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Determinants of stigma faced by people living with Human Immunodeficiency Virus: A narrative review from past and present scenario in India

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ABSTRACT

Worldwide, HIV-related stigmas had been acknowledged extensively in the literature; real time challenges of stigma faced by HIV infected patients in Indian context were understudied. The National AIDS Control Organization contributed a lot to achieve Quality of Life among People living with HIV with free Antiretroviral Therapy in India; however, underutilization of such facilities by HIV infected patients due to existing stigma showed low quality of life and poor mental health which worsen their diseased condition. This review addressed where and how stigma has formed in India since social beliefs, ethics and moral values are related to cultural backgrounds.

1. Introduction

Worldwide, Human Immunodeficiency Virus (HIV)/Acquired Immuno Deficiency Syndrome (AIDS) remains one of the most serious public health concerns. Globally, 38 million people are currently living with HIV and around 5.8 million people live in Asia.[1] As per the latest reports issued by National AIDS Control Organization (NACO) India is a home for 23.49 lakhs people living with HIV (PLHIV) and is considered as the third-largest in the world with estimated HIV prevalence of 0.22%.[2] Over the last decade, major changes took place in the epidemiology of PLHIV. Several studies has been done in understanding the pathogenesis of this disease.[3]

Earlier it was assumed worldly, that HIV is largely transmitted through sexual intercourse. AIDS also occurs generally to people who actively participate in unusual sexual behaviors (USB) and Injecting drug users (IDUs).[4] It is believed that HIV is perceived as a disease of "others", whose lifestyles are viewed "perverted" and "sinful".[5] AIDS-related stigma is molded by misconception and fear of the disease leading to negative attitude towards the people who contracted HIV and the state in which it is transmitted.

Despite substantial advances in Antiretroviral Therapy (ART) era, there is no universal remedy to reduce stigma and discrimination that occurs in both urban and rural setup across India.[6] HIV-related stigma has been widely acknowledged in the literature; however, the distressing impact and challenges it has on PLHIV in different states and regions of India is understudied.[7]

2. Methods and objective

Method: This is a review-based article. The authors reviewed different existing research papers which are conducted in India. PubMed, Google Scholar, and Scopus were searched to identify published literature. The retrieved studies from database were screened for its title and abstracts followed by full text article in accordance with the objective.

Objective: To identify determinants of HIV-related stigma faced by people living with HIV in India.

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3. Brief history of HIV/AIDS

The first few human HIV cases were reported in the early eighties which then later evolved into a global epidemic.[3] In United States of America (USA), the first cases of HIV/AIDS were among homosexuals. In the year 1986, Dr. Suniti Solomon diagnosed the first HIV case in the city of Chennai, Tamil Nadu, India in a female sex worker.[8] Prior to this, few HIV positive cases were also found among Indians who had contracted from abroad or among foreigners residing temporarily in India. Consequently, the first clinical case of AIDS was also reported in 1986 from Mumbai. Commercial sex workers, hemophiliacs, sexually transmitted diseases (STD) clinic patients and professional blood donors were the key groups known to be infected with the HIV virus as revealed by a preliminary study which showcased that blood products were also found to be contaminated with HIV.[9] In the year 1980, an instant transmission of HIV was detected among IDUs in Manipur, Mizoram and Nagaland from north-eastern states of India bordering Myanmar (Burma).[10,11] Since then, the cases continue to rise in India.

4. What is stigma?

Stigma is a multidimensional, context-driven process and an essential aspect among PLHIV as it interferes with the psychological and physical well-being due to the distinct effect on health outcomes.[12] The Greeks, who gave remarkable contributions to philosophy, originated the term stigma by referring to "bodily signs designed to expose something unusual and bad about the moral status of the signifier", as traced by Erving Goffman.[13] Gregory M Herek define stigma as "an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently dis-credits and disadvantages an individual".[14] Link and Phelan considered "labeling, stereotyping, separation, status loss, and discrimination" as components of stigma as they can all occur at the same time.[15] The concepts of "Stigma" have been extensively theorized by researchers from various countries in different fields. World Health Organization (WHO) defined stigma as "a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society".[16]

5. Why is HIV/AIDS considered as a stigmatizing illness?

It is necessary to recognize how HIV/AIDS manifest in different characteristics and why it is highly stigmatized among any other diseases. First, it is perceived to be the bearer's obligation since the main routes of transmission are actions considered to be voluntary and immoral. Second, greater stigma is perceived to be associated with illnesses and conditions that are unalterable or degenerative. Third, diseases that are contagious are perceived to be highly stigmatized. Fourth, a condition apparent to others affecting an individual's physical appearance and stamina tends to be more stigmatized.[17,18] In olden days, more than half of the responders in a study believed that "only gay men, prostitutes, and drug users can get AIDS" due to the causes and routes of HIV transmission.[19] Although stigma is generated within the society, it is paramount to understand where and how stigma has formed in special cultural and political statuses and discrimination should be acknowledged since socio-cultural beliefs, ethics and morals are related to cultural backgrounds.[4]

6. Determinants of HIV-related stigma in India

While stigmatizing attitudes towards PLHIV have declined in other countries, it remain more prevailing following variety of documented discriminatory behavior in India including denial of hospital care by healthcare team leading to medication non-adherence, expulsion from colleges and homes, unemployment or termination of employment were few which can further cause poor mental and physical health.[5,20,21] Here, we are addressing determinants of HIV-related stigma with an insight view on the issues and challenges in India.

6.1. Social stigma

In India, as elsewhere, the overall social attitude towards PLHIV has been negative despite the levels of knowledge about HIV/AIDS, precisely due to the routes of HIV transmission. It is believed that AIDS is coupled with a group of people whose social and sexual behavior does not favor community approval.[5] As per reports, PLHIV have reported numerous cases of violence and rejection by their family, spouse, and community; medical treatment refused by health workers; and denial of last rites before they die. Harassment was also reported by outreach workers and peer-educators, and school teachers experience negative responses from their student's parents for teaching them about AIDS.[11,22–24] There was also an incident where one bus driver from a village was tested positive for HIV and the entire village became the target of stigma giving rise to difficulties in finding jobs, expulsion from nearby colleges, and even caused problems in arranging marriages.[25] A study in Iran also found that society have different attitude towards PLHIV thinking that the disease is transmitted by drug injections or unwanted sexual behavior which is not accepted in their tradition. They avoid attending any public events like weddings, birthdays, and family reunions due to social stigma.[26] In Zimbabwe, a study also reported similar findings that a man after testing positive lost his wife and son, and his in-laws took away his children from him.[27]Family rejection leading to depression and delay in seeking treatment was also reported. A 5-year-old kid was humiliated and mistreated by his classmates, not allowed to touch or talk with others in school.[4]

6.2. Discrimination among women

Indian society with a history of strongly patriarchal and patrilineal culture, males are always superior to women having exclusive rights over their wife's sexuality and their inherited properties are passed on through male lineage. In contrast, women are treated as objects, should think only about the comfort of others, bound to do all the household chores, meet the husband's family expectations after marriage and can impose authority only after she gave birth to a child. A male child is always preferable than a female child as dowry system is still prevailing since paying and accepting dowry is a tradition practice in India and can be a great financial burden to the bride's family. This culture further translated or reflected in all parts of their life from birth to death. Even though majority who shared their HIV status with their families had received care and support, preference was given to men most of the time for such care. Especially in rural areas, if the husband was found HIV positive first, the family would spend all their savings, selling assets, and take loans to treat his disease. In contrast, widowed women would be rejected after her husband's death from the husband's family, while some women had to leave their deceased husband's house forcefully with her children and in some cases forcing the women along with her children to move back to their hometown or native as they are considered a burden for the husband's relatives socially and economically. In general, the quantity and prestige of work among men and women needs to be recognized equally; however, women are always perceived to be inferior to men in Indian society.[28–30] A study conducted by Oskouie F et al. also stated that women had been abandoned by their family and society mostly due to poor education and low level of awareness about the disease in the community.[26] A woman and her child were rejected by sister's husband after knowing her HIV status.[27] Saki M et al. also mentioned that society is treating HIV positive women as prostitutes which prevents PLHIV from taking treatment in a hospital.[4]

