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# SOCIAL FACETS OF THE HIV-AIDS EPIDEMIC

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## ABSTRACT

Sexuality education for adolescents is known to bring about behaviour changes, but the content of the education programmes are highly variable across India. HIV/AIDS-related discrimination, stigmatization and denial can manifest under diverse situations and are influenced by numerous determinants at individual, family and community levels intensify the gender inequalities and pre-existing prejudices. The HIV/AIDS epidemic has offered a pretext for selective targeting of vulnerable groups for imposing various types of stigma and discrimination based on criteria that pre-date the HIV epidemic. Local cultural bigotry and beliefs determine the choice of categories of individuals (based on race, religion, skin colour) or types of behaviour (homosexuality, sexual promiscuity, drug use, commercial sex work) that should be targeted. "Felt stigma" results in denial or concealment of HIV sero-status to avoid the anxiety of disclosure and also encourages secrecy, which safeguards the HIV-affected individual from experiencing "enacted stigma" (or "discrimination"). It is essential to tackle local cultural practices and beliefs that act as the basis for HIV/AIDS-related stigmatization. Since a legal approach to this multi-pronged challenge may not be effective in isolation, it is necessary to formulate culture-sensitive intervention programmes using multi-media approach to promote tolerance, confidentiality, human rights and gender equality.

**KEYWORDS:** Confidentiality, Denial, Discrimination, HIV, Social facets, Stigma.

## INTRODUCTION

HIV/AIDS is a typical example of a new and previously unknown disease, which has caused a pandemic. In 1979, undiagnosed illnesses were reported in the United States that were most probably cases of AIDS.[1] The first case in India was detected in 1986 in Chennai, Tamil Nadu, but at that time, it was dismissed as an anomaly and a "Western" disease but the "wake-up" call came in 2002, when UNAIDS reported that though HIV infections had been reported across India, 98% of people living with HIV/AIDS (PLWHA) were concentrated in ten states of India.[2] India has several simultaneous HIV epidemics that reflect country's social diversity. HIV transmission is chiefly through unprotected coitus in most parts of the country but in the northeastern states of Manipur, Nagaland, and Mizoram, transmission mainly occurs among drug injectors and their partners, some of who are also involved in commercial sex. Individuals who live away from their families for extended periods of time (for instance, long-distance truck drivers) have a potential role in disseminating HIV.[3] In India, PLWHA are having better survival rates due to increased uptake of antiretroviral treatment.[4]

## SOCIAL DETERMINANTS

Social taboos pertaining to: (a) open discussion of sexual matters and learning about sex and sexuality, (b) covert risk to a marriage if a woman does not produce a male offspring, (c) social tolerance of domestic violence against women, (d) double standards of morality for men and women, (e) low social status of women and (f) labelling persons with high-risk behaviour as "deviant" are among the social determinants that are accountable for the rapid spread of HIV infection in India.[5] Though an essential component of HIV counselling, any discussion on sexual behaviour and sexuality with clients meets with social disapproval. Ignorance about sexual matters, even among educated adults, also contributes to the spread of HIV infection.[5]

**Sexuality education for adolescents:** It is essential to start sexuality education at an early age before the

adolescents became sexually active because it has greater influence on behaviour.[6] Behaviour changes, such as, delayed first intercourse and increased condom use has been reported.[7] Programmes to promote correct scientific information regarding sex, sexuality and safer sexual behaviour have been resisted by self-proclaimed "moral guardians" who fear increase in promiscuity and irresponsible sexual behaviour.[8] Due to archaic viewpoints of some authorities, adolescent sexuality education is still banned in some states of India.[9] Where no such ban is in force, sexuality education programmes for adolescents have been rephrased as, "family life education", or "responsible parenthood education" or "life skills education" because it was realized that the word "sex" instantly makes them hesitant to participate in the programmes. The content of the education programmes are highly variable across India: some mention HIV transmission through unprotected peno-vaginal coitus but do not reveal transmission through anal and oral sex; some provide only biological information; while others merely discuss gender sensitivity and discreetly steer clear of providing information on sexuality. Confidential help lines have been established to provide counseling and referrals regarding sexuality and reproductive health issues. Most callers were adolescents; many were married individuals who sought information of sexual health issues, implying that the current curriculum does not meet the needs of the intended beneficiaries.[9] Under the canopy of "extra-curricular" activities, the centrally-funded National Council of Educational Research and Training (NCERT) developed a School AIDS Education module. The Union Ministry of Human Resource Development's Department of Youth and Sports is involved in Universities Talk AIDS (UTA) programme of the National Service Scheme and an AIDS awareness programme through its autonomous body Nehru Yuvak Kendra (NYK).[2]

