

Social stigma and its determinants among people living with HIV/AIDS: A cross-sectional study at ART center in North India

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ABSTRACT

Introduction: HIV/AIDS-related stigma and discrimination together have long been recognized as one of the main obstacles in the prevention, care, and treatment of HIV and AIDS. Yet, little has been done on a large scale to combat them. Stigma still precludes many in need of treatment and care for people living with HIV/AIDS (PLHIV). The purpose of this study was to assess the social stigma among PLHIV and the factors influencing it. **Material and Methods:** This hospital-based cross-sectional study was conducted among four hundred PLHIV attending the antiretroviral therapy (ART) center of a tertiary care institute of Haryana, India, using a semi-structured questionnaire and Berger Stigma Scale. Data analysis was performed using SPSS version 20.0 software to explore the relationship between a dependent (social stigma score) and other independent variables. **Results:** The overall mean stigma score in our study was found to be 110.96 ± 17.05 . The stigma score in the male PLHIV was higher than in females. Male gender, younger age group (18–25 years), nuclear family, and rural residents PLHIV experienced more stigma as showed by the logistic regression analysis. **Conclusion:** Stigma and discrimination are a continuous deterrent for program implementation or successful outcomes. Education, behavior change strategies, and building supportive environments to the targeted population (young, single, and rural residents) can provide a roadmap in ending stigma and discrimination.

Keywords: Discrimination, HIV, PLHIV, stigma

Introduction

The advances in care and treatment in recent times have turned HIV into a “chronic and manageable condition”. Despite these advances, people living with HIV/AIDS (PLHIV) continue to suffer from stigma and discrimination from their family and

communities as well. As a result, HIV/AIDS is increasingly being recognized as not merely a medical problem, but a social problem as well.^[1] AIDS-related stigma and discrimination prevent millions of PLHIV from accessing effective prevention and treatment services.^[2] It has been around four decades into the AIDS epidemic, but still, the questions of stigma loom large over a substantial population affected worldwide.^[3] HIV-associated stigma not only represents one of the greatest barriers in prevention and control of new HIV infections but also deeply and negatively affects multiple aspects of

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Received: 25-05-2020

Revised: 31-08-2020

Accepted: 23-09-2020

Published: 30-11-2020

Access this article online

Quick Response Code:



Website:
www.jfmpc.com

DOI:
10.4103/jfmpc.jfmpc_981_20

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How to cite this article: Sahoo SS, Khanna P, Verma R, Verma M, Mahapatra S, Parija PP, *et al.* Social stigma and its determinants among people living with HIV/AIDS: A cross-sectional study at ART center in North India. *J Family Med Prim Care* 2020;9:5646-51.

HIV treatment, as well as the physical, mental, and emotional well-being of the PLHIV.^[4]

AIDS-related stigma and discrimination refer to prejudice, negative attitudes, abuse, and maltreatment directed to PLHIV, which have long been recognized as one of the main obstacles in the prevention, care, and treatment of HIV and AIDS.^[5]

In India, as elsewhere, HIV is perceived as a disease of “others”—of people living on the margins of society, whose lifestyles are considered “perverted” and “sinful.” Discrimination, stigmatization, and denial (DSD) are the expected outcomes of such values, affecting life in families, communities, workplaces, and health care settings.^[6] Because of HIV/AIDS-related DSD, appropriate policies and models of good practice remain undeveloped. In many communities, HIV/AIDS leads to an attitude of fear, disgrace, and hatred making people reluctant to test them and seek active care, disclose their positive status and hence arrest the progression of the disease and its active spread. PLHIV continue to be burdened by poor care and inadequate services, while those with the power to help do little to make the situation better. Gender-based reported discrimination has also been reported. Other factors influencing whether people received support included the quality of past familial relationships, age, economic and educational status, and the apparent or suspected source of infection.^[7]

Although there have been few Indian studies on HIV/AIDS-related DSD, it remains the case that relatively little is known about these negative responses and prevalent stigma. Thus, this study was carried out to assess the social stigma prevailing among the PLHIV and the various contributing factors.

Material and Methods

Study design, setting, and participants

This cross-sectional descriptive hospital-based study was conducted at the Antiretroviral Therapy Centre (ATC) situated at a tertiary medical college hospital in Haryana, India. It caters to PLHIV from Haryana as well as neighboring states like Punjab, Chandigarh, Rajasthan, and Delhi. The study included adult registered PLHIV who were on Anti-Retroviral Therapy (ART) for six months or more, registered, and receiving services at the ART center of the medical college.

