pISSN 2394-6032 | eISSN 2394-6040

Original Research Article

DOI: http://dx.doi.org/10.18203/2394-6040.ijcmph20190619

Stigmatization and discrimination towards people living with HIV/AIDS attending antiretroviral clinic in a centre of excellence in HIV care in India

Trinath Sarkar¹, Nabarun Karmakar²*, Aparajita Dasgupta³, Bibhuti Saha⁴

Assistant Professor, Department of Community Medicine, ¹Medical College, Kolkata, West Bengal; ²Tripura Medical College & Dr. BRAM Teaching Hospital, Hapania, Tripura, India

Received: 03 January 2019 **Revised:** 04 February 2019 **Accepted:** 07 February 2019

*Correspondence: Dr. Nabarun Karmakar,

E-mail: drnabarunkarmakar@gmail.com

Copyright: © the author(s), publisher and licensee Medip Academy. This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial License, which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ABSTRACT

Background: HIV/AIDS is a serious challenge globally. Plethora of morbidities due to crippling immune system reduces quality of life (QOL). The advent of HAART has changed this deadly disease to a chronic manageable illness with focus shifting from fighting virus to ensuring a good QOL. Objective of the study was to assess stigma and discrimination among PLHA and factors influencing, if any in Indian setting.

Methods: A cross sectional study was carried out among 220 male aged >15 years (PLHA) attending ART centre of centre of excellence in HIV care in India (CSTM, Kolkata) from May 2012-April 2013 using a pre-designed and pretested schedule regarding socio-demographic characteristics and social stigma. Statistical analysis was done using SPSS version 16.0 and p<0.05 was considered as significant.

Results: Nearly half (45%) and one-fifth (20.9%) of the study population were discriminated by the family and community respectively. Most (74.5%) of the study population had disclosed their HIV status to their family members. Maximum participants (96.4%) agreed that those who know their HIV status will tell that to others. In the multivariate model with increase in PCI the odds of score of dependant variable increases, so the odds of social stigma decrease (as increase in score means decrease in social stigma).

Conclusions: The results show that factors associated with stigma should be further explored as it's important in considering public health interventions to improve care of PLHA in India.

Keywords: Family, India, Male, Social stigma

INTRODUCTION

HIV and its manifestation AIDS remains a highly stigmatized illness globally, resulting in a pandemic with wide influence on life of the sufferer, physically, socially and culturally. Numerous studies have shown that stigma is associated with poor adherence to antiretroviral therapy

(ART), mental health disorders such as loneliness, depression and anxiety, non-disclosure of HIV status, and overall poor health outcomes.²⁻⁶

WHO report on India has shown that of the HIV patients eligible for Anti retrovirus therapy (ART) only 50% were

³Director-Professor, Department of Preventive and Social Medicine, All India Institute of Hygiene and Public Health, Kolkata, West Bengal, India

⁴Professor and Head of the Department, Department of Tropical Medicine, Calcutta School of Tropical Medicine (CSTM), Kolkata, West Bengal, India

receiving ART treatment in 2012 which showed no improvement from the ART coverage in 2011(50%).⁷

It is widely accepted that HIV-related stigma is influenced by socio-demographic characteristics such as age, gender, marital status, educational attainment, socioeconomic status, and area of residence with a heavy burden in rural PLWHA than urban PLWHA.

U.N. secretary general Ban Ki Moon has stated "stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have HIV, or to seek treatment". ¹⁰ Because stigma continues to be a major barrier in seeking HIV testing, care, and treatment services, it is recognized as a priority for both primary and secondary prevention of HIV and AIDS. ¹¹⁻¹⁴

With the above backdrop a study was conducted in antiretroviral therapy (ART) centre of Calcutta school of tropical medicine (CSTM) with the aim of finding out social stigma of people living with HIV/AIDS (PLHA) (males more than 15 years). The scientific findings gathered from this epidemiological study will help in building an insight on how to prevent the spread of HIV, how to improve their quality of life and also how to prepare mitigation efforts to eliminate the social stigma of HIV.