**Role of the media:** In spite of obsolete conservative views held by a section of the population and the authorities, the electronic mass media has recognized the urgent need to address the misinformed or uninformed adolescents by including topics on sexuality in various programmes, such as, talks and panel discussions.[9]

**STIGMA**

Stigma has been defined as a "deeply discrediting attribute" possessed by a person with an "undesired difference".[10] This discredited attribute could be overt (ethnicity and skin colour, religion, body size, physical deformities, blindness) or covert (sexual orientation, mental illness, addictions). Stigmatization pre-dates the HIV-AIDS epidemic and functions as a type of power that is utilized by various entities to create and sustain social inequality[11] by marginalizing, excluding and exercising power over individuals or groups who display certain traits[12] so that the stigmatized individual or group is disqualified from full social acceptance.[10] The stigmatized individuals may be cautious in interactions with those who do not share their "stigma", and those without a particular "stigma" may ridicule or try to disregard stigmatized individuals. Consequently, stigmatized individuals may face overt or covert exclusion from socio-political life and employment. People humiliate others on the basis of "differences" and the tag of "deviance" results in "spoiled identity".[10] The personal experience of stigma and perception of stigma have been termed "enacted stigma" and "felt stigma", respectively.[13] The "hidden distress model" postulated for stigma in epilepsy, states that a profound sense of "felt stigma" encourages secrecy, which protects from "enacted stigma" and this "felt stigma" rather than "enacted stigma" acts as the prime source of the concealed distress of 'being epileptic'.[13]

The process that leads to stigmatization includes: (a) identifying the individual or group to be targeted; (b) identifying differences, assigning stigma to this individual or group and stereotyping them; (c) categorizing those labelled as "them" and separating them from "us"; and (d) initiation of discrimination against those labelled.[14, 15] Stigma is not an individualised process in which, some individuals or groups ostracise or shun others; it is primarily driven by "power" and "domination" that lie beneath inequalities, whereby some groups are devalued and excluded - this process has been termed "scapegoating"[15] - in comparison to others who are more valued and more privileged.[12] Pre-existing social power imbalances and inequalities can boost the stigmatisation of some individuals and groups. In case of HIV-AIDS, stigma builds upon and encourages existing prejudices based on class, gender and sexual orientation.[12, 16]

Over time, the very "discredited attributes" that were once the causes for social stigmatization, have got converted into symbols of identity with privileges because of changes in: (a) social norms and social acceptance of single mothers, migrants, differently-abled and mentally-challenged persons; (b) legalization of homosexuality and marijuana use in some countries; and (c) variations in responses across stigmatized groups and societies.[17] The ascendancy of a culture of victimhood, coupled with social acceptance has encouraged the adoption of labels and emblems that were deemed stigmatising in the past. For instance, "LGBTQ", an acronym for "lesbian, gay, bisexual, transgender and queer" has become a symbol of identity along with the LGBTQ rainbow flag. Such symbols of identity are now perceived by the victimized groups as emblems of being "different" or being "cool".[18] Stigma Assessment Scales utilize context-specific and cultural aspects to measure stigma and have potential value in future research.[19]

