



ASSESSMENT OF STIGMA EXPERIENCED BY PEOPLE LIVING WITH HIV/AIDS (PLHA) ATTENDING ANTIRETROVIRAL THERAPY CENTRE IN A METROPOLITAN CITY

Paediatrics

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ABSTRACT

This cross-sectional study was conducted using convenience sampling technique on 319 newly registered HIV positive persons – 166 females (52.03%) and 153 males (47.97%) – (mean age: 37.90 +/- 8.33 years), attending antiretroviral therapy centre in a teaching hospital in a metropolitan city. After obtaining written informed consent, participants were interviewed for socio-demographic data and data related to stigma was collected using HIV Stigma Scale questionnaire that contained personalized stigma subscale, disclosure subscale, negative self-image subscale and public attitude subscale. Out of 319 participants, 40.8% belonged to 35-45 years age group, 80.88% were literate, 75.9% were married, 65.83% belonged to socio-economic class-II. The overall stigma experienced by participants 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. Counselling of people living with HIV/AIDS is an essential tool to build up their morale in view of the stigma experienced by them.

KEYWORDS

HIV/AIDS, People living with HIV/AIDS (PLHA), Stigma

INTRODUCTION

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 minimise morbidity and reduce its occurrence. [1] As HIV /AIDS pandemic continues, people throughout the world experience stigma and discrimination in some or the other form. [2] Diseases associated with 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. [3]

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 behaviour 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 behaviour 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 individuals 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. [4]

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. [5]

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). [6] On the other hand, a person who did not contract HIV/ AIDS through either homosexual behaviour or drug use but are infected due to their partner's behaviour or got it through infected blood have been categorized as the "innocent" victims. The other group of innocent victims are the children of the infected mothers. [7]

The objectives of the present study were to determine the socio-demographic profile of people living with HIV/ AIDS and to assess stigma faced by them.

MATERIALS AND METHODS

After obtaining approval from the Institutional Ethics Committee, this cross sectional study was conducted at antiretroviral therapy centre (ART Centre) attached to a tertiary health care centre in a metropolitan city using convenience sampling method. A total of 319 newly registered HIV positive patients (age group 18-60 years) who gave written informed consent were included, while pregnant & lactating women and seriously ill patients on ART were excluded. Data on socio-demographic profile were collected using questionnaire and data pertaining to stigma were collected using HIV Stigma scale questionnaire containing personalized stigma subscale, disclosure subscale, negative self image subscale and public attitude subscale was used to assess the stigma experienced by people living with HIV/AIDS.

Data were analyzed using software SPSS 20 and Microsoft Excel 2010. Continuous data were presented as Mean and Standard Deviation (SD) and categorical data as percentages. The 95% Confidence interval (CI) was calculated as: [Mean-(1.96)*Standard Error] – [Mean+(1.96)*Standard Error]. Statistical significance was determined at p<0.05.

RESULTS AND DISCUSSION

Demographic factors

Of the total study subjects of 319, 166 (52.03%) were females and 153 (47.97%) were males. 130 (40.8%) of the total study population belonged to 35-45 yrs age group followed by 107 (33.5%) in 25-35 yrs age group, 52 (16.30%) in age group 45-55yrs, 26 (8.15%) & 4 (1.25%) belonged to age groups < 25yrs & >55 yrs, respectively. 75.9% were married, 17.9% were widowed, 4.7% were unmarried while 1.6% of study subjects were divorced. Hindus comprised 252 (80.6%), Muslims 50 (15.7%), Buddhists 9 (2.8%), Christians 1 (0.3%) and others constituted 2 (0.6%). Of the total study subjects of 319, 19.1% were illiterates & among the literate, 27.9% of the study subjects completed primary school education, followed by 36.4% who completed Secondary school education, 15.7% studied up to Higher secondary while 0.9% of them completed Graduation. 113 (35.4%) were housewife and 17 (5.3%) were unemployed, unskilled workers accounted for 69 (21.6%), followed by semi-skilled workers 31 (9.7%) and skilled workers 89 (17.6%). Among the skilled workers, 24 (26.97%) were drivers. As per Modified B. G. Prasad Classification, [8] 210 (65.83%) of the study subjects belonged to socio-economic class-II followed by 89 (27.9%) class-I, 10 (3.13%)

class-III, 9 (2.82%) class-IV and only 1 (0.31%) of the subject belonged to class-V. (Table-1)

