Psychiatry Section

Perceived HIV Related Stigma among Patients Attending ART Center of a Tertiary Care Center in Rural West Bengal, India

SAIKAT DATTA[1], SHARMISTHA BHATTACHERJEE[2], PASANG LAHMU SHERPA[3], SMARAJIT BANIK[4]

ABSTRACT

Introduction: Despite the advent of modern technologies, India is still grappling with the HIV/AIDS pandemic. Stigma is one of the key aspects which can interfere with HIV test-seeking behaviour, care-seeking behaviour upon diagnosis, quality of care given to HIV-positive patients and perception and treatment of People Living with HIV/AIDS (PLHA) by communities, families, and partners.

Aim: To determine the perceived stigma associated with HIV/AIDS and its correlates among PLHAs attending the Anti Retroviral Therapy (ART) centre of North Bengal Medical College, Darjeeling, West Bengal, India.

Materials and Methods: An observational cross-sectional study was conducted over a period of four months among 454 patients aged ≥18years attending ART centre of North Bengal Medical College. Perceived stigma among the study subjects were assessed using a face and content validated version of Berger's HIV stigma scale. Linear regression analysis was used for statistical analysis of the predictors of perceived stigma. Data were analysed using SPSS version 16 software.

Results: The majority of the study population had moderate to low stigma. Regression analysis showed that being on treatment with ART had the highest contribution towards stigma followed by gender and HIV serostatus of the patients.

Conclusion: The patients attending ART centre of North Bengal Medical College had moderate to low level of stigma. In absence of any efficacious stigma reduction programs in this region, more work needs to be done to assist PLHA in coping with stigma.

INTRODUCTION

HIV is a global pandemic with wide influence on the life of the sufferer, physically, socially and culturally. According to the World Health Organization (WHO), there were an estimated 36.9lacs (34.0 lacs–39.8lacs) People Living with HIV/AIDS (PLHA) worldwide at the end of 2015, although the burden of the epidemic varies considerably between countries and regions [1]. With an estimated 21.17 lacs (17.11 lacs–26.49 lacs) people living with HIV/AIDS in 2015, India is still grappling with the HIV/AIDS pandemic [2].

One key aspect of the HIV epidemic that is significantly affected by culture and knowledge of HIV transmission is stigma, specifically HIV/AIDS related stigma. Stigma is associated with HIV/AIDS for its link with behaviours that are themselves stigmatized, such as having multiple sexual partners, using intravenous drugs, and engaging in sex with same-sex partners [3]. In addition, HIV/AIDS is perceived as contagious disease and it is also associated with the possibility of suffering a painful death [4].

According to the United Nation Programme on HIV/AIDS, HIV-related stigma and discrimination is a process of devaluation of people either living with or associated with HIV and AIDS. Discrimination is a facet of stigma, where, there is segregation, or limitation of expression, marginalization, or prevention from access to something or services resulting in unfair and unjust treatment of an individual based on his or her real or perceived HIV status [5,6].

Stigma against PLHAs is widespread and almost universal. A UNAIDS report suggests that in roughly 35% of countries with available data, more than 50% of women and men report discriminatory attitudes towards PLHAs [7]. A systematic review of studies of HIV/AIDS-related stigma and discrimination in India by Bharat S revealed that the results are fairly consistent in respect to attitudes towards PLHA. In these studies, most of the respondents blame HIV-infected people for their infection, are afraid of infection from casual contact, try to avoid them in daily life and support their seclusion in health settings [8].

HIV/AIDS-related stigma may manifest itself by negatively affecting preventive behaviours such as condom use, HIV test-seeking behaviour, care-seeking behaviour upon diagnosis, quality of care given to HIV-positive patients and perception and treatment of PLHA by communities, families and partners [9,10]. It also has serious ramifications, like poor treatment adherence and hence increased risk of HIV disease transmission and progression. Not withstanding the pervasiveness of HIV-related stigma and discrimination, they remain seriously ignored and are relegated to the bottom of AIDS program priorities [11,12].

Though widespread development has been made in the battle against the AIDS epidemic, discrimination and stigma still lurk at the fringes. At a time, when the whole world is embracing the concept of Universal Health Coverage (UHC) which means that all people receive the quality health services they need, stigma and discrimination has got renewed importance. As part of the Sustainable Development Goals, the world has committed to "ending the AIDS epidemic" with a subtarget related to elimination of HIV-related discrimination by 2020 where 90% of people living with, at risk of and infected by HIV report no discrimination, especially in health, education and workplace settings [7,13].

