



EXPLORING SOCIAL AND DEMOGRAPHIC FACTORS CONTRIBUTING TO HIV/AIDS STIGMA IN URBAN INDIA

Community Medicine

Bhavesh Panot	Professor, Department Of Paediatrics, Dr G. D. Pol Foundation 's YMTAMC, Kharghar , Navi Mumbai , Maharashtra, India
Pradnya Jadhav*	Assistant Professor, Department Of Community Medicine, Rajiv Gandhi Medical College, Kalwa, Thane-400605, Maharashtra, India *Corresponding Author
Jayesh Panot	Associate Professor, Department Of Paediatrics, Rajiv Gandhi Medical College, Kalwa, Thane-400605, Maharashtra, India

ABSTRACT

Title: Exploring Social and Demographic Factors Contributing to HIV/AIDS Stigma in Urban India **Aims and objectives:** 1. To Analyze the Socio-Demographic Characteristics of Individuals Living with HIV/AIDS 2. To Evaluate the Stigma Experienced by Individuals Living with HIV/AIDS 3. To Identify Determinants Influencing Stigma Among Individuals Living with HIV/AIDS **Material & Methods:** A descriptive cross-sectional study was conducted between Jan and March 2014 (3 months) on newly registered HIV positive persons, of either gender, aged between 18 and 60 years attending Antiretroviral therapy Centre in a teaching hospital in Mumbai. Socio-demographic profile data & data pertaining to stigma were collected using HIV Stigma scale questionnaire containing subscales such as personalized stigma, disclosure negative self image and public attitude from those subjects consenting for studies. Data were analyzed using SPSS software and MS Excel. **Results:** Out of 319 subjects studied, 52% were female, 40.8% belonged to 35-45 yrs age group, 80.88% were literate, 75.9% were married, 65.83% belonged to socio-economic class-II while 27.9% belonged to class-I. 52.98% had CD4 count less than 300 cells per mm³. The overall stigma experienced by subjects was 2.94 ± 0.15 , which was maximum in public attitude subscale (3.04 ± 0.18) and minimum (2.92 ± 0.16) in personalized subscale. Significant difference in stigma levels perceived between genders (female>male) literacy status (literate>illiterate), age (younger age> elder), employment status (unemployed> employed), Socio-economic status (lower socioeconomic strata > higher socioeconomic strata), family type (joint family> nuclear) observed in study with p value (<0.05) **Conclusions:** Overall Stigma experienced by people living with HIV/AIDS was (2.94 ± 0.15). Maximum score was noticed in public attitude subscale (3.04 ± 0.18) & Disclosure subscale (3 ± 0.19) whereas minimum score was noticed in personalized subscale (2.92 ± 0.16). Gender, literacy level, age, employment status, socioeconomic status and family type have significant impact on stigma perceived by PLHV

KEYWORDS

HIV/AIDS, Stigma, People living with HIV/AIDS (PLHA), B J Prasad's Classification

INTRODUCTION

According to the latest UNAIDS report, as of 2024, an estimated 38 million people worldwide are living with HIV, with 1.5 million new infections reported annually. The global HIV response has led to significant progress: approximately 29 million people now have access to antiretroviral therapy (ART), which is essential for managing HIV effectively and reducing the risk of transmission. HIV/AIDS is known to affect individual not only physically but also mental, socially & financially.[1] HIV/AIDS has been having a great impact on society both as an illness & as a source of discrimination & stigma. As HIV/AIDS pandemic continues affect population worldwide people throughout the world experience stigma & discrimination in some nor the other form. HIV/AIDS is known to affect individuals physically, mentally, socially and financially. People with HIV infection or disease suffer great psycho-social and psychological stresses through a fear of rejection, social stigma, disease progression, and the uncertainties associated with future management of HIV. Good clinical management requires that such issues be managed with consistency and professionalism, and counselling can both minimize morbidity and reduce its occurrence. [2] As HIV/AIDS pandemic continues, people throughout the world experience stigma and discrimination in some or the other form. [3] Diseases associated with the highest degree of stigma share the following common attributes - the person with disease is seen as being responsible for having illness; the disease is progressive and incurable; the disease are not well understood among the public and the symptoms cannot be concealed. [4] In the 1980's, AIDS was perceived as a lethal disease of gay men and intravenous drug users in the West and persons with promiscuous behavior in other countries. The definition of syndrome resulted in dual stigma, first from identification of AIDS as serious incurable disease and second from identification of AIDS with persons and group already stigmatized due to their behavior prior to the epidemic. The fear of death due to an incurable disease is a psychological burden for the infected individual and coping with disease is a challenge. The psycho-social impact of the disease falls on the significant others of this infected individuals e.g. spouse, family members, children, etc. As a consequence of coping with the infected individual, the healthy individual's distance themselves by defining illness as an affliction of others whose death is certain within a stipulated time. In addition, they give a moral judgement to rationalize their distancing from HIV

