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Impact of HIV on Family Life of infected Women

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Abstract – India has registered a significant rise in the HIV/AIDS cases with nearly 2.4 million people estimated to fall prey to this deadly viral infection. However, between 2001 and 2009, HIV incidence fell by nearly 25 percent and the national prevalence was evaluated to be less than 1 percent. From the total number of HIV infected Indians, nearly 39 percent are women. HIV has emerged as a diverse epidemic in India with strong presence in a few states like Andhra Pradesh, Maharashtra, Karnataka and Tamil Nadu, that make up for nearly 55 percent of the HIV population while West Bengal, Gujarat, Bihar and Uttar Pradesh collectively account for 22 percent of the HIV/AIDS population in India. The main reasons for the spread of this deadly disease in India have been recognized as unprotected sex between sex workers and their clients, usage of infested injecting tool for drug infusion. Thus, sex workers form a major section of the HIV positive women in India. This study intends to comprehend the status of the women HIV patients in India, understand their present situation and what atrocities they have to face within the family and society due to their HIV status.

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INTRODUCTION

Introduction to HIV/ AIDS among women in India

India has witnessed a steep rise in the number of HIV patients ever since the first HIV/AIDs case in India was acknowledged in Chennai in 1986. According to the National HIV Sentinel Surveillance, nearly 2.4 million Indians were found to be HIV positive in 2010 against the total population of 1.2 billion in mid- year 2010. However, between 2001 and 2009, HIV incidence fell by nearly 25 percent and the national prevalence was less than 1 percent (Chakraborty and Hazarika, 2011). From the total number of HIV infected Indians, nearly 39 percent are women. HIV has emerged as a diverse epidemic in India. Though only 0.3 percent of Indian adults are HIV positive, due to the humongous size of the population, it is ranked as world's third-largest HIV hub after South Africa and Nigeria (New York Times, 2013). HIV stigma is invasive and inescapable in India's socio-cultural knit where HIV positive people are considered "sinners" especially women. Women, especially in rural areas are illiterate, have very little knowledge about the disease and its treatment and have to face extreme marital power differences to survive from the disease (Nyamathi et. al, 2010). Though not all women infected with HIV are sex workers, studies show that the main reasons for the spread of this deadly disease in India are unprotected sex between sex workers and their clients, usage of infested injecting tools for drug infusion. The risk is quite alarming with persistently high prevalence disease rates especially amongst rural women (The World Bank, 2012). UNICEF anticipated that at present there are between 22000 and 61000 HIV infected pregnant women in India. The corresponding percent was 2 percent in 2005 which elevated to 23 percent in 2010. The actual figure may be much more as testing coverage is yet truncated (UNICEF, 2012).

Present condition of women infected with the disease in India

India is one of the top 10 countries that has the largest number of pregnant women infected with HIV/AIDS and nearly 80 percent of these would-be-mothers do not get antiretroviral (ARV) drugs to avert parent-to-child transmission (PTCT) of the virus (Rastogi, Charles and Sam, 2012). It is evident that nearly 85 percent of HIV transmission in India is through unprotected intercourse and 75 percent of the infected women get positive within the initial years of marriage. However, apart from the disease and its impact, the HIV positive women have to face a lot of social stigmas. In India, there persists severe heterogeneity in HIV prevention and treatment. The management and handling of HIV scourge in India has been impacted with escalated rate of gender stratification wherein women are exposed to severe social disadvantage. Indian women experience disparate defenselessness to HIV/AIDS because they are illiterate or insufficiently educated, do not have access to information to get HIV awareness, dwells in poor conditions and deep-rooted gender inequity. Moreover, HIV women patients have diminishing levels of psychological health as well. This is fostered by the fact that most HIV infected women reside in rural sects of the country and are deprived of social and physical help from government and other sources. Rural women face difficulties in travelling to government hospitals for free medicines, cost and time involved in travelling and above all the prejudice from hospital employees (Nyamathi et. al., 2010).

