

# Effect of Internalized Stigma on Sexual Relations of PLHA with their Regular Partners in Delhi, India

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**Abstract:** *HIV is predominantly a sexually transmitted infection; hence, it is one of the most stigmatized infections. The internalized stigma is the outcome of widespread overt stigma. Research shows that it causes depression, stress, and reduced quality of life (QOL), social support, and ART adherence of PLHA. Its impact on the sexual relations between married /regular partners has not been explored. The researcher conducted mixed-method research with 105 HIV-positive consenting adults recruited through snowball sampling from HIV prevention projects and care homes. This research assessed the impact of the internalized stigma on sexual relations between married partners through a semi-structured interview schedule developed in Hindi. Chi-square tests were employed to check for the relationship between various variables. In addition, focus group discussions and case studies were thematically analyzed to understand the internalized stigma and its impact on the sexual behavior of the infected. Both methodologies indicated the adverse impact of internalized stigma on the sexual relations between married / regular partners.*

**Keywords:** overt, covert and internalized stigma, positive prevention, sexual relations, fear of transmission, low libido, HIV infected

## 1. Introduction

### Effect of Internalized Stigma on Sexual Relations of PLHA with their Regular Partners in Delhi, India

HIV is transmitted primarily by sexual route, making it a stigmatized infection that causes internalized stigma among infected. The impact of internalized stigma on the sexual behavior of infected persons with their regular partners has not been explored. Due to the sexual route, the infection of HIV causes a stigma of immorality (Sontag 1989). According to the World Health Organization's definition, sexual health is "...not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence." WHO. The inquiry around sexual behavior of PLHA primarily remains restricted to the impact of counseling and Behaviour Change Communication (BCC) on risk behavior (Bunell Kwaru, Sonvell 2006; 6Cornman et al., 2008.; Wolf and young 2003) . Stigma affects sexual behavior and reduces relationships and couple formation. However, it was in the context of homophobia among MSM Mayer and Dean (1998). Sero-discordant couples with HIV-negative men had more frequent sex both with and without a condom than couples with HIV-positive men; reflects decreased libido in HIV-positive men, either from physical or physiological factors (Allen et al., 2003) . Similarly in a meta-analysis, Scanavino (2011) listed mental, physiological, pathophysiological, hormonal, and co-morbid conditions to explain sexual dysfunctions among HIV-positive persons (Scanavino M. (2011) Similarly, Bouhnik (2008) stated that infected having a more extensive HIV infected network, taking anti-depressants, and suffering from lipodystrophy were significantly associated with sexual difficulties. In qualitative research on women's sexual interest in the pre and post-HAART era, Seigal and Scrimshaw (2006) discussed the anxiety, fear of rejection,

transmission, and sense of sexual unattractiveness that led to voluntary celibacy. HAART has been linked to a higher prevalence of sexual dysfunction among HIV-positive men (Colson et al., 2002) Marks and Crepaz (2005) found that the sexual risk-behavior reduces after the infected become aware of their HIV + status. Psychosocial factors were also found affecting sexual behavior Rojas et al., (2010)

Schönnesson et al. (2018) stressed that the Swedish law of compulsory notification and fear of rejection upon disclosure results in sexual dissatisfaction. Since the focus remains on transmission prevention, there is a gap in knowledge of intimate sexual behavior between married couples with HIV. The present study assesses internalized stigma of HIV and its impact on the sexual relations of the infected with their married/regular partner.

The researcher being a master trainer at various HIV prevention bodies like National AIDS Control Organisation (NACO), Delhi State AIDS Control Society DSACS), Global Fund to fight AIDS TB Malaria (GFATM), has been actively involved with the critical population (High-Risk Groups). She also trained the project managers and outreach workers to manage interventions with communities of high-risk groups. This engagement helped the researcher get familiarity and credibility with the infected population.

