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An Exploratory Survey Measuring Stigma and Discrimination Experienced By People Living With HIV/AIDS

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ABSTRACT

Background: The continued presence of stigma makes it an extraordinarily important, yet difficult issue to eradicate. The study aimed to assess HIV/AIDS related stigma and discrimination trends experienced by people living with HIV/AIDS (PLHA).

Methodology: The cross sectional study was conducted in ICTC and STI clinic among 378 PLHA. Convenience sampling method was used as the study was limited to only participants who had voluntarily disclosed their HIV status could be involved for ethical reason. Consent was taken. A pre-tested questionnaire was used.

Result: Findings suggest that PLHA have experienced significant levels of stigma and discrimination. Internalized stigma was among 89% of the participants and they blamed themselves for their status. While 86% respondents facing discriminatory attitudes from the society. Stigma and discrimination observed more in female and it was statistically significant.

Conclusion: The current measures for dealing with stigma should be expanded to incorporate the issues related to health, education and discrimination experienced in various places. Family, Peer and Individual counseling should be an essential component for care of PLHA.

Key words: HIV/AIDS, Stigma, Discrimination

INTRODUCTION

During the past two decades, a number of new diseases have emerged to threaten the health of hundreds of millions of people.[1] The most dreaded four letter disease 'AIDS' when it first emerged on the global scenario was never imagined to undertake such a devastating form in such a short span.[2]

Stigma, defined as a mark of disgrace associated with a particular circumstance, quality or person, is not new to public health, nor it is unique to HIV/AIDS.[3] Stigma interferes with HIV prevention, diagnosis and treatment and can become internalized by people living with HIV/AIDS (thereafter referred to as 'PLHIV').[4] Importantly, stigma is often enacted through discrimination (defined as the rejection or prejudicial treatment of different categories of people or things, especially on the grounds of race, age, health status or gender), hostility and prejudice against PLHIV (as well as their partners and families), denying them equal access to essential services in many cases.[5]

India represents the largest burden for HIV/AIDS worldwide. The reasons may be 'S' factor:

Stigma,Shame ,Silence.

The continued presence of these three "S" makes HIV/AIDS difficult to eradicate. And rightly said *"…if we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful. AIDS is probably the most stigmatized disease in history." – Edwin Cameron.*[6]

There are three phases of AIDS epidemic in any society.[7] First phase in which epidemic of HIV infection enters in the community silently and unnoticed. In second phase, epidemic of AIDS itself triggered life threatening infection. In third phase,

there is an epidemic of Stigma & Discrimination, blame and collective denial that make it difficult to effectively tackle the first two.

The physical illness and psycho-social impact caused by HIV/AIDS and its fatal consequences jeopardize quality of life of people living with HIV/AIDS (PLHA). The study aimed to assess stigma and discrimination trends as experienced by People Living with HIV/AIDS (PLHA).

OBJECTIVES

The research was undertaken to study the socio demographic profile of PLHA affected by HIV related stigma and discrimination also to study the internalized form of stigma among PLHATo determine the attitude of family towards PLHA.

METHODOLOGY

The present cross sectional study was conducted in ICTC center and STI clinic of civil hospital Ahmedabad, with an interview of total 378 PLHA. Convenience sampling used as the study was limited to only participants who had voluntarily disclosed their HIV status could be involved for ethical reason. Consent was taken and complete anonymity was ensured. We conducted extensive literature review to find out different questionnaires that measures HIV-related stigma and discrimination that had previously been used in international research settings[8,9]. From them we have prepared the set of questionnaires with some modification and additions and used to elicit information about various types of stigma and discrimination. Exit interview was taken of every eligible and willing visitor of ICTC center and STI clinic. Data was entered in Microsoft Excel 2007 and was analyzed using Epi info 7. Chi Square test was applied.