Sampling and sample size

The sample size was calculated using the Cochran’s sample size formula for qualitative categorical data,^[8]

$$N = 4pq/d^2$$

, Where

Z is the value for selected α level (type 1 error) of 0.05 = 1.96;

d is the acceptable margin of error = 5%;

p is the estimate of variance = 0.5 {in the absence of any data regarding stigma in PLHIV in Haryana therefore, assuming, $P = 0.5$ (maximum variability).}

$$q = 1-p = 1-0.5 = 0.5$$

Therefore, sample size comes out to be: $N = (1.96)^2 \times 0.5 \times 0.5 / (0.05)^2 = 385$.

Hence, a total of 400 registered adult PLHIV were selected for the study. Systematic random sampling was employed in which every third subject was selected from the ART clinic among those who attended it on Wednesdays and Fridays. Adults who were on ART for six months or more were included in the study. Enrollment was continued until the adequate sample size was achieved. Written informed consent was obtained from the patients before their enrollment. Seriously ill patients, those with cognitive dysfunction, and those who did not give consent were excluded from the study.

Study tool

The socio-demographic details of the participants were recorded using a pretested questionnaire schedule. Social stigma related to HIV was assessed using the Berger HIV Stigma Scale.^[9] During the process of patient interaction, queries/questions regarding HIV/AIDS/ART were clarified and solved. Any additional open-ended responses of the subjects were noted, without further probing. Nonjudgmental attitude and nonresponsive body language were followed to minimize bias.

Berger HIV stigma scale

In the Berger Stigma Scale, four factors emerged from exploratory factor analysis: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV. Stigma experienced by an HIV-positive person is measured across four domains of stigma: Personalized Stigma (18 items), Disclosure Concerns (10 items), Negative Self-Image (13 items), and Public Attitude (20 items). There is an overlap of few items across the domains giving a total of 40 items. The scores for each domain vary with the number of items in the domain (1 multiplied by the number of items is the least score and 4 multiplied by the number is the highest score). The least total score is 40 and the highest total score is 160. The higher the score the greater is the stigma. Coefficient alphas between 0.90 and 0.93 for the subscales and 0.96 for the 40-item instrument gave evidence of internal consistency reliability. The HIV Stigma Scale was reliable and valid with a large, diverse sample of people with HIV.^[9] The scale has been validated in the Indian context. The average time required to administer the scale was 15–25 minutes.

Data analysis

The completed questionnaire was checked for completeness and consistency and was coded. Data entry was done using

MS Excel 2010. Data clean-up was performed to check for accuracy, consistency, and completeness. Any error identified was corrected. Binary logistic regression was applied to analyze the relationship between the dependent (social stigma scores) and independent variables. Data analysis was performed using scores and odds ratios using Statistical Package for Social Sciences (SPSS) version 20.0 software (SPSS Inc., Chicago IL).

Ethical consideration and consent

The study was approved by the Institutional Ethics Committee of Post Graduate Institute of Medical Studies, Rohtak February 2013. Participation in this study was voluntary, and a written informed consent was obtained from each study participant after a detailed description of study objectives and methodology. The study participants could refuse or discontinue participation at any time. Privacy was strictly protected by conducting the interviews at a private place, and we ensured the confidentiality of the respondents by removing all personal identifiers from the survey questionnaires.

Results

A total of 400 patients were interviewed. Out of them, 247 (61.8%) were males and 153 (38.2%) females. The mean age of study subjects was 32.85 ± 7.39 years. More than two-thirds (69.8%) of the study subjects were living with a spouse while the rest ($n = 121$, 31.2%) were single (unmarried/separated/widowed). 15% of the respondents were unmarried. Among the female respondents, more than two-thirds (71.9%) were married and living together while 18.3% were widowed. Most (81.67%) of the unmarried subjects were males. Nearly 45% of the study subjects were either illiterate or educated up to primary level. Illiteracy and lower level of education (primary) were more (60.8%) in female respondents as compared to males (35.2%) [Table 1].

The overall mean stigma score in our study was found to be 110.96 ± 17.05 . The mean score for personalized stigma subscale was 36.53 ± 6.38 (possible range 18–72). The mean scores for the disclosure subscale were 21.71 ± 4.13 (possible range 10–40), for negative self-image 24.98 ± 2.99 (range 13–52), and for public attitude subscales was 27.75 ± 5.21 (range 20–80) [Table 2]. The mean score in each of the individual subscales in males was higher than females, and the association was statistically significant in each of them [Table 3]. Stigma among illiterates was higher than literates in all the subscales except the disclosure subscale in which it was more or less found to be similar (illiterate- 24.92 ± 3.09 , literate- 24.99 ± 2.97).

Taking the mean stigma score (110.96 ± 17.05) as the cut-off, the respondents were categorized into those experiencing higher and lower stigma. Nearly 60% of male study subjects reported higher stigma as compared to only 40.5% of the females. In a similar context, lower social stigma was found in nearly three-fifths (59.5%) of the females. This association of overall stigma with gender was found to be statistically significant.