infected individual.[5] Initially, the epidemic had been socially defined as a disease of the marginalized groups, especially gay men and intravenous drug users. Thereby the stigma attached to AIDS was layered upon pre-layered stigma.[6] HIV/AIDS related stigma interacts with pre-existing stigma in various ways. Identification of a person with HIV/AIDS transforms a man from "discreditable" (covertly gay) to "discredited" (overtly gay). [7] On the other hand, a person who did not contract HIV/AIDS through either homosexual behavior or drug use but are infected due to their partner's behavior or got it through infected blood have been categorized as the "innocent" victims. The other group The other group of innocent victims are the children of the infected mothers. [8]

HIV-related stigma refers to all in favorable attitudes, belief & policies directed towards people perceived to have HIV/AIDS as well as towards their significant others, loved ones, close associate, social groups & communities,[9]

Objectives

1. To Analyze the Socio-Demographic Characteristics of Individuals Living with HIV/AIDS
2. To Evaluate the Stigma Experienced by Individuals Living with HIV/AIDS
3. To Identify Determinants Influencing Stigma Among Individuals Living with HIV/AIDS

MATERIAL & METHODS

It is a Ccross-sectional type of observational descriptive study. Sample Size is 319

Selection Of Subjects:

The Study was carried out at Antiretroviral therapy Centre (ART Centre) attached to Tertiary Health Care Centre between the period Jan 2014 to March 2014 using convenient sampling method, total of 319 newly registered HIV positive patients (age group 18-60 yrs) a consenting for study were included while pregnant & lactating women & seriously ill patient on ART were excluded. Data pertaining sociodemographic profile and HIV stigma scale containing subscale like public attitude, disclosure, negative self-Image, personalized was use to assess the stigma perceived by PLHV. Data was analyzed using

software SPSS 20 and Microsoft Excel 2010. Mean, Standard deviation, t test was applied to find statistical significance.

Ethics:

Institutional Ethics Committee approval was taken prior to the study.

Risk involved: Nil

RESULTS & DISCUSSION

Demographic Factors

The study population consisted of 319 individuals, with a slight majority of females (166 or 52%) compared to males (153 or 48%). The largest age group was 35–45 years, comprising 130 participants (40.8%), followed by the 25–35 age group with 107 participants (33.5%). The remaining participants were distributed as follows: 45–55 years (52 participants, 16.3%), under 25 years (26 participants, 8.1%), and over 55 years (4 participants, 1.3%).

In terms of marital status, 75.9% were married, 17.9% were widowed, 4.7% were unmarried, and 1.6% were divorced. The majority of participants (252 or 80.6%) identified as Hindu, followed by Muslims (50 or 15.7%), Buddhists (9 or 2.8%), Christians (1 or 0.3%), and others (2 or 0.6%).

Regarding educational attainment, 19.1% of participants were illiterate. Among those who were literate, 27.9% had completed primary school, 36.4% had completed secondary school, 15.7% had studied up to higher secondary, and 0.9% held a graduate degree. 113 participants (35.4%) were housewives, and 17 (5.3%) were unemployed. The unskilled worker group included 69 participants (21.6%), while 31 (9.7%) were semi-skilled workers and 89 (27.9%) were skilled workers. Among the skilled workers, 24 individuals (26.97%) were employed as drivers.

According to the Modified B J Prasad Classification, a majority of the study participants, 210 individuals (65.83%), were classified under socio-economic class II. This was followed by 89 participants (27.9%) in class I, 10 participants (3.13%) in class III, 9 participants (2.82%) in class IV, and just 1 participant (0.31%) in class V. 169 participants (52.98%) had CD4 levels below 300 cells/mm³, indicating a compromised immune status, while 150 participants (47.02%) had CD4 counts above 300 cells/mm³, reflecting relatively better immune function among this subset.