RESULTS

Majority of study participants (82.3%) were in the age group 25- 49 years and males and females are almost equal in number in each age group. Almost one third (65%) of the participants were male. As far as marital status is concerned married participants are equal in both in males and females but proportion of unmarried among male (16.7%) is more than female (8.3%) while proportion of widower is more among females (18.3%) than males (5.7%). 93.9% of the participants were Hindus. 19.84% of the participants were illiterate. Among total female participants, 37.9% were illiterate and 47.7% were with primary education only. Illiteracy among male participants was only 10.2%. (Table 1).

In this study it is noted that majority of people (58.20%) have been living with HIV since 5-9 years. 65.8% of the participants had reported that their partners are also HIV positive. It is also seen that 22.75% participants have not disclosed their HIV status yet and most of them attributed this non disclosure to fear of stigma (Table 2). Feel ashamed and suicidal tendency were more among females than the males while other types of internalized stigma more among males. Except feeling suicidal and blaming others, association between gender and all other types of internalized stigma was found statistically significant. (Table 3).

Discrimination by family members was significantly ($p < 0.05$) more in female and except verbal harassment other discrimination like exclusion from social gathering, physical assault, exclusion from family activities etc. were more among females and this association is statistically significant(Table 4).

Table 1: Demographic profile of PLHA (n=378)

Characteristics	Male (n=246) (%)	Female (n=132) (%)	Total (%)
Age (years)			
15-24	19 (7.7)	9 (6.8)	28 (7.4)
25-49	202 (82.1)	109(82.6)	311 (82.3)
> 50	25 (10.2)	14 (10.6)	39 (10.3)
Marital status			
Single	41 (16.7)	11 (8.3)	52 (13.8)
Married	182 (73.9)	91(68.9)	273 (72.2)
Remarried	5 (2.1)	1 (0.7)	6 (1.5)
Widowed	14 (5.7)	24 (18.3)	38 (10.1)
Divorced	4 (1.6)	5 (3.8)	9 (2.4)
Religion			
Hindu	231 (93.9)	124 (93.9)	355 (93.9)
Muslim	15 (6.1)	8 (6.1)	23 (6.1)
Education			
Illiterate	25 (10.2)	50 (37.9)	75 (19.8)
Primary	130 (52.8)	63 (47.7)	193 (51.1)
Secondary	57 (23.2)	15(11.4)	72 (19.0)
Graduate & above	34 (13.8)	4 (3.0)	38 (10.1)

Table 2: HIV/AIDS profile of PLHA

Characteristics	Frequency (n=378) (%)
Years living with HIV	
< 1 yr	34 (8.99)
1-4	72 (19.04)
5-9	220 (58.2)
> 10	52 (13.75)
HIV status of partner	
Negative	129 (34.1)
Positive	249 (65.8)
Disclosed HIV status	
Yes	292 (77.24)
No	86 (22.75)

Table 3: Stigmatizing attitude in PLHA (n=378)

Internalized stigma	Male (n=246)		Female (n=132)		p-value
	Yes (%)	No (%)	Yes (%)	No (%)	
Feels guilty	56 (22.76)	190 (77.23)	45 (34.09)	87 (65.90)	p <0.05
Feels ashamed	23 (9.34)	223(90.65)	32 (24.24)	100 (75.75)	p <0.05
Blames others	64(26.01)	182 (73.98)	89 (67.42)	43 (32.57)	p >0.05
Blames self	93 (37.80)	153 (62.19)	23 (17.42)	109 (82.57)	p <0.05
Have low self esteem	140 (56.91)	106(43.08)	54 (40.90)	78 (59.09)	p <0.05
Feels suicidal	30 (12.19)	216 (87.80)	45 (34.09)	87 (65.90)	p>0.05

Table 4: Experience of discrimination (n=378)

	Male (246)		Female (132)		P value
	Yes (%)	No (%)	Yes (%)	No (%)	
Discrimination attitude by family member	91 (36.99)	155(63.01)	106(80.30)	26(19.69)	<0.05
Verbally insulted/harass	137(55.69)	109(44.30)	68(51.51)	64(48.48)	>0.05
Excluded from social gathering	42(17.07)	204(82.92)	41(31.06)	91(68.93)	<0.05
Physically assaulted	20(8.13)	226(91.86)	43(32.57)	89(67.42)	<0.05
Restriction /excluded from family activities	98(39.83)	148(60.16)	78(59.09)	54(40.90)	<0.05
Restriction /excluded from social activities	58(23.57)	188(76.42)	54(40.90)	78(59.09)	<0.05
Rejection by family/spouse	31(12.60)	215(87.39)	48(36.36)	84(63.63)	>0.05
You had to hear repeatedly that "no more useful to anybody"	124(50.40)	122(49.59)	69(52.27)	63(47.72)	>0.05