Table 1: Socio-demographic characteristics of the study subjects

Characteristic Group	Male	Female	Total	
Age group (in years)	18-25	44 (17.8)	36 (23.5)	80 (20.0)
	26-35	130 (52.6)	65 (42.5)	195 (48.8)
	36-45	68 (27.5)	42 (27.5)	110 (27.5)
	>45	5 (2.0)	10 (6.5)	15 (3.7)
Marital status	Married	169 (68.4)	110 (71.9)	279 (69.8)
	Married but separated	9 (3.6)	4 (2.6)	13 (3.2)
	Unmarried	49 (19.8)	11 (7.2)	60 (15.0)
	Widow/Widower	20 (8.1)	28 (18.3)	48 (12.0)
Place of residence	Rural	126 (51)	102 (66.7)	228 (57)
	Urban	121 (49)	51 (33.3)	172 (43)
Education level	Illiterate	19 (7.7)	58 (37.9)	77 (19.3)
	Primary	68 (27.5)	35 (22.9)	103 (25.8)
	Secondary	115 (46.6)	35 (22.9)	150 (37.5)
	Higher Secondary	30 (12.1)	15 (9.8)	45 (11.2)
	Graduate and above	15 (6.1)	10 (6.5)	25 (6.2)

The independent association of socio-demographic parameters of study subjects, that is, gender, age group, marital status, family type, area of residence with social stigma was analyzed by binary logistic regression analysis. It was observed that males experienced almost six times (a OR = 5.70, CI = 2.95–11.02, $P = 0.000$) more stigma than females. Study subjects in the age group of 36–45 years experienced four times lesser stigma (OR = 0.25, CI = 0.10–0.64, $P = 0.004$) than those in the 18–25-year age group. Meanwhile, widow/widower and unmarried subjects experienced almost 44 times and 30 times, respectively, more stigma than their married counterparts. Social stigma faced by study subjects in nuclear families was 20 times more (aOR = 0.05, CI = 0.02–0.10, $P = 0.000$) than that in joint families. Similarly, urban respondents experienced 10 times (aOR = 0.12, CI = 0.06–0.25, $P = 0.000$) lesser stigma than their rural counterparts [Table 4].

The correlation within individual social stigma subscales along with the overall stigma scale calculated by Pearson's correlation coefficient. The correlation between each subscale was significantly related to the overall stigma score ($P < 0.01$). Moreover, each stigma subscale was significantly related to others ($P < 0.01$) [Table 5].

Discussion

A diagnosis of AIDS brings with it considerable physical and emotional suffering, especially in a context of limited treatment that includes no access to antiretroviral medications. It is not surprising that with the degree of stigmatization there is a corresponding level of denial and secrecy that supports the silence.

In our study, males reported higher stigma than the females, which was also reported by Kumar N *et al.* in their study in Mangalore, South India.^[10] Contrary to the present findings, some of the Indian studies had found that females experience

Table 2 : Mean of individual subscale scores of HIV stigma scale (n=400)

Subscale	Mean Score	Male	Female	P (independent t-test)
Personalized Stigma	36.53±6.38	37.34±6.35	35.20±6.23	0.001*
Disclosure	24.98±2.99	25.22±2.75	24.58±3.30	0.047*
Negative self-image	21.71±4.13	22.32±4.19	20.74±3.87	0.000*
Public attitude	27.75±5.21	28.46±5.07	26.61±5.25	0.001*
Overall	110.96±17.05			

*Statistically significant

Table 3: Distribution of overall social stigma score with gender

Social stigma	Male	Female	Total
High	148 (59.9)	62 (40.5)	210 (52.5)
Low	99 (40.1)	91 (59.5)	190 (47.5)
Total	247 (100)	153 (100)	400 (100)

Table 4: Association of socio-demographic parameters of study subjects with social stigma (Logistic Regression analysis) n=400

Variables	Social stigma		P
	Prevalence (%)	aOR (95% CI)	
Gender			
Female	153 (38.2)	Reference	
Male	247 (61.8)	5.70 (2.95-11.02)	0.000*
Age group (years)			
18-25	80 (20.0)	Reference	0.000*
26-35	195 (48.8)	0.120 (0.58-2.51)	0.615
36-45	110 (27.5)	0.25 (0.10-0.64)	0.004*
>45	15 (13.7)	3.08 (0.78-12.09)	0.105
Marital status			
Married	279 (69.8)	Reference	0.000*
Married but separated	13 (3.2)	6.22 (0.87-44.24)	0.068
Unmarried	60 (15.0)	44.87 (15.32-131.39)	0.000*
Widow/widower	48 (12.0)	30.53 (9.86-44.56)	0.000*
Family type			
Nuclear	177 (44.2)	Reference	0.000*
Joint	223 (55.8)	0.05 (0.02-0.10)	0.000*
Area of residence			
Rural	228 (57.0)	Reference	0.000*
Urban	172 (43.0)	0.12 (0.06-0.25)	0.000*

more stigma as compared to males.^[11-13] A possible explanation for this contradiction maybe, in our study most of the females reported having acquired the infection from their husbands. The stigma associated with the behavior of having multiple sexual partners is less in these women and their parents, siblings, and in-laws sympathize with them. Males are also more likely to interact with other members at their workplace, hence more chances of experiencing stigma than females who are confined to the households.^[10]

