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Stigma and Discrimination Related HIV-AIDS

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Abstract

Stigma refers to negative beliefs, feelings and attitudes towards people living with, or seen to be linked to HIV. Stigma also promote social exclusion. Stigma is a socially debilitating label that makes the stigmatized person or group feel secluded from mainstream society. Discrimination refers to the unfair and unjust treatment of someone based on their real or perceived HIV status. It is blaming and showing negative emotions onto a certain group/ population, attributing them or their morals to be the cause of their illness. This research paper is meant for Government departments, the Private sector, Non-Governmental Organizations (NGOs), Civil Society Organizations (CSOs), Advocacy groups, and the Community Based Organizations (CBOs) to provide an understanding of prevention and management of stigma and discrimination associated with HIV and AIDS. The research also attempts to provide stigma and discrimination mitigation strategies in different settings such as in the workplace, health care, educational and community settings and the role of media and FBOs in addressing HIV-related stigma and discrimination. causes for HIV-related stigma and discrimination.

Keywords: stigma, discrimination, mitigation, workplace, community

1. Introduction

Stigma refers to negative beliefs, feelings and attitudes towards people living with, or seen to be linked to HIV. Stigma also promote social exclusion. Stigma is a socially debilitating label that makes the stigmatized person or group feel secluded from mainstream society. (Goffman, 2009) Stigma often lies at the root of discriminatory actions denying the right to healthcare, work, education, and freedom of movement, among others. It is expressed in stigmatizing language and behavior, such as shunning and avoiding everyday contact, verbal harassment as well as physical violence. Stigma may also be internalized by stigmatized individuals in the form of feelings of shame, self-blame and worthlessness. On a personal level, stigma may mean loneliness, abandonment, ostracism, violence, starvation and death. Internalized stigma or self-stigma occurs when a person living with HIV agrees with the negative attitudes associated with HIV and accepts them as applicable to themselves. Other stigma experiences are perceived stigma, which refers to perceptions about how stigmatized groups are treated in a given context, and 'Anticipated stigma', which refers to expectations of bias being perpetrated by others if their health condition becomes known

(Evidence for eliminating HIV-related stigma and discrimination). (UNAIDS, 2020). 'Courtesy stigma', also referred to as 'stigma by association', involves public disapproval evoked as a consequence of associating with a stigmatized individual or group for e.g., stigma experienced by family members, healthcare and other service providers (Rachel Phillips, et.al.). Discrimination refers to the unfair and unjust treatment of someone based on their real or perceived HIV status. It is blaming and showing negative emotions onto a certain group/ population, attributing them or their morals to be the cause of their illness (Gilmore & Somerville, 1994). It adversely affects family and friends, and those who care for people with HIV. Discrimination is often fuelled by myths of casual transmission of HIV and pre-existing biases against certain groups, certain sexual behaviors, drug use, and fear of illness and death. 'Covert discrimination' is defined as discriminatory behavior that can be justified by the context as neutral or even moral behavior (Lennartz C, Proost K & Brebels L. 2019).

This research paper is meant for Government departments, the Private sector, Non-Governmental Organizations (NGOs), Civil Society Organizations (CSOs), Advocacy groups, and the Community Based Organizations (CBOs) to provide an understanding of prevention and management of stigma and discrimination associated with HIV and AIDS. The research also attempts to provide stigma and discrimination mitigation strategies in different settings such as in the workplace, health care, educational and community settings and the role of media and FBOs in addressing HIV-related stigma and discrimination. causes for HIV-related stigma and discrimination.

2. Structural Causes of Stigma and Discrimination

2.1 Economic Inequality

HIV-related stigma negatively impacts the health and well-being of people living with HIV, with deleterious effects on their care, treatment and quality of life. Lack of employment, shelter, food security and the burden of HIV treatment and at times forced migration for living increases vulnerability and drastically reduces self-esteem resulting in increased self-stigma.

2.2 Gender Inequality

Stigma is at its peak among the MSM and TG population. Women account for a growing proportion of people living with HIV and experience higher levels of poverty and encounter greater barriers to accessing services because of multiple work and child-care burdens, restricted mobility, and economic dependence upon men. The traditional patriarchal societies put women at higher risk of HIV infection. The social hierarchy and the differential power relations that exist, blame women for bringing the infection in the family, especially seen when the woman has been tested for HIV before the husband, as happens in several antenatal clinics. Women have greatest risk because of husband's behavior ranging from 1 per cent in general population of antenatal cases to 14 per cent in monogamous women attending STD clinics. Gender norms combined with taboos about sexuality have a huge impact on the ability of adolescent girls and young women to protect their health and prevent HIV, seek health services and make their own informed decisions about their sexual and reproductive health and lives.

2.3 Lack of Knowledge

The greatest fear is that of transmission which arises out of myths and misconception and it is worsened in societies where health literacy is poor. Only one in three young people globally can demonstrate accurate knowledge about HIV prevention and transmission. Knowledge about HIV prevention among young people has remained stagnant over the past 20 years. The National Family Health Survey (NFHS-5) indicates that 21.6% women and 30.7% men have comprehensive knowledge of HIV and AIDS.

2.4 Social and Cultural Norms

The socio-cultural norms prevailing in the society considers sex as a taboo. As the predominant route of HIV transmission in India is through the sexual route, society has a tendency to appraise the person negatively with HIV. The social stratification in the form of gender, caste and class further accentuate stigma against the infected communities. Certain religious beliefs that condemn homosexuality and substance abuse contribute to or strengthen sources of HIV stigma.

3. HIV-Related Stigma and Discrimination at Institutional Settings

HIV-related stigma and discrimination manifests itself in many ways. PLHIV in India, often face stigma and discrimination in a variety of

situations. Both individual and institutional factors contribute to HIV-related stigma. Therefore, self stigma, or internalized stigma, is also deemed as an equally damaging form of stigma that affects the mental wellbeing of people living with HIV or other key populations.

The battle against reduction of HIV-related stigma and discrimination remains weak when it is viewed, understood and addressed only through one particular form. It should include multi-dimensional approach with bio-psycho and social aspects making a path for resilience and empathy in the communities, thus addressing stigma. It is imperative that in order to end stigma and discrimination, it demands a comprehensive effort to mitigate it. Stigma and discrimination touch every aspect of our lives — including the family, community, workplace, education and health care settings. Where efforts are being undertaken to build capacities of the personnel in these various settings to address stigma and discrimination issues, care should be taken to use the UNAIDS Terminology Guidelines which could serve as a good tool for stigma free language in these trainings. Language shapes beliefs and may influence behaviors hence use of appropriate language has the power to strengthen the appropriate response to the HIV epidemic. There have been numerous studies conducted to understand the effects and impact of HIV-related stigma in various institutional settings. Additionally, it is known that manifestations of stigma take many forms, including isolation, ridicule, physical and verbal abuse, and denial of services and employment. Experiences of stigma can differ by sex, reflecting broader gender inequalities, etc. Some of the various settings where HIV-related stigma negatively impacts the persons regardless of their HIV status, sexual orientation, gender identity, or other key population characteristics are healthcare setting stigma and discrimination experienced within the health sector represents one of the most inimical forms of institutional stigma. HIV-related stigma hampers the people's access to, or quality of, healthcare. Discrimination in health-care settings is one of the major obstacles to ending the AIDS epidemic as a public health threat by 2030. This seriously undermines the ability to reach people with HIV testing, treatment and prevention services. The lack of training and educational programmes to inform health workers of the needs, health issues and strategies and interventions for HRGs and PLHIV contributes to marginalization. It leaves providers ill-equipped to address health needs and perpetuates stigmatizing and discriminating practices, even to the point of refusing services.

3.1 Workplace Setting

The workplace setting is a very important environment where issues of stigma and discrimination are detrimental to the majority of those infected as they are in their prime productive period. People living with HIV have higher unemployment rates and face lack of access to work which increases the vulnerability of people living with HIV and affected communities. Confidentiality of HIV status, including loss of confidentiality as a result of mandatory testing, remains a central workplace issue.

3.2 Educational Settings

Stigma and discrimination in education settings can have a profound impact on school retention, self-image and self stigma, and can exacerbate vulnerability to HIV. Gender non-conforming and non-binary young people are particularly vulnerable to violence and bullying at school. Children and young people living with HIV may drop out of school or be excluded altogether. The stigmatized person becomes laden with intense disabling feelings of anguish, shame, dejection, self-doubt, guilt, self-blame and inferiority. They may perform poorly and leave school with little gained. Teachers living with HIV are also subject to stigma and discrimination in education settings.

