A cross-sectional study on stigma and discrimination confronted by HIV positive patients in the economic capital of India

Ajaykumar C. Sahu¹,², Kiran S. Akhade³,⁴

¹Former Junior Resident, Department of Community Medicine, Lokmanya Tilak Municipal Medical College, Sion, Mumbai, Maharashtra, ²Currently Assistant Professor, ³Currently Associate Professor, Department of Community Medicine, Raipur Institute of Medical Sciences, Raipur, Chhattisgarh, ⁴Former Assistant Professor, Department of Community Medicine, Rajiv Gandhi Medical College, Kalwa, Thane, Maharashtra, India

ABSTRACT

Context: HIV/AIDS is a serious public health, economic and social problem. Stigma is a common human reaction to disease and discrimination follows stigma. Stigma and discrimination act as impediments to uptake of HIV testing, treatment, care and adherence to treatment. Aim: The aim of this study was to estimate the prevalence of the stigma and discrimination faced by HIV positive patients receiving antiretroviral therapy (ART). Settings and Design: A cross-sectional, observational study conducted at ART center of a tertiary care hospital in an urban area. Methods and Material: Participants were selected by simple random sampling among HIV positive patients. A predesigned, pretested and self-administered, semi-structured questionnaire in local language was used to assess stigma and discrimination. Statistical Analysis Used: The data were entered in Microsoft Excel and analyzed with SPSS version 20 statistical software. Simple proportions, mean, standard deviation, median, range and inter-quartile range were calculated.

Results: Of 336 participants, 170 were male, whereas 166 were females. The mean age was 36.42 years. The total mean scores for Berger’s HIV stigma scale experienced was 122.82, whereas for individual subscale Personalized stigma, Negative self-image, public attitudes and disclosure of HIV status were 38.31, 27.46, 33.09 and 23.97, respectively. The maximum participants expressed the stigma regarding disclosure concerns (58.63%) followed by negative self-image stigma (43.45%). Conclusions: Stigma hinders the delivery of effective medical social care. People Living with HIV and AIDS (PLWHA) need to have greater involvement in their care, support and treatment. Support groups of PLWHA need to be established so that stigma and discrimination at various levels can be challenged collectively.

Keywords: Antiretroviral therapy, ART, discrimination, HIV, PLWHA, stigma

Introduction

A disgrace or blame attached to anyone OR “A social disgrace” OR “Stigma is significantly dishonoring attitude possessed by a person with an undesired difference”. HIV/AIDS related stigma refers to all unfavorable attitudes, belief policies directed towards people perceived to have HIV/AIDS, and their significant others, loved ones, close associates, social groups, and communities. Description of stigma incorporates an acknowledgement of cultural values; it depicts life as an individual within the social and cultural milieu experiences it. In HIV/AIDS, stigma is associated with devastating medical progression of opportunistic infection, social transgressions in the context of both homosexual and heterosexual relations.
It focuses on the action, treatment and policies that arise from such attitudes that violate the human rights of PLWHA and those close to them. The term focuses on any form of discrimination, restriction or exclusion a person may encounter because of an inherent personal characteristic. HIV/AIDS is a serious public health, economic and social problem with approximately 36.9 million people living with HIV (PLHIV) globally at the end of 2017, with 1.8 million people becoming newly infected and 940,000 people died of HIV-related causes, whereas 21.7 million PLHIV were receiving antiretroviral therapy (ART) (http://www.who.int/en/news-room/fact-sheets/detail/hiv-aids). HIV/AIDS has been having a significant impact on society both as an illness and as a source of discrimination and stigma. Stigma is a natural human response to disease, and discrimination follows stigma. The health care sector is perhaps the most conspicuous context for HIV/AIDS-related stigmatization, discrimination and denial. Stigma and discrimination act as impediments to the uptake of HIV testing, treatment and care and treatment adherence. A consistent, negative association is usually found between fear of stigma (or perceived stigma) and the use of testing and treatment services.