Table.1 Demographic factors of People living with HIV/AIDS

Variables		No. of Workers		Total (%)
		Male (%)	Female (%)	
Age Group (Years)	< 25	10 (6.5)	16(9.6)	26 (8.2)
	25 – 35	39 (25.5)	68 (41)	107 (33.5)
	35 – 45	68 (44.4)	62 (37.3)	130 (40.8)
	45-55	33 (21.57)	19 (11.45)	52(16.30)
	>55	3(1.96)	1(0.6)	4(1.25)
Marital Status	Unmarried	13 (8.5)	2 (1.2)	15 (4.7%)
	Married	129 (84.3)	113 (68.1)	242 (75.9%)
	Widowed	10 (6.5)	47(28.3)	57 (17.9%)
	Divorced	1(0.7)	4 (2.4)	5(1.6%)
Religion	Hindu	126(82.35)	131(78.92)	257(80.56)
	Muslim	22(14.38)	28(16.87)	50(15.67)
	Buddhists	4(2.61)	5(3.01)	9(2.82)
	Christian	1(0.65)	0(0)	1(0.31)
	Others	0(0)	2(1.2)	2(0.63)
Literacy Status	Illiterate	24 (15.7%)	37 (22.3%)	61 (19.1%)
	Primary	43 (28.1%)	46 (27.7%)	89 (27.9%)
	Secondary	55 (35.9%)	61 (36.7%)	116 (36.4%)
	Higher Secondary	28 (18.3%)	22 (13.3%)	50 (15.7%)
	Graduate	3 (2%)	0 (0%)	3 (0.9%)
Occupation Skills	Unemployed	15 (9.2)	2 (1.2)	17(5.3)
	Unskilled	35 (22.9)	34 (20.5)	69 (21.6)
	Semi skilled	31 (20.3)	0	31 (9.7)
	Skilled	72 (47.05)	17(10.2)	89 (27.9)
	Housewife	0	113 (66.9)	113 (35.4)
SES	Upper	40(26.14)	49(29.52)	89(27.90)
	Upper middle	109(71.24)	101(60.84)	210(65.83)
	Middle	1(0.65)	9(5.42)	10(3.13)

	Lower Middle	2(1.31)	7(4.22)	9(2.82)
	Lower	1(0.65)	0(0)	1(0.31)
CD4 count	<300	85(55.56)	84(50.60)	169(52.98)
	>300	68(44.44)	82(49.40)	150(47.02)
Total		153	166	319 (100)

Table 2: Stigma experienced by people living with HIV/AIDS

Domain	Mean	Standard deviation
Overall Stigma	2.94	0.15
Public attitude subscale	3.04	0.18
Disclosure subscale	3	0.19
Negative Self Image subscale	2.94	0.19
Personalized subscale	2.92	0.16

Table 2: shows descriptive statistics of scores in various subscales of Stigma scale measured in the subjects. The stigma score was lowest in Personalized subscale (2.92±0.16) followed by Negative Self Image subscale (2.94±0.19). The stigma score was highest in Public attitude subscale (3.04±0.18) & Disclosure subscale (3±0.19)

Table 3: Socio demographic determinant of Stigma experienced by people living with HIV/AIDS

Variable		N	Mean	Standard deviation	P value
Gender	Male	153	113.16	2.38	0.000*
	Female	166	121.56	5.28	
Literacy status	Illiterate	61	65.74	3.27	0.000*
	Literate	258	75.39	3.70	
Age Group	<25	26	74.19	5.12	0.007*
	25-35	107	73.81	4.80	
	35-45	130	73.29	5.66	
	45-55	52	74.02	4.68	
	>55	4	64.25	2.50	
Marital Status	Unmarried	15	73.28	4.04	0.248
	Married	242	73.27	5.27	
	Divorced	5	72.20	3.42	
	Widowed	57	72.37	5.463	
Employment Status	Unemployed	130	123.05	4.84	0.000*
	Employed	189	113.74	2.70	
Religion	Hindu	257	73.66	5.28	0.631
	Muslim	50	72.90	5.18	
	Buddhist	9	73.89	5.33	
	Christian	1	67	0.00	
	Others	2	75	1.41	
Socioeconomic status	I. Upper	89	119	6.89	0.000*
	II. Upper middle	210	116	5.41	
	III. Middle	10	114.60	2.32	
	IV. Lower middle	9	123.56	1.24	
	V. Lower	1	129	0.00	
Type of family	Nuclear	299	116.54	4.49	0.000*
	Joint	20	132.30	4.62	

Table 3 : The analysis indicates that certain socio-demographic factors significantly influence the stigma experienced by people living with HIV/AIDS. These factors include gender, literacy status, age group, employment status, and low socio-economic status ($P < 0.005$). In contrast, marital status and religion were not found to have a significant impact on stigma levels.

When comparing total stigma scores, women reported experiencing higher levels of stigma than men. Furthermore, individuals who were literate experienced more stigma than those who were illiterate. Age also played a role, with participants under 25 years and those in the 45–55 age group reporting higher stigma levels than other age groups. Similarly, unemployment and lower socio-economic status were associated with an increased vulnerability to stigma, highlighting these as critical factors in understanding and addressing stigma within this population.