## 2. Methods

### Quantitative

**Participants:** In this mixed-method research, the researcher recruited 105 HIV-positive consenting adults using snowball sampling from NGOs where they were registered and care homes where they get treatment for opportunistic infections. The various sub-categories of the key population invoked a relatively larger sample size as the researcher wanted to have a representation of key population groups. Due to the

hidden nature of the population, the confidentiality clause did not allow revealing the infected persons' identity, so there was no published list of the infected. Hence the researcher could approach them only through snowball sampling. The inclusion criteria were above 18 years of age and consent to participate.

**Tools:** The researcher developed a semi-structured interview schedule in Hindi, the native language of the respondents, with the help of counselors of NGOs and joint director of DSACS; pilot-tested and administered. The schedule had open-ended and closed-ended questions to get qualitative and quantitative information. Since inquiry was around personal and intimate behavior, the semi-structured interview schedule was the most appropriate tool. The researcher's familiarity with the population helped her develop the conversational tool and gather adequate data and information. Her credibility and familiarity with the population encouraged the respondents to speak without feeling judged, allowing a free flow of communication. It also helped her investigate sensitive issues more deeply. There were probing (how, why), contrast (gender), and sensitive (disclosure, sexual behavior, feelings during sex) questions. Additionally, the researcher organized the focus group discussions to understand the internalized stigma. She tried to understand the interpersonal and sexual relations between regular/married/ living-in partners.

Key informants were involved during the development of the schedule and later for validation of the qualitative findings.

**Data analysis:** Quantitative data was entered into excel on the same day to prevent any loss of information. The treatment of the data was done after exporting it into SPSS. Descriptive statistics are used to explain the context and profile of the respondents. In addition, the researcher conducted inferential statistical tests with independent variables of age, gender, marital status, income, internalized stigma, with the dependent variable of sexual behavior, to explore the relationships.

### Qualitative

**Participants:** The researcher recruited the participants for the focus group discussions from NGOs and the care homes after obtaining permission from the project manager with support from the Delhi State AIDS Control Society (DSCAS). The researcher held focus group discussions with the key population groups of men having sex with men (MSM), Transgender women (TG), Female sex workers (FSW), heterosexual males, and negative partners of positive persons. The respondents for the FGD were conveniently selected from the people who were willing and consented to participate.

**Tool:** The researcher held discussions in focus groups to get information about 'sexual orientation & sexual behavior, 'last week condom use, 'positive prevention, 'If they were 'sexually active'; 'feelings during sex. 'The researcher asked key questions to assess internalized stigma; that included, a) 'disclosure status, 'b) fear of transmission, 'c) 'separating food and utensils, 'and d) 'whether infected should marry

and have children?' The stigma research and the Stigma Index also covered these issues (FPAI, IPPF, UKaid, 2010 pp7-23; Steward et al., 2008) . After obtaining consent, the researcher recorded the information using a Sony USB port for voice recording. Each interview session took more than an hour, and mostly the second session was also called. The researcher administered the schedule herself. The researcher collected the data between April 2010 to February 2011.

To conduct focused group discussions, the researcher used the platform of 'support group meetings' (first Saturday or Sunday) where infected and their family members (who knew the status) assembled in the NGOs. Firstly the researcher obtained permission from the NGO director and manager, who announced to participants about FGD and introduced the researcher. Then the researcher obtained the consent to hold the meeting and record the same. The researcher held FGDs in the care homes too. Groups of MSM & transgender women, heterosexual males, commercial sex workers, and other infected women participated in FGDs. The researcher targeted ten members for each group of key population. However, for the commercial sex workers group, the number was eight. The topics ranged from general to specific. It also involved inquiry on felt stigma and their efforts to prevent it. The researcher asked situational questions to assess internalized stigma concerning disclosure, community attitude, and self-image. In addition, the researcher asked questions on guilt, anger, sexual life, serodiscordant living, and the marriage of PLHA. The researcher steered the discussion till it reached saturation.