Table 5: Experience of stigma (n=378)

	Male (246) (%)	Female (132) (%)	p-value
Stigma in interaction			
Yes	97 (39.43)	58 (43.93)	>0.05
No	149 (60.56)	74 (56.06)	
Stigma at work place			
Yes	158 (64.22)	62 (46.96)	<0.05
No	88 (35.77)	70 (53.03)	
At hospital			
Yes	64 (26.01)	37 (28.03)	>0.05
No	182 (73.98)	95 (71.96)	
Violation of right			
Yes	53 (21.54)	41 (31.06)	<0.05
No	193 (78.46)	91 (68.93)	

Most of the participants reported experience of stigma mainly at workplace (58.2%), during interaction (41.0%) and at hospital (26.7%). Only workplace did show association with gender in terms of experiencing stigma (Table 5).

DISCUSSION

In this study female participants had reported that they are experiencing more stigma discrimination than male and it could be due to illiteracy and being widow. Same finding also reported by Kushwaha et al.[10] Similarly, in Chennai, Thomas et al[11]. (2005) reported enacted stigma among 30% of women and 20% of men, while Subramanian et al[12]. (2009) reported it among 33% of PLHA with significantly more HIV positive women reporting perceived stigma (41%) than positive men (28%).

In most developing countries, families and communities are generally supportive settings for illness management and treatment.[13] However, data from some African and Asian countries reports both supportive and non supportive household responses to HIV-positive people. Negative responses are particularly evident in the case of HIV-positive women. This means that, in addition to the patient, their family is also influenced by the community negative attitudes. Discrimination attitude by family member more toward women in this study which is also found in the study done by Bharat et al.[13] and Saki M et al[14].

The health care sector is perhaps the most conspicuous context for HIV/AIDS-related discrimination, stigmatization, and denial. Negative attitudes from health care staff generate anxiety and fear among PLHA. The most commonly reported responses include a refusal to admit or treat HIV-positive patients[15], the tendency to neglect patients. A study in Kenya[16] having the similar finding highlighted the fear of being infected among midwifery caregivers, which concluded social stigma and discrimination for patients.

In the present study shows that 77.24% participants disclose their HIV positive status and rest of the participants did not disclose their status due to fear of discrimination by othe people. Similar finding present in study by Priyanka et al[17]. F S Vaz et[18] al, in their study in Goa found that 83.8% respondents said that HIV infected individuals should not keep their HIV positive status a secret.

After doing this study it seems that employment-related discrimination and stigmatization has begun to emerge. Individual cases of job loss, emotional isolation, and denial of employment on the basis of HIV status have been reported in the media to NGO workers and social counselors and to medical practitioners etc. similar finding also reported by Laurel et al.[19]

LIMITATIONS OF THE STUDY

The study population may not be representative of the wider PLHIV population as only participants from ICTC and ART Center sites of civil hospital Ahmedabad were recruited. Retrospective answers has potential difficulties associated with it, such as the problem of recall and the possibility that events and circumstances might be reinterpreted or presented in ways that suit the individuals' current perspective and perception of self. However, the aim of the study was not to provide a basis for substantial generalization, but rather to provide an explorative and descriptive account of the attitudes of a group of PLHIV.

CONCLUSION

Most of the PLHA (89%) experienced internalized stigma. While 86 % respondents facing discriminatory attitudes from the society. PLHA experience a lot of verbal stigma and social exclusion and deny of access to facilities such as health care. Stigma and discrimination observed in PLWHA significantly higher in females.

RECOMMENDATIONS

The findings of the study can be used to inform general population, public health providers and other stack holders to reduce stigma and discrimination experienced by PLHIV.