Hence the current study was planned to estimate the prevalence of the stigma and discrimination faced by HIV positive patients receiving ART. In addition, this study will also help recognize and establish measures and interventions that will help to reduce the victimization of HIV positive patients for stigma and discrimination in society.

**Subjects and Methods**

**Study design**
Observational cross-sectional study.

**Study setting**
ART center of a tertiary care hospital in an urban area.

**Study subjects**
HIV positive patients attending ART center of a tertiary care hospital in an urban area.

**Study duration**
1 year

**Sample size estimation**
Formula for calculating sample size:

\[ n = \frac{Z^2 \times P(1-P)}{d^2} \]

Estimating a population proportion with specified absolute precision,

a) Anticipated population proportion \( P = 50\% \) (as this gives maximum possible sample)

b) Confidence level 100(1–0) = 95% and \( Z (1-\alpha/2) = 1.96 \)

c) Absolute precision required on either sides of the proportion \( d = 5\% \)

Substituting above-mentioned values:

\[ n = \frac{(1.96)^2 \times 50}{25} = 3.84 \times 2500 = 384 \]

Thus, Sample set \( n \) comprises 384 study subjects.

**Sampling technique**
Simple Random Sampling by lottery method

**Inclusion criteria**

i. All the registered HIV-positive patients on ART from both the sexes of age group more than 18 to 60 years.

ii. All the registered HIV-positive patients on ART willing to give consent for his/her participation in the study

**Exclusion criteria**

iii. Pregnant and lactating women on ART.

iv. Seriously ill patient on ART whose follow-up is doubtful.

v. Those not willing to participate.

vi. Patients staying outside Mumbai Metropolitan Region Development Area (MMRDA).

**Ethical approval procedure**
Permission obtained from the Institutional Ethical Committee of the Tertiary Care Hospital & Teaching Institution also Project Director, Mumbai District AIDS Control Society (MDACS), in the urban area before initiating the study.

**Data collection tools**
A pre-validated questionnaire used to collect sociodemographic details.

Health status, stigma and discrimination of study participants collected with the help of a predesigned, semi-structured pretested and self-administered questionnaire in the local language. Berger’s HIV stigma scale used to assess the stigma and discrimination faced by the study subjects. Berger’s HIV stigma scale has 40 questions. The response to questions is scored on 4-point Likert scale.

**Berger’s HIV Stigma Scale**

| Subscale                           | No. of questions | Score range |
|------------------------------------|------------------|-------------|
| Personalized stigma                | 12               | 12-48       |
| Stigma of negative self-image      | 9                | 9-36        |
| Stigma related to public attitudes | 11               | 11-44       |
| Stigma of disclosure concerns      | 8                | 8-32        |
| **Total**                          | **40**           | **40-160**  |

**Study protocol**

**Data management and analysis**
The data were entered in Microsoft Excel sheet and were analyzed by using IBM SPSS software program, version 20.0.
Sahu and Akhade: Stigma and discrimination faced by HIV positive patients receiving ART

Simple proportions, mean, standard deviation, median, range and inter-quartile range were calculated.

Results

Total 336 study subjects were identified as per inclusion and exclusion criteria, 170 were male, whereas 166 were female. The mean age of the study subjects was 36.42 years with a SD 10.29 years. Approximately 21.73% were illiterate, whereas 7.14% were unemployed. More than one third of population was Hindu and more than 60% of population was married. Most (73%) of the population was having CD4 count more than 300/cumm.

Table 1 depicts the mean score and standard deviation for Berger's HIV stigma scale experienced regarding Personalized stigma, Negative self-image, public attitudes and disclosure of HIV status. The total mean score for stigma was found to be 122.82 with standard deviation 6.66.

