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# Understanding the Socio-Psychological Implications of HIV/AIDS in India

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#### ABSTRACT

More than being a virus, HIV (human immunodeficiency virus), in Indian society has become like a syndrome which has been the prey of multiple social stigmas and myths. The result of this is that the people who suffer from it have to not just overcome this virus physiologically and medically but also socio-psychologically which further has a deep-rooted impact on their lives. The present research paper humbly attempts to highlight the problems that are witnessed by the HIV infected patients such as lack of social support, social isolation leading to psychological traumas and many other such issues. The paper also highlights the current situation of these people in India, the prevalence of various myths and discriminations against them and the legal support that is available for them. The paper concludes with some suggestions that are needed for stringent implementation of the laws and their penalties and also brings into focus the loopholes that need to be removed from the legal framework to make the socio-legal support system stronger along with more awareness among the people.

Keywords: HIV/AIDS, India, legal, facts, stereotype, discrimination

# INTRODUCTION

The popular saying that health is wealth has become true in today's time. To have a healthy lifestyle means to have a long and happy life. However, it is not in everyone's hand to lead a healthy life forever as there are some instances where despite doing the best for your health, people get caught by such kinds of diseases which change their lives forever. Recently, the pandemic of COVID-19 has done the same thing. But, before the arrival of this pandemic, there have been many diseases which have been termed as incurable diseases and have severely impacted the lives of people, despite the tremendous progress in the world of medical science. One such disease is HIV/AIDS (human immunodeficiency virus/acquired immunodeficiency syndrome).

This disease has been the prey of many misconceptions and these misconceptions have led this incurable disease to be termed as an impure disease incurable. In HIV/AIDS, AIDS is the most advanced stage. In it 'immunodeficiency' means when the immune system's ability to fight against infections is compromised, as the body's defence mechanism gets weakened which further destroys the cells in the immune system. These cells help protect our body against viruses. This may also infect the body with some types of cancer as well. There is no doubt that this life-threatening disease has the capacity to put the life of the patient in peril. It is due to this reason that there is currently no complete cure available for its treatment.

A threatening fact about AIDS is that (depending upon person to person infected with it) this disease (if not treated on time) can take years to develop. The reason that it is termed as 'acquired' is because once it enters the body, it has the capacity to develop grave infections, some types of cancer or other severe long-term clinical symptoms in the body (WHO, 2022).

#### HIV/AIDS: THE UNDERSTANDING:

To further understand this disease, it is important to know about its stages as well. There are 3 stages of HIV and each stage has its own symptoms, varied infections and repercussions. These stages are follows:

- 1<sup>st</sup> stage **ACUTE HIV:** in which flu-like symptoms occur in a person.
- 2<sup>nd</sup> stage CHRONIC HIV: This is an asymptomatic stage where a person is unaware about being infected with HIV.
- 3<sup>rd</sup> stage **AIDS**: AIDS stands for acquired immunodeficiency syndrome which is diagnosed when the CD4 T cell count falls below 200. CD4 T cell measures cell count in the immunity system and in this the cell count should be above 200. (HIV Info, 2021)

Without treatment, people with aids mostly survive up to 3 years. But with proper timely treatment with the antiretroviral therapy (ART) and by making some dietary changes it is manageable. The ART which is the most apt medication for it, helps reduce the viral load in the body i.e., it helps to make this disease manageable but it cannot permanently eliminate or cure it. HIV is a transmissible disease which can be transmitted by semen, rectal fluids, vaginal fluids, blood and breast milk (HIV, 2020.), however, it must be understood that this disease has nothing to do with the fact that it gets transmitted if the patient and a non-infected person sit together. Keeping this in mind, there are some myths and facts about this disease that need to be clarified and eliminated to make people aware about this disease in a correct manner.

#### MYTHS AND FACTS

In our society, there are undoubtedly many negative attitudes and myths floating about HIV/AIDS. Let's have a look at the following:

- MYTH: HIV spreads by being around HIV positive people.
  - **FACT**: No. HIV doesn't spread by being around HIV positive people. Neither does it spread through any of the following ways: using the same toilet seat; touching a door handle; hug; sharing of food, utensils, sharing fitness apparatus, etc. (Pathak, 2021)
- MYTH: If I am HIV positive, I can't procreate.
  - **FACT**: Yes, there are chances that it may spread to the partner, however with correct medical interventions this spread of virus can be reduced. (Pathak, 2021) for this there are some recommended antiretroviral drugs such as *EFV*, *lamivudine* (3TC) OR FTC, and tenofovir disoproxil fumarate (TDF) to protect the couple and due to which they may plan to have a child without any stress.
- MYTH: No need to take excessive stress, the medication for this is effective.
  - FACT: Yes, antiretroviral drugs do improve the lives of HIV patients and help them survive longer, but these drugs do have side effects, and also drug-resistant strains of HIV can make treatment harder. (Pathak, 2021) Also, the various medicines that are available to help this disease be manageable work to reduce the mutation of this disease in the body and being able to do this much only in this disease is worth a credit. Some of the medicines for this are: *Nucleoside reverse transcriptase inhibitors (NRTIs)* which helps in blocking an enzyme called reverse transcriptase; *Non-nucleoside reverse transcriptase inhibitors (NNRTIs)* that binds to and later on changes the reverse transcriptase; *Integrase inhibitors helps in blocking* an enzyme called integrase; *Protease inhibitors (PIs)* blocks an enzyme called protease, *Fusion inhibitors* helps in blocking HIV from entering the cells (National Library of Medicine, 2022).
- MYTH: HIV is spread through mosquitoes also.
  - **FACT**: The fact that HIV spreads through blood is true however believing that it spreads through mosquitoe's bite has not been proved in medical studies till date. Also, there are several studies conducted at CDC (Centre for Disease control and Prevention) that have shown that when the bugs bite even then the bugs do not inject the blood of the HIV infected animal or person to a healthy person. (Pathak, 2021)
- MYTH: If both partners have HIV, there is no need for protection during sexual intercourse.

**FACT**: No, this is not true, as there are different strains of HIV and they also change overtime. If both the partners have two different strains then there are chances that they may transit from each other. So, protection is always necessary. (Schaefer, 2020)

• MYTH: I am straight, I am safe.

**FACT**: Yes, that is the fact that men mostly carry HIV from the male sexual partners, but you can carry HIV if you have heterosexual partner too. But homosexual women have the lowest risk of transmitting the disease. (Pathak, 2021)

• MYTH: Being HIV positive means the end of life.

FACT: If this was the case some years back then this myth could have been true as during the earlier years, there was lack of medical help for this virus, but with the advancement in the field of medical science and that too a good progress in dealing with this virus, now this myth is not true as now due to various drugs, HIV is quite manageable and help people to lead normal and productive lives. (Pathak., 2021)

MYTH: HIV and AIDS is a same thing

**FACT**: No, this is not true. HIV is a virus and AIDS is a consequence of that virus. AIDS is the most advanced and the last stage of the virus. If handled on time and with proper medications then HIV doesn't always lead to AIDS.

MYTH: HIV related infections are unavoidable

**FACT**: No, that's not always the situation, as with on time prescribed medications, it will definitely reduce the risk of infecting and this is also called as *opportunistic infections*, as the antiretroviral drug helps in increasing your CD4 cells. (Schaefer, 2020)

• MYTH: It is a very expensive treatment. It is not affordable for everyone.

**FACT**: No. Now, there are various schemes and fundraising organizations, which can help in the medical treatment of this virus. One such organization that helps in this direction is the - Asha Foundation Trust Bengaluru, Karnataka.

#### **CURRENT SITUATION**

The National AIDS Control Organisation in collboration with Indian Council of Medical Research-National Institutte of Medical Statistics undertook the period HIV estimation process for the year 2020 and 2021 to provide the updated information about present status of this epidemic in India(NACO & ICMR, 2020). The following points are the glimpse of this estimation:

- According to India's 2020 HIV estimation report the prevalence of HIV in adults (15-49 years) is estimated at 0.22%. Among males it was 0.23% and among females it was 0.20%.
- In the last 10 years the count has declined, as in 2000-2001 it was 0.54% and in 2020 it has declined to 0.22%. This means that there has been a decline of 33.3% of the spread of this virus.
- The highest count of HIV is present in Mizoram (2.37%) followed by Nagaland (1.44%) and Manipur (1.15%).
- The total number of People Living with HIV (PLHIV) means those people who are on Antiretroviral therapy, are roughly around 23.19 lakh in 2020. In this the females accounted for 44.3% of total infections, and children accounted for 3.5%.
- The year 2020 witnessed approximately 51,000 deaths out of which 63% deaths were due to AIDS and in this Andhra Pradesh recorded the highest number of deaths in 2020.
- The threat of HIV to the Indian working population is apparent from the fact that nearly 90% of the reported HIV infections are from the most productive age group of (15-49 years). (Ministry of labour and Employment et al., n.d)
- If we look upon the Prevention of Mother to Child Transmission (PMTCT) then the report of 2020 shows that approximately 29 thousand pregnant women required the antiretroviral treatment for the prevention of mother to child transmission. The final mother-to-child transmission rate was estimated at 27.4%, which saw a steep fall when compared to the data of 2010 at 40.2%.