Table-1: Demographic factors

Parameter	Males (n=153)	Females (n=166)	Z value	'p' value	
Marital Status	Unmarried	13 (08.50%)	02 (01.20%)	3.073	0.002 *
	Married	129 (84.31%)	113 (68.07%)	3.386	0.0007 *
	Widowed	10 (06.54%)	47 (28.31%)	14.638	<0.0001 *
	Divorced	01 (0.65%)	04 (2.41%)	1.261	0.207
Literacy Status	Illiterate	24 (15.69%)	37 (22.29%)	1.498	0.133
	Primary	43 (28.10%)	46 (27.71%)	0.078	0.936
	Secondary	55 (35.95%)	61 (36.75%)	0.148	0.880
	Higher Secondary	28 (18.30%)	22 (13.25%)	1.238	0.214
	Graduate	03 (01.96%)	0 (0.00%)	1.812	0.070
Occupation	Unemployed	15 (09.80%)	02 (01.20%)	3.416	0.0006 *
	Unskilled	35 (22.88%)	34 (20.48%)	0.518	0.603
	Semi-skilled	31 (20.26%)	0 (0.00%)	6.103	<0.0001 *
	Skilled	72 (47.06%)	17 (10.24%)	7.324	<0.0001 *
	Housewife	0 (0.00%)	113 (68.07%)	12.699	<0.0001 *
Socio-economic status	Upper	40 (26.14%)	49 (29.52%)	0.671	0.502
	Upper middle	109 (71.24%)	101 (60.84%)	1.956	0.05
	Middle	01 (0.65%)	09 (05.42%)	2.441	0.014 *
	Lower Middle	02 (1.31%)	07 (04.22%)	1.568	0.116
	Lower	01 (0.65%)	0 (0.00)	1.043	0.298

Z=Standard error of difference between two proportions; *Significant

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	3.00	0.19
Negative Self Image subscale	2.94	0.19
Personalized subscale	2.92	0.16

The scores in various sub-scales of stigma scale are depicted in Table-2. 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) and Disclosure subscale (3 +/- 0.19)

Table-3: Gender-wise comparison of stigma experienced by people living with HIV/AIDS

Domain	Males (n=153) #	Females (n=166) #	'p' value
Personalized Stigma	52.28 +/- 3.08	52.62 +/- 2.81	0.314
Negative self image	38.14 +/- 2.48	38.34 +/- 2.51	0.464
Public attitude	60.66 +/- 3.76	60.78 +/- 3.37	0.747
Disclosure	30.0 +/- 2.009	29.92 +/- 1.78	0.580

#Values indicate Mean +/- Standard deviation

In a South Indian study, [7] stigma was reported in 27% of PLWHA, severe stigma - 28.8% in personalized subscale, 30.3% in negative self image subscale, 18.2% in perceived public attitude subscale, 26% in disclosure subscale & responded who experienced severe personalized

& negative self image stigma had 3.4 & 2.1 times higher risk of severe depression. An interventional study [9] conducted in Jamnagar (Gujarat) reported coercive attitude 64-71%, avoidant behavioural intentions 58-73%, blaming attitude 79-89% and sympathetic feeling 39-42%. Findings of study carried out in Maharashtra [10] 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 Kolkata-based study [11] 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. [12]

The present study highlights that stigma is experienced by people living with HIV/ AIDS in the society as well as in health care settings may be one of the reasons for non-adherence, early dropout and not seeking health care services despite being aware of serostatus.

CONCLUSION

Apart from pre- and post-test counselling, periodic counselling of the HIV positive patients is extremely important to boost the morale of the patients and for successful outcome after initiation of treatment. Counselling should also be undertaken for the family of HIV positive patients to build up the family support system for better treatment outcome of HIV positive who have been started on ART therapy. HIV is a devastating illness having profound impact on various dimensions of life, evaluation of stigma should be mandatory along with medical modality of treatment. Counselling of patients and family is utmost important for better treatment outcome. Capacity building of counsellor to periodic counselling session for patients to be emphasized upon

REFERENCES

- Chippendale, S., & French, L. (2001), "HIV counselling and the psychosocial management of patients with HIV or AIDS." *BMJ*, 322(7301), 1533-1535.
- Mann, J. M. & WHO Special Programme on AIDS. (1987), Statement at an informal briefing on AIDS to the 42nd session of the United Nations General Assembly, New York, Oct 20, 1987.
- Goffman, E. (1963), "Stigma - Notes on the management of Spoiled Identity." Englewood Cliffs, NJ: Prentice Hall, page 3.
- 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.
- Center for Disease Control. (1988), *AIDS Weekly Surveillance Report*, June 6, 1988.
- 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.
- 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.
- Dudala, S.R., Reddy, K.A.K., & Prabhu, G.R. (2014), "Prasad's socio-economic status classification - An update for 2014." *Int J Res Health Sci*, 2(3), 875-878.
- 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.
- 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.
- Taraphdar, P., Dasgupta, A., & Saha, B. (2007), "Disclosure among People living with HIV/AIDS." *Ind J Community Med*, 32(4), 280-282.
- Lester, P., Partridge, J. C., Chesney, M. A., & Cooke, M. (1995), "The consequences of a positive prenatal HIV antibody test for women." *J Acquir Immune Defic Syndr Hum Retrovirol*, 10(3), 341-349.