatment, and emotional and social isolation after their HIV status was discovered. Health professionals associate HIV/AIDS with particular groups, such as truck drivers, commercial sex workers, slum dwellers and illiterate people, and attribute HIV infection to immoral behaviour and “bad habits”. The study also reports that health professionals acknowledge that stigma and discrimination occurs in health facilities, despite reasonably good knowledge of the basic facts about HIV/AIDS. Doctors in public hospitals tended to blame private practitioners and vice versa. However, health care professionals in both the facilities felt that PLWHA experience most stigma and discrimination in the family rather than hospital, because of lack of adequate knowledge about HIV/AIDS among the family members.

The study also reveals the discrimination experienced in other contexts like schools and childcare institutions and with regard to life insurance. In many instance HIV/AIDS infected and affected children had been forced to withdraw from school, and of institutions that test and segregate HIV positive children. PLWHA are also raised concerns about denial of life insurance. The Life Insurance Company of India has added the HIV test to the list of medical tests required when individuals apply for a policy, and policies are declined for those who test HIV positive. However, the insurance company honours policies that were taken prior to a person testing positive. The respondents are reported that PLWHA are subject to discriminatory behaviour even after death. Differential treatment because of fear of contamination is a “great source of agony and distress to positive people”. PLWHA’s reported that dead bodies of AIDS patients “are packed in black plastic bags and handled with disregard and a casual attitude” by mortuary and ambulance staff. This study also reveals cases where Non Governmental Organizations (NGOs) have failed to respect the rights of PLWHA. It has been reported that photographs of PLWHA has been taken for
publicise an AIDS programme without their consent, PLWHA are denied services by NGOs due to rivalry with other NGOs.

Sandelowski. (et al 2004), in a meta-synthesis of 93 reports of research studies, examined the issue of stigma and discrimination in women living with HIV/AIDS. The study revealed that for women, living with HIV/AIDS meant living with terror, and the painful effects of stigmatization and discrimination including social exclusion, denial, violence within family and community. The rejection and discrimination extends to treatment by health care professionals. The study also highlighted that women are facing higher levels of discrimination from society just because they are women.

The study on situational analysis of HIV/AIDS-related discrimination in Kerala, India by Elamon, J. (2005), highlighted the impact of current legislation and policies in the health care sector on providing care to PLWHA. The study recognizes ambiguity in the health care-related laws and policies that increase the scope for illogical discrimination, refusal to provide treatment, differential treatment, compulsory testing, withholding of test results, revealing of test results to family and communities without consent, isolation and segregation, and lack of confidentiality and privacy of PLWHA. The raised deep concern that even though the UNGASS declaration of commitment on HIV/AIDS states that all PLWHA will be treated without discrimination but PLWHA are facing severe discrimination in the hospital settings. The study recommends training for health care providers to increase sensitivity towards PLWHA; and to enact PLWHA-sensitive legislations.

The study on unheard voices: Experiences of families living with HIV/AIDS in India conducted by Krishna, V. A. S. (et al 2005), this study describes the feelings of families caring for relatives living with HIV on fear of being stigmatized or discriminated by extended family members and health care providers. The study findings provides evidence on how these families are consider or take extreme measures to deal with the consequences of stigma by association. The findings also show that disclosure consented or not by the PLWHA, does not happen all of a sudden and families disclose the HIV status of their member only after understanding the possible consequences of the action. The family members felt supported and understood when they disclosed the HIV status of their relatives to others. Thus, this
study highlights the need for tailored interventions for caregivers to reduce fear related to HIV and to develop strategies to cope up with the stigma they face from others.

The study on Confidentiality, Stigma, Discrimination and Voluntary Disclosures by Mulye, R. (et al 2005) found that PLWHA experience high level of discrimination in health care settings when compared with other settings such as family and workplace. Forms of discrimination include, HIV testing without explicit consent, segregation and isolation in the hospitals, refusal of medical treatment. Moreover this study found that due to fear of being rejection by family or social discrimination, isolation, fear of being avoided and ignore, fear of being insulted and loss of trust are the main reason for non disclosure of HIV/AIDS status. However this study highlighted the reasons for disclosure of HIV/AIDS status, which includes, need for emotional support, sharing their feelings with others, care and support during sever illness etc. Thus, the study highlights the need to address these concerns of PLHIV during counselling to help them in deciding whether or not to, to whom, and how to disclose their HIV status to others.