3.3 Children and Teachers Excluded from Formal Educational Settings

It is important that educational institutions address the specific needs of populations "being left behind" — including but not limited to people living with HIV, key populations, indigenous populations, people in prisons and other incarcerated people, migrants, and women and girls, particularly adolescent girls and young women — alongside protecting their rights to confidentiality, freedom from stigma and discrimination, and equal treatment. It is recommended to use contact strategies in educational settings (e.g., inviting people living with HIV to present at schools or teacher training sessions) to raise awareness about stigma and its harmful effects and to reduce negative attitudes towards populations "being

left behind" from.

3.4 Household Setting

Communities and Families PLHIV often face a double burden, stigmatizing attitudes and behaviors from family and community members too. Within their own families and communities, people living with and affected by HIV, face internalized stigma and isolation as a result of judgment and rejection. It is often observed that in household and community settings, HIV related stigma and discrimination can also manifest through subtle gestures, such as refusing to share food or utensils with people living with HIV, as well as more overt actions, such as rejecting or shunning a person living with HIV. Stigma or anticipation of stigma may cause affected people to conceal their condition from family and community and hence they may withdraw themselves from taking part in any social activity's educational settings. (UNAIDS, 2020)

4. Mitigating HIV Related Stigma and Discrimination at Health-Care Settings

Stigma towards people living with or at risk of HIV drives acts of discrimination in healthcare settings. A stigma free health facility is one in which PLHIV, and other key populations are treated with respect and compassion and are provided with high-quality care. Improving access to health-care services by reducing HIV-related stigma and discrimination is both possible and essential to achieving the targets of eliminating stigma and discrimination by 2024. A variety of interventions to address the issue of stigma and discrimination at healthcare settings include — sensitization of all healthcare workers on the HIV and AIDS (Prevention and Control) Act, 2017, providing equal access to quality health services for all, ensuring respect, confidentiality of PLHIV and HRGs, building capacities of healthcare workers, putting in place grievance redressal mechanisms and continuous monitoring and evaluation of all these activities.

5. Mitigating HIV Related Stigma and Discrimination at Workplace Settings

In order to mitigate the issue of stigma and discrimination at workplaces, it is imperative to understand that HIV and AIDS should be recognized and treated as a workplace issue. These organizations should be included in the national response in addressing the HIV related stigma with full participation of employers and workers. There should be no discrimination against or stigmatization of workers, in particular jobseekers and job applicants, on the grounds of real or perceived HIV status, gender or sexual orientation whether or not they belong to a vulnerable group and perceived to be at greater risk of or more vulnerable to HIV infection.

Some of the measures to mitigate HIV-related stigma and discrimination in workplace settings should include: Sensitization of key personnel of workplaces settings on the HIV and AIDS (Prevention and Control) Act, 2017. The workplace settings to have a Complaints Officer (in case of hundred or more people while in case of healthcare setting for 20 or more people). Workplace settings to report to SACS the number and nature of complaints received, the action taken, and orders passed in relation to such complaints.

Establish a central apex body and monitor system to capture stigma, discrimination and rights violations experienced by people living with HIV and key populations in workplace settings for support and redress.

Implementation of the HIV and AIDS Policy for Establishments, 2022 and also Ministry of Labor and Employment's National Policy on HIV and AIDS and world of work.

Development of workplace health and safety policy to ensure a safer work environment which includes occupational health services for the entire workforce so that access to HIV prevention, treatment, care and support can be attained by the organization. Integrated training programme inclusive of workers' rights and stigma reduction, into existing training programmes to be developed.