Whilst there is literature regarding the other aspects of HIV/AIDS, there is an information gap on the issue of HIV related stigma and discrimination in this part of the country. In India, research shows that stigma against PLHA have been promulgated by ignorance about HIV/AIDS, traditional beliefs, and a moralistic sexual label [14]. Keeping this in context, the present study was undertaken

with the aim to determine the perceived stigma associated with HIV/AIDS and its correlates among PLHA attending the Anti Retroviral Therapy (ART) centre of North Bengal Medical College, Darjeeling, West Bengal, India.

MATERIALS AND METHODS

An observational cross-sectional study was conducted over a period of four months (September to December 2015) among patients attending ART centre of North Bengal Medical College. Patients ≥ 18years attending ART centre of North Bengal Medical College during the study period constituted the study population. Patients who were not able to read and write Bengali or Hindi were excluded from the study.

On account of scarcity of published literature in this part of the country, anticipated prevalence of stigma among PLHA was taken as 50%. Considering 95% level confidence, 10% relative precision, 20% non-response, the sample size was calculated to be 480, which were rounded off to 500. Simple random sampling technique was applied to select the study subjects from their list (prepared beforehand) using computer generated random number table.

The data was collected from the study population by using a pre-designed, pre-tested, semi-structured questionnaire in both Bengali and Hindi, consisting of a first part dwelling on age, marital status, residence, occupation, educational qualification of the patient and a second part comprising of Berger's HIV stigma scale [15]. In both the languages, by initial translation, back-translation, and re-translation, the questionnaire was customized for the study. Pre-testing of the questionnaire was carried out on a convenience sample of 30 patients. The clarity and relevance of items were assessed and certain modifications were made on the basis of the findings of the pre-test.

Perceived stigma among the study subjects were assessed using Berger's HIV stigma scale, consisting of 40 items which requires participants to respond on a four item Likert scale (strongly disagree=1, disagree=2, agree =3 and strongly agree=4) to statements about their feelings and opinions regarding how people treated them because of their HIV status. Stigma experienced 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. The scale assesses perceived stigma cross-sectionally without a recall period. All items are coded so that a higher score indicates more stigma and vice versa. Total stigma scores are categorized into four stigma levels: minimal (40-70), low (71-100), moderate (101-130) and high (131-160) [10]. The average time required to administer the scale was 15–25 minutes.

Completed questionnaires were collated and entered in MS Excel datasheet after proper data cleaning activities (validation, range and consistency checks). Data were analysed using SPSS version 16 software. Linear regression analysis was used for statistical analysis. In this analysis, overall perceived stigma was used as the dependent variables; the predictor variables included current CD4 count, age and gender of the patient, HIV serostatus of the patient and treatment with ART.

Ethical considerations: Ethical approval was obtained from the Institutional Ethics Committee of North Bengal Medical College, Darjeeling, West Bengal and National AIDS Control Organization prior to the study. Written informed consent was taken from the respondent before administration of the questionnaire after ensuring anonymity and confidentiality.

RESULTS

Among the 500 people approached for the study, questionnaires were filled up by 478. Among the filled up questionnaires, 24 were found to be incomplete. Ultimately, 454 questionnaires were

analysed. The mean age of the participants was 33.45±5.21 years and males comprised of 59.3% of the study population. As for religion, it was seen that majority (79.1%) of the study population were Hindu whereas 10% and 11.9% were Muslims and Christians respectively. While calculating socio-economic status, it was seen that majority of the study subjects (78.9%) belonged to families with per capita income of Rs. 2000 or above. As far as education was concerned, majority of them (46.9%) were educated upto Standard VIII. Out of the total study population 56.4% were asymptomatic and the rest were symptomatic. Among the study population, 278(61.2%) were on ART and the mean CD4 count of the patients was 678.92±106.7 per cu.mm.

Analysis of perceived stigma among the sample revealed an average score of 100.53 (SD, 14.45). Among the four subscales of stigma, the concern with public attitudes about people with HIV was the highest, followed by personalized stigma, negative self-image and disclosure concerns [Table/Fig-1] Males {113.42 (SD 22.4)} were found to have higher levels of overall stigma than their female counterparts {92.67 (SD 18.7)}.