**Data Analysis:** The researcher transcribed the qualitative information from open-ended questions. This information was coded and segregated. The codes having similar meanings were categorized into themes and given a numeric value for treatment. The information thus received was decoded for analysis.

The researcher transcribed the information from the focus group discussion after listening to it multiple times. Next, the researcher read the transcriptions repeatedly to extract themes to develop categories. Finally, the researcher segregated the themes manually.

**Ethical considerations:** The research protocol adhered to the 'Guidelines for Ethical Research involving Human Participants' developed by the Indian Council for Medical Research (ICMR 2006 p21). The protocol also complied with the Helsinki Guidelines of researching with human participants (WMA 2018, pp 1-5). This research was not a clinical trial; however, the researcher maintained the confidentiality and privacy of the respondents and obtained informed consent before the data was collected. The researcher explained to the prospective respondents that denial of consent would not affect their relationship with the project with which they were associated. Before initiating the session, the researcher signed the declaration promising anonymity and to use the information only for research purposes. There was no timeline fixed for data usage. The Board of Study (BOS) of Lucknow University, India, approved the study protocol.

3. Results

**Profile:** The following Error! Reference source not found. reflects the profile of the respondents, which shows that the gender ratio of infected was similar to the national ratio. The majority had low education and income. Marital status included a substantial number of unmarried and once married (currently widowed or divorced)

Table 1: Profile

SN	Attribute	Distribution N=105	%
1	Gender	60 males	57
		40 females	38
		Five Transgender	5
2	Marital Status	60 Married	57.1
		19 Unmarried	18.1
		26 Divorced or widowed	24.8
3	Sexual Orientation	84 hetero-sexual	80
		14 Homosexual	13.3
		Seven Bisexual	6.7
4	Literacy	34 non-literate	32.4
		47 upto Middle school	44.8
		24 Above middle school	22.8
5	Income	30 No income	28.6
		47 USD< \$7-\$74, (INR 500-4000)	44.8
		28 USD> \$74 (INR 4000 and above)	26.7
6	Migration	20 original Settler	19
		85 Migrated	81
7	NGO association	77 Registered	73.3
		28 no association with any NGO	26.6
8	ART	60 ART	57.1
		45 not on ART	42.8

**Integration of methodologies:** The researcher conducted both methodologies simultaneously. There was a constant comparison between both kinds of findings. As is evident from the results section, the same/similar themes were covered in both the methodologies for a deeper understanding of the issue.

Results and findings are presented in a blended mode so that the integration of the two methodologies is easily comprehended.

There was a range of feelings after HIV diagnosis; Those unaware of HIV and its impact did not feel anything at

diagnosis. There were feelings of repentance, ‘guilt’ in 20 (19%) and ‘suicidal ideation’ in 13 (12.4%). Ten (9.5%) reported to be angry with the partner for bringing in the infection. Fear of loss of income, care of children, shame were also reported

The feeling of guilt is predominant. One infected man who was in the last stage was sad and guilty of being irresponsible and acquired the infection. His widowed mother used to take care of him, he felt it should have been him taking care of her.

The diagnosis of HIV results in suspicion on the character of the infected. An HIV-positive married woman was angry at her husband for bringing infection and blamed him. Similarly a TG woman was angry at her partner for infecting her.

**Internalized stigma**

Separating utensils and food was a manifestation of internalized stigma. The data showed that 26 respondents had separated their food and eatables from the family. One respondent during a semi-structured interview schedule stated.

‘I do not want anyone to get infected with HIV, and blame me for that. I have separated my utensils and wash them. If any of them gets it, they will blame me, hence I am cautious. Before ‘they’ separate my stuff; it is better that I do it myself.

This reflects perceived stigma from family and internalized stigma too. This also shows isolation and self-blame, indicating low self-esteem.

**Behavior change communication v/s internalized stigma.**

In response to a multiple-choice question on preventing their loved ones from getting infected, twenty-five responses were of ‘abstaining from sex’ along with other responses that included keeping food separate. Figure 1 reflects that information, education, and communication of HIV prevention gets entangled with behaviors manifesting internalized stigma causing cocooning, isolating, or not disclosing, and risking the lives of loved ones.

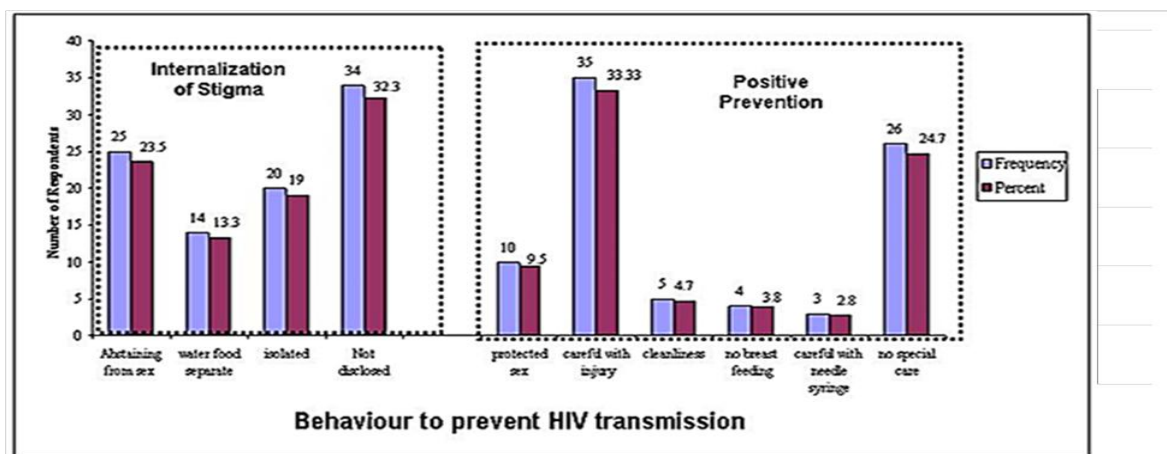


Figure 1: Behavior adapted to prevent HIV transmission

**Presence of internalized stigma** The behavior change communication at Integrated counselling and testing centers suggested refraining from any sexual activity. The A-B-C (Abstinence, Be careful and use a condom) of condom use. This seems a way to prevent transmission to negative partners. One HIV negative married woman in a focused group discussion held with negative partners stated,

'We are fine without sex in our marriage. We love each other and have been blessed with three kids. I am not very keen on having sex with my husband, I will take care of him. ' (*Negative wife of an HIV-positive man.*)

Here the sex is assumed to be required only for the progeny; besides, she does not want to make her husband feel guilty of bringing infected. Here, the husband, who works as paramedical staff, has told his wife that he got infected by a needle prick in hospital.

**Feelings during sex:** The researcher assessed the feelings during sexual intercourse. Out of 105 respondents, the majority 62 (59%) N=105 stated that they did not have sex last week, while the rest 43 (41%) N=105 had sex, of them, 28 (65%) N=43 were tense over HIV transmission and had low libido.

#### **Fear of transmission in serodiscordant relationships**

Out of 105 respondents, 41 (39%) respondents had a negative partner. Out of 41, 23 (56%) had disclosed, and 18 (44%) had not disclosed to the partner. Fear of transmission was present in 37 (90%) N=41 respondents, irrespective of disclosure to the partner.

During an FGD with seronegative wives, this fear of transmission was prevalent. In the qualitative section, one of the respondents reiterated this,

"I am not able to enjoy sex. I have this fear of infecting her. I love her. Sometimes I do it just because I feel that it is my duty as a husband; if I do not, she may go to someone and leave me." (*HIV-positive man, wife is HIV negative.*)

The undercurrent of fear of transmission affects both partners infected and non-infected. The fear of transmission was found in the negative partner too. They participated in the focused group discussion on serodiscordant living as they contributed a lot to that understanding. The dyadic internalized stigma impacted the sexual life of the couple.

Another respondent reported erectile dysfunction due to the impact of HIV diagnosis.

'Earlier, I used to be active, ma'am, but now my heart sinks when I see anything provocative. It reminds my mistake. I do not want it anymore. That dreaded moment became alive when the doctor told me that I am HIV positive. ' (An HIV Positive man-status undisclosed, has stopped having sex with wife (*status unknown*) since HIV diagnosis.

The infection seems to have impacted the infected man's desire, drive, and libido. Here, a person's self-confidence is diminished, and he has a reduced self-concept, which manifests in his disinterest in sexual activity. It could also

emerge from the guilt of bringing infection through the sexual route.

**Non-Disclosure and sexual relations.** Thirty-four (32.3%) respondents have not disclosed their status; of them, 24 (70%) N=34 were sexually active; Of them, 18 (75%) N=24 reported fear of transmission.

'I have not disclosed my status to anyone and am concerned about my wife as I don't know how to hide it (HIV). If she gets infected, I will be blamed, and if I stop having sex, she will get suspicious. I have to find a way out. I have to ensure that she does not get infected. I avoid it now. '

Here it is evident that the infection impacts the sexual behavior of the infected, especially with a known regular partner of unknown status.

In the qualitative findings, this theme was manifested. Despite the fear of transmission, many people reported that they continue unprotected sexual behavior since the non-disclosure prevents them from changing the previously established sexual behavior; however, the fear of transmission results in reduced encounters.

**Opinion on marriage of PLHA.** The opinion about the marriage of PLHA was assessed in bivariate statistics 'yes' and 'no. ' A majority of the respondents, 86%, opposed marriage and childbirth for HIV-infected persons. In addition, some stated that they think that PLHA should not marry at all, if they do they must marry another PLHA but should not bear child. Nevertheless, on the other hand, some were keen to have a child as they wanted it for progeny and to prove masculinity.

**Impact of Internalized stigma on sexual relations:** HIV is a sexually transmitted infection; and directly bears on couples' interpersonal and sexual relations.

Internalized stigma was crossed with sexual relations to check for any association between the two using a chi-square test. The internalized stigma affected the sexual encounters significantly with  $p^2=0.01$

**Table 2:** Internalization of stigma & sexual relations

Sex vs internalization	Internalized stigma found	No Internalized stigma	Total
Increased sex	0	01	01
Reduced sex	13	32	45
Same as before	02	19	21
No sex reported	11	27	38
Total	26	79	105

Chi square 0.016718.

#### **4. Limitations of the Study**

In the snowball sampling, the "seed" or the original person initiating the process, may refer to others having similar behavior, attributes, and backgrounds, resulting in over-representation of people with similar behavior or issues. This is called 'in social network bias. ' To overcome this, extra effort is needed (Biernacki & Waldorf, First 1981 p147). For example, there is no representation of intravenous



drug users, a significant segment of the key population in the current study. Another issue is that there is an overrepresentation of respondents associated with NGOs.

## 5. Discussion

The research findings focus on two major components; first the internalization of stigma, and second its impact on sexual relations. Internalized stigma is present as respondents have reported isolation, suicidal thoughts, worry, non-disclosure, guilt, separation of utensils, and non-suitability for marriage.

Internalized stigma manifests itself in many ways. Self-blame (Li. L. et al 2007) personalized responsibility (Valles, et. al.2013) and non-disclosure are a few such manifestations. This research corroborates the findings of Simbayi et. al. (2007) and Hasan et al. (2012) about the presence of internalized stigma and depression among HIV-positive persons. The presence of suicidal ideation, guilt and a sense of personal responsibility reiterated the findings on the presence of depression. Separating utensils and isolating corroborated the findings of (Audet, Mc Gowen, Wallston, & Kipp 2013; UNAIDS, 2011) There is a sense of shame in getting infected (Charles, Jeyaseelan, Pandian, Sam, Thenmozhi and Jayaseelan, 2012) The finding of stigma impacting disclosure behavior corroborates finding by many studies (Kingori et al.2012; Overstreet, Earnshaw, Kalichman &Quinn 2013; Tsai, Kegals, Muzoora & Hunt 2013).