The present study highlight stigma experienced by PLHV in different subscale with highest score in Public attitude subscale (3.04±0.18) & Disclosure subscale (3 ± 0.19) & lowest in Personalized subscale (2.92±0.16) followed by Negative Self Image subscale (2.94±0.19). A study conducted in 2009 reflected Severe stigma in 28.8% of PLWHA

in personalized subscale, 30.3% in negative self-image subscale, 18.2% in perceived public attitude subscale, 26% in disclosure subscale [12]

An interventional study [10] conducted in Jamnagar (Gujarat) reported coercive attitude 64-71%, avoidant behavioral intentions 58-73%, blaming attitude 79-89% and sympathetic feeling 39-42%. Findings of study carried out in Maharashtra [11] 44.6% - medium level of Stigma by blaming the affected individual, 51.77% reported medium or high level of stigma in violation of rights of HIV positive individual; and medium and high level of stigma was reported in stigma in interaction. Overall disclosure rate of 69.56%, acceptance reported by 87.5%, anger reported by 16.6% respondents in a Kolkatbased study [12] Higher level health care discrimination, personal isolation and negative psychological sequelae in sero-positive women as compared to their sero negative counterparts was reported in USA based study.[13].

The present studies highlight significant difference in stigma levels between genders, with females having a higher mean score than males .Finding of Study carried out in USA provides insights into the gendered nature of HIV/AIDS stigma, specifically focusing on how societal expectations and gender norms increase stigma for HIV-positive women, [14]Study in 2004 identifies specific barriers to health faced by HIV-positive women due to stigma, such as reduced access to healthcare and social support& how stigma is often more intense for women, [15] A study carried out in USA (year 2010) investigates the impact of stigma on women's access to HIV/AIDS treatment and social services, finding that stigma can delay or discourage women from seeking care. [16]

In present study,literacy significantly impacts stigma levels ($p=0.000$), with literate individuals experiencing higher mean scores than illiterate individuals , Finding of study carried out in Sub-Saharan Africa among 14,203 participant suggest that increased awareness sometimes correlates with heightened perceived stigma, supporting the idea that literacy can influence stigma experiences among PLHA.[17] Study carried out in 4 sub-Saharan 1 southeast asia region among 655 participants discusses how higher literacy can increase perceived stigma by raising awareness of societal discrimination [18] Younger age groups report higher stigma in comparison to older age group in present study. Study in congruence with present include study by Emler C A which state stigma among older adults living with HIV and highlights that older adults may experience less perceived stigma, possibly due to increased resilience or acceptance with age.[19] Study by Rueda , et, al reviews the psychosocial issues associated with aging and HIV, noting that older adults may experience unique coping mechanisms that help reduce stigma perception. It also highlights that younger individuals may face more challenges due to concerns about future life prospects, which can increase stigma[20]

The Present study reports Unemployed individuals experiencing higher stigma than their employed counterparts, However Systematic review by Sweeney et al. Suggests that employment may reduce stigma by providing social roles, identity, and stability, aligning with findings that unemployed individuals experience higher stigma. [21] Similarly study carried out among 400 participants in 2009 indicate that unemployment is strongly associated with increased stigma and poorer quality of life[8]

The present study highlight SES significantly impacts stigma, with lower socioeconomic groups showing higher stigma levels .A systematic review and meta-analysis Zelalem G. Dessie1 et al highlights socioeconomic factors were positively associated with HIV-related stigma reports similar observation[22]

Individuals from joint families reported higher stigma levels compared to those in nuclear families A Study by Jaiswal et al in (2018) found out that individuals from joint families reported higher levels of stigma due to greater family involvement in personal matters, which sometimes led to judgment and scrutiny [23] Finding of study by Ravi et al.in (2018) highlighted that people from joint families often face more scrutiny and pressure from extended family members, which can contribute to higher stigma levels, compared to those from nuclear families where privacy and autonomy are more maintained [24]

HIV is a devastating illness that profoundly impacts various aspects of life. Therefore, the evaluation of stigma should be a mandatory component alongside medical treatment. Patient and family counseling is essential for achieving better treatment outcomes. It is crucial to focus on building the capacity of counselors and ensuring that periodic counseling sessions are provided to patients to support their ongoing care and well-being.