METHODS

This epidemiological study was conducted among people living with HIV/AIDS (PLHA) attending anti retro viral therapy (ART) centre of Calcutta School of Tropical Medicine (CSTM) for a period of 12 months from May 2012-April 2013. All male (>15 years) PLHA, newly registered in 2012-13 at ART centre and giving consent to participate except those who were severely morbid to answer the schedule were included.

Calcutta school of tropical medicine (CSTM), Kolkata is the only institution in India exclusively dedicated to research, postgraduate education, and healthcare of tropical and infectious diseases. The institute possesses a centre of excellence in HIV care where presently advance research is going on regarding HIV/HBV co-infection and hepatitis B anti-viral therapy. Here, weekly meeting of state AIDS clinical expert panel (SACEP) to finalize line of ART, home visit of patients on 2nd line ART for adherence and family counselling, nutritional counselling of all 2nd line and alternate 1st line ART patients and management of referral cases from ART centres of linked six states namely Assam, Chattisgarh, Jharkhand, Odisha, Sikkim and West Bengal.

Target study population size was obtained from taking average of previous 3 years records of total number of male PLHA registered at CSTM (n=620) and taking 1/3rd of that (as 2 days in a week were allotted for work by simple random sampling), the sample size came as 207.

Further taking 5% as non-response; final sample size found was 217; ultimately, 220 male (>15 years) living with HIV/AIDS were taken.

Male (>15 years) PLHA after being attended by medical officer at ART centre were interviewed with a predesigned and pre-tested schedule regarding sociodemographic characteristics and social stigma (this part of the schedule was obtained from USAID document to elicit social stigma), in a separate room after taking informed written consent and complete anonymity and confidentiality of each participant were ensured. Each participant was informed about academic nature of this research and ensured that he would not suffer from any form of hardship, discrimination or stigmatization as a consequence of having participation in this research work.

Data analysis and interpretation

The collected data were entered in Microsoft excel worksheet (Microsoft, Redwoods, WA, USA) and checked for accuracy, duplicate or erroneous entry. Data were presented in tables; initially descriptive statistics were described, later QOL and social stigma were explained with multivariate regression models. P value less than 0.05 was considered as statistically significant.

Ethical issues

Ethical was obtained from clearance from Institution Ethics committee All India Institute of Hygiene & Public Health (AIIH&PH), Kolkata and study was initiated after getting approval from institution's ethical committee. Informed written consent in local language (Bengali) was obtained from every interviewee.

RESULTS

Socio- demographic features of 220 PLHA men showed that, maximum (40.5%) belong to 31-40 years followed by 24.1% in 41-50 years and least (0.9%) in >60 years age. Most of them were hindu (80%), 17.3% were muslim; among hindus half (51.1%) were general, 22.2% scheduled caste. Majority (28.6%) respondents studied up to secondary level, majority (26.4%) were unskilled worker by occupation, 19.5% were unemployed. Majority were married (47.7%), 31.8% unmarried. Maximum (79.5%) belong to nuclear family. Majority (44.5%) belonged to upper lower social class, 30.5% in lower middle class as per modified Prasad scale 2012. Majority (46%) of the married participants had 2 children; 36.8% participants were having 3 dependants.

Table 1 showed that nearly half (45%) and one-fifth (20.9%) of the study population were discriminated by the family and community respectively.

Most (74.5%) of the study population had disclosed their HIV status to their family members. Disclosure status at

community and workplace were 30.5% and 18.2% respectively. Surprisingly, lowest disclosure (3.6%) was seen at health centre (Table 2).

Table 1: Distribution of the study population as per discrimination faced by them at family and community level (n=220).

Discrimination	Number (%)		
By family			
Yes	99 (45.0)		
No	121 (55.0)		
By community			
Yes	46 (20.9)		
No	174 (79.1)		

Table 2: Distribution of the study population as per disclosure status of HIV to family, community, workplace and health.

Discrimination	Number (%)				
Disclosed to family (n=220)	•				
Yes	164 (74.5)				
No	56 (25.5)				
Disclosed to family members (n=164	Disclosed to family members (n=164) *				
Father	108 (65.8)				
Mother	113 (68.9)				
Brother	82 (50.0)				
Sister	67 (40.8)				
wife	69 (42.1)				
Son	6 (3.7)				
Daughter	3 (1.8)				
Disclosed to community (n=220)					
Yes	67 (30.5)				
No	153(69.5)				
Disclosed to community members (n= 67)*					
Neighbour	50 (74.6)				
Friends	28 (41.7)				
Disclosed to workplace (n=220)					
Yes	40 (18.2)				
No	180 (81.8)				
Disclosed to workplace persons (n=	40)*				
Boss	7 (17.5)				
Colleague	33 (82.5)				
Disclosed at health centre (n=220)					
Yes	8 (3.6)				
No	212 (96.4)				
Disclosed to health centre persons (n=8)*					
Counsellor	3 (37.5)				
Sweeper	3 (37.5)				
Clerk	2 (25.0)				

Table 3 showed maximum participants (96.4%) agreed that those who know their HIV status will tell that to others. Around two-third (65.5%) would like to keep their HIV-positive status as secret by their near and dear ones. Most of them (81.8%) were very careful in disclosing

HIV-positive status; 75.5% agreed that it's something very risky to tell someone that I have HIV. Two-third of them (67.3%) kept a big effort to make sure that their HIV is kept a secret.

Table 3: Attitude of the study population regarding the stigma associated with HIV/AID (n=220).

Statements	True/agree N (%)	False/disagree N (%)
I am worried thinking that those who know I have HIV will tell that to others	212 (96.4)	8 (3.6)
I would like it if my family and my close friends keep my HIV- positive status a secret	144 (65.5)	76 (34.5)
I am very careful to whom I tell that I am HIV- positive	180 (81.8)	40 (18.2)
To tell someone that I have HIV is something very risky	166 (75.5)	54 (24.5)
I make a big effort to make sure that my HIV is kept a secret	148 (67.3)	72 (32.7)

Table 4: Bivariate and multivariate regression model explaining social stigma (n=220).

Socio-demographic characteristics		Social stigma	
Variables	Coding	OR (95% CI)	AOR (95% CI)
Age (years)	≤40	1.36 (0.77-2.39)	1.55 (0.85-2.84)
	>40	1	1
Educational status	HS and above	2.78 (1.33-5.88)	1.39 (0.52-3.03)
	Up to secondary level	1	1
Marital status	Married	1.44 (0.85-2.44)	1.66 (0.92-3.01)
	Unmarried	1	1
Family type	Nuclear	0.76 (0.39-1.47)	0.94 (0.46-1.91)
	Joint	1	1
PCI	> Rs.1949/-	7.69 (2.63-25.0)	6.67 (2.13-20.0)
	≤ Rs.1949/-	1	1
Quality of life	≤51 (median)	1.28 (0.76-2.18)	0.96 (0.54-1.71)
	>51	1	1

Table 4 showed that in the multivariate model with increase in PCI the odds of score of dependant variable increases, so the odds of social stigma decrease (as increase in score means decrease in social stigma).

DISCUSSION

HIV/AIDS is a global challenge in today's date, not only hampering physical health but also mental and social wellbeing. It is not simply a virus that causes disease, but also a social and historical event that impacts how others react towards people living with HIV and AIDS (PLHAs). Further, more often young men suffering from HIV/AIDS are literally forced to flee from their family and place of origin to avoid the social stigma and discrimination from family, friends and to get better job opportunities without disclosing HIV infection status.

In this present study among 220 PLHA men, maximum (40.5%) belong to 31-40 years followed by 24.1% in 41-50 years age consistent with Kumar and Nebhinani. 3,16 Majority were male whereas equal representation was shown by Muralidharan. 3,17,18 In this study, maximum (94.1%) literate and 28.6% respondents studied up to secondary level whereas Nebhinani found that 63% were school non-completer. 16 Datta found 46.9% were educated up to standard VIII.¹⁷ Majority were married (47.7%) in this study similar to other study findings. 21,23,24 Maximum (79.5%) belong to nuclear family; consistent with Nebhinani (68%). Majority (44.5%) belonged to upper lower social class, 30.5% in lower middle class as per modified Prasad scale 2012, similar to Kumar on the contrary Datta found 78.9% participants belonged to families with per capita income of Rs. 2000 or above; Muralidharan found 95.3% of the participants belonged to the lower class. 3,17,18 In this study, nearly half (45%) and one-fifth (20.9%) of the participants were discriminated by the family and community respectively. Datta found majority had low stigma (50.7%), followed by 42.7% who had moderate stigma. 17 Kumar found 53.8% of the study participants had experienced personalized stigma.3

