International Journal of Community Medicine and Public Health
Rajmohan P et al. Int J Community Med Public Health. 2020 Apr;7(4):1498-1503
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: http://dx.doi.org/10.18203/2394-6040.ijcmph20201463

Original Research Article

A study on the impact of HIV related stigma on adherence to anti-retroviral treatment among people living with HIV/AIDS in central Kerala, India

Priyanka Rajmohan*, Joe Thomas, Jubina Bency Anthoora Thodi, Unnikrishnan Uttumadathil Gopinathan

Department of Community Medicine, Jubilee Mission Medical College and Research Institute, Thrissur, Kerala, India

Received: 31 January 2020
Revised: 04 March 2020
Accepted: 05 March 2020

***Correspondence:**
Dr. Priyanka Rajmohan,
E-mail: priyankarajmohan@gmail.com

ABSTRACT

Background: In India, an estimated 20,88,638 people are living with HIV/AIDS (prevalence 0.27%). The people living with HIV/AIDS (PLHA) are facing double burden of physical and psychosocial impact of infection. This study is conducted to determine prevalence of HIV related stigma among PLHA and to find the association between stigma and adherence to Anti-Retroviral Therapy (ART) among HIV patients in central Kerala.
Methods: A cross-sectional study was done from July to December 2018 among 105 adult HIV positive patients who have enrolled in Thrissur Network of People living with HIV/AIDS (TNP PLUS). After obtaining informed consent, the participants were interviewed using a structured interview schedule consisting of questions on socio-demographic details, stigma and ART adherence.
Results: The prevalence of high stigma was found to be 21% and moderate stigma 61%.Out of 105 study subjects,68 (64.8%) were found to have a high adherence to ART (≥95%) and 37 (35.2%) were found to have a low adherence (<95%). Patients who had a moderate/high internalized stigma tend to have a low adherence to ART as compared to patients who had low stigma (OR=3.4 (1.2-12.8) p=0.04). On analyzing the association between the different forms of stigma and adherence to ART, isolation by family members, abandoned by friends and verbal stigma were significantly associated with low ART adherence.
Conclusions: HIV related internalized stigma was pervasive among the study subjects. These patients also experience other forms of enacted stigma. The presence of internalized stigma was found to be significantly associated with low adherence to ART.

Keywords: Adherence, Anti-retroviral therapy, HIV related stigma, People living with HIV/AIDS

INTRODUCTION

According to estimates by WHO and UNAIDS, 36.9 million people were living with HIV globally at the end of 2014.[1] In India, the adult HIV prevalence is 0.27% with an estimated 20,88,638 people living with HIV/AIDS.[2] The people living with HIV/AIDS (PLHA) are facing the double burden of physical and psychosocial impact of the infection. Many of them face stigmatizing reactions from the society in which they live and work, which in turn lead to developing a negative self-image, depression and social withdrawal. HIV related stigma is manifested as prejudice, discrediting and discrimination directed at people perceived to have HIV, along with the groups and communities to which they belong.

HIV related stigma has serious public health impact. It is the single most important factor which makes the patient reluctant to test for HIV, disclose the positive result to partner, noncompliance to Anti-Retroviral therapy and not accessing preventive services. UNAIDS defines HIV-related stigma and discrimination as a process of devaluation of people either living with or associated with HIV and AIDS. Discrimination follows belief in negative stereotypes associated with stigma resulting in unfair and unjust treatment of an individual based on his or her real or perceived HIV status.[3]

According to National Family health survey (NFHS) 3 surveys, only 34% of female and 37% of male respondents gave non stigmatizing replies to individual questions focused on HIV related stigma.[4] Several Indian studies have reported that PLHA face a high prevalence of stigma.[5,6] Majority of HIV patients, at some point of time after their diagnosis, experience feeling of self-hatred, guilt and shame which may be expressed as depression. Stigma also affects adherence to therapy and thereby potentially increasing the risk of HIV transmission.[7]Even after thirty years of reporting of the first case of HIV in India, and the efforts by the NACO to reduce stigma and discrimination towards PLHA, HIV related stigma, especially internalized stigma, still remains widely prevalent among HIV patients and act as a major constrain to ART adherence.