**Types of stigma:** The types of stigma[20] include: (a) Public Stigma: the public endorses negative stereotypes and prejudices; (b) Self-Stigma: individual with stigmatizing disease (condition) internalizes public stigma; (c) Perceived Stigma: this is a belief that others have negative beliefs about people having a stigmatizing

disease (condition); (d) Label Avoidance: a person decides not to seek treatment to evade being assigned a stigmatizing label; (e) Stigma by Association (also called "Courtesy Stigma" or "Associative Stigma"): an individual associated with or treating a person with stigmatizing condition[19] also faces stigma; (f) Structural Stigma: Institutional policies or other societal structures that decrease opportunities for people with stigmatizing illness; (g) Health Practitioner Stigma: a health care professional lets stereotypes and bias about an illness to negatively affect a patient's care. Shaming of PLWHA has been reported in health care facilities and probing questions are frequently asked by health personnel with the intention to shame them.[19] Indices have been developed to measure the impact of stigma reduction interventions in hospital settings.[21, 22]

Another type is "Compounded" or "Layered" stigma, which is experienced by PLWHA who belong to already marginalized groups. HIV-positive women, sex workers, men having sex with men (MSM) and transgender people experience multiple stigmas. Specific interventions would be necessary to deal with the burden of multiple stigmas among diverse marginalized groups.[19]

**DISCRIMINATION**

Discrimination defined as the acts or behaviours that arise out of stigma and that disadvantage people in various ways.[23] Since "discrimination" refers to the acts that the victims of stigma experience, it is also referred to as "enacted stigma".[24] HIV-AIDS stigma frequently leads to social and economic marginalization and denial of services that violate human rights of PLWHA.[16] Health disparities and unequal distribution of material resources is primarily attributed to discrimination against stigmatized groups.[17] Both stigma and discrimination may occur at family, community or institutional levels (workplaces, educational institutions, or health care settings) and may be overt (visible) or covert (concealed). For instance, Indian studies[25-27] have reported that PLWHA are isolated in their homes, forced to use separate utensils and not allowed to cook.

**SECRECY**

Secrecy, silence and HIV status are features of same-sex relations and sexual violence.[28] Keeping secrets is a instinctive trait in conflict-ridden unstable societies and marginalized groups,[29, 30] wherein secrecy helps to hide the type and degree of violence and abuse, which operates as a tool for repression, domination and for maintaining unequal power relations.[31] Adult educators have been found to be uncomfortable when talking about sex and they reportedly focused only on the perils of sexual activity, which created a gap between their formal learning and their actual experience.[28] Adolescents have a propensity for keeping their knowledge and awareness of sexual matters as a secret from disapproving parents and adults.[28] Persons indulging in high-risk sexual behaviours are likely to conceal their sexual orientation and sexual behaviour from family members and close friends and consequently they may not be able to share the news of their HIV positive test result with them. This leads to lack of social support that intensifies their stress. People generally react to PLWHA with fear and prejudice. Even if infected through medical interventions, such as, contaminated blood transfusion, PLWHA have to put up with the prejudiced assumption that they may have been infected through "deviant" or illegal activities. Anticipation of social discrimination complicates the psychological response to the news of HIV positive test, dents the person's self-esteem and affects the person's ability to cope. In order to avoid anticipated social stigma, some individuals opt to keep their HIV sero-positive status a secret from family, friends, and colleagues.[32]

**DENIAL**

Denial occurs primarily at individual level. Though some individuals cope with early HIV infection by denying its reality, denial is difficult to sustain as a coping mechanism with the onset of symptoms and visible signs of illness. Since diagnosis of HIV positive status give rise to a enormous changes in life, pre- and post-test counselling is essential. Counselling sessions are also necessary when patients develop symptoms. The social support system available to the individual and pattern of coping with major stressors in the past determine the individual's reaction of an individual to the news of HIV positive test result. These are also predictors of physical and psychological illnesses.[33] Receipt of HIV positive test result leads to emotional shock, leading to feeling of "guilt" (self-blame) or "denial" (refusal to accept the diagnosis). Due to denial, the individual may get the HIV test repeated at several laboratories anticipating a negative test result. Guilt about high-risk behaviour (promiscuity or use of injecting drugs) can also trigger psychological stress. On realising the gravity of the situation and the eventual outcome, the person gets frustrated and depressed. Worry about social stigma leads to withdrawal and isolation. People are perceived as infected ("us") and non-infected ("them") and this dichotomy in HIV status becomes the central defining issue. The individual may start worrying about his or her spouse and family members and may have fear of infecting others. If the individual is acquainted with others who also have the same high-risk behaviour but are HIV negative, the reactions vary from anger, distress, feeling of powerlessness, and blaming one's fate or destiny.[34]