Most (74.5%) of the study population had disclosed their HIV status to their family members. Disclosure status at community and workplace were 30.5% and 18.2% respectively. Surprisingly, lowest disclosure (3.6%) was found at health centre. Kumar found (46.6%) participants themselves revealed their HIV status in their workplace.³

In present study, multivariate model showed with increase in PCI the odds of score of dependant variable increases, so the odds of social stigma decrease (as increase in score means decrease in social stigma). Datta S found through 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. ¹⁷

Kumar found compared to females (48.2%), more than half (51.5%) of the male participants had experienced HIV/AIDS-related personalized stigma (p>0.05).³ Majority (83.1%) of the study participants who experienced stigma due to disclosure status belonged to a lower socioeconomic status (p>0.05).

Social stigma among PLHA can be divided into internal and external stigma. External stigma or enacted stigmas are actions fuelled by stigma and which are commonly referred to as discrimination. Discrimination of PLHA by the family members and members of the community, stem from fear of contagion of HIV which is considered like a "living dead" in the society. Many study such as Cloete et al, Varas-Diaz et al, Stutterheim et al, Mlobeli reported discrimination of PLHA by the family members, but none of them reported quantitative data as majority of the research work were qualitative in nature except few, such as Bogart et al reported 79% of the PLHA experienced discrimination, which is quite higher than the present study. 19-23 Possibility of such discrepancy might be due to conscious falsification of the data stated by the participants in present study. Intern stigma can be of two types, viz. perceived stigma and felt stigma. Perceived stigma manifested as fear of disclosure of PLHA's seropositive status to others. Rao et al stated PLHA's resolve to keep their status a secret due to interpersonal rejection.²⁴ Stutterheim et al further elaborated this fear of disclosure results in psychological distress among PLHA eg. Depression.²² Li et al further elucidated depression was significantly associated internalised shame and perceived stigma.²⁵ They found internalized stigma and emotional social support were significant predictors of depression after controlling for gender, age, income and education. Mlobeli showed Internalised stigma such as PLHA's own shame, guilt, uselessness leads to selfwithdrawal and prevent people from testing of HIV as well as health seeking behaviour.²⁰ In the current study only 75.5% of PLHA felt risk in disclosing their seropositive status against 83.4% reported by Vaz et al.²⁶ This can be explained by the fact that Vaz et al conducted their study at rural community, whereas majority of the study population in the current research work were from peri and sub urban area where the general population's knowledge regarding HIV is better than the rural counterpart, owing to the better media access, and better penetration of the health care delivery system.²

A study among MSM at capetown by Cloete et al, reported 56% concealed their HIV status and Taraphdar et al at Kolkata reported 65% of the study population disclosed their serostatus to their sexual partner. Lower disclosure among MSM in the above study was probably due to the stigmatized societal norm of MSM to keep themselves as hidden societal group. Though in the current study no item was there eliciting the disclosure status of the male PLHA to their sexual partner(s), it was found 42.07% of the study population who disclosed their HIV status to their family members, disclosed their serostatus to their wife. Attitude of the PLHA judges their

internal stigma, i.e. both felt and perceived stigma. Internal stigma impedes both willingness and ability to adopt HIV preventive behaviour and to access treatment. Vaz et al found 93.2% of the participants showed negative attitude regarding revelation of HIV status, where as in the current study it varied from 65.5% to 96.4%. ²⁶ It is to be noted, that though former did it's study among general population in the rural community, current study was among PLHA and institution based. On explaining social stigma among PLHA by multivariate regression model Wolitski et al found higher levels of stigma were experienced by women, homeless participants, those with high school or less education, those with recently diagnosed with HIV. ²⁸

Half of the subjects blamed self for contracting HIV. Only 38 subjects reported others behaving differently with HIV-positive subjects. HIV status disclosure was reported by 98 subjects (73 to family or relatives). Urban subjects reported higher primary stigma and shame or blame. Psychiatric disorders, present in 45 subjects, showed no association with stigma items.

CONCLUSION

The results show that factors associated with stigma should be further explored as it's important in considering public health interventions to improve care of PLHA in India. For instance, offering more counselling and encouraging the patients to seek out support groups may provide emotional support for those battling HIV-associated stigma. The 2012-13 national AIDS control organization (NACO) report says that one of the key priorities of the 4th NACP for 2012-17 (national AIDS control program) is reducing stigma and discrimination through greater involvement of people living with HIV (GIPA). To achieve better outcomes, more focus should be on interventions reducing disclosure stigma and perceived public concern stigma along with education of Public against discrimination.

ACKNOWLEDGEMENTS

The authors express their sincere gratitude towards all the study participants for their co-operation.

Funding: No funding sources Conflict of interest: None declared

Ethical approval: The study was approved by the

Institutional Ethics Committee of AIIH&PH, Kolkata

REFERENCES

- 1. Chambers LA, Rueda S, Baker DN, Wilson MG, Deutsch R, Raeifar E, et al. Stigma, HIV and health: a qualitative synthesis. BMC Public Health. 2015;15:848.
- 2. Wang K, Chen W, Zhang L, Bao M, Zhao H, Lu H. Facilitators of and barriers to HIV self-management:

- perspectives of HIV-positive women in China. Appl Nurs Res. 2016;32:91–7.
- Kumar N, Unnikrishnan B, Thapar R, Mithra P, Kulkarni V, Holla R, et al. Stigmatization and Discrimination toward People Living with HIV/AIDS in a Coastal City of South India. J Int Association Providers AIDS Care. 2017;16(3):226– 32.
- 4. Fekete E, Williams S, Skinta M. Internalised HIV-stigma, loneliness, depressive symptoms and sleep quality in people living with HIV. Psychol Health. 2017:1–18.
- Burke SE, Calabrese SK, Dovidio JF, Levina OS, Uuskula A, Niccolai LM, et al. A tale of two cities: stigma and health outcomes among people with HIV who inject drugs in St. Petersburg, Russia and Kohtla-Jarve, Estonia. Soc Sci Med. 2015;130:154– 61.
- Shrestha R, Copenhaver M, Bazazi AR, Huedo-Medina TB, Krishnan A, Altice FL. A moderated mediation model of HIV-related stigma, depression, and social support on health-related quality of life among incarcerated Malaysian men with HIV and opioid dependence. AIDS Behav. 2017;21(4):1059– 69.
- Global Update on HIV Treatment 2013: Results, Impact and Opportunities, 2013. Available at https://www.who.int/hiv/data/global_treatment_repo rt_presentation_2013.pdf. Accessed 3 November 2018.
- 8. Huang Z, Fu Z, Zhao X, Qiu T, Zhao Y, Cao X, et al. Investigation on self-stigma and discrimination among HIV/AIDS patients in Suzhou. Jiangsu. J Prev Med. 2015;26(2):10–2.
- 9. Costelloe S, Kemppainen J, Brion J, MacKain S, Reid P, Frampton A, et al. Impact of anxiety and depressive symptoms on perceptions of stigma in persons living with HIV disease in rural versus urban North Carolina. AIDS Care. 2015;27(12):1425–8.
- Ban Ki-Moon. The Stigma Factor: Biggest Hurdle To Combat Hiv/Aids. The Washington Times (Us). 2008.
- 11. Li H, Wei C, Tucker J, Kang D, Liao M, Holroyd E, et al. Barriers and facilitators of linkage to HIV care among HIV-infected young Chinese men who have sex with men: a qualitative study. BMC Health Serv Res. 2017;17(1):214.
- 12. Treves-Kagan S, Steward WT, Ntswane L, Haller R, Gilvydis JM, Gulati H, et al. Why increasing availability of ART is not enough: a rapid, community-based study on how HIV-related stigma impacts engagement to care in rural South Africa. BMC Public Health. 2016;16:87.
- 13. Brent RJ. The value of reducing HIV stigma. Soc Sci Med. 2016;151:233–40.
- 14. Fee E. The stigma of HIV. Am J Public Health. 2013;103(10):1747.
- 15. Nyblade L, MacQuarrie K. Can We Measure Hiv/Aids-Related Stigma and Discrimination?