[Table/Fig-2] shows that when the stigma scores were coded, the majority of the study population had low stigma (50.7%), followed by 42.7% who had moderate stigma. Only 10 subjects had a high level of stigma and 20 had minimal stigma.

Factors associated with perceived stigma: Multiple Linear regression analysis between perceived HIV stigma and demo-graphic and disease variables showed that being on treatment with ART had the highest contribution towards stigma followed by gender and HIV serostatus of the patients. Age of the patient and CD4 count had negligible contribution toward perceived stigma.

The regression model for this purpose can be best expressed by the equation:

Perceived stigma = 113.79 – 0.14 (Age of the patient) – 3.17 (Gender of the patient) + 2.89 (HIV serostatus of the patient) – 7.85 (On treatment with ART) – 0.001 (Current CD4 count in cu.mm).

Thus, applying the above model, approximately 25.8% of the total variation in perceived stigma can be best explained [Table/Fig-3].

DISCUSSION

Though recent advances in medical technologies have made HIV a chronic and manageable condition, PLHA continue to suffer from stigma [16]. The level of stigma was found to be low to moderate in the study setting. This was quite similar to the findings of Li et al., in Henan province of China and Lingaraj et al., in Coimbatore, India [17,18]. This may be explained by the fact that with the wide scale ART roll out and better management of HIV in India, the fear of developing AIDS has now decreased in common people and resulted in a decrease in stigma [19].

Domains	Mean	SD
Personalized Stigma	44.79	8.57
Disclosure Concerns	23.00	3.32
Negative Self-Image	32.30	4.63
Concern with Public Attitudes about People with HIV	49.49	9.23
Overall stigma	100.53	14.45

[Table/Fig-1]: Domains of stigma among the study population.
N=454.

Levels of stigma	Frequency	Percent
Minimal	20	4.4
Low	230	50.7
Moderate	194	42.7
High	10	2.2
Total	454	100.0

[Table/Fig-2]: Levels of stigma among the study population.
N=454.

		Descriptive statistics	Unstandardized Coefficients	Std. Error	Sig.
Adjusted R Square = 0.258	(Constant)		113.787	5.235	0.000
	Age of the patient (Mean ± SD)	33.45 ± 5.21	-0.138	0.067	0.041
	Sex of the patient	-3.174	1.545		0.040
	Males	269 (59.3)			
	Females	185 (40.7)			
	HIV serostatus of the patient	2.888	1.580		0.038
	Asymptomatic	256 (56.4)			
	Symptomatic	98 (43.6)			
	On treatment with ART	-7.851	3.264		0.017
	Yes	278 (61.2)			
	No	176 (38.8)			
	Current CD4 count (Mean ± SD) per cu.mm	678.92 ± 106.7	-0.001	0.003	0.789

[Table/Fig-3]: Correlates of stigma by regression analysis.
a. Dependent Variable: Perceived stigma
b. Predictors: (Constant), Current CD4 count, Sex of the patient, Age of the patient, HIV serostatus of the patient, on treatment with ART.

However, the actual stigma experienced might be quite different than the perceived stigma. A study by Thomas et al., in Chennai substantiated the findings where the perceived stigma was 97% whereas, only 26% of the PLHAs had actually experienced stigma [20]. Similarly, in a study by Subramanian et al., 96% reported perceived stigma whereas actual stigma was mentioned by only 33% [21].

The expression of stigma in PLHAs not only depends on the cultural/national setting, but also on the interplay between personal and societal levels of stigma. Understanding the societal levels of stigma, plays an important role in implementing effective HIV surveillance programs [22]. National Aids Control Organization advocates anonymous reporting of HIV results to lessen the risk of stigma and discrimination faced by HIV-infected persons [23]. Likewise in the present study, concern with public attitudes about people with HIV was the major contributing factor towards stigma. However, in another study done among HIV positive women in Coimbatore showed the highest score for disclosure stigma followed by public attitude concern [17]. This difference may be due to the different cultural contexts in both the studies.