**DENIALISM**

Denialism is a large scale effort that involves denying the existence, truth, or validity of something despite proof or strong evidence in order to evade a psychologically unpleasant truth. Fringe groups that challenge well-established historical (for instance: war crimes and genocides) and scientific facts (for instance: humans landing on the moon, global warming, the greenhouse effect) have become increasingly noticeable, especially

on the Internet.[35] HIV denialism includes disregarding the existence of HIV epidemic and neglecting to respond to the needs of those living with HIV infection.[36, 37] Until recently, scientists have ignored HIV denialists, stating that they are not a threat to treatment and care.[38] HIV denialism is supposedly thriving precisely because of ignoring HIV denialisits.[39] The Internet is used for targeting young people and for spreading misinformation within a group that is at high risk for HIV infection. Many members of the general public also accept and publicize the statements of these denialists.[40] Denialism leads to erroneous perceptions of vulnerability and can also discourage voluntary testing which may increase the potential risk of HIV transmission within the community.[41] HIV denialism can thwart public education efforts and adversely affect public funding for AIDS research and prevention programmes.

## IMPACT OF HIV-RELATED SOCIAL STIGMA

**Stigmatization and discrimination in health care facilities:** Ignorance and lack of knowledge about HIV/AIDS transmission;[42-44] apprehensions[45,46] and moralistic assumptions of guilt[47,48] may result in stigmatization and discrimination against HIV positive individuals, which is manifested as: (a) not attending to or not examining patients;[49,50] (b) HIV testing without consent; (c) breaches of confidentiality and (d) denial of hospital facilities and medications[51]

**Breach of confidentiality:** Lack of confidentiality has been repetitively mentioned as a drawback in health care settings with wide inter- and intra-country variations. In some health care facilities, signs bearing words, such as, "HIV-positive" and "AIDS" have reportedly been placed near hospital beds occupied by PLWHA or mentioned in bold letters on their discharge cards. In some places, registers of HIV-positive people have been compiled and their names released to media and police without permission.[52] Notions of confidentiality also vary between countries and cultures. In some places, confidentiality is more of a collective concern and less an individual issue. The term "shared confidentiality" describes a situation where family and community members feel they have the right to know the sero-status of family members, neighbours and friends.[53]

**Impediments to HIV control programmes:** In India, HIV-related stigma continues to be an obstacle[54, 55] to the achievement of the 90-90-90 target set by UNAIDS to scale up testing and treatment so that 90% of people living with HIV will know their status, 90% of those diagnosed will be on antiretroviral treatment, and 90% of those receiving antiretroviral medications will be virally suppressed.[56] Stigma is significantly associated with delay in seeking care due to apprehensions about protection of confidentiality.[57, 58] Rumours and gossip about discrimination of PLWHA can result in evasion of status disclosure and delay in seeking treatment.[59, 60]

**Discriminatory laws:** Many countries have enacted laws that provide for: (i) mandatory screening and testing of groups and individuals; (ii) medical examination, isolation, detention and compulsory treatment of infected persons; (iii) a ban on PLWHA from specified occupations and types of employment; (iv) restrictions on international travel and migration and (v) curbs on injecting drug use and prostitution.[61] Such legislations result in increased stigmatization of PLWHA and those at greatest risk of contracting the virus. This specific targeting of "high-risk groups" creates a false sense of security among those who do not perceive themselves as belonging to these "high-risk groups".[12] Laws that require obligatory notification of PLWHA and the curb a person's right to anonymity and confidentiality have been enacted on the pretext that HIV/AIDS constitutes a public health emergency. The infected and those at "high-risk" may be driven underground due to punitive measures in the case of a highly stigmatized condition.[61] Many countries have now taken a "u-turn" and enacted laws to ensure the right to employment, education, privacy and confidentiality; the right to information and treatment; to support protect the rights and freedoms of PLWHA and to protect them from discrimination.[62, 63]