Table 1: Distribution of mean score and standard deviation for stigma

| Type                     | Total mean score | Std. deviation |
|--------------------------|------------------|----------------|
| Personalized stigma      | 38.31            | 2.511          |
| Negative Self Image      | 27.46            | 2.518          |
| Public Attitudes         | 33.09            | 2.862          |
| Disclosure Concerns      | 23.97            | 2.055          |
| Total                    | 122.82           | 6.66           |

Figure 1 shows that maximum prevalence of stigma seen regarding disclosure of HIV status (58.63%) followed by negative self-image stigma (43.45%), personalized stigma (38.39%), and public attitudes (37.8%).

It is observed in Figure 2, the range for personalized stigma ranges from 31 to 46, negative self-image 21 to 34, public attitude 27 to 41, whereas stigma related to disclosure concern ranges from 19 to 30. The distribution of score of stigma related to negative self-image is positively skewed, as most of the participants shows higher scores for the same. Similarly, distribution of scores related to disclosure concerns is negatively skewed, as most of the participants shows lower scores for the same. However, distribution of personalized stigma and stigma about public attitude is symmetrical.

Discussion

It is an observational cross-sectional study done in the ART center of a tertiary care hospital in an urban area. Total 336 HIV-positive patients were receiving ART selected as study subjects. The data collected by filling the case record forms and a questionnaire related to Berger’s HIV stigma scale.

This study determined that Personalized stigma, Negative Self Image stigma, stigma related to Public Attitudes and Disclosure Concerns stigma observed in 38.39%, 43.45%, 37.80%, and 58.63% of study subjects. Though the maximum participants revealed stigma about disclosure concerns, higher scores are seen in Negative self-image stigma.

Chitra et al.[6] observed that the mean score of stigma was more than 60% for each domain with the highest score for disclosure followed by public attitude and a study by Charles et al.[7] reported that 27% of PLWHA experience severe stigma. Maximum stigma was seen for negative self-image in 30.3%, followed by personalized stigma 28.8%, followed by 26% in disclosure concern and 18.2% in public attitude.

Toth al et al.[8] studied HIV stigma in HIV-positive and HIV-negative patients in a community dental clinic; the HIV-negative cohort had a higher stigma score, including personalized stigma, disclosure concerns, negative self-image, and public attitudes. The disclosure concern represented the most significant deviation between the two cohorts.

Koyra[9] performed a cross-sectional study to assess adherence and predictors of poor adherence among adult ART patients.
at Dubbo St. Marry Hospital, Southern Ethiopia. 81.3% of the respondents reported that they suffer from stigma due to their HIV status. The majority (48.7%) of respondents said they avoid friends or relatives due to stigma during ARV treatment. However, rest respondents, 104 (32.6%), reported having self-stigma.

Murtidharan et al.[10] conducted a cross-sectional study among 170 adults on ART in Raichur Taluka, Karnataka, India. They observed that 25.3% of the 170 participants isolated themselves, whereas 30% voluntarily avoided functions and get-togethers. In comparison, older men reported staying indoors and not meeting friends and relatives. 91.8% of patients’ families knew their seropositive status, and 10.9% of their family members had changed in attitude towards the patient. In addition, 18.2% had revealed their status to their friends, of which 12.9% faced discrimination.

Nikus Fido et al.[11] carried a facility-based cross-sectional study in ART clinics in Jimma town. The mean score of experienced HIV stigma was 41.5 ± 12.6 (20.0–86.7), internalized stigma was 50.5 ± 16.4 (20–96.5), and perceived stigma was 56.2 ± 19.2 (20–100).

Zhang et al.[12] performed a cross-sectional study in the Guangxi Autonomous Region (Guangxi) in China to measure various types of stigma. The mean score of perceived, internalized and enacted stigma was 15.53 ± 3.53, 18.49 ± 4.35 and 2.09 ± 0.45, respectively. The author concluded from the research that stigma increases the chances of depression and anxiety, significantly affects physical health and physical activity and is more likely to report a higher viral load level than people who had lower stigma scores.