Socio-demographic factors can predict stigma among the PLHA [24]. Regression analysis revealed that stigma was found to be significantly related with younger age, male patients and HIV seropositivity. Age is an important predictor when it comes to appreciating stigma among adults living with HIV/AIDS. Emlet et al., suggested that the relationship between age and stigma is intricate [25]. In another study, Emlet et al., showed that older age was associated with lower levels with stigma [26].

Evidence shows that in male dominated societies like ours, women are more likely to suffer from stigma than their male counterparts [27-29]. However, this was quite the opposite scenario in the present study. This may be due to the fact that in Darjeeling district as in other North Eastern states, males and females share a similar footing.

Treatment with ART was shown to increase the stigma among the PLHA. This was found to be quite discouraging because stigma can compromise participants' abilities to successfully adhere to ART [30].

A significant strength of the study is that, it is first of its kind to be held in this district, which has been categorized as Category B according to NACO.

LIMITATION

Include recruitment of participants who were already receiving care from an ART clinic. This could have biased the data, as those with few experiences with stigma were less interested in participating in the study, thereby resulting in the over-reporting of stigma experiences.

Anti-stigma programmes, simultaneously addressing individual, organizational and public policy factors are crucial to the success of HIV control programs both at national and global level. This may include approaches at modifying the elements that impact the stigmatization process [31]. Additionally, it can include measures to ensure that complaint redressal systems and legal aid available for PLHAs to seek justice in cases of discrimination [32].

CONCLUSION

Despite the improvement in awareness regarding HIV among the general population, HIV stigma continues to impact PLHA in this part of the country. As no efficacious stigma reduction programs have been scaled up effectively in this region, more work needs to be done to assist PLHA in coping with stigma.

REFERENCES

[1] HIV/AIDS [Internet]. World Health Organization. 2016 [cited 21st July 2016]. Available from: http://www.who.int/gho/hiv/en/http://www.who.int/gho/hiv/en/
[2] India HIV Estimations 2015 Technical Report. http://naco.gov.in/upload/2015%20 MSLNS/HSS/India%20HIV%20Estimations%20201.pdf.
[3] Nachega JB, Morroni C, Zuniga JM, Sherer R, Beyrer C, Solomon S, et al. HIV-related stigma, isolation, discrimination, and serostatus disclosure: a global survey of 2035 HIV-infected adults. J IntAssoc Physicians AIDS Care (Chic). 2012;11(3):172-78.
[4] Fife BL, Wright ER. The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. J Health Soc Behav. 2000;41(1):50-67.
[5] Joint United Nations Programme on HIV/AIDS. Reducing HIV stigma and discrimination: A critical part of national AIDS programmes-a resource for national stakeholders in the HIV response. Geneva: UNAIDS; 2007.
[6] UNAIDS. World AIDS Day Report 2015: On the Fast-Track to end AIDS by 2030. Focus on location and population. Joint United Nations Programme on HIV/AIDS (UNAIDS); Geneva, Switzerland: 2015. Available at:http://www.unaids.org/sites/default/files/media_asset/WAD2015_report_en_part01.pdf.
[7] Monjok E, Smesny A, Essien EJ. HIV/AIDS - Related stigma and discrimination in Nigeria: review of research studies and future directions for prevention strategies. African Journal of Reproductive Health. 2009;13(3):21-35.
[8] Bharat S. A systematic review of HIV/AIDS-related stigma and discrimination in India: current understanding and future needs. SAHARA J. 2011;8(3):138-49.
[9] Florom-Smith AL, De Santis JP. Exploring the concept of HIV-related stigma. Nursing forum. 2012;47(3):153-65.
[10] Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: what have we learned? AIDS Educ Prev. 2003;15(1):49-69.
[11] Ports KA, Haffejee F, Mosavel M, Rameshbabu A. Integrating cervical cancer prevention initiatives with HIV care in resource-constrained settings: A formative study in Durban, South Africa. Global Public Health. 2015;10(10):1238-51.
[12] Mahajan AP, Sayles JN, Patel VA, et al. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. AIDS (London, England). 2008;22(Suppl 2):S67-S79.
[13] Vega J. Universal health coverage: the post-2015 development agenda. Lancet. 2013;381:179–80.
[14] Nebhinani N, Mattoo SK, Wanchu A. HIV stigma and specified correlates in North India. Indian Journal of Psychological Medicine. 2012;34(4):330-37.
[15] Berger, B, Ferrans, CE, & Lashley, FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Research in Nursing and Health. 2001;24:518-29.
[16] Grossman CI, Stangl AL. Global action to reduce HIV stigma and discrimination Journal of the International AIDS Society. 2013;16(2):1-6.
[17] Li Z, Sheng Y. Investigation of perceived stigma among people living with human immunodeficiency virus/acquired immune deficiency syndrome in Henan Province, China. International Journal of Nursing Sciences. 2014;1:385-88.
[18] Lingaraj C, Lingaraj J, Vinod R. Stigma in women living with HIV in Coimbatore District of Tamil Nadu. IOSR Journal of Dental and Medical Sciences (IOSR-JDMS). 2014;13(12):29-32.
[19] Kaai S, Bullock S, Sarna A, Chersich M, Luchters S, Geibel S, et al. Perceived stigma among patients receiving antiretroviral treatment: a prospective randomised trial comparing an m-DOT strategy with standard-of-care in Kenya. SAHARA J. 2010;7(2):62–70.
[20] Thomas BE, Rehman F, Suryanarayanan D, Josephine K, Dilip M, Dorairaj VS, et al. How stigmatizing is stigma in the life of people living with HIV: a study on HIV positive individuals from Chennai, South India. AIDS Care. 2005;17(7):795-801.
[21] Subramanian T, Gupte MD, Dorairaj VS, Periannan V, Mathai AK. Psycho-social impact and quality of life of people living with HIV/AIDS in South India. AIDS Care. 2009;21(4):473-81.