REFERENCES

1. UNAIDS Report on the global AIDS epidemic 2023; [internet]. Available from: <https://www.unaids.org/en/resources/fact-sheet>
2. Chippendale, S., & French, L. (2001), "HIV counselling and the psychosocial management of patients with HIV/AIDS." *BMJ*, 322(7301), 1533-1535.
3. Mann, J. M. & WHO Special Programme on AIDS. (1987), Statement at an informal brieng on AIDS to the 42nd session of the United Nations General Assembly, New York, Oct 20, 1987.
4. Goffman, E. (1963), "Stigma - Notes on the management of Spoiled Identity." Englewood Cliffs, NJ: Prentice Hall, page 3.
5. Albert, E. (1986), "Illness and deviance: The response of the press to AIDS." In: D. A. Feldman & T. M. Johnson (Eds.), *The social dimensions of AIDS: Method and theory* (p. 163-178). Westport, CT: Praeger Publishers.
6. Center for Disease Control. (1988), *AIDS Weekly Surveillance Report*, June 6, 1988.
7. Mawar, N., & Paranjape, R. S. (2002), "Live and Let Live. Acceptance of People Living with HIV/ Aids in an era where stigma and discrimination persists." *ICMR Bulletin*, 32(11&12), 105-114.
8. Charles, B., Jeyaseelan, L., Pandian, A.K., Sam, A. E., Thenmozhi, M., & Jayaseelan, V. (2012), "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* 12, 463.
9. 108 Live and let live: Acceptance of PLWHA in an era where stigma and discrimination persist, *ICMR Bulletin*. Vol 32, No. 11 & 12, Nov–Dec, 2002(108)
10. 9.Raizada, N., Somasundaram, C., Mehta, J. P., & Pandya, V. P. (2004), "Effectiveness of various IEC in improving awareness and reducing stigma related to HIV/AIDS among school going teenagers." *Ind J Community Med*, 29(1), 30-34.
11. Kaulagekar, A., & Godbole, A. (2007), "Prevalence of Stigmatizing Attitude Among Urban Middle Class in Maharashtra: Implication for HIV/ AIDS Education Strategy. *Ind J Community Med*, 32(4), 297-299.
12. Taraphdar, P., Dasgupta, A., & Saha, B. (2007), "Disclosure among People living with HIV/AIDS." *Ind J Community Med*, 32(4), 280-282.
13. Lester, P., Partridge, J. C., Chesney, M. A., & Cooke, M. (1995), "The consequences of a positive prenatal HIV antibody
14. Sandelowski, M., Lambe, C., & Barroso, J. (2004). "Stigma in HIV-positive women." *Journal of Nursing Scholarship*, 36(2), 122-128.
15. Carr, R. L., & Gramling, L. F. (2004). "Stigma: A health barrier for women with HIV/AIDS." *Journal of the Association of Nurses in AIDS Care*, 15(5), 30-39.
16. Paudel, V., & Baral, K. P. (2015). "Women living with HIV/AIDS: Stigma and access to care." *Journal of the International Association of Providers of AIDS Care*, 14(2), 136-142.
17. Genberg, B. L., Hlavka, Z., Konda, K. A., Maman, S., Chariyalertsak, S., Chingono, A., ... & Celentano, D. D. (2009). "A comparison of HIV/AIDS-related stigma in four countries: Negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS." *Social Science & Medicine*, 68(12), 2279-2287.
18. Maman, S., Abler, L., Parker, L., Lane, T., Chirowodza, A., Ntongwisangu, J., & Fritz, K. (2009). "A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings." *Social Science & Medicine*, 68(12), 2271-2278.
19. Emler, C. A. (2006). "Aging with HIV disease: Age-related challenges to health care access and quality of life in a sample of older adults." *Journal of Aging and Health*, 18(6), 754-771.
20. Rueda, S., Law, S., & Rourke, S. B. (2014). "Psychosocial, mental health, and behavioral issues of aging with HIV." *Current Opinion in HIV and AIDS*, 9(4), 325-331.
21. Sweeney, S. M., & Venable, P. A. (2016). "The association of HIV-related stigma to HIV medication adherence: A systematic review and synthesis of the literature." *AIDS and Behavior*, 20(1), 29-50.
22. Dessie ZG, Zewotir T. HIV-related stigma and associated factors: a systematic review and meta-analysis. *BMC Public Health*. 2020;20(1):202. doi:10.1186/s12889-020-8230-2.
23. Jaiswal, A. et al. "Family Structure and HIV Stigma: A Study Among People Living with HIV in India." *International Journal of Family Medicine*. 2021.
24. Ravi, S. et al. "Family Dynamics and HIV Stigma: The Role of Joint and Nuclear Family Systems." *Journal of Health and Social Behavior*. 2018.

CONCLUSIONS: