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Research Article

Power, Economy and Responsibility: Implications of HIV/AIDS on Gender in Karnataka

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Abstract

HIV/AIDS is one of the major diseases that affect people adversely through various means, including social, economic and psychological among others. In this paper, the impact of HIV/AIDS on women through changes in their economic and social status is analysed. On the one hand, HIV-positive women are socially disowned and marginalised, and on the other hand, they also faced several economic challenges including decrease in income due to illness and burden of health expenditure. In some cases, they were vulnerable to the extent that they were thrown out of their homes after detection of the disease without any assurance of rights. This study found that some source of earning after HIV made a few women economically independent. Yet with the economic position alleviated, a few women could not question their social subjugation. On the basis of the findings of this study, it is argued that until and unless women are provided with some earning opportunities along with measures of empowerment, they would not live comfortably.

Keywords: Stigma and Discrimination, Assurance of Rights, Empowerment.

INTRODUCTION

In a patriarchal society, women generally lead a powerless life. Living with a sense of social, economic and political powerlessness, women are usually prevented from taking decisions, even regarding their own body (Sen *et al*. 2002; Menon 2004), which increases their vulnerability towards certain health problems. In the case of HIV/AIDS, women remain biologically, socially, culturally and economically more vulnerable to the disease (NACO 2007). Power relations in several spheres of life increase women's vulnerability to HIV/AIDS. Hence, when it comes to utilisation of available facilities, starting from the micro-family level, women are neglected in several ways. Less control over resources, lack of information and narrow exposure to the outside world make women less aware about their health rights. Politically, in a patriarchal system, women have very less power on decision making influencing their reproductive life. The cultural restrictions too make them much more susceptible to contracting HIV. It has also been found that the infection from men to women is four times more efficient than from women to men. At present, among HIV-positive people in India, around 37% are women and off late, the rate of infection has been increasing among women (NACO 2007).

HIV/AIDS, as a health problem has created different social, economic and cultural impacts on different genders and groups of people in the society. A huge stigma is attached to it, and unlike many other communicable diseases it has made women much more vulnerable to adverse social and economic impacts in comparison with men. The economic implication of HIV/

AIDS has both macro-level and micro-level contours (Anand *et al.* 1999). In a household, when a member is infected with HIV, it affects the economy of the individual who is infected as well as hits the economy of the household in terms of reducing monthly income or increasing health-care expenditure (CHGA 2004). In such a case, it is quite likely that the economic responsibility of earning increases and falls on the non-earning members like children, old people and women. In addition, women are blamed to be the carriers of the disease, and people accuse women's sexuality particularly that of sex workers, as vectors of the disease. Hence, even within a normal legitimate relationship, it is the woman's sexuality that is often blamed. Even after a woman is infected by the virus, when it comes to treatment seeking or care seeking, a woman is highly stigmatised and neglected.

On this backdrop, this paper analyses the socioeconomic impact of HIV especially on women. The existing literature has provided a general focus on the stigma and discrimination faced by HIV-positive people, which has specifically curtailed health-care accessibility by HIV-positive people (Monjok *et al.* 2009; UNAIDS 2000). There is very less literature that empirically addresses the social impact of the diseases on females. There is also hardly any literature that analyses the economic implications of HIV/AIDS on women. This study also analyses the economic implications of HIV/AIDS on women living with HIV, wherein a link between economic (dis)empowerment and individual rights and developments is explored.

As there are possibilities of existence of discrimination at different levels, in this paper, we examined whether discrimination exists at different levels and which are the major sources of discrimination by HIV-positive women. This paper deals with female vulnerability towards the social implication of the diseases. This paper also focuses the economic impact of HIV on women and analyses whether economic independence influenced women's power of decision making in the household and whether the alleviated economic condition could change the perspective of women as care givers and could empower them to take care of themselves. The paper is divided into six sections. After the 'Introduction' section, the second section outlines the methodology of the study. The subsequent section provides detail about the socioeconomic background of the respondents. Sections four and five, respectively, deal with the social and economic implications of HIV on women. The last section provides conclusions.

METHODOLOGY OF THIS STUDY

Women samples were taken from institutions (public, and NGO-led care centres) from Karnataka state. This is due to inherent privacy issues and difficulty to interview HIV-positive women within the family. At the outset, a list of all hospitals where treatment for HIV-positive people is provided was collected. From the list of all hospitals, through a lottery method, three government hospitals and two civil society organisation-led hospitals were selected. In the next step, from the above-selected institutions, hundred women from the state were selected through snow ball sampling. The questionnaire administered on women covered both open- and close-ended questions. For the field study, ethics committees' clearance was undertaken in the state. A prior consent was taken from all the women interviewed, and in order to maintain confidentiality, in all the cases their original names were changed to provide them anonymity and to preserve their privacy.

THE SOCIOECONOMIC BACKGROUND OF THE RESPONDENTS

The socioeconomic features of the selected women show that all respondents who were infected with HIV were married (Table 1). In terms of age distribution, more than 76% of women were under the age group of 22-35 years, i.e., at their reproductive age. Although a large number of respondents were from urban areas, they were also poor and literate[1]. Most of them were infected by their husbands (more than 70%). In addition, 36% of them were widows[2]. In total, fifty-five respondents were

[1]Literate are people who know signature, alphabets and numbers.
[2]Women's widowhood was because of their husband's death due to HIV/AIDS.

Table 1: Socioeconomic details of selected women in Karnataka

Variables	Indicators	Percentage of respondents
Marriage	Percentage of respondents married	100.00
Age	Percentage of respondents falling within the age group of 22-35 years	76.00
Rural or urban	Percentage of respondents from urban location	53.00
Literacy rate	Percentage of literate among respondents	82.00
Economic independence	Percentage of respondents who were economically independent (working)	55.00
Literacy rate	Percentage of literate among the respondents	82.00

Source: Primary data.

working women, involved in either organised or unorganised work, out of which forty earned only a minimal monthly income, i.e., Rs. 3000 per month. Only ten respondents had an income of over Rs. 6000 per month.

Several studies on HIV/AIDS have already made a correlation between poverty or low income and high prevalence of the diseases in the group. However, the reason behind such a correlation may be many. For instance, the data used for enumerating the prevalence are mostly dependent on the figures provided by the government hospitals, NGOs or blood banks, as data from private hospitals are not readily available. It is most likely that many middle- and upper-class people prefer private hospitals where treatment and facilities may be better, as well as for the sake of keeping their health status hidden. Therefore, HIV/AIDS is expected to be more prevalent among the lower socioeconomic class people. Even this study is likely to come up with a similar correlation, which is only partial towards the poor[3]. However, it is vital to analyse the poor and women for their special vulnerabilities to the disease, as HIV/AIDS has a more adverse impact on poor and marginalised sections like women or specifically poor women (Gupta 2002; Sibal 2002).

SOCIAL IMPLICATIONS OF HIV ON WOMEN: POWER PLAY THROUGH ISOLATION, STIGMA AND DISCRIMINATION

Stigma is a social process that produces and reproduces the relation of power and control (Parker and Aggleton 2003). In the Indian society, sexuality discourse has often been considered a hidden discourse. HIV/AIDS is a disease that is associated with sexuality[4]. Sexuality issues in India are considered taboo and have been a subject associated to morality. Therefore, HIV/AIDS is considered predominantly a sexual disease and is treated as an immoral disease caused by an immoral act. Generally it is perceived that if a woman indulges in sex work or if a man visits sex workers who are already a stigmatised community, they get HIV/AIDS. In addition, people having very less knowledge regarding the modes of infection and cause of infection accuse women (as sex workers or women who have sexual relationships with many men) as the vectors of disease. Stigma is also more apparent when the condition of the infection or disease is unalterable, incurable and leads to an undesirable death (Alonzo and Reynolds 1995; Cogan and Herek 1998; De Bruyn 1998). Stigma exists mostly due to fear; but when a particular gender is discriminated only because of an infection, the reason behind stigma manifests itself more as a power play of

[3]This is also applicable to this study as the samples were drawn either from government hospitals or hospitals run by voluntary organisations. Our study also finds that a majority of HIV-positive people were from poor backgrounds. Such a finding in this case may be biased as it has not taken into account private hospital data.

[4]In India, the infection spreads predominantly through the sexual mode (NACO 2006).

Table 2: Source of infection of the respondents in Karnataka (in percentage)

Source of infection	Percentage of respondents
No knowledge	2.0
Blood transfusion	2.0
Sex work	14.0
Husband	78.0
Extra/pre-marital affair	4.0
Rape	0.0
Total	100.0

Source: Primary data.

Table 3: Discrimination faced by respondents at different places

Source of discrimination	Number of respondents
In-laws	36
Community	9
Parents	2
Work place	1
Hospital	24
N (Total)	72

Source: Primary data.

Note: In 41% cases, women faced discrimination at in-laws' house, community and hospitals. In 23% cases, women faced discrimination in the community and hospitals.

one gender over the other. This particularly happens in patriarchal families.

In case of the sample, as far as HIV infection is concerned, in 78% cases, women were infected by their husbands and they had not ever experienced any extramarital or pre-marital affairs (Table 2). Only 14% of the respondents were infected through sex work. In case of discrimination, women faced it at several levels, at their household and community level, at the medical level and at work place. Discrimination was manifested differently, prevailed in several places and in general women were blamed for the infection. In case of respondents, 72% experienced one or other form of stigma or discrimination. Out of sample of 72 respondents, 50% of them faced discrimination by their in-laws and were blamed as the vector of the disease (Table 3). This is evident in several cases wherein despite their husband spreading the infection, they kept quiet, particularly when their wives were discriminated by other family members. In other words, women faced isolation, stigma or discrimination for a reason for which they were not responsible. Moreover, 24% respondents faced stigma and discrimination in the hospitals either by medical staff or para-medical staff. Very few of the respondents were subjected to discrimination by the community (other than family members), and by their parents. Since these categories were not mutually exclusive, we found that in 41% cases women faced discrimination at different levels, by in-laws, community and hospitals.

At the household level, discrimination took place in many forms. Family members stigmatised HIV respondents verbally and abused them repeatedly (Bharat and Aggleton 1999). In some cases, they were isolated; those infected with the virus were given a different room, a few clothes and a few specific utensils to use and were restricted from sharing the room or utensils with the other members of the family. They were also forbidden from participating in household works. Such an attitude of family members was very humiliating for HIV-positive people, and more than the diseases, stigma and isolation made their life more miserable. Such discrimination towards HIV/AIDS was not confined to the household rather it was also extended to the community level. Some of the families with a HIV-positive member were outcaste from community life. The respondents mentioned that due to the stigma to HIV/AIDS their relatives did not include them in social functions like marriage, thread ceremony and so on. In one of the villages, a HIV-positive woman was denied using a public water tap. In a household where there was HIV-positive person, sometimes it was difficult to find marriage alliance for any member at the marriageable age.

The case-studies below show a woman's feeling of hopelessness as she faced stigma by her own daughter, and the condition of a woman, Sobha (name changed), who was infected by her husband and was abandoned and thrown out of her home.

Case-Study 1

Ratna (name changed) was a 50-year-old woman from the district of Bangalore Urban in Karnataka; she was a Hindu, upper-caste woman. Two years earlier, her husband tested HIV positive, and following his detection when she got the HIV test done she too was found to be HIV positive. Coming to know about their HIV-positive status, Ratna's extended family cut their relationship with Ratna, her husband and their only daughter. However, most astonishing for Ratna was her daughter's behaviour. Ratna's daughter was 18-years-old and a graduate student; she also started discriminating her parents. Her daughter isolated herself from her parents. She separated her own clothes, started using different utensils and so on. Such actions by Ratna's own daughter made Ratna unhappy. She said "Dusre aise kare to koi samjh sakta hai…par khudki beti kare to bahaut dukh hota hai" (if relatives or others behave badly or discriminated, one can be indifferent to them but if one's own daughter does this, it becomes painful).

Case-Study 2

In another case, a woman named Sobha (name changed), was a 26-year-old woman staying in the Tumkur District of Karnataka; she was a Hindu belonging to a lower caste. She was infected by her husband, but at her in-laws' home, she was abused verbally by her mother-in-law and brother-in-law. They accused her for the infection and for bad and immoral behaviour (she claimed that she was never indulged in any immoral acts like pre-marital or post-marital affairs), and often tagged her as a *Randi* (a prostitute). Her husband kept quiet and moderately supported her. Sobha had to tolerate all these in her in-laws' home, as her maternal home socially and economically was not in a position to accommodate her (she had two more sisters who were not married, she said if she would go home her HIV-positive status could be a problem for her sisters' marriage). Although, she tolerated all the abuse, stigma and discrimination, ultimately she was thrown out of her in-laws' house. She said she requested them a lot to keep her at their home but nobody responded including her husband. She was not given any right over property or compensation from her husband or in-laws.

Stigma and discrimination were also prevalent at the medical level, and it was relevant to note that discrimination manifested in the hospitals could be fatal for many. Owing to fear of infection, many doctors, both the government and private practitioners, denied treatment to HIV-positive people the moment they came to know their HIV-positive status. Even para-medical staff members were not devoid from discriminating against patients. In a few other cases, although they provided treatment, they were abused by doctors. In the state, in many incidences, medical personnel had violated health rights of human beings, where due to stigma and discrimination, accessibility to health was hampered[5]. It is pertinent to mention here the case of Fatima (name changed) a female who belonged to the Dhawangiri district of Karnataka. She was frequently discriminated by a doctor, because of which she preferred not to consult the doctor and preferred to bear the pain. The section below focuses on the economic implications of HIV/AIDS in Karnataka.

ECONOMIC IMPLICATIONS OF HIV/AIDS IN KARNATAKA

Economic condition is one of the most vital determinants of human relationships. It acts as an equaliser in providing economic independence to women on their path of progress. It is broadly believed that with improvement in the economic level, women's position or their power improves. In other words, enhancement of economic capability is the harbinger of women's empowerment (Young 1994). Empowerment can be seen in terms of giving equal priority to their (HIV-positive women) own health and well-being, taking decisions in the household decision-making process and going beyond the patriarchal notion of sacrifice and care giving while allocating equal attention to their own needs. The specific questions to the respondents to examine their empowerment include after earning, or having control over the money whether they were in a position to spend money for themselves, their treatment and care? With their economic position alleviated, whether they could

[5]As per the human rights paradigm, accessibility of healthcare and treatment is one of the most prominent and crucial points of human rights (Marks 2004).

Table: 4: Status of respondents' income after HIV/AIDS (in percentage)

Income Status during post HIV	Number of respondents
Respondents involved in income earning activities	55
Respondents experienced decrease in income	20
Respondents experienced no change in income	25
Respondents experienced increase in income	10
Decreased in total	36.35

Source: Primary data.

question their social subjugation? Were they aware about their rights, property rights, reproductive rights and so on?

The results show that 55% respondents were involved in income-earning activities (Table 4). After being infected with HIV the income of 25% respondents remained unchanged, whereas 20% respondents experienced a decline in their income levels. The reason behind the decrease in their income level was that they could not work during all the working days as they remained un-well. There is another reason for their decreasing income. A few of them, in order to take care of their sick husbands, had voluntarily withdrawn themselves from regular work fully or partially, thus, earning less income than their earlier income. Three women in different incidences, remained victims of stigma and discrimination and voluntarily left their jobs as they could not tolerate the discrimination and isolation, and thus, preferred to leave their jobs.

It is also important to note that 10% respondents experienced an increase in their income levels after HIV; they could earn more money as compared with the time when they were not infected with HIV. This was specifically as 6% of them joined a new work or job (either joined an NGO or some other informal job), 2% had gone for additional overtime work and 2% of them started petty business that fetched them some additional money. It is pertinent to mention here that 5% women who got new jobs in NGOs were educated up to matriculation or above. In the interview, some women expressed their willingness to join a job or NGO but they could not get it as most of them were either illiterate or studied below the seventh class. Now, the moot question is whether women who were able to earn more income or started earning after HIV were empowered. Whether with the improved economic conditions their stereotypical social role changed and finally whether changes in economic status of women resulted in an upliftment of their social status.

We found that only a few women who earned more income after HIV infection gained much empowerment in the household or society and a majority of them were not empowered much. We noticed several reasons behind less empowerment. For instance, when a man in a family gets infected by AIDS, there are possibilities that he will lose his job after a point of time due to occasional sickness. This results in an increased tendency of dependency on other household members, particularly their wives. In such cases, generally women take up the new responsibility of earning than remaining fully dependent on other family members. Even when a woman becomes a widow, she is generally forced to take up multiple responsibilities, including education of children among others. We came across several women during the interview, who had taken up new economic responsibilities for the family (joined work and earned money) and had been playing a sacrificing role, but their social condition remained unchanged.

In this situation, even when women go out for work, it does not add on to their empowerment. In fact, even their economically uplifted positions sometimes created situations in which they were found to be more disempowered. The feeling of disempowerment may be due to several reasons. For instance, it might be because their husbands lost employment, and they remained as the sole earning members in the family. In such a condition, when they got the disease and did not have adequate resources to spend on their own healthcare, medicine and so on, they generally ended up feeling a sense of powerlessness. A case-study of Smita (name changed), an HIV-positive woman, is worth mentioning here.