The study also accounted that higher stigma was associated with younger age group (18–25 years), single/unmarried/widow/widower subjects, rural residents, and nuclear families.

Younger study subjects had a higher stigma, which can be attributed to the fact that most of them were unmarried and their sexual life is seen with suspicious eyes. Moreover, they are considered a burden on society after contracting the disease. Being young they are more likely to practice unsafe sex practices and engage in high-risk behaviors and indiscriminate drug use. The higher stigma in rural areas may be attributed to age-old traditions and customs prevalent in these areas where AIDS is seen inextricably linked to promiscuous sexual behavior and existing misconceptions and myths in the community at large due to lack of adequate knowledge and awareness. Single/unmarried/widow/widower subjects are vulnerable to higher stigma because of lack of social support resulting from isolation, discrimination, prejudice, and lack of psychosocial support from the family members and the society once the status is revealed.

Mahalakshmy *et al.* carried out a study in Puducherry among 200 PLHIV and found similar observations i.e., social stigma being more in males as compared to females.^[14] They also assigned a high level of stigma in younger age groups like in the current study. Blessed *et al.* in their study in Nigeria on PLHIV attending the ART clinic quoted the mean stigma score to be 104.96 ± 16.45, which is comparable to our study.^[15] Buseh *et al.* described a mean stigma score of 110.4 ± 17.4 on HIV-positive African-American men, which is quite similar to our study.^[16]

HIV-stigma reduction initiatives are most effective when they encompass a range of activities involving various stakeholders at multiple levels: interpersonal level (educational/sensitization activities), institutional level (nondiscrimination policies and guidelines), and structural level (laws and mass media campaigns to change societal negative attitude toward PLHIV). The inclusion of PLHIV and the target communities where this epidemic thrives, in the stigma alleviation programs will help in devising correct and appropriate interventions.^[17] Primary care physicians and consulting medical personnel can screen for common mental health problems among the PLHIV and provide an adequate referral if necessary. Primary care institutions should develop community-based interventions to promote psychosocial well-being among PLHIV. These community-based interventions can be developed taking into consideration societal and local factors. They also need to incorporate regular follow-ups and a long-term continuum of care approach.^[18] Elimination of discrimination and stigma from the day to day life of PLHIV will bring them to mainstream and help in reducing the barriers in counseling and treatment, improving the quality of care.

Table 5: Correlation between subscales of the HIV stigma scale

Subscale	Personalized Stigma	Disclosure	Negative self-image	Public attitude	Overall
Personalized Stigma	1.000				
Disclosure	0.414**	1.000			
Negative self-image	0.720**	0.740**	1.000		
Public attitude	0.952**	0.601**	0.898**	1.000	
Overall	0.946**	0.661**	0.945**	0.985**	1.000

**Correlation is significant at 0.01 level (2 tailed)

There are some limitations of the study, which need to be kept in mind while interpreting the results. The first limitation concerns the representativeness of the study population. The degree to which the study is representative of the larger HIV-infected population is influenced by the potential selective factors associated with recruiting from HIV treatment settings. Also, the stigma was self-reported as narrated by the study participants. This may have led to social desirability response bias and the possibility of under or overreporting of stigma. Another limitation is the cross-sectional nature of the study that does not give an insight into the causal interpretation. A longitudinal study with a cohort of PLHIV will be insightful in this regard.

Conclusion

Notwithstanding the limitations, we believe that the findings have important implications for directing health policies and interventions for improving the health and quality of life of PLHIV in India. Our study reported that male gender, younger individuals, single study subjects, and those residing in rural areas experienced higher social stigma. Stigma and discrimination still continue to prove a major roadblock for program implementation. This underlies the felt need for community-based interventions in the general public and to help PLHIV to combat these negative perceptions. Education, behavior change strategies, and building supportive environments can prove formidable blocks in weeding out stigma and discrimination from our societies. Elimination of stigma will facilitate equitable access to health care, reducing the overall burden, and spread of the disease.

Acknowledgement

Nil

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patients have given consent for their clinical information to be reported in the journal. Data collection was anonymous and no identity is revealed.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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