



VOICES OF WOMEN LIVING WITH HIV/AIDS FROM PUNJAB

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ABSTRACT: There are many attempts made to understand the problems of People Living with HIV/AIDS around the world, and to highlight the life lived by them. In this paper, an effort has taken to highlight the problems faced by the HIV/AIDS infected women in the state Punjab, India. An exploratory design has been adopted for the study to examine the situation in which these women were surviving. Interview method was used to collect data. In all the cases, these women got the virus from their husbands and the results suggest that they were living an ostracized life. Their innocence and commitment to relationship is obvious from the fact that they continue to live with their partner. Due to illiteracy and poverty, they were living a miserable life.

Keywords: Women, HIV/AIDS, Gender, Socio-economic Status, Problems



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1. INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) emerged as the most dreaded disease of the century. This is dreaded not because of the fact that death is certain, but it is due to the stigma and social ostracism that is attached to its very name. AIDS is just the tip of an iceberg. In fact, it is the host of social problems ranging from poverty, accessibility to adequate health care, stigma and discrimination. There exists a deep link between human rights, gender and HIV/AIDS. The HIV related prevention and care services are directly impacted by the stigma surrounding HIV, which for the large part stems from the social constructs of masculinity and femininity. Gender inequality, thus not only impacts the spread of HIV, but also its consequences.

Gender roles and relations directly and indirectly influence the vulnerability to HIV infection in various ways. Gender plays a crucial role in defining the vulnerability to HIV. Females, biologically, socially and psychologically, are more vulnerable to HIV infection than their male counterparts. In traditional societies like India, where mere discussion about sexual or reproductive health is a taboo, one can assess the amount of difficulty a woman faces in trying to enforce condom use to male partner.

This makes it very difficult for many women to manage their own sexuality, health, and well-being. The females have to suffer physically, economically and psychologically. It becomes all the more shattering when they have to face stigmatization, blame and abandonment from their own spouse, family members, relatives, neighbors and community. The stigma discourages women from being

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tested and even telling their family and others about their sero-status, leaving them without the much needed support and treatment. Women's issues in health have, until recently, received little attention from health managers, policy makers and researchers (Vlassoff, 1994). Women are in part made vulnerable to HIV due to social norms and values that:

- undervalue their contributions to society, as home makers
- persist in casting them in the role of upholders of family honor
- fail to recognize their sexuality, or cast their sexual desires and expression in a judgmental framework.

2. SITUATIONAL ANALYSIS OF WOMEN AND HIV/ AIDS IN INDIA

There are various epidemics which are localized in nature, reflecting the diverse socio-cultural realities of our country. There are significant structural and socio-economic factors serve to aggravate the existing vulnerabilities to HIV infection. The high poverty levels, with more than 35 percent of the population living below the poverty line are facing the following problems:

- Pitiabale gender relations
- Male resistance to condom use
- Low levels of literacy and awareness
- Cultural myths, misconceptions, silence and stigma regarding sex, sexuality and HIV
- Commercial sex and unprotected sex with multiple concurrent partners;
- High prevalence of sexually transmitted infections
- Low status of women, resulting in inability to negotiate safer sex
- Women's limited control over and access to economic resources (NACO, 2008)

However, numerous key quantifiable indicators point to the fact that prevailing gender norms are biased against women and impact them adversely, especially their health and quality of life and thereby overshadow the gains (if any) from the schemes and programmes.

3. RESEARCH METHODOLOGY

The present study was exploratory in nature, as the researcher attempted to explore the problems faced by these HIV+ women in the state of Punjab. Purposive sampling was used. Only the women who were married and belongs to the age group of 18 to 49 years were taken for the case studies.

3.1 Objectives of the research

The research focused on the following:

- The socio-economic status and family background of the women living with HIV/AIDS
- Explore the nature of problems faced by them.

3.2 Ethical considerations

The researcher tried to maintain the ethical considerations as the top most priority. The confidentiality of the respondents was the most important concern. To maintain their status secret, prior verbal informed consent was appropriately taken. They were ensured that the information taken from them will be used entirely for the research purposes. On the request of the respondents, the location of their residence has been kept secret. The level of stigma and fear was

completely visible from all the above mentioned aspects among these HIV positive women.

3.3 Limitations of the study

It was really a great challenge to ask someone about their HIV status and especially to women in an area where the research was conducted. It was one of the most intimate issues about someone's life. The researcher wanted to do more and more case studies, but women didn't want to open up about their HIV status and or related issues. Another difficulty was, that no-one wanted to go back to their history and to narrate the whole journey of sorrows and misery. Due to a small size, the findings cannot be generalized.