6.3. Discrimination in healthcare

Discrimination is perhaps the most noticeable act in the health care

sector. Frequently reported reactions addressing physician's denial to admit or treat HIV-positive patients due to negligence, testing HIV without consent, breaches of privacy and misconceptions about HIV transmission continue to fuel discrimination in the healthcare settings in India. According to a study conducted in southern India, 60% responders said that "only gay men, prostitutes, and drug users can get AIDS", 36% thought PLHIV deserved their fate and felt if infected individuals killed themselves, it would be better. 34% stated they would avoid people affected with AIDS and the hostility index revealed almost 90% harbored one hostile view, and more than half held such views.[5,19] A report also stated that over a list of 95% patients for surgical procedures are involuntary tested for HIV and for those whose test shows positive results, their treatment/surgery remain cancelled.[31] As a result, discrimination and traumatic experiences expressed by healthcare workers has created anxiety and fear among majority of PLHIV. Due to this, many keep their HIV status secret.[32] Many reports were identified from different studies where physicians refused to provide service to PLHIV in the hospital and among health professionals, dentist denial of treating PLHIV was frequently seen. An incident was also reported where a dental appointment was sought from a dentist neighbor where their confidentiality was disclosed to others and the apartment supervisor advice people not to keep close contact with them.[4,26]

6.4. Discrimination in workplace

A study conducted in Mumbai reported that a policy on HIV/AIDS victims was not adopted anywhere and mid-level management was done based on the number of workers if it creates a negative impact on their productivity. Individual cases such as loss of job, emotional isolation due to negative attitudes, and denial of employment have been reported in the media to non-governmental organization (NGO) workers, social counselors and healthcare practitioners.[5] Another study also revealed a strong evidence of stigma where 74% employees in their workplace hesitate to disclose HIV status to their colleagues due to fear of discrimination and among those who disclosed has faced prejudice as a result.[24] Similar findings was also found in Iran where a person who works in a barber lost the job due to the illness.[26]

6.5. Discrimination among marginalized groups

By definition, marginalized groups are different groups of people within a given culture, context and history at risk of being subjected to multiple discrimination due to the interplay of different personal characteristics or grounds, such as sex, gender, age, ethnicity, religion or belief, health status, disability, sexual orientation, gender identity, education or income, or living in various geographic localities.[33] In India, people in marginalized groups such as commercial sex workers, hijras (transgender) and gay men are often stigmatized not only due to their HIV status but mostly due to belonging in a socially excluded group.[11] These group of people also experienced discrimination even from their own communities.

Sex workers not only face stigma and discrimination but were also prejudice in healthcare settings leading to denial for treatment; given unsatisfactory care and letting them wait longer than other patients. They also do not disclose their HIV status to their house owner due to fear of isolation, ostracism, loss of income and destitution since their source of income was access through them. The house owner themselves deny AIDS as major health problem, even after knowing that these workers get infected due to HIV.

Gay and other homosexually active men were hard to identify them as a group or community in India. If found HIV positive, they have no one to support them and tends to change their sexual identity to escape from being "found out". As there is a greater stigma attached to homosexuality than to AIDS in India according to explanation given by one HIV positive gay man. Once discovered with HIV-positive, they would stop attending counseling center for gay men and more drawn towards positive people's group, feeling a sense of belonging there where they would conceal their gay identity. Doctor's assumptions on all men to be heterosexual resulted in difficulty for gay men and felt discouraged from consulting them in healthcare set up since most doctors were unaware and tended to overlook upon married men having sex with another men.