In spite of the fact that HIV related stigma is pervasive in the PLHA and it adversely affects the treatment, there is absolute dearth of published literature on HIV related stigma, and its impact on ART adherence. Better knowledge and understanding of these factors will inform more comprehensive strategies for disclosure of HIV status, and HIV transmission risk initiatives amongst PLHA including adherence to ART treatment. The present study is conducted to gather information regarding the prevalence of HIV related stigma among PLHA and also to find out whether there is an association between stigma and adherence to ART among HIV patients in central Kerala in South India.

Aim of the study was to study the impact of HIV related stigma on adherence to Anti-Retroviral Treatment (ART) among People living with HIV/AIDS in central Kerala.

Objectives of the study were

- To determine the prevalence of HIV related stigma among People Living with HIV/AIDS.
- To assess the impact of HIV related stigma on adherence to Anti-Retroviral Treatment among the study subjects.
- To evaluate the factors associated with HIV related stigma among the study subjects.

METHODS

A cross-sectional study was done from July 2018 to December 2018 among the adult HIV positive patients (≥18 years), who have enrolled in the Thrissur Network of People living with HIV/AIDS (TNP PLUS), those who met the eligibility criteria was included in study.

Inclusion criteria

- HIV positive patients, registered in the Thrissur network of people living with HIV/AIDS association, aged 18 years and above.
- Patients initiated on ART treatment and had been on treatment for at least six months.
- Patients who are willing to give consent to participate in the study.

Exclusion criteria

- Patients who are physically unfit to attend the interview.
- Those who do not give consent to participate in the study.

There were 105 adult HIV positive patients, who satisfy the inclusion criteria and have registered with the Thrissur network of People Living with HIV/AIDS. All of them were included in the study.

Study tools and data collection

Data was collected using a structured interview schedule consisting of questions on sociodemographic details and to measure stigma, and ART adherence. Stigma was measured using the negative self-image subscale of the revised HIV stigma scale.[8,9] It consisted of seven questions with emphasis on self-blame and concealment of HIV status. It was tested for internal validity and had Cronbach's coefficient alpha (ά) more than 0.7. The median of the scale was used as the cut-off point between patients who had internalized stigma and who did not.

Four forms of stigma were reported dichotomously as yes or no, and the results are presented as frequencies of each item. Dimensions of stigma that were assessed included Isolation (5 items), verbal stigma (2 items), Loss of identity or role (2 items) and loss of access to resource and livelihood (5 items). Adherence to ART was assessed using a structured, self-report questionnaire developed by Adult AIDS Clinical Trials Group10. Adherence index was calculated by the formula:

$$\frac{\text{Total number of pills taken}}{\text{Total number of pills prescribed}} X\ 100$$

Patients with more than 95% of adherence were considered as having high adherence and those with less than 95% were considered as having low adherence.

Statistical analysis

Data was coded and entered into Microsoft excel and analyzed using SPSS version 20. Qualitative data was

expressed in frequencies and percentages, and quantitative data in mean and standard deviation. Association between HIV related stigma and ART adherence was assessed using chi-square tests. P value <0.05 was considered to be statistically significant.

Ethical consideration

Study was initiated after obtaining approval from the Institutional ethical committee. Prior permission was attained from the authorities of TNP PLUS organization. Informed consent was taken from each study participant before including them in the study. Strict confidentiality was assured to the study participants.

RESULTS

Socio-demographic profile of the study subjects

The mean age of the study population is 45±7.86 years. Majority of the study subjects, 75 (71.4%) were in the age group 30-49 years. Female constituted 61 (58.1%) of the study subjects. More than half, 63 (60%) were married, whereas, 34 (32.4%) were either widowed or divorced. Hindus constituted 62 (59%) of the study subjects, 35 (33.3%) were Christians and 8 (7.6%) were Muslims. Majority of the study participants, 80 (76.2%) had an educational qualification of secondary school and below. There were 58 (55.2%) participants who were employed and 47 (44.8%) who were unemployed (Table 1).

Table 1: Sociodemographic details of the study subjects.