4. CASE STUDIES

Case Study 1

The respondent, Ms Harshdeep Kaur, w/o of Late Sh. Kulbir Singh (names changed) got married, while she was studying in eleventh class. She left her school in-between because of marriage. Her in-laws were having agricultural land and her husband was working in the fields. After, four months of her marriage, suddenly, her husband died. The reason of his death was not known to her. At the time of his death, she was pregnant. When she went to the hospital for her delivery they informed that she was HIV positive. She was shocked and later on probing, she came to know that her husband was already suffering from AIDS and the in-laws knew it before her marriage. Unfortunately, she lost her child immediately after birth. After the death of her child when she confronted her in-laws but they threatened her initially. They said that she had eaten up their son and the grandson. Day by day the torture and trauma by her in-laws was increasing and finally, she was thrown out on the roads. Her in-laws said that there is no place for you in this house. Her life was on the crossroads. She said that "she wanted to end her life at that moment but suddenly she thought that, at least she should narrate the whole instance to her own parents....."

The ultimate resort was her paternal house, somehow she managed to reach at their place. Her parents were shocked and traumatized, when they heard the whole episode of miseries and sufferings of their daughter. Since then, there was no communication between her and her in-laws. She is surviving and is alive because of her parents. She said "she could have been to a college or possess some skills, she might be able to earn her livelihood. She was very much worried about her dependency on her parents.

Discussion

The case study clearly indicated the intense trauma and pathetic condition of the respondent. It was during the time of her schooldays, that the respondent got married and altogether entered into a new phase of her life. The bluff of hiding the status of her husband from her in-laws was really tragic. This had lead to miseries and sufferings. She was not aware about any kind of services available for the HIV+ people. When she was thrown out of the house, she had developed suicidal tendencies. It was just because of her parents, she was alive and survived. She had no formal education to sustain nor does she possess any technical skills to survive and this was the biggest concern. She was not aware of any social welfare scheme. She did not know anything

about widow pension. She was not having any BPL card. All these aspects indicated about the lack of awareness on the part of respondent about HIV and her rights.

Case Study 2

The respondent Ms Harjeet Kaur, (name changed) had huge aspirations to have a happy and prosperous life. Said like every girl I kept on thinking about the Prince / Hero of my life: My would be soulmate.....

She got married to a truck driver and he was very supportive, caring and loving. The new phase of her life was like a dream come true. She got pregnant and becoming a mother for the first time was extremely exciting. She was blessed with a baby boy. At the same time, her husband was not keeping well. During winters, the condition of her husband became worse and he came back home in-between from after a short trip. Her in-laws took him to the local doctor /quack (not professionally qualified) and he gave some medicines which helped him for few days only but afterwards, these were not responding to his illness. Almost after a month, some elderly people of their own village advised them to take him to Chandigarh, at Post Graduate Institute for Medical Education and Research PGIMER for check-up. It clearly indicates the level of ignorance and illiteracy. After wasting time on local doctors, the patient was taken to PGI, Chandigarh. She spent few days with him in the hospital and then they were sent back home and after the third day of his discharge she lost him forever.

It was at the hospital, where she came to know about the cause of death about her husband. It was difficult for her to understand the meaning of HIV. She thought of something like cancer at that time. She narrated the instances like: I don't know which punishment has been given to me by God and why?

After two-three months of the death of her husband, she was asked to visit the hospital for the test by her in-laws. This hospital was the place where she understood the exact meaning of HIV. She was in great stress and anger. She thought that she was cheated by her husband. She was shocked to know about HIV and the ways of its spread for the first time. She was in the dilemma, that how her husband had acquired it.

She said, My life had come to an end but my little son was looking at me and as if he is saying that I need you my mother.....

Now, she was supposed to visit the hospital regularly after every six months for the follow-up tests and they also instructed her to get a HIV test done of her son. She was not able to gain strength for the test of her son.

She said "she was back home and continuously crying and thinking about what was going on in her life.....?"

During those days, she was irritated, frustrated, facing lot of mental stress and even once she had thought of committing suicide too.

