

Opinion Paper

Combating HIV-related Stigma and Discrimination: A Crucial Imperative in India

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Received: August 20, 2024

Accepted: November 9, 2024

Citation: Uniyal et al,

JAAPI 4(1, 2):38-42, 2024

The Context and Background: The continuing persistence of stigma and discrimination related to HIV poses a formidable challenge. Despite significant strides in HIV and AIDS awareness and treatment, individuals living with HIV grapple with prejudice, social marginalization, and egregious violations of their fundamental human rights. This pervasive issue is not confined to specific region but is a global phenomenon. Stigma and discrimination against people living with HIV (PLHIV) are rampant in general population, family and peers, within institutions and social constructs and ranges from verbal and physical assault to disenfranchisement, breach of confidentiality and denial of essential health services. Loss of employment due to HIV status highlights the devastating economic repercussions of stigma and discrimination. In India, where the HIV epidemic is concentrated among key populations such as female sex workers, men having sex with men, migrant men, transgender individuals, and injecting drug users, stigma and discrimination cast a long shadow over efforts to combat HIV.

Key Words: HIV, AIDS, Stigma, Discrimination, Combating HIV

Introduction: HIV-related stigma and discrimination is a reality in every part of the world, although it may look unique to countries like India (1). To effectively tackle this multifaceted issue, it is imperative to delve into the intricate dynamics of HIV-related stigma and discrimination. Only through a comprehensive understanding of the underlying factors driving stigma and discrimination at workplace, community, healthcare and educational settings, can meaningful interventions be designed and implemented to dismantle barriers. At the global level, significant strides have been made through initiatives such as the Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination was launched in 2018 under the auspices of UNAIDS and other key partners (2). This partnership globally bolsters the

implementation of stigma-reduction programs across six pivotal settings: healthcare, education, workplace, justice, humanitarian, and emergency contexts. By fostering collaboration and collective action, this initiative dismantles the barriers of stigma and discrimination that impede progress in the fight against HIV/AIDS.

Within India, the National AIDS and STD Control Programme (NACP) Phase V, 2021-26 has taken proactive measures to integrate stigma reduction as a central tenet of its strategy (3). Through targeted interventions, the NACP endeavours to combat stigma and discrimination by fostering awareness, empathy, and inclusivity. These efforts encompass a range of activities, including sensitization trainings for healthcare providers, provision of legal aid services for

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individuals living with HIV, community mobilization, empowerment initiatives for key populations, and media campaigns aimed at dispelling myths and challenging misconceptions surrounding HIV/AIDS. To foster the vision of a world free of stigma and discrimination, much needs to be done. Here we describe strategies to build an inclusive and just world for everyone. Through holistic approaches, our endeavours should be to dispel myths regarding transmission of HIV and build a supportive environment that promotes community acceptance and understanding. This will contribute to better health outcomes and a decrease in fear and discrimination faced by PLHIV.

Understanding HIV-related Stigma and Discrimination: The United Nations Programme on HIV/AIDS (UNAIDS) defines 'HIV-related stigma' as the negative attitudes, beliefs, and prejudices directed towards individuals living with HIV/AIDS or are perceived to be at risk of HIV infection (4). Stigma often leads to social rejection, isolation, and marginalization of affected individuals and communities. It can manifest in various forms, including verbal abuse, social exclusion, and denial of healthcare services. 'HIV-related discrimination' involves the unfair or unequal treatment of individuals based on their HIV status. It encompasses actions, policies, and practices that violate human rights and denial of opportunities for people living with HIV/AIDS. Discrimination may occur in healthcare settings, workplaces, educational institutions, and within communities, leading to profound social and economic consequences for affected individuals.

Stigma and discrimination can affect the emotional wellbeing and mental health of people living with HIV/AIDS. Negative self-perception occurs if the stigma encountered is internalized for example regarding fear of discovery of their HIV status. Self-stigma or internalized stigma can evoke feelings of shame, hopelessness and fear of social isolation. These emotions can be detrimental for individuals to come out and seek care and treatment (5). For mitigation of internalized stigma, it is important that there is an open dialogue about HIV/AIDS and awareness is spread through use of multi and mass media as street plays, posters, hoardings at bus/train stations, wall paintings, newspaper, radio, social media etc that gives opportunity to dispel misconceptions and spread the

correct information about HIV/AIDS so affected individuals are empowered to acknowledge their health needs and reach out for right care, support, diagnosis and treatment.