	Variable	Number	%
Age group (Years)	18-29	3	2.9
	30-49	75	71.4
	50-69	27	25.7
Gender	Male	44	41.9
	Female	61	58.1
Marital status	Married	63	60
	Unmarried	1	1
	Divorced/widowed	34	32.7
	cohabiting	7	6.7
Religion	Hindu	62	59
	Christian	35	33.3
	Muslim	8	7.6
Education	Secondary and below	80	76.2
	Higher secondary and above	25	23.8
Occupation	Employed	58	55.2
	Unemployed	47	44.8

Magnitude of HIV related internalized stigma

Majority of the study subjects, 64 (61%) had moderate levels of HIV related internalized stigma, while 22 (21%) of them had a high level of internalized stigma. The overall prevalence of HIV related internalized stigma (moderate and high stigma) in this study was found out to be 82%. 19 (18.1%) of the respondents had a low level of internalized stigma (Table 2). In this study males, 42 (95.5%) were experiencing a higher level of self-stigma, than females, 44 (72.1%).

Table 2: Magnitude of HIV related internalized stigma.

Level of internalized stigma	Number	%
High stigma	22	21
Moderate stigma	64	61
Low stigma	19	18
Total	105	100

Forms of stigma

Table 3 summarizes the forms of stigma as experienced by the study participants, i.e., being treated differently by others because of their HIV positive serostatus. The assessment was done by asking a series of questions for each of the four stigma forms, namely, isolation, and verbal stigma, loss of identity/ role and loss of access to resources.

Adherence to anti-retroviral treatment

Out of the total 105 study subjects, 68 (64.8%) were found to have a high adherence to Anti-Retroviral treatment (≥95%). 37 (35.2%) were found to have a low adherence (<95%). Among patients with low ART adherence, 22 (21%) said that they forgot to take the medicine, 13 (12.4%) did not consume medication due to side effects of medicines (Figure 1).

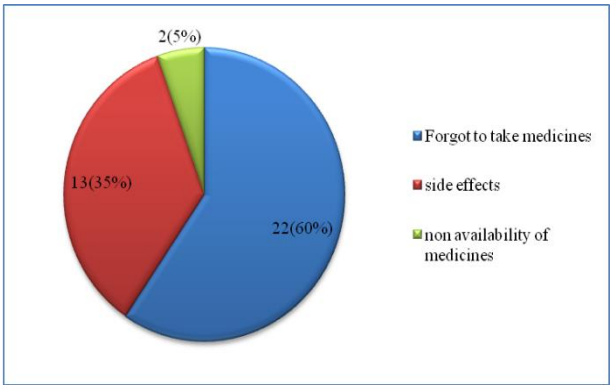

Figure 1: Reasons for low ART adherence.

Association between HIV related stigma and ART adherence

HIV patients who had a moderate/ high internalized stigma tend to have a low adherence to anti-retroviral treatment as compared to patients who had low stigma (OR=3.4 (1.2-12.8); p=0.04).

Table 3: Forms of stigma experienced by the study participants.

Forms of stigma			Number	%
Isolation	Isolated from social gathering	Yes	11	10.5
		No	94	89.5
	Abandoned by spouse/partner	Yes	15	14.3
		No	90	85.7
	Abandoned/sent away by family	Yes	5	4.8
		No	100	95.2
	No longer visited/visited less by family and friends	Yes	14	13.3
		No	91	86.7
	Isolated in household	Yes	12	11.4
		No	93	88.6
Verbal stigma	Teased/insulted/sworn at	Yes	9	8.6
		No	96	91.4
	Gossiped about	Yes	21	20.0
		No	84	80.0
Loss of identity/role	Loss of respect within family/community	Yes	25	23.8
		No	80	76.2
	Denied religious rites/services	Yes	10	9.5
		No	95	90.5
Loss of access to resources	Loss of job	Yes	9	8.6
		No	96	91.4
	Loss of promotion	Yes	1	1.0
		No	104	99.0
	Lost housing	Yes	11	10.5
		No	94	89.5
	Given poor quality health service	Yes	9	8.6
		No	96	91.4

Table 4: Association between HIV related stigma and adherence to ART.