LITERATURE REVIEW

Life of HIV-infected women in India: Financial, Personal and Social

There has been substantial research done in regards to identify the changes HIV infection brings to lives of women in India. Habib and Rehman (2010) have highlighted the humiliations and stigma attached with the chronic disease of HIV/AIDS. Apart from physical disability, HIV creates a loss of self-worth as they are unfit for their jobs and family responsibilities. Socially, HIV infected people especially women are rejected from friends and family, sacked or compelled to resign from jobs and even have to face violent assault. Such stigma is not exclusive to India but has a universal presence. Chakraborty and Hazarika (2011) have identified the biological, socio-cultural and economic factors that make women more susceptible to HIV and its associated stigma. Biologically, women are more prone to infections than men. Indian women, especially of rural and weaker sections of the society are prone to brutality, maltreatment and desertion. Economically, women are not independent and are unable to support their treatment after rejection. Charles et. al (2012) have also deduced that stigma, discrimination and psychosocial characteristics are indispensible associates of HIV. HIV infected people especially the weaker sex, women, are highly prone to discrimination, ignorance, humiliation, and inequality from their spouses, families, social groups, communities, workplace etc. Women have to face financial, personal and social trauma along with combatting the deadly disease. Sachdeva and Wanchu (2006), Williams and Bhatula (2012) and the global report of UNAIDS (2010) also portray similar picture of the women patients of HIV/AIDS especially in developing countries like India.

A review of condemnation received by these women and how they handle it

The humiliation and prejudice attached with HIV/AIDS is a ubiquitous predicament. HIV patients, not only in India but anywhere in the world have to experience bigotry and stigma in varied magnitudes in places like homes, community, place of work and hospitals (Mahendra, et. al., 2006). HIV/AIDs are perhaps the most denounced diseases in the history of humankind. The diagnosis of the disease in itself is destructive but it also culminates to loss of job, dismissal from educational institute, violence, social banishment, loss of property and refusal for health services at hospitals and emotional encouragement. Even discrimination is reflected in activities of the media, government policies and initiatives and the prevalent legislative measures. It is this stigmatic condition that compels people to succumb to living in fear, isolation, embrace deterrent behavior, and avoid visiting health care centers for tests and treatment. These reactions are most common due to the kinds of stigma women have to undergo. Verbal stigma like abuses, scoffs, denunciation, tattlers and rumors. Institutional stigmas are loss of job, houses, deprivation of educational opportunities and requisite health care. Women, girls, sex workers are the most vulnerable groups to the disease and its associated stigma who even experience violence and social boycott (ICRW, 2010).

Family life of HIV/AIDS infected women in India

Women either married or single, divorcee or widow, sex worker or family woman, all are highly vulnerable to the deleterious effects of HIV/AIDS irrespective whether they are infected or affected by the disease. HIV/AIDs are a deadly disease that impacts the families in an intense and catastrophic manner and inexplicably makes the families susceptible (Das and Sarma, 2013). Lekganyane and Plessis (2012) highlighted the stigma of the HIV infected women which is universal. Once the diagnosis come positive, infected women are engulfed with a sense of shock that fosters feelings of fear and shame and gradually they start living in self-imposed isolation and attempt to maintain confidentiality about their health status quo. They are filled with a sense of shame and remorse along with multiple negative discernments by significant others thereby creating an impulsive self-stigmatization. However, there are many courageous women who have attempted to face this disease with courage and have selectively disclosed the reality to family and friends to gain support. Many government-aided and privately run social groups are also working towards spreading awareness and helping women infected with this disease to live their lives with dignity and treatment.

There are multiple intricate psychological and social issues concerning the family's capability of handling HIV/AIDS infection. Women, due to the undercurrents of social and culture setups find themselves helpless and thus, HIV/AIDS hamper inter or intra social relationships of the patients along with the economic health of the families, businesses and society as a whole. HIV makes people weak not only physically but mentally as well. They lose their productive potentiality. This brings in financial constraints on to the family especially amongst poor sections of the society. HIV offers a bundle of constraints packaged as one ruining not only the life of the victim but also his/her family (Kalpana and Iyer, 2013).

RESEARCH METHODOLOGY

The research methodology adopted for the study included both the primary and secondary research.