Transgender community also faces discrimination and specially those who are in a sex trade for earning money through "unnatural sex" are stigmatized and HIV/AIDS added their sense of isolation and marginalization. Some even face stigma and discrimination in their early stage of life where normal childhood and education were denied. As they grew up, people mock at them even when they managed to get jobs and felt that street life where they practice sex work was the only option which suits them best. In healthcare settings, surgery and interventions involving injections were denied by medical staffs to prevent themselves from any possible infection through needle scratches or punctures even if recommendations were made previously.[5]

6.6. Internalized stigma

Internalized Stigma referred to an extent where an individual agrees their discredited status and accepts it. If internalized by stigmatized individuals themselves, it is called self-stigma. The psychology of an individual is influenced by their external environment and discrimination against PLHIV would develop negative attitudes about HIV-related stigma prior to their infection. A person infected with HIV might choose not to disclose his/her status to others due to perceived stigma leading them to be socially isolated. A feeling of embarrassment, blame oneself and unworthiness can contribute to the spread of HIV by imparting fear of being rejected by sexual partners, low self-esteem, hindering condom use, poor quality of life and Non-adherence to ART. Such isolation prevents PLHIV to seek support and avail resources they need and tends to face psychological distress directly or indirectly. This condition would make one more vulnerable to internalized stigma even without facing discrimination.[25,34]

Other studies also found that feeling of shame and embarrassment, feeling useless, guilty, and lonely, fear of unknown and occupying self with stressful thought leads to self-isolation from the community. Fear of disclosure affected treatment leading to non-adherence as they are afraid to take medicine in front of others due to fear of rejection which leads to self-medication or taking alternative therapies.[4,26,27]

7. Current scenario of HIV-related stigma from the year 2010–2022

A summary of available literatures on the current scenario on determinants of HIV-related stigma from the year 2010–2022 with an insight view on the issues and challenges in India due to their distinct socio-cultural and ethnic background is discussed in Table 1.

8. Conclusion

Our review found that although NACO and other organizations had contributed lots of awareness programs and measures to prevent HIV in India, PLHIV still experienced HIV-related stigma at different stages of their life such as at individual, family, community, and health-care settings which may vary from region to region. Although advances in medical treatments were available in India, underutilization of such facilities by the people for their HIV treatment showed low quality of life and poor mental health which in turn worsen their HIV diseased condition. In addition, our review concluded that all health care professionals and health care providers including non-medical staffs should focus to achieve patient-focused quality care with empathy towards PLHIV.

Table 1
Current scenario on Determinants of Stigma faced by HIV infected patients in India during 2010–2022.