		Low adherence	High adherence	P value	OR (95% CI)
Type of stigma	Moderate/high stigma	34	52	0.04*	3.4 (1.2-12.8)*
	Low stigma	3	16		
Isolation from gathering	Yes	14	19	0.3	1.5 (0.6-3.6)
	No	23	49		
Isolation by partner	Yes	6	9	0.6	1.2 (0.4-3.8)
	No	31	59		
Abandon by family	Yes	10	12	0.25	1.7 (0.6-4.4)
	No	27	56		
Abandon by friends	Yes	27	35	0.03*	2.5 (1.1-6.1)*
	No	10	33		
Isolated in family	Yes	22	20	0.003*	3.5 (1.5-8.1)*
	No	15	48		
Teased about	Yes	21	25	0.04*	2.2 (1.2-5.1)*
	No	16	43		
Gossiped about	Yes	22	31	0.17	1.7 (0.7-3.9)
	No	15	37		
Loss of respect in family	Yes	27	33	0.01*	2.8 (1.2-6.8)*
	No	10	35		

Table 5: Association between other selected variables and adherence.

	Variables	Low adherence	High adherence	P value
Age group (in years)	18-29	0	3	0.25
	30-49	25	50	
	50-69	12	15	
Gender	Male	19	25	0.14
	Female	18	43	
Marital status	Married	25	38	0.23
	Unmarried	1	0	
	Divorced/widowed	10	24	
	Cohabiting	1	6	
Religion	Hindu	24	38	0.34
	Christian	12	23	
	Muslim	1	7	
Occupation	Employed	19	39	0.55
	Unemployed	18	29	
Education	Secondary school and below	27	53	0.56
	Higher secondary and above	10	15	

Regarding the association between the different forms of stigma and adherence to ART, isolation by family members, abandoned by friends and verbal stigma were significantly associated with low ART adherence (Table 4).

Other factors like age, gender, marital status, religion, education and employment status were analyzed for association with adherence to ART, but there was no statistically significant association between these socio-demographic factors and treatment adherence.

DISCUSSION

The present study found that, HIV related internalized stigma is pervasive among the HIV positive individuals. The prevalence of high stigma was 21% and that of moderate stigma was 61%. The overall prevalence of HIV related internalized stigma was found to be 82%. In the study, males, 42 (95.5%) were experiencing a higher level of self-stigma, than females, 44 (72.1%). In a study done by Yakhmi et al, in Punjab, females had higher stigma scores when compared to males.[11]

The study also enquired about the different forms of enacted HIV related stigma experienced by the subjects. 10.5% of the subjects said that they were isolated in the society due to their HIV status. Partner isolation was faced by 14.3% of the study subjects and 11.4% said that they were isolated in their own household. Verbal stigma was experienced in the form of gossip/tease by 20% of the study subjects. 23.8% of them lost respect within their own family/community and 8.6% of them believe that they were given poor quality of health services. Various qualitative studies done by Nyablade et al and Mahendra et al, support presence of patterns that reflect negative attitudes towards PLHA within the community and from health care providers that would support these high levels of enacted stigmatizing.[12,13]

Adherence to the prescribed antiretroviral treatment was assessed and it was found that 37 (35.2%) of the study subjects had a low adherence (<95%) to medications. The most important reason for low adherence in this study was forgetfulness and experience of side effects of medications. This finding was consistent with the adherence level assessed in another study done by Hansana et al, where nonadherence to the prescribed medication and dosage was reported by 39.1% PLHIV. The major reasons given for non-compliance were being too busy and forgetfulness (97.0% and 62.2%) respectively.[14]

Another study by Pahari et al, in West Bengal, found that 73 per cent of the study participants were in 'well adherent' category and the remaining 35 (27%) were grouped as 'poorly adherent.[15]

On analyzing the association between the presence of HIV related stigma and ART adherence, the present study found out that those with high levels of stigma were likely to be having low adherence to anti-retroviral therapy and the association was found to be statistically significant. A study done by Sayles et al, also found a statistically significant association between stigma and ART adherence.[16]