Primary Research

The primary or the first-hand data for the study was gathered through the survey method in which a structured questionnaire was served to the respondents. The sample size chosen for the study was 300 women infected with HIV. The geographical

areas chosen for the study were state of Karnataka. A structured questionnaire was served to the respondents mainly through face-to-face. Only few respondents were contacted through emails, online survey tools and social networking portals. The data gathered has been assimilated and evaluated through statistical tools like Ms-Excel and SPSS.

Secondary Research

Secondary research for the study was highly helpful in getting an appreciated insight into the concept of HIV/AIDS and its impact on Indian women. Secondary data was judicious in laying the foundation of the primary research and provided the requisite guidance for concluding the research constructively. The resources employed to gain valuable secondary data for the study are:

- Books, articles, journals and other recognized publications.
- Newspaper articles, books and similar publications.
- Magazines and other significant information portals.
- Blogs, e-paper and e-journal articles and government reports.
- Official Websites of the international health organizations.

Analysis

The primary data reveals a lot of striking facts about the women infected with HIV/AIDS in India.

Marital state of the respondents and their age are co-related in the following table:

Co-relation between Marital state of the respondents and their age

Marital Status	Age group							
	15- 20	21- 25	26- 30	31- 40	41- 50	50 and above	Total	Percentage
Married	7	15	33	51	16	1	123	41%
Separated	3	6	8	19	12	1	49	16.33%
Divorced	-	2	7	8	-	-	17	5.67%
Devadasi	7	2	8	19	6	-	42	14%
Live in	2	4	1	3	-	1	11	3.67%
Widow	1	6	21	20	7	3	58	19.33%
Total	**20**	**35**	**78**	**120**	**41**	**6**	**300**	
Percentage	**6.67**	**11.67**	**26**	**40**	**13.66**	**2**	**100%**	

The tabulated data reflects that nearly 6.67 percent of the married respondents got infected in the age group of 15-20 years. This implies that still early marriage is prevalent in spite of the restrictive laws for the same. Other factors like Parent-to-child-transfer and unsafe intercourse practices. Another outstanding revelation is the presence of the *Devadasi*[1] system. Nearly 14 percent of the respondents fall into this category across age groups. Devdasi system is still prevalent in the rural sections of scheduled castes and tribes wherein devdasis are regarded as prostitutes. However, the highest number of infected women falls into the category of married which might have got infected through their husbands or through unprotected sexual acts. Women in India, especially in rural areas do not have a say in sex related decisions and cannot demand protected sex if their partners are unwilling to do so. Majority of the women got infected during their mid-life span though no conclusive inference can be drawn on life expectancy on grounds of the disease.

The study was carried out secularly and caste and religion are no criteria for HIV/AIDS as anybody can get the infection. It is observed that HIV infected people are high amongst backward classes and Schedule castes as compared to Schedule tribes ad Brahmins. This is so because tribal population lives in seclusion, have little contact with the outside world and people stay in close observation of the family. Thus, are relatively safe from the epidemic.

Illiteracy have been observed as a key catalysts for the spread of the infection with 58% respondents are included in illiterate and lower primary education level. This implies that illiteracy results in unawareness about the disease and such people tend to fall prey more than the educated ones.

Study shows that 77.33 percent of the infected women gave birth to children. This shows that HIV does not hinder pregnancy. However, it is not clear whether infected women took preventive drugs to avoid Parent-to-Child-transfer and deliver a healthy baby. Moreover, most women came to know about their infection after marriage, yet many of the respondents were hesitant to discuss about the tabooed “extra marital affairs”.

HIV patients need a lot of family support and fear disclosure of their disease to their families. The following table shows that living with HIV is very challenging and only very few people get support and positive support from family.