Authors	Study population	No. of Participants	State	Study Design	Determinants of Stigma	Future Directions
Kumar et al.[35]	HIV positive registered at ART center between 18 and 49 years of age	288	Varanasi, Uttar Pradesh	Cross-sectional Study	Non-disclosure of HIV status due to social stigma. Married couple, single sexual partner and linkage to social welfare agencies had higher rate of HIV status disclosure as compared to unmarried, multiple sexual partners and who had no linkage to social agencies.	Create awareness about importance of disclosing HIV status to others and evolve strategies to those not likely to disclose their status.
Nair M et al.[36]	35 PLHIV, 10 community members, 26 healthcare providers	71	Patna, Bihar	Qualitative study	Social stigma as HIV is still perceived as dirty illness at the community level. Discrimination by health providers due to lack of knowledge and fear of HIV transmission, refusal to treat PLHIV and referring them to other centers and intentional disclosure of HIV status were chief factors.	To upgrade knowledge on HIV transmission and health system to perform universal precautions to ensure proper infection control.
George[37]	PLHIV with 28–40 years of age	14	Ernakulam, Kerala	Qualitative Study	Social stigma, discrimination towards women, healthcare workers discrimination and media's way of victimization and false portrayal of PLHIV create fear among general population which worsen the situation.	Behavior change communication through different mass media for the community are required.
D.R. Garfin et al.[38]	Women living with HIV	600	Rural areas of Andhra Pradesh	Randomized Controlled Study	Fear of stigma, internalized stigma, and depression influence QOL.	Interventions combining focused education with Asha-support approach may be beneficial for women living with HIV/AIDS and improve their QOL.
Chan et al.[39]	388 men, 268 women and 4 hijras PLHIV	660	Chennai, Tamil Nadu	Cross-sectional study	Fear of disclosure concern due to social stigma and internalized stigma due to self-dislike which associated with depression symptoms	Further study to understand the correlation of these elements and the effect it may have among the Indian HIV positive patients
Sarkar et al.[40]	11 caregivers (mother) of pediatric HIV positive patients	11	Chennai, Tamil Nadu	Qualitative Study	Due to social stigma, caregivers faced many difficulties to prevent the disclosure of their child's HIV diagnosis. To ease their fear of transmission, caregivers should be well informed about the myths and misconceptions and mode of HIV transmission.	Effective disclosure approaches to assist parents and health-care providers in disclosing the HIV status to infected children without adverse consequences.
Arjun B. Yathiraj et al.[41]	256 male, 153 female PLHIV	409	Mangalore, Karnataka	Cross-sectional Study	Disclosure, public attitudes, negative self-image, personalized stigma were found to be main factors. Married couple, high socioeconomic status, prolonged intake of ART, and those travelling in long distances to procure ART have higher stigma.	Interventions involving healthcare professionals, investigators, social workers, and counselors is important to remove HIV-related stigma.
Ekstrand et al.[42]	Women living with HIV	600	Nellore, Andhra Pradesh	Cross-sectional Study	Fear of social stigma, discrimination towards women and internalized stigma leads to non-disclosure, isolation, avoid social support, poor medication adherence and low QOL.	Longitudinal research of women on the causal pathways as well as the impact of these factors on their children is needed. Interventions directing this vulnerable group are urgently needed including strategies to reduce HIV stigma among family and community members.
Shrikanth Muralidharan et al.[6]	88 Male, 82 Female PLHIV from 19 to 60 years of age	170	Raichur Taluk, Karnataka	Cross-sectional Study	Social stigma, disclosure concern due to internalized stigma, discrimination of women from family, friends and neighbors and discrimination by healthcare workers	More humanitarian approach with qualitative study is needed rather than focusing on achieving number of papers and make business towards these people
Deepak Madi et al.[43]	76 Men, 35 Female PLHIV	111	Mangalore, Karnataka	Cross-sectional Study	Non-disclosure of HIV status due to social stigma as well as fear of shame in the family.	Doctor's commitment is vital in generating awareness about the

(*continued on next page*)

Table 1 (*continued*)