Other sociodemographic factors were not found to be significantly associated with adherence to treatment. A study done by A. Sarna et al, at Pune, it was found that less than university education, being unemployed were associated with lower adherence.[17]

CONCLUSION

There is lack of awareness and inadequate knowledge related to dog bite and its management: 77% were aware that dog bite causes disease; whereas out of these 46.8% were aware that Rabies is caused by dog bite. 44.4% participants were aware that dog bite wound should be cleaned with soap and water, 95.8% were aware about the vaccine availability for the dog bite. Eighty eight percent of dog bite victims received treatment.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. World Health Organization - 'Ten Facts on HIV/AIDS'- available at: http://www.who.int/features/qa/71/en/. Accessed 10 January 2020.
2. Department of AIDS Control Ministry of Health and Family Welfare Government of India; state fact sheets March 2014. Available at: naco.gov.in. Accessed on 26 January 2020.
3. Progress Report on the Global Response to the HIV/AIDS Epidemic, 2003 - Follow-up to the 2001 United Nations General Assembly Special Session on HIV/AIDS (UNAIDS, 2003) available at: http://data.unaids.org/topics/ungass2003/ungass_report_2003_en.pdf. Accessed 10 January 2020..
4. HIV/AIDS-related knowledge, attitudes, and behavior; chapter 11 of the NFHS-3 final report; available at: http://hetv.org/india/nfhs/nfhs3/NFHS-3-Chapter-11-HIV-AIDS-Related-Knowledge-Attitudes-and-Behaviour.pdf. Accessed 10 January 2020.
5. Stevelink SA, Van Brakel WH, Augustine V. Stigma and social participation in Southern India: Differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS. Psychol Health Med. 2011;16(6):695-707.
6. 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.
7. Zelaya CE, Sivaram S, Johnson SC, Srikrishnan AK, Suniti S, Celentano DD. Measurement of self, experienced, and perceived HIV/AIDS stigma using parallel scales in Chennai, India. AIDS Care. 2012;24(7):846-55.
8. Bunn JY, Solomon SE, Miller C, Forehand R. Measurement of stigma in people with HIV: a reexamination of the HIV Stigma Scale. AIDS Edu Preven. 2007;19(3):198-208.
9. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale¶. Res Nurs Health. 2001;24(6):518-29.
10. Adult AIDS Clinical Trial Group-Baseline and follow up adherence questionnaires. Available at: www.fstrf.org./qol/aactg/adult_ql.htm. Accessed 10 January 2020.
11. Yakhmi S, Sidhu BS, Kaur B, Dalla EK. Study of HIV related stigma in people living with HIV/AIDS (PLHA): Role of gender differences. Ind J Sci Res. 2014;5(2):35-9.
12. Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works?. J Inter AIDS Soci. 2009;12(1):15.
13. Mahendra VS, Gilborn L, Bharat S, Mudoi R, Gupta I, George B, et al. Understanding and measuring AIDS-related settings: A developing country perspective. SAHARA-J: J Soci Aspe HIV/AIDS. 2007;4(2):616-25.
14. Hansana V, Sanchaisuriya P, Durham J, Sychareun V, Chaleunvong K, Boonyaleepun S, et al. Adherence to antiretroviral therapy (ART) among people living with HIV (PLHIV): a cross-sectional survey to measure in Lao PDR. BMC Pub Health. 2013;13(1):617.
15. Pahari S, Roy S, Mandal A, Kuila S, Panda S. Adherence to anti-retroviral therapy and factors associated with it: a community based cross-sectional study from West Bengal, India. Ind J Medi Res. 2015 Sep;142(3):301.
16. Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. J General Inter Med. 2009;24(10):1101.
17. Sarna A, Pujari S, Sengar AK, Garg R, Gupta I, Dam JV. Adherence to antiretroviral therapy and its determinants amongst HIV patients in India. Indian Journal of Medical Research. 2008;127(1):28-36.

Cite this article as: Rajmohan P, Thomas J, Thodi JBA, Gopinathan UU. A study on the impact of HIV related stigma on adherence to anti-retroviral treatment among people living with HIV/AIDS in central Kerala, India. Int J Community Med Public Health 2020;7:1498-503.