

Social Life of HIV Positive Women in Kashmir Valley

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Abstract

Although gallons of ink has been drawn to describe the general inequitable status of women in Kashmir society, there appears to be limited research on the social life of HIV/AIDS affected people in Kashmir and especially how Kashmiri women infected with HIV/AIDS are coping with their lives in such a society which is strongly guided by socio-religious norms. Since the HIV prevalence is considerable low in Kashmir as compared to other states of India and the factors responsible for such low prevalence to HIV/AIDS are not known, but definitely this is being attributed to strong socio-religious factors prevalent in Kashmir society. The primary goal of this study is to find out the social stigma and discrimination experienced by these women in contemporary Kashmir society both at the individual as well as societal level.

Keywords

HIV/AIDS, Women, Health, Kashmir Valley

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1. Introduction

AIDS is an acronym of “acquired immune deficiency syndrome” which is a fatal disease described variously as modern plague, modern scourge, devastating disease, insidious microbiological bomb. It has emerged as an unprecedented pandemic cutting across all boundaries international, socio-economic, age, race and gender. AIDS emerged as one of the most important public health issues of late twentieth and early twenty first centuries and is now one of the leading causes of global morbidity and mortality (Wallace, 2014). AIDS is also considered a socio-cultural issue because when this epidemic emerged in 1981, it was perceived as a deadly disease that was transmissible from person to person, as well as closely associated with historically disenfranchised groups and culturally and historically taboos and issues such as sexual orientation, drug use, unethical sex, prostitution, commercial sex workers etc. The combination of these factors led to societal hostility from

community and other immediate social groups as well as slow response by state, federal, and country governments. Although both knowledge of HIV/AIDS and government response has increased across the time in almost all societies now, but the stigma and hostility still persists more than 30 years later (Tomaszewski, 2012).

1.1. Women and HIV-A Look at the Statistics

Women whether, married or single, divorced or widowed, sex workers or seasonal migrants or even may be adolescent girls, are most susceptible to the negative impacts direct or indirect, i.e. infected or affected, of HIV and AIDS owing to the dynamics between the structural and cultural factors which places them in a weaker and vulnerable position than most others. Further, women are biologically more prone to HIV infections than men in terms of any single act of unprotected sex with an infected partner, with the male to female transmission of the virus being 2 to 4 times higher than the female to male transmission among such discordant couples

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(Kalpana and Iyer, 2013: 29). The biological structure of women thus also renders more vulnerable than others to HIV and AIDS. Gender disparities in terms of access to education, resources, income, political power, coupled with incidences of sexual violence, coercion, social dislocation in conflict situations like armed conflict in Kashmir society during the last decades etc or owing to migration to other places due to displacement, serve to increase the risk of HIV infection to women through unprotected sexual contacts. As a result, women now account for more than half of those living with HIV worldwide (NACO, 2005). They constitute a significant number of those infected with HIV in India which is indicative of the manner in which gender disparities serve to pose increasing and disproportionate risk to women even in places which have relatively low national prevalence rates. In India, 35% of all reported AIDS cases are among the age group of 15-24 years, indicating the vulnerability of younger population to the epidemic (Verma, 2008: 380). Thus while efforts are being made to curb the spread of the epidemic, there however remain a number of challenges to be addressed and streamlining the policies to the actual trends in the tangible ground which is critical. As studies reveal that young women and girls are more susceptible to HIV than men and boys. Their vulnerability is primarily due to inadequate knowledge about AIDS, insufficient access to HIV prevention services, inability to negotiate safer sex and lack of female controlled HIV prevention methods. Thus this epidemic is moving from high risk groups, such as sex workers to the general population (Park, 2007: 285-297). As statistics for national level of India puts it; there were five million new HIV infections in the world during 2002, of these 2 million were women as per National AIDS Control Organization (NACO) reports (2013). It is also estimated that about 2,400,000 people in India are living with HIV/AIDS.

Though in contemporary India there are discussions about women's vulnerability to HIV, but these deliberations often focus on individual factors which increase risk; there is generally less focus on the underlying causes of poverty, violence and gender inequality (Verma, 2008: 387). As the concerns of gender equity and equality, and women's empowerment in all respects are essential to the prevention, treatment and care in relation to HIV and AIDS. So there is an urgent need to study the socio-cultural life of these infected women and this aspect provides a fertile ground for sociological investigation.

1.2. Status of HIV/AIDS in Jammu and Kashmir

The Srinagar city is situated between the geographical coordinates of (34°18' N latitude and 74°9' 1E longitude) at an average altitude of 1583 m. As per the statistics of J&K

AIDS prevention and control society (ACS), Jammu and Kashmir has 3492 people living with HIV. Jammu division has highest number of HIV positive with 90% of these cases, while Kashmir with only 13% of HIV positive cases detected so far. This puts the total number of HIV positive cases in Kashmir division at 452 in 2011-12 (International AIDS Society, 2010: 45). According to IANS/Daily India.com there are 745 HIV cases in Kashmir. However many other unofficial estimates put the number at 2500 for these affected cases? According to the latest figures of Jammu and Kashmir AIDS prevention and control society (JKAPCS), J&K has 2406 HIV patients registered while Kashmir has 373 such patients as on August 31, 2013. Data revealed by the JKACS earlier in Dec. 2012 stated 3492 cases of HIV in Kashmir from 2005-2011, and as per these reports 223 patients died of HIV in the state. In 2011, 3066 HIV positive cases were registered in the state. In 2010 there were 2649 HIV patients in J&K (76 in Kashmir and 582 in Jammu) which numbered at 2222 in 2009. Currently as in December 2014, 1101 patients are registered at Anti -Retroviral therapy (ART) clinic in Jammu and 141 in ART centre Kashmir. According to Jammu and Kashmir state AIDS prevention and control society, the state is a low prevalence state where the mean prevalence rate of HIV infection among high risk groups (STD) is 0.3% and low risk groups (ANC) is 0.04% as per various setline surveillance rounds conducted during last eight years (Gassh *et al.*, 2003:101-9). The HIV/AIDS is 2-3 times more common in males than females peaks in the persons dyed between 15-50 years. The other important aspect of this phenomenon is that there may be a chance of secondary infections in HIV patients like infection of mycobacterium tuberculosis which was prevalent in 70% of patients (Kashmir times, 2013). The challenge before us is that the influx of migrant workers, security personnel, truck drivers, tourist in Kashmir, commercial sex industry, low literacy rate and socio-cultural diversity had made fighting HIV/AIDS difficult (Greater Kashmir, 2012). In J&K one of the major prevalence groups among women is found to be wives and associated partners of truck drivers. The fact that HIV infection is more likely to be found in women with lower education status is an additional challenge in Kashmir society. The present study was envisaged to identify the socio-economic background of HIV/AIDS infected women in Kashmir Society and to ascertain the amount of awareness these infected women have about HIV/AIDS. It was also explore in present study how HIV infected women are coping up with their lives in a religious bound society of Kashmir and to determine the level of social stigma attached for being an HIV positive.

2. Methodology

For the present study the researchers used exploratory research design to draw the relevant inferences. In addition to it Purposive Random Sampling Technique was employed to gather the data from primary respondents. Though the universe for this study was whole Kashmir division but the study was conducted in an ART centre in Sheri Kashmir Institute of Medical Sciences Srinagar (Kashmir) during the year 2014. A Sample of 20 HIV positive women from both the rural and urban areas of Kashmir were selected randomly for the study. A semi-structured pre-tested interview schedule was administrated to the these women to gather information about their socio-economic condition, knowledge about means of transmission of the infection, modes of prevention, attitudes towards them from general community for being HIV positive, counselling and testing, social stigma these woman experience and level of awareness these infected women have about HIV/AIDS. The study was also complemented with observation method to elicit the information on facilities available for these vulnerable social groups and the discrimination and exclusion they experience from society at large.

3. Result and Discussion

In order to ascertain the specific nature of the problem under investigation the research carried out in ART centre in Sheri Kashmir Institute of Medical Sciences Srinagar (Kashmir) present the following relevant information mentioned below:

- 85% of infected respondents were married and 15% of the respondents were un-married, which included one little girl student from 9th standard infected by parents, and another girl from studying in B.A. 1st- year who was infected by her boy-friend. This female student would come in her college uniform to the ART centre pretending to be going to college at home. Majority of the respondents (75%) were infected by their husbands and remaining 10% were unaware about the source of their infection.
- Economic status of the respondents was comparatively low as compared to the general population, as these respondents were in critical financial condition. Husbands of the married respondents (85%) were all labourers, and for those respondents whose husbands were also positive (75%) the economic condition was much worst, as their husbands were not in the position to work much due to their repeated illness.
- It was remarkable to note that 70% of the HIV positive women had never heard of HIV/AIDS before they came

into contact with this disease. Among those who were aware only few (2%) were having the accurate knowledge about HIV/AIDS, rest were ignorant.

- Knowledge about the modes of transmission was scanty among those who were not aware of the disease before they come into its contact. A little less than half of the respondents (30%) had no idea about the possible modes of transmission. Majority of the respondents were married (85%), so they blamed it to sexual contact with an infected person, only (8%) to infected blood, (5%) to use of infected needles and syringes, only about (3%) were aware of the fact that HIV/AIDS can be transmitted from mother to child, and only few (20%) were using condoms during sexual intercourse.
- Most of the respondents believed that HIV/AIDS could also spread through eating with victim (20%), sharing clothes (9%), sleeping with victim (30%). While as sizeable portion didn't comment at all.
- The chief sources of information about HIV/AIDS to vast majority of (80%) respondents were doctors who treat them, then friends/relatives and family (15%), followed by radio/TV (5%) and print media (1%). In addition to it 30% of the respondents had no access to TV/radio.
- Those with the correct knowledge of various preventive measures were (60%), a great majority named sterilization of needles before infection (25%) followed by safer sex (20%) and ensuring safe blood practices (15%).
- In response to the question that whether respondents ever discussed HIV/AIDS with someone, 45% admitted that they never pulled enough courage to discuss the topic with anyone. About 60% of the respondents admitted having discussed about HIV/AIDS at some time with their husbands but only after coming into contact with the disease.
- About 75% of the respondents face different problems when their HIV positive status was revealed. Married respondents whose husbands were negative (10%) reported that they were violated and ill-treated and even beaten by their husbands.
- About (30%) of the respondents reported violence by their in-laws and about (20%) had kept their HIV (+ve) status hidden. Even a little portion (1%) of the respondents was facing violence by their own Kids. (75%) respondents reported discrimination from general society after their HIV positive status was revealed.
- Availability of ICTCS (integrated counselling and testing centres) centres was in fewer regions of the residing places of respondents. Majority of respondents (70%) didn't visit their nearby testing centre with the fear that

their HIV positive status might be disclosed. Respondents visit the ART centre in SKIMS (Srinagar) the only ART centre in Kashmir, where they feel that their HIV positive status is kept hidden. A very vast majority of respondents (98%) were satisfied with the treatment and medicines they got in this ART centre.

The majority of the respondents had come into contact with this disease unknowingly, even they had never heard about the disease before. Most of these respondents were in critical financial condition, i.e. economically their status was slow. In addition to it, majority of respondents were facing different problems in their social life e.g. married respondents whose husbands were negative reported to be violated, ill treated and even beaten by their husbands. There were respondents who were facing violence not only by their husbands but from their own kids too. They were also facing violence and discrimination from their in laws and relatives. The threat of domestic violence and discrimination had made many women to keep their HIV positive status hidden; they don't even dare to visit their nearby counselling testing centre with the fear that their HIV positive status might be disclosed. Respondents prefer to visit ART centre SKIMS (Kashmir) where they feel free that their HIV positive status is kept hidden. From these results and the subsequent observations made during the study, what can be rightly said in this regard is that HIV/AIDS doesn't discriminate but society does. These women get stigmatized and discriminated both at the individual as well as societal levels. At the individual level, AIDS stigma takes the form of behaviours, thoughts, and feelings that express prejudice against these women living with HIV or AIDS, and can also be experienced by persons perceived to be living with HIV/AIDS people (like their husbands). Concerns about stigma affect these individual's decision to get tested, access health care, and withhold information about their status from family members, friends, and care providers. In addition to this social isolation also negatively affects the lives of people living with HIV (HRSA, 2009). At the societal level, AIDS stigma is manifested in laws, policies, popular discourse, and the social conditions of these women living with HIV/AIDS and those at risk of infection. These women infected with HIV/AIDS, and sometimes even those that have been tested for the virus, continue to face discrimination in employment, housing, access to health services, social and community programs, and basic civil and human rights. Societal stigma emerges in the form of laws, regulations, and policies that single out even the children of these women. For example, local school boards' refusal to enrol HIV-positive children; the criminalization of HIV transmission and forcible segregation of HIV-positive daughter in laws; and reducing the protections afforded to these HIV-positive women.