Authors	Study population	No. of Participants	State	Study Design	Determinants of Stigma	Future Directions
						importance of voluntary disclosure.
Z. Gohain, M. A. L. Halliday[18]	13 males, 18 females PLHIV	31	Aizawl, Mizoram	Pilot study using purposive sampling	Internalized stigma along with depression and anxiety	To conduct more robust studies on issues and challenges of HIV-related stigma in all its forms, incorporating their social and religious beliefs of the population under study.
Nyamathi et al.[44]	68 women, 34 in intervention and 34 in usual care group	68	Kovur and Kotavalur, Andhra Pradesh	Pilot study using cluster randomization	Internalized stigma. It was reduced using Asha-Live intervention along with avoidant coping strategies among PLHIV having depression.	The intervention can impact rural communities and will benefit healthcare professionals and policy makers to promote resources and support WLA.
P. Isaakidis et al.[45]	12 HIV-TB patients, 5 caregiver and 10 health workers	27	Mumbai, Maharashtra	Qualitative Study	Social stigmas cause non-disclosure, leading to lack additional support from family and friends. Drugs side effects were reported to be terrifying than the disease itself followed by financial burden to sustained treatment. Family caregivers also reported high levels of fatigue and stress to sustain the mental and physical health of PLHIV.	Current treatment plans for MDR-TB and ART require great levels of support from family and caregivers to improve patient adherence and retention in care.
Charles et al.[46]	188 male, 212 female PLHIV	400	Kancheepuram, Kanyakumari, Karur, Villupuram, Trichy, Thirunelveli and Tuticorin in Tamil Nadu	Cross-Sectional Study	Personalized and negative stigma with depression leads to poor QOL. Married PLHIV likely to have depression due to obligation in caring their children and fear of disclosing HIV status to family members. Patients attending ART services show poor QOL due to discrimination towards illiterate and poor PLHIV at the services.	Need to strengthen interventions emphasizing on emotional and psychological support along with available ART services to improve overall QOL.
Nebhinani et al.[47]	PLHIV outpatients attending clinic without receiving ART.	100	PGIMER, Chandigarh	Cross-sectional Study	Internalized stigma due to shame and blame to self and social stigma among urban patients were mainly observed. No association between psychiatric disorders and stigma.	Need to create awareness on enlightening knowledge about HIV/AIDS, especially towards treatment aspects.
Valerie Phamdo et al.[48]	Mother-child dyads	108	Rural Nellore and Prakasam	Cross-sectional Study	Mother's community stigma fear was negatively associated with child's CD4 count while mother with Christian faith was associated with higher CD4 count in their child	In depth qualitative and longitudinal quantitative studies that seeks to understand how stigma impacts clinical outcomes among children needs further research.
Soumya S Sahoo et al.[49]	PLHIV attending ART center	400	Haryana	Cross-sectional Study	Male gender, younger age group, nuclear family, and rural residents experience more stigma.	Providing education, behavior change strategies and creating supportive environment among young, single, and rural residents of PLHIV can help in ending stigma and discrimination
Roopal J Singh et al.[50]	Alcohol consuming male PLHIV on ART from 4 ART centers	752	Mumbai, Maharashtra	A crossover randomized controlled trial	Baseline study shows that stigma remains a problem even among experienced patients. At the end of the study intervention, the participants show maximum reduction in stigma.	Multilevel stigma reduction interventions are advice to be include in HIV prevention and treatment program.
Sangeeta Sharma Dhaor[51]	PLHIV of 60 males, 40 females and 5 *trans*-gender women	105	Delhi	Mixed-method study	Internalized stigma was identified through reports like separating utensils, isolation and not disclosing their status. Perceived stigma has also been reported to be more than the real stigma.	Internalized stigma can be reduced by training and educating the infected about transmission, high risk, low risk, and no risk behavior.
Nambiar et al.[52]	PLHIV of 120 unexposed, 77 recently exposed, 60 exposed a month ago	257	Tamil Nadu	Quasi-experimental study	Higher HIV related knowledge, lower felt stigma and improvement in behavior was found among PLHIV who are exposed to radio and theatre based educational program.	A collaboration between arts-based non-governmental organizations and government hospitals may increase better patient outcomes in HIV treatment settings.

AIDS Acquired Immune Deficiency Syndrome, *ART* Antiretroviral Therapy, *HIV* Human Immuno Deficiency Virus, *PLHIV* People Living with HIV, *QOL* Quality of Life, *TB* Tuberculosis.

9. Strengths and weaknesses

This study is a narrative review and we conducted literature search only from 3 databases i.e., PubMed, Scopus, and Google Scholar. There are chances that we might miss some important articles conducted in India which are published in different database. Despite these limitations, we believe that the study covers the insight views on all the possible areas in HIV-related stigma, from past to the current scenarios in India.

10. Future directions

HIV-related stigma among children of HIV positive women and marginalized groups such as commercial sex workers, transgender, and gay men as well as IDUs are not well addressed in India because of real time stigma issues. Further research is needed in Indian context, on HIV-related stigma experienced by PLHIV in all its forms i.e., at individual, family, society, workplace, healthcare settings incorporating socio-cultural and ethnic background, identifying the knowledge gap within a specific region to prevent barriers to face the challenges of HIV related stigma issues in Indian HIV infected patients.

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Data availability statement

The data related to this work is not deposited in any repository. It will be available from the corresponding author on appropriate request.

Declaration of competing interest

All authors report no conflicts of interest to declare.

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