

PSYCHOSOCIAL CONDITION OF HIV-POSITIVE MOTHERS AND PREGNANT WOMEN OF KOLKATA

Nivriti Mitra

Program Officer, Solidarity and Action Against the HIV/AIDS in India (SAATHII), Masters of Rural Studies(MRS), University of Kalyani, Kalyani Nadia, West Bengal, India

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ABSTRACT

Human Immunodeficiency Virus (HIV) has been a major global health issue for a long time and it continues to be challenging for humanity. The virus affects by destroying and impairing the immune cell functions, the affected person becomes immune-deficient. An HIV-infected person can live a life like a normal person with proper care, support and treatment. An HIV- positive person needs emotional support from family members, colleagues and health care providers. Stigma and discrimination are one of the main reasons HIV is continuing to be challenging in the life of people. Moreover, lack of information regarding HIV/AIDS is one of the reasons people still suffer from the disease mentally and physically. This paper aims to address the mental and social aspects of the disease by discovering its psychosocial impacts of the disease. Psychosocial factors affect both emotional as well as physical functioning over time. The social traumas and stigmas are extremely negative relating to AIDS, which further affects the patient's physical wellness. This paper aims to address the perception and knowledge regarding HIV/AIDS by HIV-positive mothers and pregnant women. Further, the study has been carried out to extensively understand the social stigmas related to the disease and the psychological impacts of these stigmas.

Keywords: HIV, AIDS, Psychosocial, Maternal Health, Discrimination

Introduction

Prior to the advent of Covid-19 to bluster the health care situation of the world one such epidemic that threatened the human society and continues to be challenging for the public is Acquired Immune Deficiency Syndrome (AIDS) caused by Human Immunodeficiency Virus

(HIV), HIV as a major global health issue. The virus affects by destroying and impairing the immune cell functions, the affected person becomes immune-deficient. Whenever the same disease equally threatens the health of a mother and future child certainly, it becomes a major issue of concern to prevent the threat of the HIV epidemic. In India, the overall HIV prevalence level among pregnant women attending clinics was found to be 0.24 per cent (HSS, 2019).

The word psychosocial is associated with the blend of psychological and social behaviour. Psychosocial behaviour determines a person's fear and social interactiveness. It includes creativity and thoughts, appearance and self-confidence, concentration, as well as emotional mindfulness and sympathy. Psychosocial factors affect both emotional as well as physical functioning over time. Among many issues faced by a common person in society, being an HIV-positive person is another challenge in society.

As already stated by Isabella Lövin "Improved maternal health benefits the whole of society", a healthy mother gives birth to a healthy baby thus leading to a healthy society. According to WHO, "Maternal health refers to the health of women during pregnancy, childbirth and the postnatal period". It comprehends the health care scopes of family planning, preconception, prenatal, and postnatal care in order to lessen maternal morbidity and mortality. The factors that constitute maternal health include Pre-natal care and Post Natal Care. Moreover, during pregnancy antenatal check-ups in a health institution whether government or private is necessary.

Along with the above-mentioned health-related consequences, there are other HIV-related psychological and social issues, a HIV infected person suffers from stigma (in its various forms) and discrimination, non-adherence to Antiretroviral Therapy, disclosure concerns of HIV, and also the struggle of living with an HIV-positive identity are some of the common psychosocial challenges faced by an HIV positive person.

This paper aims to address the perception and knowledge regarding HIV/AIDS by HIV- positive mothers and pregnant women. Further, the study has been carried out to extensively understand the social stigmas related to the disease and the psychological impacts of these stigmas.

Objectives

1. To understand the perception of HIV/AIDS by HIV-positive mothers and pregnant women.
2. To understand the stigma and discrimination related to HIV in the regular life of HIV-

positive mothers and pregnant women.

Methodology

The study has been conducted with help of primary sources. The primary data has been collected in a specific method. It has been conducted with HIV-positive women. A total of twenty positive women and mothers were interviewed in a case study manner. Further, the respondents were categorically selected within two specific brackets:

- Pregnant women
- Women who have babies within the age of 18 months.