Case-Study 3

Smita is an HIV-positive person who has just recently started taking ART first regimen that is available free of cost. She got the infection from her husband and her husband was surviving on ART second regimen as an AIDS patient. Her family had three members, her husband, herself and her only son who was studying in standard 5, in a public school. Smita's husband, when was healthy was a driver and she was a housewife. Owing to his illness, her husband could not work for long hours and subsequently stopped working. For the survival of the family, and to take care of her sick husband, Smita joined the Bangalore-based network of positive people namely, Arunodaya. With the help of the CSO, she got a job as a peer counsellor in a government hospital of Karnataka. In addition, with the help of the CSO, she underwent training in zari work, doll making and candle making, and started doing extra work after 5 o'clock in the evening after her usual office hour. Along with it, she also used to do all the household chores. She said despite her ill health, she had to work day and night to maintain her home and to continue her child's education. A major part of her earning used to be spent on buying medicine (second-line ART costs around 6 thousand per month) for her husband. After meeting the expenses for her husband's medicine and for her child's education, she used to be left with no money to spend on herself. When we asked her what if she would be prescribed for second-line regimen then what she would do? She replied with tears that "Deknewala koi nahi hai mujhe aur mere bachho ko. Bimar padungi to kaun dekhega? Paisa bhi nahi hai mere pass, koi bachat nahi hai aage ke liye, lekin apne marad ko kaise marte hueye dekh sakti hun? marad keliye dabai kharidungi." She said, in case, if she would need medicine which would demand more expenses on top of the present expenditure, then she would not buy medicine for herself and continue her husband's medication. She further said that there was nobody to take care of her or her kid. She also does not have any saving. There is no one even who could look after her child particularly after her death.

Finally, she was worried about her child and not about herself. She said that if her husband and she would be prescribed for second-line ART medicine, due to inadequate money, she would sacrifice her own life for her husband.

This case-study clearly shows how women have been subjected to patriarchal values like sacrifice, *stree dharama* and so on. Smita is a classic example of a woman who performed her role and duty according to those values and ideologies. Despite her uplifted economic condition, she could not internalise empowerment in any way. She indeed ended up thinking about the welfare of others and preferred playing a sacrificing role in the household. Although her health condition equally demanded some amount of rest, care and treatment, she was ready to sacrifice her health and life for her family. The socio-cultural conditions of women irrespective of their economic status often prevent many of them from playing a deviant gender role. There were a few other cases as well who thought in a similar direction.

Only in four cases, women were empowered to the extent that after earning they also started having some control over the income, and they started giving priority to their health (although in the process they did not neglect their husband's health or other member's health). They expressed their opinion that women needed to take adequate food, rest and so on. It was found that these women were associated with some civil society organisations, which made them aware about their rights. Two respondents after earning (who were facing discrimination by in-laws) reported to have questioned their subjugation and stigma, and were conscious of their property rights. Thus, by retaining the rights, these respondents started exercising their power in decision making in their household.

CONCLUSIONS

HIV/AIDS as an epidemic has brought several socioeconomic challenges to people. Women remain doubly vulnerable to HIV/AIDS infection as well as to the adverse implication of the infection. As far as social stigma and discrimination is concerned, 72% of HIV-positive respondents faced discrimination in several places. At the household level, women were often blamed to be the vector of diseases and thus were stigmatised and discriminated. Some of them were compelled to have an isolated life, whereas in a few cases they were thrown out of their homes without being given any compensation

or right over property. Moreover, women also faced stigma at the hospital level that was manifested in several forms and by both medical and para-medical staff.

The economic status of some respondents changed after being infected with HIV. This study found that in a few of such cases, some source of earning made some women empowered. Yet with the economic position alleviated, they could not question their social subjugation. In 20% of cases, respondents experienced a decline in their income and adverse economic impact. However, in 18% cases, women's income also increased; it happened due to several reasons basically because of joining new jobs and also because of increasing the working hours by women. In most of the cases, women faced the responsibility of managing the household, children's education and so on that put them in the job market.

In spite of a few women's increasing economic status, because of other socio-cultural underpinning, women remained disempowered. Despite having an earning and having a hold over it, women preferred spending the whole amount for other's needs in the family. In the process, they repeated their gender role, emphasised on the concept of sacrifice and also neglected their own health and treatment. In most of the cases, they prioritised their husband's health needs. It was only in 4% cases, where having some income empowered women to the extent of prioritising their own health in comparison with their partner's health. These were women while questioning their subjugation expressed their opinion regarding exercising several rights like reproductive and property rights. In most of these cases, women were associated with CSO, which could have instrumented them in realising their rights and power in the households. From this study, it is implied that until and unless some earning opportunities along with measures of empowerment are provided to HIV-positive women, they would not live comfortably.

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