The study conducted to explore the factors influencing the uses of Prevention of Mothers to Child Transmission (PMTCT) by Wang Ailing (2006) reveals that prevention of mother-to-child transmission of HIV (PMTCT) is an important way to reduce children getting HIV, most of the women are willing to use of PMTCT services, whereas the biggest barrier to using PMTCT services is the quality of prenatal care and PMTCT services. Stigma and discrimination towards HIV/AIDS comes from service providers, their family members, women themselves, and the community. The main stigma and discrimination comes from service providers in the health care settings, which restricted HIV infected women to access PMTCT services. Based on the cultural understanding of HIV/AIDS, women try to carefully conceal the information on their HIV positive status. The study found that majority of respondents in this study infected by HIV from their husbands or ex-husbands. Condoms were rarely used in the families. Women are lack in decision making in the family. In cases where the husbands are HIV negative, the wife suffered domestic violence. However the study reveals that all husbands are supportive to their partners in case of using PMTCT services, the reason behind is that the husband wanted to
have a healthy and HIV free baby. The study strongly recommended for reducing the stigma and discrimination in health care facilities to improve the utilization of PMTCT. A supportive and understanding husband is an important factor in the shaping of a pregnant woman’s decision to use PMTCT services.

The study on understanding and measuring AIDS-related stigma in health care settings by Mahendra, V. (et al 2007), found AIDS-related stigma and discrimination remain persistent problems in health care settings in worldwide. The finding highlighted that HIV status of PLWHA are informed without his/her consent, Linen of HIV infected patients are burned, unnecessary and unethical charges for the cost of infection control supplies, and the use of gloves only with HIV-infected patients. The findings indicate that the stigma index is sufficiently reliable (alpha = 0.74). Higher scores on the stigma index – which focuses on attitudes towards HIV infected persons, were associated with incorrect knowledge about HIV transmission and discriminatory practices. Stigma scores also varied by type of health care providers, physicians reported the least stigmatizing attitudes as compared to nursing and ward staff in the hospitals. The study findings highlight issues particular to the health care sector and recommended for successful, stigma-reduction interventions, and the measures used to assess changes, need to take into account the socio-cultural and economic context within which stigma occurs.

The study on Women living with HIV: Stories of powerlessness and agency conducted by Souza, R.d. (2010) highlighted the changing scenario of HIV/AIDS infection, it reveals that married monogamous women in India are now considered to be at higher risk from HIV/AIDS than previous. The study also illustrate that strong patriarchal social system and gender disparities making Indian women more marginalize within the family and society, which lead them more susceptible to the infection. In particular, the study explores “how culture and power inequities shape their unique experiences of stigma and how women demonstrate agency in their lives in a context of seeming powerlessness”. The analysis reveals that “stigma is inextricably linked to systemic patriarchy, but women demonstrate agency by articulating their own understanding of disease and illness, reflexively contesting cultural assumptions, and appropriating the courage to speak out for themselves and others”.

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The Study on differences in testing, stigma, and perceived consequences of stigmatization among heterosexual men and women living with HIV in Bengaluru, India by Malavé, S (et al 2014) reveals gender differences in HIV testing, forms and consequences of stigma faced by the HIV infected PLWHA. Generally men are tested for HIV once they become ill, women were tested for HIV after their husbands were diagnosed with HIV. The study found that men experienced higher levels of internalized stigma than women, whereas women reported higher levels of discrimination than men, as they are blamed by other for the HIV infection although they are infected by their husband only. The study reported that majority of the infected women leave their family or neighborhood after HIV diagnosis possibly reflecting the differences in the way the general public treats men and women living with HIV. The study strongly recommended for taking measures to prevent HIV/AIDS related stigma and discrimination, especially addressing the internalized stigma faced by men infected with HIV/AIDS, and the need to improve skills among women living with HIV to cope up with discrimination.

Despite the huge enormity of the problem in worldwide, only in recent time responses are shifted beyond documenting negative experiences to implementing preventive interventions to combat HIV/AIDS related stigma and discrimination. A review of interventions that attempted to explicitly diminish HIV/AIDS related stigma and discrimination in developed and developing countries, concluded that it would be unrealistic to abolish stigma, but possible to reduce it through a diversity of intervention strategies. This has been recommended that intervention strategies aimed at individuals in an institutional setting be developed and tested in order to address structural as well as individual determinants of stigma (Brown, Macintyre, and Trujillo 2003). Parker and Aggleton (Horizons 2002) noted that to challenge stigma and discrimination, “social action is required to change the context within which individuals and communities respond to HIV/AIDS”. In order to do this, individual approaches need to be complemented by actions to address environmental and structural constraints that foster HIV/AIDS related stigma and discrimination.