[22] Audet CM, McGowan CC, Wallston KA, Kipp AM. Relationship between HIV stigma and self-isolation among people living with HIV in Tennessee. *PLoS ONE*. 2013;8(8):e69564.

[23] Department of AIDS Control. Ministry of Health and Family Welfare. *National AIDS Control Organization (NACO) Annual Report* 2014-15.

[24] Nyamathi A, Ekstrand M, Zolt-Gilburne J, Ganguly K, Sinha S, Ramakrishnan P, et al. Correlates of stigma among rural indian women living with HIV/AIDS. *AIDS and Behaviour.* 2013;17(1):329-39.

[25] Emlet CA. A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. *AIDS Patient Care STDS*. 2006;20(5):350-58.

[26] Emlet CA, Brennan DJ, Brennenstuhl S, Rueda S, Hart TA, Rourke SB. OHTN Cohort Study Team. Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada. *AIDS Care*. 2013;25(10):1330-39.

[27] Asiedu GB, Myers-Bowman KS. Gender differences in the experiences of HIV/AIDS-related stigma: a qualitative study in Ghana. *Health Care Women Int*. 2014;35(7-9):703-27.

[28] Mugoya GC, Ernst K. Gender differences in HIV-related stigma in Kenya. *AIDS Care*. 2014;26(2):206-13.

[29] Tarakeshwar N, Krishnan AK, Johnson S, Solomon S, Sikkema K, Merson M. Living with HIV infection: perceptions of patients with access to care at a non-governmental organization in Chennai, India. *Cult Health Sex.* 2006;8(5):407-21.

[30] Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society.* 2013;16(3Suppl 2):18640.

[31] Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works? *Journal of the International AIDS Society*. 2009;1215. doi:10.1186/1758-2652-12-15.

[32] Stangl AL, Lloyd JK, Brady LM, Holland CE, Baral S. A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society.* 2013;16(3Suppl 2):18734.

PARTICULARS OF CONTRIBUTORS:
1.   Associate Professor, Department of Medicine, North Bengal Medical College, Sushrutanagar, Darjeeling, West Bengal, India.
2.   Assistant Professor, Department of Community Medicine, North Bengal Medical College, Sushrutanagar, Darjeeling, West Bengal, India.
3.   Associate Professor, Department of Medicine, North Bengal Medical College, Sushrutanagar, Darjeeling, West Bengal, India.
4.   Assistant Professor, Department of Medicine, North Bengal Medical College, Sushrutanagar, Darjeeling, West Bengal, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:
Dr. Sharmistha Bhattacherjee,
Assistant Professor, Department of Community Medicine, North Bengal Medical College,
Sushrutanagar, Darjeeling-734012, West Bengal, India.
E-mail: sharmistha.bhattacherjee@gmail.com

FINANCIAL OR OTHER COMPETING INTERESTS: None.