She narrated that her son was very weak and sometimes he behaves in some unusual manner like excessive crying and got something like fits also. The only bond between her and the in-laws was their grandson. When her son was not well and had breathing problems. She took him to two-three different doctors of near-by town but all in-vein. Finally, at the time of her visit the hospital after a year for her CD-4 test, she took him along to the hospital for his check-up. The doctors

started with a positive note that he is not HIV positive. They added that he is suffering from a heart ailment that he is having a hole in his heart and also there are some jumbled veins too and an immediate surgery is required. The complete cost of the surgery, medication, hospitalization etc would cost a few lakhs of rupees. Since, that day, she has been trying to arrange for money, so that her son can be operated.

She said, My husband had left me with HIV, an ill son and old in-laws.....

Discussion

The Case study highlighted the pain and agony of this HIV+ widow. She was worried about the day by day deteriorating health of her of own due to HIV and her son, who required an immediate surgery. There was an intense stress for the surgery of her only but money was a major problem. The lack of awareness about the issues of HIV/AIDS had hit her badly. The after affects of HIV were making her life more miserable. This had lead to miseries and sufferings. Not only, did she loose her husband but there was a whole financial breakdown. HIV was acting as a disability to her. She was not aware about any kind of services available for the HIV+ people. During her initial days, when she was revealed about her HIV status, she had developed suicidal tendencies. But, just because of her only son (suffering from major heart ailment), she was still surviving. Neither she was literate, nor did she possess any skills to become independent. She was not aware of any social welfare scheme. She was not having a BPL card. All this clearly indicated about the lack of awareness on the part of respondent about her rights.

Case Study 3

This was a case where the respondent had taken her husband to the ART centre at one of the locations in Punjab and broke into tears while narrating her story to the researcher. During that visit, she was going through intense trauma and dual stigmatization. On one hand the couple was HIV+ positive and on the other hand her husband was a regular drunken (taking huge amount of alcohol) and other drugs too (as per the availability). She said that because of access of money and affluent nature of her husband, he was into drugs almost every time. She said that, he starts drinking from the morning and there is no break. Due to this, he was not able to take his regular dose of ART medicines. She was in a great dilemma that, whether, there was any of opportunity available for him for de-addiction. She was totally reluctant to put him in any private drug de-addiction centre because of lot of bad things associated with them. She said, even if I put him in a government hospital, he might not be ready to visit any such place. She said that she had her own health problems coupled with the problems of her husband. She was facing intense discrimination from the society and especially her relatives. Other issues related to her were accessibility of ART and drug-de-addiction centre because the couple had to move from a far place and that too from another district. Due to lot of stigma associated, they were not visiting the local civil hospital. She said, her husband is continuously wasting all the money on such useless issues and she is bothered about the future of her children.

Discussion

It was evident that this respondent was facing multiple problems other than stigma and

discrimination like drug addiction, no adherence of husband to ART and discrimination from the relatives. She was also worried about the affluent nature of the husband who was spending a lot on drugs. The above mentioned Case study indicates that, she had no control over the financial issues of the family and was totally dependent on her husband. She was facing intense discrimination and hence they were travelling from far –off place to a new ART centre.

4. RESULTS

These HIV+ women especially widows were living an ostracized life. In all the cases, these women got the virus from their husbands. It was completely visible that their innocence and commitment in the relationship had paved way for getting infected. Another shocking aspect emerged from the study, is that these most of these women were illiterate and very young at the time of their marriage. Young age with illiteracy had multiplied their sorrows. After they lost of their bread earner, these HIV positive widows are on the crossroads. They had no support from their in-laws and even their children were facing lot of stigma and discrimination. These women were undergoing a lot of stress, depression and anger. They were facing all kinds of problems which include psycho-social cum economic. While interviewing it was revealed that most of them feel stressed most of the times. Sometimes they develop suicidal tendencies too. The researcher felt that lack of counseling services was an important aspect for these HIV+ women. Most of them had no support from their in-laws and they were struggling at their own for everything. Widowhood further brings economic hardship along with stigma and discrimination. The widows are also vulnerable to denial of legal rights to property or inheritance (Gaur, 2015). These HIV+ widows face blame and abandonment by in-laws. This can lead to the loss of shelter and any means of subsistence, resulting in poverty. This forces women to feed for themselves and their children by engaging in any other kind of activities (fair/unfair) for their family's survival. This in turn amplifies the risk of HIV spread as the societal discrimination.

5. CONCLUSION

Thus, it is critical that any response to HIV in the context of women is based on the socio- cultural norms and ideologies that determine gender roles and relations. A gender sensitive response to HIV with a focus on empowering women, must account for the attitude and behavior of men which are largely conditioned by the same socio- cultural gender norms.

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