Critical Settings of HIV-related Stigma and Discrimination: Healthcare professionals may deny care for HIV patients due to their own myths and beliefs related to HIV/AIDS which largely stems from their fear to contract the disease. Inadequate education and discriminatory policies at workplace and educational settings are the main cause of harassment of HIV positive individuals leading to many missed opportunities to pursue their preferred education streams or employment. Misconceptions in HIV transmission and labelling them as people with immoral character leads to social ostracism and exclusion of HIV positives in community-based settings.

Zero Discrimination Day observed annually on March 1st is committed to end discrimination in societies and across geopolitical borders for the HIV community and is embedded in the ethos of human rights for everyone to lead a meaningful live with respect and dignity. Yet, the UNAIDS report still mentions 46 countries that impose restrictions on entry and residency based on HIV status (6).

The Government of India's NACP V emphasizes countering stigma and discrimination against people living with HIV across healthcare facilities, educational institutions, workplaces and communities (3). Rendering non-discriminatory care and support services within healthcare settings is the key mandate achieved by trainings healthcare professionals to deliver non-stigmatizing care. Education emerges as a pivotal tool in dispelling myths and misconceptions surrounding HIV/AIDS and fostering empathy and understanding towards affected individuals. NACP recommends that all educational institutions should incorporate comprehensive HIV/AIDS education to foster acceptance and inclusivity among faculty and students.

Workplaces are encouraged to adopt non-discriminatory policies and provide workplace education programs to foster a supportive environment for employees living with HIV/AIDS. The community-level interventions carried out as a part of NACP activities are designed to challenge misconceptions about HIV transmission, promote empathy, and

encourage social integration of affected individuals and families (3). In our experience, internalized stigma is often experienced by women who got infected by the virus from their spouse. They suffer depression and live in shame and fear of social exclusion. Furthermore, our social hierarchy and patriarchy blames women for harbouring and spreading the infection when the virus gets diagnosed first during antenatal clinics before the husband is tested. Gender biases and social constructs make it difficult for women and adolescence girls to seek the right information about their sexual and reproductive health due to taboos around the topic. Female sex workers often solicited into unprotected commercial sex live in fear of losing their source of income if they contract the infection and the positive status is disclosed. This self-stigma prevents them from seeking the right care and support. Stigma and discrimination can be dispelled by educational material and communication tools that highlight “no discrimination” based on HIV positive status. Such a communication campaign #AbNahiChalega has been developed by SHARE INDIA with support from NACP’s Information, Education, and Communication (IEC) Division.

Through coordinated efforts across these four settings, NACP seeks to mitigate the repercussions of HIV-related stigma and discrimination while upholding the rights and dignity of all individuals affected by HIV/AIDS in India (3). Effectively addressing HIV-related stigma and discrimination necessitates a comprehensive approach that considers societal attitudes, promotes human rights and ensures access to equitable healthcare and support services. Additionally, legal frameworks must be strengthened to safeguard the rights of individuals living with HIV and eradicate discriminatory practices in various settings.

Navigating Change with Triumphs in Combating HIV-related Stigma and Discrimination: The HIV and AIDS (Prevention and Control) Act, 2017 published through a Government of India Gazette notification safeguards the rights of people living and affected with HIV/AIDS. NACP has published a handbook and created e-trainings tools to offer valuable insights and practical examples to mitigate stigma and discrimination related to HIV/AIDS. The Handbook on Prevention & Management of Stigma and Discrimination Associated with HIV and AIDS (2022) addresses various stakeholders including government,

non-government bodies, civil society, private entities and advocacy groups to adopt strategies for prevention and addressing stigma and discrimination associated with HIV/AIDS (7). The handbook is tailored to counter stigma and discrimination at workplace, healthcare facilities, educational institutions, and communities. The role of media and Faith-Based Organizations (FBOs) in building support systems for individuals affected by HIV/AIDS is exemplified through the handbook (7). The hallmark of the handbook is to understand key provisions outlined in the HIV and AIDS (Prevention and Control) Act, 2017 to dispel stigma and discrimination associated with HIV. The Act not only provides a legal framework to uphold rights and dignity of individuals living with HIV/AIDS but also delivers a robust grievance redressal mechanism (7).