The study on “reducing HIV/AIDS related Stigma and Discrimination in Indian Hospitals” conducted by UNAIDS (2001) clearly indicated there is need to address stigma and discrimination in the hospital setting, the study found that through
health care workers are claiming that their hospital never refused admission and/or
treatment to the HIV/AIDS infected, however on the other side caregivers and
patients reported that the access to and quality of in-patient care in New Delhi
hospitals depended on a patient’s HIV status, for the reason and fear of discrimination
some patients hide their HIV from health care workers. Common manifestations of
differential treatment of PLWHA in the participating hospitals included delay in
treatment, unwarranted referrals to other facilities, segregation, labeling, excessive
use of barrier precautions, breaches of confidentiality, un-consented HIV-testing,
inadequate pre-and post-test counseling, and withholding HIV test results from
patients. The study also found that many health care workers lacked adequate
knowledge and training in the basics of HIV transmission, infection control, and
clinical management of HIV/AIDS. Therefore, reducing HIV/AIDS related stigma
and discrimination in clinical settings requires addressing not just the attitudes and
practices of health care workers but also their needs for information, training, and
supplies.

2.2.5 : Human Rights and HIV/AIDS

Human rights are exceptionally relevant to the response to HIV in the three
ways. First, lack of human rights protection creates vulnerability to HIV/AIDS,
particularly among marginalized and underserved groups such as women, children,
sex workers; people who use drugs; migrants; men who have sex with men (MSM);
transgendered persons and prisoners.

Second, lack of human rights protection lead stigma, discrimination, and
violence against HIV/AIDS infected/affected. These hurtful attitudes and practices are
rooted in a lack of understanding of HIV, misconceptions about how HIV is
transmitted, and “fears and prejudices surrounding sex, blood, disease, and death as
well as the perception that HIV is related to ‘deviant’ or ‘immoral’ behaviors such as
sex outside marriage, sex between men, and drug use”.

Third, lack of human rights protection blocks effective national responses to
HIV/AIDS. Discriminatory, coercive, and disciplinary approaches to HIV increase
vulnerability to infection and worsen the impact of the epidemic on individuals,
families, communities and countries.
Rau and Rajagopalan in their study found that 87% of respondents had no knowledge that they were being tested for HIV and 80% had no knowledge about meaning of HIV positive. Almost one third reported that they had been rejected by doctors and other hospital staff after being diagnosed as HIV positive, and had been discharged immediately. Almost majority of the respondent reported that their HIV status had been revealed to their relatives without their prior consent.

A landmark anti-discrimination case in the Bombay High Court that affirmed the rights of PLWHA s in the workplace, where a casual labourer of a public sector corporation, was tested for HIV prior to being regularised into a permanent position. The casual labourer tested positive for HIV, and though otherwise fit, was rejected from being regularised, and his contract was terminated. The casual labour filed a writ petition in the Bombay High Court, arguing that the company’s rules (mandatory HIV testing and denial of employment to positive people) and actions violated Articles 14 (Equality before the law), 16 (Equality of opportunity) and 21 (Right to life and personal liberty) of the Indian Constitution. The court ruled that, a government/ public sector employer cannot deny employment or terminate the service of an HIV-positive employee solely because of their HIV-positive status, and any act of discrimination towards an employee on the basis of their HIV-positive status is a violation of fundamental Rights.

The services of HIV-positive employees can only be terminated if they pose a substantial risk of transmission to their co-employees or are unfit or unable to perform the essential functions of their job. Determining whether a person is unfit or incapable of performing their job must be made on the facts of each specific case by conducting an individual enquiry (beyond a mere diagnostic test). The court also held that an HIV-positive person can suppress their identity and use a pseudonym in the course of court proceedings in order to protect themselves from further discrimination.

HIV/AIDS related stigma and discrimination are now broadly accepted as key obstructions to successful care and prevention throughout the world particularly amongst more disadvantaged and marginalized groups such as women. Stigma and discrimination translate into human rights violation and are some of the main factors for high prevalence of silence blanketing HIV/AIDS.
2.2.6 HIV/AIDS and Social Work Intervention.