6. Mitigating HIV-Related Stigma and Discrimination at Educational Settings

Educational institutions should provide access to HIV and AIDS education programmes especially relating to stigma and discrimination and its ill-effects on both boys and girls. Education also gives HIV infected and affected children a better understanding to equip themselves with life skills to cope with the challenges brought about by both the HIV infection and also the ill-effects of stigma and discrimination. Educational institutions can play a vital role in limiting the HIV related stigma and also the spread and effects of the HIV infection. There should be no discrimination against students with respect to the normal

health benefits accessed and enjoyed by other students in these educational settings. Some of the child centered approaches / strategies that address HIV-related stigma and discrimination at educational settings are:

Capacity building of students and teachers regarding HIV and AIDS to be regularized. The training should also include comprehensive SOGIESC (sexual orientation, gender identities and sexual expressions) as per the international framework of UNAIDS with accurate knowledge about HIV transmission and emphasis on the importance of equal rights for people living with HIV.

Implementation the AEPs in right spirit and also form and strengthen the Red Ribbon Clubs (RRC) to play a crucial role in educational institutions and create awareness on stigma and discriminatory practices with children (CABA).

Impart Psychosocial Counseling Support including life skill education with psycho-social counseling techniques including the physical, emotional, social, mental and spiritual needs of an individual, all of which are considered to be essential elements for students coping with HIV related stigma and discrimination. These counseling sessions must impart healthy living information (on nutrition, positive living, and sexual behavior).

Ensure that no employee, student, or parent on behalf of the student, is compelled to disclose HIV status to authorities at the education institution or service and all health records of students and employees of educational institution to be kept confidential. A special consideration can be made in terms of sickness. Considering the individual's case, the school may provide necessary support but in no way should limit their participation in any activity or extend differential treatment which warrants unwanted attention.

Establishment of grievance redressal mechanism as per the HIV and AIDS (Prevention and Control) Act, 2017. The institutions should train the Complaints Officer on her/his service conditions and aide in speedy disposal of cases. All investigations should be child friendly and should involve the guardian/parent.

Regular reporting to SACS, the number and nature of complaints received, the action taken, and orders passed in relation to such complaints.

Opportunities at staff meetings, Parent-Teacher Association meetings, institutional assemblies or other meetings as appropriate to discuss steps taken to mitigate HIV related stigma.

7. Mitigating HIV-Related Stigma and Discrimination at Household Setting: Communities and Families

HIV-related stigma and discrimination has profound effects on the family system. It acts as a powerful barrier to access healthcare as it inhibits HIV testing and disclosure of HIV status. In addition, it poses a serious problem to PLHIV and their immediate family members as judgment and constant scrutiny from relatives, community members and other social institutions can be one of the worst personal struggles that they have to deal with. The HIV status often puts the spouses, children and family of the infected person exposed to stigmatization often compromising the family support particularly required at these initial stages for the PLHIV to cope with. The family members are forced to limit their social interactions with relatives, friends and community members to look after the HIV patient at home. PLHIV conceal their HIV status often risking their health conditions and also accessing treatment services. Children become the unwarranted targets of neglect as adult caregivers are forced to give much time and attention to the PLHIV. Families also face financial difficulties adversely affecting their economic situations often incurring debts owing the expenses of treatment, travel and food.

Some of the community centered approaches that address HIV-related stigma and discrimination at community / family settings are:

Increase awareness among families and communities on prevention, treatment and care, support for PLHIV through participatory training of family members of PLHIV, community leaders, influential persons, ASHA/AWW, faith-based leaders, etc. on HIV related information especially focusing on ill-effects of stigma and discrimination. Sensitize members on key areas to discuss gender inequality, violence against PLHIV especially children and women and Rights of the PLHIV.

Appropriate steps to sensitize PLHIV on HIV-related stigma and discrimination and ways to address them by strengthening and building capacity of PLHIV / stigmatized individuals and

groups, e.g., through "know your rights" campaigns, skills-building, legal services, network building, counseling, training, income generation, etc.

The community should be mobilized for PLHIV support groups for social, legal and human rights, economic support and action for campaigning and advocacy against stigma and discrimination.

'Advocates for change' campaign among community organizations like SHGs, ICDS/ICPS and women PRIs/ ULBs etc. This should include training of ICDS/ICPS/ SHGs programme and women PRI/ULB/RWAs members to disseminate information about HIV prevention and reduce stigma and discrimination for women and children living with HIV. Greater involvement of community leaders is vital to the acceptance, success and sustainability of the activities that meet the needs of people living with HIV and their families. Extension of social protection to people infected and affected by HIV and AIDS and their family members through existing schemes.