By increasing literacy level so, it will help HIV positive patients in tackling the stigma and discrimination efficiently and as the same time it will also help to prevent new HIV patients by knowing the mode of acquiring the HIV infection.

Behaviour change communication can be helpful to address internalized stigma as well as discriminatory behaviour towards PLHIV[20].

Strong implementation of the HIV and AIDS (prevention and control act, 2017) is highly recommended to prevent the discrimination at various places and situation like at work place, at school, at hospital etc and thus we can achieve our goal of zero AIDS related stigma and discrimination.

People living with HIV/AIDS need to be better educated about their legal rights and about how to get help to challenge the discrimination and stigmatization they face in health care settings.

REFERENCES

1. K Park. Park's Textbook of Preventive and Social Medicine, 21st ed. Jabalpur (India): Bhanot Publishers; 2007. p 329-34.
2. AIDS knowledge in North West India: recent trends. Chandigarh: Sachdeva S; Available at: http://prcs-mohfw.nic.in/writereaddata /research /219.pdf Accessed 21st Oct,2013
3. Goffman E. Stigma: notes on the management of a spoiled identity, Engelwood Cliffs, New Jersey: Prentice Hall; 1963.
4. Alonzo AA, Reynolds NR er al. Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. Soc Sci Med. 1995; 41(3):303–315.
5. Link BG, Phelan JC. Stigma and its public health implications. Lancet. 2006; 367(9509):528–529.
6. Cameron E. Legislating an epidemic: the challenge of HIV/AIDS in the workplace. Geneva: ILO; 2007.
7. R. Parker, P. Aggleton. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social Science & Medicine.2003; 57: 13–24.
8. G Letamo, Prevalence of, and factors Associated with, HIV/AIDS-related Stigma and Discriminatory attitudes in Botswana. J Health Popul Nutr. 2003;21(4):347-357.
9. Becky L., Genberg E., Surinda K., et al, Assessing HIV/AIDS Stigma and Discrimination in Developing Countries. AIDS Behav. 2008;12:772–780.
10. Kushwaha A, Kumkar M. Journey from victim to a victor—a case study of people living with HIV and AIDS. Medical Journal, Armed Forces India. 2012; 68(1):58-60.
11. Thomas, B.E., Rehman, F., Suryanarayanan et al, How stigmatizing is stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai, South India. AIDS Care. 2005; 17(7): 795-801.
12. Subramanian T., Gupte, M.D., Dorairaj, V.S et al. Psychosocial impact and quality of life of people living with HIV/AIDS in South India. AIDS Care.2009: 1-9.
13. E. Maxine Ankrah. The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. AIDS Care, 2007; 5(1): 5-22.
14. Saki M, Sima M, et al. Perception of Patients with HIV/AIDS from Stigma and Discrimination. Iran Red Crescent Med J. 2015; 17(6):1-7.
15. R. Parker, Peter Aggleton. HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action. Horizon programmes:population council;2002.
16. Turan JM, Miller S, Bukusi EA, et al. HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services. AIDS Care. 2008; 20(8):938–45.
17. Priyanka, T Singh., S. Deepti, A cross-sectional Study of attitude of Attendants accompanying HIV positive persons at Integrated Counselling and Testing Centre of a tertiary care Hospital in Punjab, India. International Research Journal of Medical Sciences.2014; 2(1): 11-14.
18. Vaz F., Ferreira A., Motghare D., et al,Discriminatory Attitudes of a Rural Community towards People with HIV/AIDS: Experiences From Goa. Indian J Community Med. 2005; 30:72.
19. Laurel S, Sara S, Courtenay. Employment discrimination and HIV stigma: survey results from civil society organisations and people living with HIV in Africa. African Journal of AIDS Research 2011; 10(supplement): 311–324.
20. Monika M., Santos, Pieter K. et al, An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the People Living with HIV Stigma Index. BMC Public Health. 2014; 14:80.
21. HIV/AIDS act 2017. http://naco.gov.in/hivaids-act-2017. Accessed on August, 14th, 2018.