More than anything, the biggest threat of this virus, till date, has been the lack of awareness among people about it. More than physiologically this virus troubles the person psychologically due to the prejudices and stereotypes attached to it. There are incidents that are proof for it. In 2003 in Kerala's Kottiyoor, a mother fought for her kids as the officials in a school expelled them after learning that they were HIV positive. After sitting on

a hunger strike, the mother made sure that authorities kneel in front of her. Seeing her confidence and power, the state government later recruited her for 3 years as a positive worker during which she tried to remove the misconceptions in the minds of people in regard to this disease and also helped in spreading awareness about it. It was due to this dedication of her, that today her children have completed their education and are ready to be employed for work. However, again the misconceptions continued to haunt her family as later, her daughter was selected for a job but was removed from the job when the recruiters got to know that the girl was a HIV patient. (Babu., 2022) This incident is a clear indication towards the fact that even after 18 years (of this incident), society's views remain unchanged. People still have a serious hatred/inhibition towards HIV people.

There is no second thought to the fact that an HIV-infected person has to go through a number of traumas. One such trauma is the impact of this virus on their employment status. One such case of this discrimination was seen in the year 2015 where a Pune-based company removed one of their woman employees, as she was an HIV-positive person. The company got to know about her HIV status by a medical document submitted by her, for claiming medical benefits, following which the company asked her to resign on the same day. She was forcefully made to resign but, however, she took the company's injunction to court and got justice after three years by fighting the battle against this injustice. (Asian News International, 2018)

It is quite surprising to know that discriminations against HIV patients are done not just by people (who are unaware about it) but also by the medical staff who are well versed about this disease. In this the health care centres are the major source of discrimination, as the nurses, medical physicians and the ward staff who seem to be well versed about HIV/AIDS due to their medical profession and the knowledge that they gather by being in profession, are the ones who lacked appropriate information about it. They were aware of certain basic facts, but they had a lot of major misunderstandings. The worst scenario was that in many cases, the workers were absolutely unaware of the difference between HIV and AIDS. (Bharat, Aggleton & Tyrer, 2001)

It is these kinds of discriminations and other forms of exploitation by health care centres that prevent people from obtaining services or receiving proper treatment. An incident in Uttar Pradesh's Bareilly district highlighted this situation in a grave manner, where an HIV positive woman gave birth to a stillborn child after a hospital in Badaun refused to treat her because she didn't have enough money to buy gloves for medical staff. (Tomar & Kaul, 2017) Due to this grave discrimination, people refuse to go to hospitals due to fear of being stigmatized which makes their HIV testing treatment and other services more difficult to get.

# LEGAL SUPPORT: A RAY OF HOPE

When people do not get help from their loved ones, friends, etc. then they look towards the legal support system. The Indian Constitution has provisions that support these people on various fronts. Some of the provisions are as follows:

## THE HIV/AIDS (PREVENTION AND CONTROL) ACT 2017:

On September 10, 2018, the HIV/AIDS (Prevention and Control) Act of 2017 came into effect. With an aim to prevent and control the spread of HIV and AIDS in the country, this act also includes penalties against those who discriminate against the infected person. This bill was introduced in 2014 by senior Congress leader Ghulam Nabi Azad and on April 20, 2017, the President gave his assent to it. (Indian Express, 2018) The act includes the following provisions:

- The Act has strict provisions against those who do any form of discrimination or unfair treatment with the HIV-infected person. Further this act
  prohibits the denial or discontinuation of healthcare services, the denial for the right to move, right to reside, purchase, rent, or occupy
  property, and the right to hold public or private office etc., to the infected person.
- Also, every HIV-positive person has the right to live in a shared household and to enjoy facilities without any form of discrimination.
- The Act states that "no person shall, by words, either spoken or written, publish, propagate, advocate, or communicate by signs or by visible representation or otherwise the feelings of hatred against any protected person or group of protected person"
- The state and the Centre must ensure that all HIV-infected people have access to diagnostic services, antiretroviral therapy, and opportunistic
  infection management, and that this information is widely disseminated. No HIV-positive person shall be subject to medical treatment, medical

interventions, or research without their informed consent, according to the law. Furthermore, sterilising or doing abortion of the HIV-positive pregnant woman without her consent is prohibited.

- Every Institution is required to keep HIV-related information secure. Every HIV-positive person is required to take proper precautions to
  prevent the spread of HIV to others.
- Except by court order, the disclosure of being an HIV infected person is completely voluntary by the infected person. Any violation in this
  regard is punishable by up to two years of imprisonment or a fine of up to Rs 1 lakh, or both.
- In order to investigate potential violations of the Act's provisions, every state is required to appoint one or more Ombudsmen. The Ombudsman issues a decision within 30 days of receiving a complaint, failing which he has to pay a penalty up to Rs. 10,000 (Express web desk, 2018)

#### THE NATIONAL AIDS CONTROL PROGRAMME

Introduced in the year 1992, the first project of NACP (National AIDS Control Programme) concentrated on raising awareness, establishing a surveillance system to monitor the HIV epidemic, ensuring access to safe blood, and providing preventive services to high-risk populations. In order to show the commitment of this project, the project was financially supported during its launch with USD 84 million in International Development Association (IDA) credit.