- Current Knowledge About Quantifying Stigma In Developing Countries, 2006. Available at http://bibliobase.sermais.pt:8008/BiblioNET/upload/PDF/0638_Can%20we%20measure%20HIV%20Aids%20related%20stigma.pdf. Accessed 06 November 2018.
- 16. Nebhinani N, Mattoo SK, Wanchu A. HIV Stigma and Specified Correlates in North India. Indian J Psychol Med. 2012;34(4);324-31.
- 17. Datta S, Bhattacherjee S, Sherpa PL, Banik S. Perceived HIV Related Stigma among Patients Attending ART Center of a Tertiary Care Center in Rural West Bengal, India. J Clin Diagnos Res. 2016;10(10):VC09-12.
- Muralidharan S, Acharya AK, Margabandu S, Purushotaman S, Kannan R, Mahendrakar S, et al. Stigma and Discrimination faced by HIV-infected Adults on Antiretroviral Therapy for more than 1 Year in Raichur Taluk, Karnataka, India. J Contemporary Dental Practice. 2017;18(9):765-70.
- Varas-Díaz N, Serrano-García I, Toro-Alfonso J, AIDS-Related Stigma and Social Interaction: Puerto Ricans Living With HIV/AIDS. Qual Health Res. 2005;15(2):169-87.
- Mlobeli R. HIV/AIDS Stigma: An Investigation into the Perspectives and Experiences of People Living With HIV/AIDS, 2007. Available at: https://core.ac.uk/download/pdf/58913100.pdf. Accessed on 25 November 2018.
- Cloete A, Simbayi LC, Kalichman SC, Strebel A, Henda N. Stigma and discrimination experiences of HIV-positive men who have sex with men in Cape Town, South Africa. AIDS Care. 2008;20(9):1105-10.
- 22. Stutterheim SE, Pryor JB, Bos AE, Hoogendijk R, Muris P, Schaalma HP. HIV-related stigma and psychological distress: the harmful effects of

- specific stigma manifestations in various social settings. AIDS. 2009;23(17):2353–7.
- Bogart LM, Cowgill BO, Kennedy DP, Ryan G, Murphy DA, Elijah J, et al. HIV-Related Stigma among People with HIV and their Families: A Qualitative Analysis. AIDS and Behavior. 2008;12(2):244-54.
- 24. Rao D, Pryor JB, Gaddist BW, Mayer R. Stigma, Secrecy, and Discrimination: Ethnic/Racial Differences in the Concerns of People Living with HIV/AIDS. AIDS and Behavior. 2008;12(2):265-71.
- 25. Li L, Wu Z, Wu S, Zhaoc Y, Jia M, Yan Z. HIV-Related Stigma in Health Care Settings: A Survey of Service Providers in China. AIDS Patient Care and STDs. 2007;21(10):753-62.
- 26. Vaz FS, Ferreira AMA, Motghare DD, Kulkarni MS. Discriminatory Attitudes of a Rural Community Towards People with HIV/AIDS: Experiences From Goa. Indian J Community Med. 2005;30(2):73.
- 27. Taraphdar P, Dasgupta A, Saha B, Disclosure among people living with HIV/AIDS. Indian J Community Med. 2007;30(4):80-2.
- 28. Wolitski RJ, Pals SL, Kidder DP, Courtenay-Quirk C, Holtgrave DR. The Effects of HIV Stigma on Health, Disclosure of HIV Status, and Risk Behavior of Homeless and Unstably Housed Persons Living with HIV. AIDS and Behavior. 2009;13(6):1222-32.

Cite this article as: Sarkar T, Karmakar N, Dasgupta A, Saha B. Stigmatization and discrimination towards people living with HIV/AIDS attending antiretroviral clinic in a centre of excellence in HIV care in India. Int J Community Med Public Health 2019;6:1241-6.