Additionally, social stigma is practiced through failure of public policy and practices, as well as private groups; non-government organizations (NGO's), and faith based organizations that do not recognize or ensure equal rights for these marginalized and excluded social groups.

4. Conclusion

The study shows a dismal picture of HIV/AIDS related stigma, discrimination and the awareness, among HIV affected women. In view of the fact that every hour 50 young women are newly infected with HIV globally, the wide spread and ignorance about HIV/AIDS among women in Kashmir is a serious concern and needs to be addressed appropriately, through intensive HIV/AIDS awareness campaigns in both rural and urban areas. Media can be an important tool to spread the information and awareness about the said deadly disease.

The high rates of stigma and discrimination towards HIV/AIDS appear to be driven primarily by negative feelings towards PLHIV (people living with HIV), lack of experience as well as misconceptions and fear of casual transmission. Stigma reduction interventions are, thus, urgently needed to target transmission misconception and to increase interactions with these AIDS affected women. Such programmes need to be designed and implemented in collaboration with PLHIV and use of right based and gender sensitive approach.

References

- [1] AIDS prevention and control society J&K state. (2012). Retrieved online at: <http://jksacs.org/prevalence.php>.
- [2] Gassh., Bashir. Muzaffar., Ahmad. Rehana., Kausar. Shabnam., Bashir. (2003). knowledge, attitude and belief on HIV/AIDS among female senior secondary students in Srinagar district of Kashmir, Health and population-perspectives and issued: 26 (3)101-109.
- [3] Greater Kashmir. (Dec. 01. 2012).
- [4] Health Resources Services Administration (HRSA). (2009). Care Action. (February 2009). The Graying of HIV. Retrieved [Online] on 30th December 2014 at <http://hab.hrsa.gov/newspublications/careactionnewsletter/february2009.pdf>.
- [5] Indo-Asia News Services. (2006). HIV/AIDS spreading in Jammu and Kashmir (July 30, 2006).
- [6] International AIDS society. (2010). Environmental Scan: Mapping HIV research priorities for women and children. International AIDS society. Switzerland.
- [7] Kalpana., K. Iyer., Raju Saraswati. (2013). "Psycho-Social Problems of Women Living with HIV/AIDS and its impact on their families in Andhra Pradesh, India." IOSR Journal of Humanities and Social Science (IOSR-JHSS). Volume 8, Issue 4 (Mar. - Apr. 2013), PP 29-36. E-ISSN: 2279-0837, p-ISSN: 2279-0845. www.Iosrjournals.Org.

- [8] Kashmir times. (2013). 37500 HIV patients in Jammu and Kashmir 39 died in valley since 1999. (30, September, 2013).
- [9] NACO. (2013). India: Annual report. Ministry of health and family welfare, Government of India. New Delhi.
- [10] National AIDS Control organization. (2005). India resolves to defeat HIV/AIDS. Ministry of health and family welfare, Government of India. New Delhi.
- [11] Park., K. (2007). Text book of preventive and social Medicine, 19th edition. Jabalpur: Banarasidas Bhanrt publications.
- [12] Tomaszewski., P. Evelyn. (2012). Understanding HIV/AIDS stigma and discrimination. NASW, HIV/AIDS spectrum project. March 2012. U.S.A.
- [13] Verma., Salwalia Bihiri. (2008). Rural Infrastructure Sensation Housing Health care. In (Ed.) Migration trafficking and HIV/AIDS. By Srivastava Aparna. New Delhi. Sarup and Sons Publications.
- [14] Wallace. Maxcy. Rosenau., Last. (2014). Text book of public health and preventive medicine. New Delhi. Row publications.