Datta et al.[13] conducted an observational cross-sectional study among 454 patients aged ≥18 years attending the ART center of North Bengal to assess perceived stigma among the study subjects. They revealed that the mean perceived stigma score is 100.53 (± 14.45 SD). Males were with higher levels of overall stigma than their female counterparts did. The majority of the study population (50.7%) had a low stigma, followed by 42.7% who had a moderate stigma. In comparison, only 2.2% of subjects had a high level of stigma, and 4.4% had a minimal stigma.

Li et al.[14] in a study among HIV-positive patients in Chiang Mai, Thailand used revised Berger scale to determine the HIV related stigma. It was observed that mean total score for HIV-related stigma was 21.12 with standard deviation 5. It was also seen that HIV related stigma was negatively correlated with treatment adherence.

A study conducted by Teshale and Tesema[15] using the 15 Demographic and Health Survey data in Sub-Saharan Africa (SSA) from 2015 to 2019/20 with a total weighted study sample of 318,186 showed that the prevalence of discriminatory attitude towards HIV/AIDS in the 15 sub-Saharan African nations was 47.08% (95% CI: 47.08, 47.42).

In a cross-sectional descriptive hospital-based study conducted by Sahoo et al.[16] among 400 patients attending ART Centre at a tertiary medical college hospital in Haryana, India, it was found that the overall mean stigma score was 110.96 ± 17.05. The mean score for the 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). The mean score in each individual subscale in males was higher than in females and male study subjects reported higher stigma (60%) than females (40.5%). Study subjects aged 36–45 years experienced four times less stigma than those aged 18–25 year age group. Meanwhile, widower/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 than that in joint families. Similarly, urban respondents experienced ten times lesser stigma than their rural counterparts.

A study conducted by Kalichman et al.[17] among 251 PLHA participants attending a publicly funded HIV clinic in Central Georgia serving a small city and surrounding rural areas reported a total of 109 (47%) participants experiencing at least one enacted stigma event over the 12-month observation period associated with younger age. The most common occurring stigma experiences were family reactions and acts of discrimination, with the least common experience being participant avoidance of care to conceal their HIV status.

In a descriptive cross-sectional study conducted by Oduenyi et al.[18] among 100 PLWHA residing in Abuja Municipal Area Council Nigeria, it was found that HIV/AIDS stigma prevalence was high at 67%, with a mean age of 33.01 years (SD ± 5.94 years) for respondents.
In a cross-sectional study design approach utilizing secondary data from the Indonesian Demographic Health Survey (IDHS) published by Nursalam et al.\(^{19}\) among 15,413 PLWH respondents from Indonesia, the results showed that the majority of respondents, 78.87%, discriminated against PLWH.

Conclusions

Despite awareness regarding HIV/AIDS, PLWA is the victim of stigma and discrimination in society. Stigma hinders the delivery of effective medical social care. PLWA need to have greater involvement in their care and support. Support groups of PLWA need to be established so that stigma and discrimination at various levels can be challenged collectively. Social inclusion and empowerment of PLWA are intervention for stigma reduction.

Recommendations

A robust agenda is required to guide a comprehensive AIDS stigma research program with an explicit aim to fill the existing gap in knowledge and develop evidence-based stigma reduction intervention. The role of media in creating awareness about the disease is unmatchable. To conquer the stigma and discrimination positive message about social acceptance of PLWA should be disseminated worldwide. In addition, positive cultural, social values like warmth, love and affection within the family and community should be reinforced through the media, which will decrease the stigma and discrimination faced by PLWA.

Limitations

The experience of stigma by the study subject is a very subjective feeling. It is impossible to assess objectively why a particular person becomes a target for stigma and discrimination.