Sensitizing and engaging the media in efforts to mitigate HIV related stigma and discrimination towards PLHIV and HRGs at family and community level. Media platform to be used to propagate correct and accurate information about modes of HIV transmission, prevention, treatment and care and challenging stigma and discrimination. Sensitizing and engaging the media and mass communications to address issues of HIV related stigma and reduction (e.g., compassionate messages from influential persons, political leaders, engaging celebrities for "edutainment"). Use of social media, folk media and mass media of Internet, TV and Radio to broadcast messages on Rights of PLHIV and educating people against stigma and discrimination.

8. Role of Faith-Based Organizations in Addressing HIV-Related Stigma and Discrimination

Individual's health and person's religiosity are intricately connected throughout history. An estimated 84% of the world's population is religiously affiliated. The strong influence of religion on individual's health is recognized in various cultures across the country. The influence behind faith-based organizations (FBO) is not difficult to discern. In many developing countries, FBOs not only provide spiritual guidance to their followers; they are often the primary providers for a variety of local health and social services. In fact, faith-based groups have provided care, education, and health and social support long before present development agendas were advanced. Situated within communities and building on relationships of trust, these organizations have the ability to influence the attitudes and behaviours of their fellow community members. It is also important to note that spirituality and religion are important to many persons regardless of their HIV status, sexual orientation, gender identity, or other key population characteristics. It helps people to cope with stressors, especially those emerging from stigma and discrimination. While many faith-based organizations tend to advocate abstinence and sometimes find themselves in unpleasant situations to promote condoms, continuous advocacy, capacity building have helped them the spiritual interventions utilizing the power of prayer and meditation and addressing struggle of HRG and PLHIV with stigma and discrimination. Today, many faith-based community interventions have focused on stigma and have helped improve the individual outcomes through access to spiritual and social support for HRG and PLHIV to implement an effective and sustainable programme of care and treatment. The religious organizations have strengths, credibility and are grounded in communities. This places them the opportunity to make a real difference in combating HIV related stigma. To respond to this challenge, the faithbased organizations must be transformed in the face of the HIV related stigma and discrimination crisis, in order that they may become a force for transformation — bringing healing, hope, and accompaniment to ll affected by HIV and AIDS.

8.1 Mitigating HIV-Related Stigma and Discrimination Through Faith-Based Organizations

HIV and AIDS and the stigma that fuels its spread is one of the most serious challenges. It requires courage, commitment and leadership at all levels, especially among religious leaders who can use the trust and authority they have in their communities to change the course of the pandemic. For the religious leaders who are adept at speaking about HIV and AIDS it is sometimes fraught with sensitivities. Some people find the subject difficult to talk about at all, hence, it is imperative that the NGOs/CBOs play proactive role to make the religious leaders

aware of the most appropriate language and importantly to avoid insults, hurt, disempowerment or stigmatization. Reducing HIV-related stigma and discrimination at religious settings will act in two ways: provide spiritual solace to the persons regardless of their HIV status, sexual orientation, gender identity, or other key population characteristics and provide capacity and confidence to the religious leadership to influence the large community in extending care and support to them and their family members. A variety of interventions to address the issue of stigma and discrimination through faith-based organizations include — sensitization of all religious heads on the HIV and AIDS (Prevention and Control) Act, 2017, ensuring they provide equal access for all, ensuring respect, confidentiality of PLHIV and family members, helping the religious institutions develop innovative strategies to use their influence and infrastructure for care and support and continuous monitoring and evaluation of all these activities.

9. Role of Media in Addressing HIV Related Stigma and Discrimination

The role of the media and entertainment industry in tackling HIV related stigma is crucial. Public health messages can reach large or hard-to-access audiences through these popular media formats. They are key drivers of HIV reduction, yet the media and entertainment are far from reaching its full potential. There are numerous models of media intervention: TV and radio drama; sponsored TV or radio talk shows; journalism training; the creation of journalist networks; public service announcements (PSAs); feeding storylines into existing dramas; multi-platform approaches; reactive campaigns, and comedy. Training of journalists has had a notable impact. Enabling journalists to hear the personal testimony of persons regardless of their HIV status, sexual orientation, gender identity, or other key population characteristics gives them a powerful insight into the human story. TV news reporting has emerged to be an important driver of public opinion; they influence decision makers and set the agenda for other media coverage. Television and radio drama can be used to be effective at engaging audiences and making them more sympathetic towards PLHIV and HRGs and the issue of stigma faced by them. TV soaps and drama attempts to engage the audience with a storyline, which works on a deeper, more emotional level than factual content.