[1]Devadasi was a ceremony in which girls were made “dedicated” to worship but later got transformed into religious prostitution. Though outlawed in Indian in 1988, it still prevails in scheduled castes of Karnataka and Andhra Pradesh

Reaction of family member towards respondents knowing their HIV status

Reactions	Respondents	Percentage
Feeling sad and sympathy towards the current situation and shocked knowing about the infection	69	23
Blame for responsible to transmitting the infection	61	20.33
Anger, neglected and force to go for health check-ups and stopped healthy interaction	51	17
Normal, since both are aware about the disease	36	12
Good, treating well	17	5.67
Attempted for suicide	5	1.67
Became chronic alcoholic	7	2.33
No Reply	54	18
Total	**300**	**100**

Moreover, the study indicates that most of the illiterate or poorly educated respondents have either perceived HIV infection as a punitive action for their sins while some preferred not to answer. Also, many have faced discrimination from society and family due to their HIV status. However, it has been 27.67 % who said that there is discrimination in the family in treating husband and wife, 72.33% said that there is equal treatment for husband and wife but in many families both have thrown out from parents and in-laws house. HIV infection is a deadly disease and the patients especially women are desirous of living a normal life, getting better treatment and healthcare, no discrimination at place of work and pray to God for curing their disease and lead a normal married life.

The primary data analysis deduces that it is extremely challenging to live with HIV/AIDS especially for women in regards to the social, cultural and economic factors along with the medical aspects which involve a change in lifestyle, regular medication and nutritional food intake.

DISCUSSION

Women infected with HIV/AIDS in India have to face immense humiliation at the hands of their family members. Women are blamed for being carriers of the virus and face the wrath, anger and are neglected. Most of the women experience a drastic change in the attitude of their husbands after knowing about the infection and most of the men decide to be divorced or separate from their HIV positive wives. Even husbands who continue the relationship tend to neglect and avoid sexual relationships with their wives. All this has a negative psychological impact on the women who feel the double stress of disease and strained married life. Women who get infection from their husbands feel cheated and foster a feeling of hate and anger against them. However, study does not show significant cases of domestic violence. Also, the children have mostly been supportive of the mother infected with HIV. However, they have to face the discrimination in the society. In the core, HIV/AIDS have a catastrophic impact on the married lives of the women resulting mostly in the end of marriage and life-long physical and mental turmoil.

HIV/AIDS is an epidemic in India and needs extensive measures to be taken for prevention, cure and spreading awareness about it across the inhabitants to let people infected with HIV lead their lives normally with dignity. India has been predominantly a male oriented society wherein women are considered inferior to men. The survey carried out for the study shows the plight of the women especially in rural sections where literacy levels amongst women are negligible and women are considered to be a sex object. Government must make stern laws and ensure effectual implementation of the same for abolishment of the traditional vices like child marriage and devdasi custom. NGOs and Government must work upon imparting education and spreading awareness about the disease and teaching people how to keep themselves safe from the killer disease. More healthcare centers must be setup in rural areas where free health care can be provided and also ensure availability and supply of ARV drugs to pregnant HIV patients to curb the disease from passing on to the babies. There is an ardent need for the society to stand up united to fight the disease and eliminate social discrimination. Medical centers must arrange for counselors who can help the patient as well her family members especially spouses to support her in every possible way. Legislation must be made so that rights of HIV patients can be protected especially related to their job, rights in family property etc. More research must be promoted in the country to device curative medicines and also develop generic drugs affordable by maximum people.

CONCLUSION

Considering sex and sexually transmitted diseases a taboo is no longer a viable action, spreading awareness, promoting education amongst the poor sects of the society and ensuring the reach of medical care to remote areas of the country. Laws need to be reformed and implemented sternly in purview of child marriage, human trafficking, prostitution etc. The study highlights the plight of the women HIV patients in India but such experiences are common across the globe and women are subjected to atrocities, abuses, violence, discrimination etc. for the disease and are deprived to emotional support from their families and also many times do not get requisite medical care due to lack of financial independency. Married women have to face a lot of atrocities at the hands of their husbands, family and society as a whole. Most of the marriages end in separation or divorce on the revelation of the HIV status and those which survive are not that happy as they were. Even women are subjected to isolation and neglected from husbands who were the carriers of the virus. Women very rarely seek solace in family members or spouses in India and HIV generates not only a lot of physical implications

but also a lot of mental and emotional disturbances which create a lot of stress amongst women patients.

As it is said, prevention is better than cure. There is an ardent need for spreading awareness and this is possible through education and women empowerment.

Conflict of Interest

The authors declare that there is no conflict of interest

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