Acknowledgement

Special gratitude to Dr. Balkrishna B. Adsul, Additional Professor, Department of Community Medicine, for his guidance and support. Heartfelt thanks to all the staff members of ART center, LTMMC and GH, Sion for their continuous assistance and cooperation during data collection. A special thanks to study participants who have given their precious time.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Key Messages

Stigma and discrimination faced by HIV positive patients receiving ART

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Goffman E. Stigma-Notes on the Management of Spoiled Identity. Englewood Cliffs, N.J.: Prentice-Hall; 1963. p. 1-121.
2. Live and let live: Acceptance of PLWA in an era where stigma and discrimination persist. ICMR Bull 2002;32.
3. Patel BH, Srivastava RK, Sharma R, Moitra M. A qualitative study on experience of stigma and discrimination in health care sector among PLHA attending VCTC of new civil hospital and GSNP+of Surat. Natl J Community Med 2016;7:82-7.
4. UNAIDS. HIV-related Stigma and Discrimination: A Summary of Recent Literature. Geneva; 2009.
5. Jeyaseelan L, Kumar S, Mohanraj R, Rebekah G, Rao D, Manhart LE. Assessing HIV/AIDS stigma in South India: Validation and abridgement of the Berger HIV stigma scale. AIDS Behav 2013;17:434-43.
6. Chiitra L, Jayalakshmi L, Vinod R. Stigma in women living with HIV in Coimbatore district of Tamil Nadu. IOSR J Dent Med Sci 2014;13:29-32.
7. Charles B, Jeyaseelan L, Pandian AK, Edwin A, Author S, Thenmozhi M, et al. Association between stigma, depression and quality of life of people living with HIV/AIDS (PLHA) in south India-a community based cross sectional study. BMC Public Health 2012;12:463. doi: 10.1186/1471-2458-12-463.
8. Toth S, A. York J, DePinto N. HIV stigma: Perceptions from HIV-positive and HIV-negative patients in a community dental clinic. J Dent Res Dent Clin Dent Prospects 2016;10:263-9.
9. Koyra HC. Adherence to antiretroviral therapy among adult persons living with HIV/AIDS in Southern Ethiopia. Int J Virol AIDS 2018;5:1-9. doi: 10.23937/2469-567X/1510038
10. Muralidharan S, Acharya AK, Margabandhu S, Purushottaman S, Kannan R, Mahendrarak S, et al. Stigma and discrimination faced by HIV-infected adults on antiretroviral therapy for more than 1 year in Raipur. J Contemp Dent Pract 2017;18:765-70.
11. Neno Fido N, Aman M, Brihnu Z. HIV stigma and associated factors among antiretroviral treatment clients in Jimma town, Southwest Ethiopia. HIV/AIDS-Res Palliat Care 2016;8:183-93.
12. Zhang C, Li X, Liu Y, Qiao S, Zhang L, Zhou Y, et al. Emotional, physical and financial burdens of stigma against people living with HIV/AIDS in China. AIDS Care 2016;28:124-31.
13. 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 Diagnostic Res 2016;10:VC09-12.
14. Li MJ, Murray JK. Stigma, social support and treatment adherence among HIV positive patients in Chiang Mai, Thailand. AIDS Educ Prev 2014;26:471-83.
15. Teshale AB, Tesema GA. Discriminatory attitude towards people living with HIV/AIDS and its associated factors among adult population in 15 sub-Saharan African nations. PLoS One 2022;17:e0261978.
16. 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.

17. Kalichman SC, Katner H, Banas E, Hill M, Kalichman MO. HIV-related stigma and non-adherence to antiretroviral medications among people living with HIV in a rural setting. Soc Sci Med 2020;258:113092. doi: 10.1016/j.socscimed.2020.113092.

18. Oduenyi C, Ugwa E, Ojukwu Z, Ojukwu-Ajasigwe J. An exploratory study of stigma and discrimination among people living with HIV/AIDS in Abuja municipal area council, Nigeria. Afr J Reprod Health 2019;23:88-99.

19. Nursalam N, Sukartini T, Arifin H, Pradipta RO, Mafula D, Ubudiyah M. Determinants of the discriminatory behavior experienced by people living with HIV in Indonesia: A cross-sectional study of the demographic health survey. Open AIDS J 2021;15:1-9. doi: 10.2174/1874613602115010001.