Women having babies within the cascade of 18 months were chosen since the Prevention of Parent to Child Transmission of HIV (PPTCT) guideline states that an HIV-positive pregnant woman should be linked to Antiretroviral Therapy (ART) and once the baby is born the baby should undergo four Early Infant Diagnosis (EID) or DNA/PCR screening at respective ICTCs. All HIV-exposed infants and children regardless of their HIV status are to be followed up until 18 months for monitoring and care. The final confirmatory test (i.e. the test that determines whether the baby is HIV positive or negative) is to be done at the age of 18 months for HIV- exposed infants. (NACO, 2013)

Four government hospitals from Kolkata have been randomly selected for the study. The hospitals namely:

- **IPGME&R and SSKM Hospital**
- **Calcutta National Medical College and Hospital**
- **Calcutta Medical College and Hospital**
- **R. G. Kar Medical College and Hospital**

From each hospital, five women from the above-mentioned category were randomly selected for this study. A structured interview schedule was prepared for the case studies, and 20 case studies were conducted for this study. The study has been done exclusively in a qualitative manner.

Results and Discussion

HIV/AIDS disease affects an individual's quality of life through all dimensions. An HIV-positive person's physical, psychological, social, and spiritual quality of life gets affected the most (Paul & Premraj 2017). HIV is a chronically manageable disease and a complete cure for the disease is yet to be found. Further, various misconceptions related to the disease stigma and discrimination arise in society.

A previous study with 757 pregnant women living with HIV infection, for the past 18 months in six Asian countries (Bangladesh, Cambodia, India, Indonesia, Nepal, and Vietnam) showed a variety of things. It reported that a major number of pregnant women living with HIV in these regions are deprived of their right to health care and are endangered by discrimination from health professionals, with a refusal of care provision and antenatal care, forced abortion, and sterilization (Women of the Asia Pacific Network of People Living with HIV, 2012; Head et al, 2014). Especially, in India women diagnosed with HIV infection, face widespread stigma since there is a misconception that HIV is a disease of homosexual men i.e. men who have sex with men, sex workers, and Injecting Drug Users (IDUs) therefore women are held responsible for spreading the infections to the rest of the family members. In the majority of the cases, pregnant women living with HIV are deprived of their right to health care and are endangered by discrimination from health professionals.

Perception of HIV infection by the HIV positive mothers and pregnant women

The study aims to address the perception of HIV infection by HIV-positive mothers and pregnant women. From the case studies, it has been found that a large number of respondents have very little knowledge about HIV infection before becoming HIV positive; some respondents in fact revealed to had no idea that such a disease exists.

Perception regarding Route of transmission of HIV

While talking about the route of transmission of HIV it has been observed that most of the respondents have unclear ideas of the four main routes of transmission of HIV even though respondents are completely under treatment for years. Before becoming HIV positive, some of the respondents only knew that HIV spreads through sexual intercourse with multiple partners. People suffering from this disease have a questionable character. Some of the respondents knew that HIV can spread through mosquito bites, it is a communicable disease and HIV can spread through touch, kisses, hugs, sharing of food, clothes, etc.

Perception of the Antiretroviral Therapy (ART) and adherence to ART regimen

Many respondents thought that once a person becomes HIV positive life will end forever since respondents will die soon. None of the respondents had any idea of the Antiretroviral Therapy (ART) treatment, some respondents were scared of the ART treatment, especially the HIV-positive mothers who were once pregnant shared that they were sceptical of the ART regimen since they thought it might affect their pregnancy and lead to abortion or miscarriage. Some of the pregnant women even shared that resistance came from their family members, especially spouses, and in-laws, regarding intake of the ART regimen.

Perception of expenses of treatment in Government / Private Hospitals

None of the respondents had knowledge of where the treatment is available, although some respondents shared that they thought it is a curable disease and that spending a lot of money on a reputed private practitioner can cure the disease. None of the respondents knew that ART regimens would be available in government hospitals free of cost and were scared that they have to spend a lot of money on buying medicines.

Perception of parent-to-child transmission of HIV

Before becoming HIV positive, none of the HIV-positive mothers and pregnant women knew that through proper treatment the transmission of HIV from the mother to the child could be prevented, because of the previous wrong perception many respondents even thought of medically terminating the pregnancy.

Stigma and Discrimination faced by the respondents in their regular life

People living with HIV face a lot of stigma and discrimination in their day-to-day life. People usually have a derogatory attitude and behaviour towards people living with HIV. The reasons for the prevalence of the HIV stigma may be because of certain facts like a) HIV is life-threatening and people are scared of HIV b) HIV is already linked with the stigmatised group c) People with HIV are themselves responsible for the disease. d) The spread of HIV is caused by 'moral faults' (Avert, 2017).

Stigma and discrimination faced by the HIV positive pregnant women in their Family life

Some of the HIV-positive pregnant women shared that the suffering is even more dreadful for the HIV-positive pregnant women and mothers. In India, especially in an economically backward society, a woman is deprived twice, once for being poor and another for being born as a girl.

Since in the study majority of the respondents belong from economically backward societies with little to no educational qualifications, deprivation will be an evident thing in the family. Many respondents shared that even though the spouses of the respondents are also HIV positive but women are held responsible for spreading the disease to the rest of the family. The male members being the bread earner of the family do not face discrimination related to the disease.

Stigma and discrimination faced by the discordant couple

A discordant couple is a couple in which one spouse is HIV positive and another spouse is negative. So some of the respondents whose spouses (husbands) are negative shared to have faced discrimination to the level of extremity. One of the respondents shared that after the disclosure of her HIV status to the in-law's house the respondent was forced to leave the house, and everyone in the in-law's family questioned her morale. The respondent now lives in her parents' house and is currently separated from the respondent's husband. Another respondent who is also discordant shared incidents of severe discrimination by in-laws as well as her husband. Even though the spouse did not ask for separation from the respondents but continuously threatens to get married to another woman. Besides facing discrimination in the in-laws' house some women shared to have faced similar discrimination even in their paternal house. One respondent shared that after the disclosure of the HIV status the respondent is now unwelcome in both the maternal and paternal house, even though the respondent has not been thrown out of either of the houses but the behaviour of the relatives is very unpleasant.

Stigma and discrimination by the medical service providers

Stigma and discrimination by healthcare providers are still common things in India and many respondents have shared such incidents of discrimination. Some respondents shared that even though not much discrimination has been faced by them in the ART centre (ART centre is a department in Government/Private Medical colleges and Hospital where ART regimen and HIV counselling are provided to HIV-positive people) and ICTCs (Integrated Counselling and Testing Centre) but in other departments (like in Gynaecology department, labour rooms) the discrimination is the most. Many respondents shared that the discriminating behaviour comes more from the nurses and nannies (commonly known as 'Aya' in Bengali) in hospitals. One respondent shared the experience of discrimination in a reputed private hospital where the respondent was denied immunization because of the disclosure of HIV-positive status. Later the respondent advocated for herself for the baby's immunization.

Stigma and discrimination in the workplace

From this study, it was observed that stigmatised and discriminatory behaviour persists due to a lack of awareness of HIV transmission. Although most of the respondents were homemakers, there were two respondents, one of them used to be a house cleaner but after the disclosure of her HIV status, the respondent was suddenly forced to discontinue the job with no explanation at all. Another respondent who works in a private firm has never disclosed her HIV status in the workplace keeping in mind the fear of losing her job. The respondents shared the spouse's experience in the workplace and as per the response; very few have actually disclosed their HIV status and those who have disclosed status in the workplace seem to have received derogatory behaviour from their peers/colleagues.

Conclusion

From the above study, it is evident that HIV-related stigma and discrimination persist in society due to a lack of knowledge/awareness of HIV/AIDS. As per the study, the majority of the respondents shared that before becoming HIV positive they had no idea of the HIV infection and those who had at least some idea of the HIV infection had a very vague idea of the routes of transmission of HIV. Many respondents also seem to show remorse over the lack of knowledge of HIV transmission. The respondents regret saying may be a little bit of awareness might have saved them from this deadly infection and they would lead a happy and healthy life. Many government programmes are currently running in India e.g. Prevention of Parent to child transmission of HIV (PPTCT) program, and Care Support Treatment (CST) program but all these programmes are mainly for people who are already infected with the virus. Awareness regarding HIV should be created from a very early stage so that a person is not infected in the first place. Various government/non-government institutions can develop awareness programmes that can help in spreading the awareness to a bunch of people, especially awareness regarding the transmission of HIV and the stigma and discrimination related to the disease need to be addressed from the adolescent age. Inclusion of HIV-related issues in educational institutes is also a necessity. HIV might not be a curable disease but a little bit of knowledge about the HIV infection can save a person's life from this deadly virus.

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