The second NACP project was launched in November 1999, with USD 191 Million credit support from the world bank. The policy had two key objectives:

- Reducing the spread of HIV infections in order to curtail the morbidity, mortality and impact of AIDS in the country.
- Building India's response capacity towards HIV/AIDS.

The following key policy initiatives were implemented during NACP's second project (NACPII):

- The adoption of a national AIDS prevention and control policy (2002)
- Targeted interventions for high prevalence states will be increased.
- A strategy for greater social involvement of people living with HIV/AIDS.
- The adoption of a national blood policy and the launch of a national antiretroviral treatment programme along with the establishment of a
  national council on HIV/AIDS which shall be chaired by the prime minister. Also setting up state AIDS control societies in all states.

A major milestone was etched by the NACP when in response to the evolving epidemic, the third phase of the national programme (NACP-III) was launched in July 2007. Over a five-year period, plan NACP-III aimed to halt and reverse the HIV epidemic in India by increasing prevention efforts among High-Risk Groups (HRG); vulnerable groups and the general population and also, integrating them with complete medical services. Also, administrative support was provided for the core NACP-III activities to be carried out at the national, state, and district levels.

- And now, NACP IV, which was launched in 2012, aimed at accelerating the process of reversal and strengthening of the epidemic response in
   India over the next five years through a cautious and well-defined integration process.
- The Aim of this project is to reduce new infections by half. The plan of action for this included:
  - Complete medical care and support to all people living with HIV/AIDS along with infrastructure improvement of the same at district, state and national level.
  - Increasing IEC (Information, education and communication) services for the general population and high-risk groups.

Thus, it must be understood that these laws are made to be taken help of but if we talk about the legal situation after the law making then we must blame our government's negligent behaviour towards the issue. On analysing the timeline of these laws, it can be seen that on 11<sup>th</sup> April 2017 the bill was approved by the authorities but it came into effect on 10<sup>th</sup> September 2018 which is a long duration, taking into consideration the clarion call that is needed for this disease. Also, it becomes even more important to get it implemented on a rapid timeline basis, when we know that this issue is so widespread that discrimination and aversion towards HIV/AIDS patients is pervasive in both government and private health care centres. That

throughout states HIV+ individuals are frequently refused care by paramedics, nurses and in some circumstances even by doctors and this makes the HIV people more vulnerable towards the disease. This does not mean that every medical staff is culprit but there are many who are culprit towards the injustice.

There was one such instance of the year 2017 where 24-year-old pregnant women was admitted to Tikamgarh district hospital in Madhya Pradesh and was tagged as a "Human bomb" when she was tested positive for HIV. The confidential diagnosis report was leaked by the lab technician and within hours every person from the medical staff refused to treat her. Eventually she gave birth to twins who died on the ward floor in less than 30 minutes after the delivery. However, a staff nurse and a lab technician were suspended after media reports, while a civil surgeon was handed a legal notice (Tomar & Kaul, 2017) but all this was of no use for that mother who lost her twins due to sheer negligence and discrimination done by the medical staff.

Another incident shows that on 5th October 2017 a 27-year-old HIV+ woman in Hyderabad's Osmania general hospital hung herself from pipe, after being denied admittance in hospital (Tomar & Kaul, 2017) which as per the government rules is provided for free under India's National AIDS Control programme.

These incidents took place due to slow procedures of drafting the law as had this act been implemented in 2017 itself, then maybe things could have been different for these and many other such victims.

# CONCLUSION

In this paper, an attempt was made to understand the socio-psychological entanglement of HIV/AIDS, of how the physiological malady turns into mental illness due to lack of awareness about the disease. The literature in this paper helps in understanding that HIV/AIDS is a disease that is incurable and in which immunity to fight against infections gets compromised, but, due to lack of awareness, people have some basic misconceptions about HIV/AIDS. Due to this they start discriminating against the HIV positive people which mentally affects them gravely. However, now with the enforcement of the laws to protect the rights and sentiments of HIV/AIDS sufferers to help them to live with dignity, there is a ray of hope but, with the prevalence of cases of injustice this ray of hope seems to diminish. This shows that after countless programs, schemes, laws, awareness campaigns, even now, our society is not clear of the facts. According to a survey published in 2006, one out of every three AIDS patients have experienced extreme forms of discrimination in many aspects of their lives. The similar percentage was also found in a 2016 report (Ghosh, 2021). As a result, it may be understood that laws and policies are not functioning as they should. Moreover, people themselves also need to understand the sensitivity and decimate all stereotypes against the problem and should make a better world to live in for people suffering from HIV. Let's not let a virus kill humanity, rather let us try to eliminate this virus through our humanity.

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