Another feather in NACP’s cap is the enactment of the HIV/ AIDS Policy for Establishments, (2022) as a mandate under the Act to protect rights of individuals against workplace discrimination related to HIV (8). Also aligned with Global Sustainable Development Goal 3 for Health, the policy raises awareness on prevention and HIV transmission. Equity, inclusiveness and dignity is promoted in workplaces by adopting safe, non-stigmatized and non-discriminatory behaviour. Maintaining confidentiality regarding HIV status further propels voluntary disclosure by employees thereby freeing them of the fear of discrimination and/or being fired. The policy fosters re-designing and re-engineering workplace culture to build safe non-discriminatory environment that actively discourages discrimination related to HIV.

In the realm of opinion, mobile applications serve as valuable complements to community-based interventions aimed at combatting HIV-related stigma and discrimination, enriching outreach efforts and support services for those living with HIV/AIDS. "NACO AIDS App" and the "Positive Peers" App developed by the University of North Carolina at Chapel Hill, exemplify the transformative potential of technology in addressing stigma and discrimination while bolstering support networks for affected individuals (9).

The "NACO AIDS App" complements community intervention efforts by providing access to accurate information to dispel myths, stigma and discrimination related to HIV/AIDS, counselling services, and virtual support networks, thereby bridging gaps in reaching

remote or marginalized populations, fostering solidarity among users and reducing stigma. Similarly, the "Positive Peers" App empowers individuals to connect with others, access educational resources, and adhere to treatment regimens through features like peer support forums and appointment reminders. Research findings have demonstrated that digital interventions like "Positive Peers" play a significant role in enhancing health outcomes and alleviating feelings of isolation among individuals affected by HIV/AIDS (10). These results underscore the critical importance of innovative strategies in addressing HIV-related stigma and discrimination while enhancing support networks.

Quantifying Stigma and Discrimination: It is important to quantify stigma so that effectiveness of anti-stigma initiatives can be deciphered. Quantifiable indicators support data to drive policy changes by identifying successful anti-stigma interventions across different contexts, population and geographies (11). Despite launch of multiple campaign on stigma reduction by NACP, fear of infection through casual contact with a PLHIV persists among the general population and healthcare workers (12). In an Indian study conducted across three states, it was observed that 47% hospital staff feared touching sweat of an HIV-positive person (12). The healthcare workers were reluctant in measuring blood pressure, changing clothes and bedpans of HIV-positive patients. Even more horrifying was to know that two-thirds of healthcare workers believed people living with HIV should feel shame and 28% thought men who have sex with men do not deserve treatment (12). Focused group discussions with female sex workers showed that 50% believed PLHIV should be socially excluded and expressed reluctance to share meals with those who are HIV positive (12). The study highlighted the need to bust stigma by using multi-pronged approaches that not only countered internalized stigma experienced by PLHIV but also by improving behaviour, practices and attitude of health workers and general population towards HIV positive patients (12).

Conclusions: Combating HIV-related stigma and discrimination is vital for ensuring the rights and dignity of individuals living with HIV/ AIDS worldwide, including in India. Despite advancements in awareness and treatment, stigma persists, resulting in marginalization and human rights violations. Initiatives like the Global Partnership for Action and India's NACP

Phase-V are dedicated to reducing stigma across various settings, emphasising the significance of education and empathy. Success stories, such as the "HIV is Not a Crime" movement and innovative mobile applications like NACP and "Positive Peers," exemplify effective approaches in combating stigma. The "Handbook on Prevention & Management of Stigma and Discrimination" and the "HIV and AIDS Policy for Establishments, 2022" offer vital guidance for stakeholders, emphasizing importance of legal frameworks and workplace policies. As we pursue change, collective efforts, heightened awareness, and supportive interventions play a crucial role in combating HIV-related stigma and discrimination, ensuring equitable access to healthcare and advocating for dignity among all individuals affected by HIV/AIDS. We can endeavour towards a future where individuals living with HIV/AIDS are treated with dignity and compassion by embracing a multifaceted approach that encompasses education, advocacy, policy reform, and technological innovation. Raising awareness and advocating for the engagement of institutions, communities, families and general population will create an enabling social environment to foster long lasting change in knowledge, attitudes and practices against PLHIV. It is only through collective action and unwavering commitment we can create a world where all individuals can live their lives free from fear and judgment.

Disclosure: The authors declare no competing interests

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