9.1 Challenges of Engaging Media

The challenges with regular media are observed that while there is apparent lack of appetite for HIV related content in the media, there is evidence that the media is a cost-effective way of tackling HIV. UNAIDS in 2011 released an investment framework for reducing HIV which mentioned that mass media in concentrated epidemics helps in 'normalizing treatment acceptance, encouraging adherence and notifying treatment advances.' In generalized epidemics mass media 'enables promotion of safer behavior by challenging the norms, values and culture that fuel risky behavior.' HIV and its related stigma are no longer the crisis and hence there is fatigue with the subject. Also, there is a perception in many societies that HIV is something that other people catch. This provides a very challenging environment in which to engage people with the issue of HIV related stigma because they feel they have heard it all before. Therefore, it is imperative that innovative methods such as personal testimony of people living with HIV provides a powerful insight into the human story. Language is an issue which is considered important because it can easily reinforce HIV related stigma and cultural norms. Training needs ought to include sensitization of stakeholders in media to the type of language they use. Too much sensational coverage of people living with HIV especially in various media platforms can be detrimental.

9.2 Mitigating Stigma Through Media

The media have a pivotal role to play in the fight against sexual orientation, gender identity and HIV epidemic. It is often said that education is the best weapon against HIV. It is observed that many local and international media organizations are rising to the challenge by promoting discourse on sexual orientation and gender identity. They also play crucial role in creating awareness on sexual orientation, gender identity and HIV and AIDS by educating listeners and viewers about the needs and interests of HRGs and PLHIV. Media sources such as television do play a critical role in disseminating and improving the AIDS-related knowledge. A study conducted in 2015 indicated that radio and newspapers in India have lower impact in educating individuals on AIDS prevention and transmission modes because of possibly low literacy rates in India. In 2019,

there were an estimated 762 million TV viewers recorded per week. The numbers only indicate the powerful media and the wide reach which can be used to disseminate HIV associated stigma and its adverse effects on PLHIV and HRGs. Thus, development of media sources such as television in rural areas and change in the conservative attitude of political leaders could possibly result in easy access to accurate AIDS information among all Indians through television, radio, and newspapers. It is imperative that media houses recognize stigma as one of the key impediments to the community members in seeking HIV testing and care services. Therefore, they have an important role in positively responding to the needs of stigmatized populations. The HIV programme should facilitate to use the media to show that HIV and AIDS has a human face by greater involvement of the PLHIV and HRGs. The following table provides details of proposed steps and key activities for reduction in stigma and discrimination with media settings.

9.3 Role of Social Media in Addressing Stigma and Discrimination

The social media platforms including mobile technologies and social networking sites which are being used increasingly as part of human immunodeficiency virus (HIV) prevention and treatment efforts by various organizations. Social media provides users with the opportunity to generate, share, and receive information which may transcend geographic borders and provide an opportunity for anonymity. Although stigma and cultural context may prevent PLHIV and at-risk populations from accessing in-person HIV prevention and treatment initiatives, social media can offer a neutral platform for engagement. The increased social support provided by social media has been shown to improve treatment adherence and access to HIV testing and prevention services and assist with coping with HIV-related stigma. Social media use among key populations affected by the HIV epidemic, including men who have sex with men (MSM) demonstrate that these groups use social media to form social ties, access health information and emotional support, and build a sense of community with peers.

As social media has expanded globally, the social media platforms have been adopted to deliver HIV interventions, especially for key populations by various agencies. These platforms can enable convenient access, at any time and place, to information and services on stigmatized diseases such as HIV. In addition, social media if effectively used, can help to form online communities to seek social support, which is known to improve treatment adherence and uptake of HIV services. The most common disadvantages to using social media to communicate about HIV prevention and treatment that studies reported were related to technology barriers, costs, and lack of physical interaction and its limitations in the amount of support health professionals can offer online.

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