**Impact on women:** In many developing countries, women lack equal access to treatment, financial support and education; and have to cope with hindrances on economic, cultural and social fronts. Women may be subjected to penalizing laws and traditional customs that control their bodies and sexual relations because they are not decision-makers. In a number of societies, flawed perceptions about women lead to further stigmatization of women.[64-66] There is evidence that HIV sero-positive males are more likely to be accepted by family and community, as compared to their female counterparts.[67] HIV/AIDS-related discrimination, stigmatization, double standards and denial have a crucial role in amplifying gender inequalities.[12]

**Impact on employment:** The hypothetical risk of transmission has been used as an excuse by many employers to terminate or refuse employment even though HIV is not quickly transmitted in the majority of workplace settings.[68-70] Pre-employment HIV screening is routinely conducted in resource-rich countries but in resource-poor countries, HIV screening occurs in organizations that provide health benefits to employees.[71, 72] Few organizations in developing countries have developed strategies to combat fear, stigma and discrimination in the workplace.[72, 73]

## INTERVENTIONS

Various strategies for intervention may focus on controlling or treating target health problems with informed health and social policies, countering the disposition of perpetrators to stigmatize, and supporting those who are stigmatized to limit their vulnerability and strengthen their resilience. It is essential to conduct disease- and culture-specific research that will help

countries with diverse cultures.[74] Inadequate attention has been paid to developing effective stigma reduction programmes and activities even though stigma has been identified as a barrier to HIV prevention efforts.[75,76] In India, the scope of research on stigma is still restricted and intervention research is deficient.[19]

**Role of health professionals:** Health-related stigma contributes to a hidden burden of illness because it involves social disqualification of individuals and groups who are identified with particular health problems, gender, ethnicity, sexual preferences or socio-economic status. The curbs on access to health and social services can lead to detrimental effects on health. Therefore, health care personnel ought to identify, challenge and ease the impact of stigma.[74,77] Psychological responses to HIV status may cause trust-deficit in relation to health care providers, which may lead to: (a) poor compliance with prescribed treatment; (b) missed opportunities for prevention and treatment of opportunistic infections; (c) visits to several doctors who may use multiple drug regimens and (d) self-medication with traditional or alternative medicines that lead to interactions. Family members need to be counselled because their psychological reactions may adversely affect their ability to care for the HIV-infected person. It is the responsibility of the health care personnel to provide accurate HIV-related information, deal with psychological reactions and refer the patient to organizations that provide counselling and support services. The patient ought to be fully informed so that both the doctor and the patient make their decisions with full knowledge of the circumstances.[32]

## CONCLUSION

Sexuality education for adolescents is known to bring about behaviour changes, such as, delayed first intercourse and increased condom use and though sexuality education programmes are conducted at various levels, the content of the education programmes are highly variable across India. HIV/AIDS-related discrimination, stigmatization and denial can manifest at different levels in a variety of circumstances and can be influenced by numerous determinants at individual, family and community levels. The gender bias in HIV/AIDS-related stigmatization, discrimination and denial intensifies the gender inequalities and adversely affects women. Affluent families may opt to hide away their HIV-affected family members either within their homes or in private medical facilities to thwart the impact of stigma on family members.

The advent of the HIV/AIDS epidemic has offered a pretext for infusing legitimacy for enforcing various types of stigma that are based on criteria that pre-date the HIV epidemic. These criteria include local cultural prejudices and beliefs. These prejudices and beliefs are responsible for picking out the categories of individuals (based on race, religion, skin colour) or types of behaviour (homosexuality, sexual promiscuity, drug use, commercial sex work) that should be targeted for stigmatization. "Felt stigma" arises from the perception (actual or imagined) of stigmatizing responses of others, which leads to denial or concealment of HIV sero-status to avoid the anxiety of disclosure while seeking health care. "Felt stigma" encourages secrecy, which shields the PLWHA from experiencing "enacted stigma" (or "discrimination"). It is imperative to confront local cultural practices and beliefs that act as the basis for HIV/AIDS-related stigmatization. Even though HIV/AIDS-related discrimination is outlawed in India, legal approach to this multi-pronged challenge may not be effective. Therefore, it is necessary to formulate culture-sensitive intervention programmes using multi-media approach to promote tolerance, confidentiality, human rights and gender equality.

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