The study showed that the presence of internalized stigma was widespread and tangled with the practice of positive prevention. This has not been found in any study and reflects the poor BCC exercised by Integrated Counselling and Testing Centre staff. There is an emerging need to improve behavior change communication that creates confusion and results in isolation and guilt. India has been the pioneer in reversing the pandemic of HIV in terms of numbers, but the quality of life of the infected is badly affected by the presence of stigma, which is internalized (Kingori et al., 2012; Thomas et. al., 2005)

Internalized stigma affects the sexual relation among PLHA significantly at  $p^2=0.01$ . The impact of internalized stigma on sexual behavior is manifested in a reduction in sexual encounters amongst PLHA, 'refraining from sex, 'low libido, 'sinking of heart, 'focus on a probable rupture of condom' 'not able to enjoy sex' and similar responses.

The majority of the respondents are fearful of infecting their married or regular partner, whether explicit disclosure is there or not. Whether the serostatus of the partner is known or not, withdrawing from sex is easiest in Indian culture (Dhaor 2017). Continuing unprotected sex was an easy way to stay undisclosed; this finding is supported by Kingori et al. (2012).

Fear of transmission seems to be responsible for reduced sexual urge and encounters. Non-disclosure is a manifestation of prevailing stigma and internalization of the same. It is also a coping mechanism to face a positive diagnosis. Besides, the infected tend to gauge the environment before disclosure, fearing violence or rejection.

Non-disclosure also causes withdrawal from sexual relations and 'no interest' in marriage.

The negative attitude of respondents towards the marriage of PLHA indicates that they disqualify themselves for marriage (read sexual relation). The stigma results in the infected dissociating from any sexual activity to deny any sexual behavior with the regular /married partner. The married partner's HIV status is traceable to the infected respondent due to a monogamous relationship. This finding is typical in the Indian situation where a married woman's HIV status is found only during the prevention of parent-to-child transmission (PPTCT) or spousal testing, hence it becomes a family matter escalating the concern of an infected man to keep his wife safe.

Interpersonal relationships are adversely affected when both or anyone partner is infected as there is anger and blame. There is fear of transmission in both the partners (both seropositive and seronegative partner). This corroborates the finding of the infected dyad where the internalization occurs in both the partners and affects the interpersonal relations (Liu, Xu, Lin, Shi, Chen 2013)

This is a lesser researched area where subtle behaviors reflect its presence. The possibilities only theoretically viable get extended to practices that are self-denying, self-punishing as well as self-diminishing. Internalization affects sexual relations and causes denial of sexual contact by disqualifying self for marriage and childbirth.

## 6. Conclusion

Current research reflects that the internalized stigma among the infected affects the sexual relations between the regular or married partners adversely as the fear of bringing the infection in the family persists. There is a reduction in sexual relations with the married or regular partner due to dyadic stigma, or internalized stigma. We need to look at the basic human need for sexual relations, which is a manifestation of love and intimacy hence must be met without any sense of guilt. Interventions to increase knowledge about the low risk, high risk, and no risk behaviors must be planned. At the policy level, the intervention to improve the workforce quality to handle the PLHA at the first point of contact is recommended. It is crucial to educate on non-penetrative pleasure between partners. The presentation and projection of HIV need to be improved to change its image from fatal to manageable infection. Emerging from moral stigma in a traditional society like India, internalized stigma manifests by denial of sexual pleasure, becoming asexual leading to misery for the partner needs to be recognized.

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