Social workers provide HIV/AIDS prevention and early intervention services in a range of practice settings, including child welfare, schools, criminal justice, substance use treatment, mental health centers, primary care clinics, hospitals, and private practice. Social workers have the skills, opportunity, and commitment to engage clients in HIV/AIDS prevention, care, and treatment utilizing a comprehensive bio-psycho-social approach.

Throughout the 30 year pandemic, the National Association of Social Workers (NASW) has taken an active role in addressing HIV/AIDS policy and practice issues. NASW continues to advocate for health and behavioral health equity and is committed to initiatives designed to increase consumer engagement and to build a skilled and competent social work and allied provider workforce.

HIV/AIDS crosses all fields of practice, including mental health, addictions, community development, and health care. Social work practice in this area continues to evolve, as social workers provide support to persons living with HIV/AIDS and those affected by HIV/AIDS through counselling, treatment intervention, and social justice activities.

While there is no cure for HIV/AIDS, people are living longer with all the accompanying joys and challenges this entails. Some of these challenges include dealing with the side effects of anti-retroviral medications, coping with grief and loss, and dealing with the continued stigma of HIV/AIDS.

Social workers own the knowledge and skills to work effectively with individuals who are living with HIV/AIDS and those affected by HIV/AIDS, including family members, friends, partners, and children. Social workers bring the unique skill of working with people within the context of their environment and advocating change that best meets the needs of clients.

In the community framework, social workers carry out advocacy on behalf of those living with HIV/AIDS through community organization and policy development. They also provide education to reduce the incidence of HIV infection.

The study by Elsa Rodriguez and O’Shonda Renee McDowell June 2014 “Social Workers’ perception on HIV/AIDS and the effects on their service delivery” explores the relationship between social workers’ perceptions of the HIV (human
immunodeficiency virus) /AIDS (acquired immune deficiency syndrome) population and the effects on their service delivery. This study used a quantitative online survey with a self-administered questionnaire. Data was collected for 60 social worker participants for this study. Implications from the correlation coefficients identify a significant negative relationship between stigma and HIV/AIDS knowledge, suggesting that higher levels of stigma were present based on lower levels of HIV/AIDS knowledge. This study reveals that social workers are comfortable with PLWHA (people living with HIV/AIDS) and they do not pose any stigma towards PLWHA. The findings of this study suggest further research and examination of social workers’ perception of PLWHA due to underrepresentation of social workers perceived stigma. The study also suggests that social workers need to increase their knowledge about PLWHA and the need for additional cultural competency trainings.

According to the observation, the social work profession remains an untapped resource within the community for addressing HIV/AIDS prevention and early detection (Wolf & Mitchell, 2002). Wolf and Michell (2002) conducted a study for preparing social worker to address HIV prevention and detection. It investigates 17 social workers knowledge and practices relation to HIV prevention, education, risk assessment, and case management. Licensed Clinical Social Workers (LCSW) and social workers were found to have knowledge of HIV; social workers that directly work with HIV/AIDS patients were more aware of prevention, early detection, and treatment. However, those that did not work directly with HIV/AIDS clients were unable to fully give details on prevention and treatment. Early training in education is proven to be significant in the social work practice because a social worker is unaware if they will have a client with HIV/AIDS. The importance of enhancing education about universal precautions will reduce stigma and reduce the fears of transmission amongst healthcare workers and social service providers (NASW). Social workers should be trained thoroughly in providing services to the HIV/AIDS population. With the proper training and education, social workers will gain information on intervention that will broaden the competency on PLWHA.

However, this has been observed from the above literature review of important studies have been conducted on stigma & discrimination at international level by practitioners, researchers as well as social scientist, they reveal that stigma and
discrimination is the major barriers for effective HIV/AIDS prevention programme in recent period. In Indian context few selective studies has been conducted on HIV/AIDS and Socio- Economic Impacts, HIV/AIDS and Impacts of Gender and Children, stigma and discriminations faced by the PLWHA etc by individual researchers, national level organizations, UNAIDS and National AIDS control Organization conducted most of the studies at high prevalence states i.e. southern and North Eastern part of the country. However so far no specific studies have been conducted on discrimination as well human rights violation against women infected and affected with HIV/AIDS in the region. Consequently this issue is quite new and have an opportunity for social scientist intended for in depth study and fulfil the gap. Thus, this PhD study attempts to fill this gap in the existing literature and learning’s.