

**Original Article****Study of HIV/AIDS related stigma and discrimination in people living with HIV AIDS.**

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**ABSTRACT**

**Background:** HIV/AIDS-related stigma can be described as a 'process of devaluation' of people either living with or associated with HIV/AIDS. The impact of HIV/AIDS related stigma and discrimination as a catalyst in the spread of the epidemic has yet to be understood.

**Objective:** To study HIV related stigma experienced by PLWHA and to study the different forms of discrimination faced by PLWHA.

**Methods:** Every 3<sup>rd</sup> person attending the Integrated OPD was randomly selected. Total of 186 patients were included in the study over a period of 1 year. Data regarding stigma and discrimination experienced by the subjects was collected with a pretested questionnaire. Analysis was done with Microsoft Excel and Epi Info. Chi square test was applied wherever appropriate.

**Results:** 95.12% females and 89.02% males faced discrimination in the form of segregation of food, clothing, sleeping and toilet arrangements. 28.49% reported discrimination in health care setting of which 71.7% reported discrimination was more in hospital admitted patients than OPD, majority of these were discriminated by nurses- 77.36% and reported difference in treatment, 60.38% reported segregation and 37.74% reported refusal of treatment on grounds of HIV. PLWHA have various HIV/AIDS related stigmas associated with negative self image, personalized stigma, concerns with public attitudes towards PLWHA and concerns regarding disclosure.

**Conclusion:** PLWHA should have a greater involvement in their own care and treatment. Training programmes for all categories of health care providers for bringing about change in their behavior with reference to dealing with patients with HIV/AIDS are needed. Media, community and NGO's can play important role.

**Key Words:** PLWHA (People Living With HIV/AIDS), Stigma, Discrimination

**INTRODUCTION**

Globally the HIV/AIDS epidemic has presented unique health challenges to populations including a host of ethical and moral issues related to human life and dignity [1]. Though India is a country with low HIV prevalence, it has the third largest number of people living with HIV/AIDS. As per HIV estimates 2008-09, there are an estimated 23.9 lakh people living with HIV/AIDS [2]. HIV/AIDS-related stigma can be described as a 'process of devaluation' of people either living with or associated with HIV/AIDS [3]. This stigma often stems from the underlying stigmatization of sex and intravenous drug use – two of the primary routes of HIV infection [4].

- Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV [5]. Stigma and discrimination breach fundamental human rights and can occur at a number of different levels including: family, health care setting, economic, social, psychological and institutional.
- They can lead to depression, lack of self-worth and despair for PLWHA
- When stigma and discrimination exist people become more afraid of it than the disease itself preferring to ignore their real or

possible HIV status leading to the risk of faster disease progression for themselves and the risk of them spreading HIV to others.

- Prejudiced and stigmatizing thoughts frequently lead people to do, or not do, something that denies services or entitlements to another person. For example, they may prevent health services being used by a PLWHA or terminate their employment on the grounds of their HIV status. This is discrimination.

The impact of HIV/AIDS related stigma and discrimination as a catalyst in the spread of the epidemic has yet to be understood. This hospital based study was therefore undertaken to find out the magnitude of HIV related stigma and discrimination faced by PLWHA.

## OBJECTIVE

To study HIV related stigma experienced by PLWHA. Also to study the different forms of discrimination faced by PLWHA.

## MATERIAL AND METHODS

A cross sectional hospital based descriptive study was carried out in an Integrated OPD of a tertiary hospital especially established to cater to the needs of HIV infected patients. Every 3<sup>rd</sup> person attending the OPD was randomly selected. A total of 186 subjects were thus included in the study. All these were confirmed sero-positive adult patients diagnosed as HIV positive for at least a minimum period of 1 month. Those diagnosed less than a month back and HIV positive children were excluded from the study. The study was conducted over a period of 1 year. Pretested semi structured interview schedule was used and face to face interview was conducted ensuring all privacy and confidentiality after taking an oral consent. Information regarding types of stigma and discrimination experienced by them was collected. Analysis was done with Microsoft Excel and Epi Info. Chi square test was applied wherever appropriate.

### Operational definitions-

1. **HIV/AIDS related stigma** – all unfavorable attitudes, beliefs and policies directed towards people perceived to have HIV/AIDS as well as towards their significant others,

loved ones, close associates, social groups and communities [5]

2. **Discrimination:** Any measure entailing any arbitrary distinction among persons depending upon their confirmed or suspected HIV serostatus or state of health [6].

## RESULTS AND DISCUSSION

A total of 186 HIV positive persons were included in the study.

**Table 1: Relation between types of discrimination within family and gender (n=164)**

TYPES OF DISCRIMINATION	MALES (%) N=82	FEMALES (%) N=82
<b>Segregation with regards to Food,Clothing,Sleeping,Toilet</b>	73(89.1)	78(95.1)
<b>Withdrawal of financial support &amp; inheritance rights</b>	5(6.1)	16(19.5)
<b>Others</b>	2(2.4)	8(9.8)
<b>No discrimination</b>	10(12.2)	3(3.7)

Majority of the subjects 88.17% i.e. 164 subjects disclosed their status to their families and experienced discrimination as shown in Table 1. It is comparable to a study carried out by Neeraj et al in Jamnagar in 2003 where coercive attitudes towards PLWHA ranged between 58-73 % and blaming attitudes 79- 89%. were reported against PLWHA [7]. A study conducted by Bharat S et al in Mumbai and Bangalore in 2001 similarly reported that women experienced denial, stigma and discrimination from their parents in laws after a husband's death [8].

**Table 2: Distribution of subjects according to Admission in Hospital and Discrimination faced by them (n=186)**

Hospital Admission	Discriminated (%)	Not Discriminated (%)	Total (%)
<b>Admitted in hospital</b>	38 (71.7)	50(37.6)	88(47.3)
<b>Not admitted in hospital</b>	15 (28.3)	83 (62.4)	98 (52.7)
<b>Total</b>	53(100)	133(100)	186(100)

**Table 3: Types of discrimination faced in health care settings (n=53, multiple responses)**

Type Of Discrimination	No. Of Subjects	Percentage
H/o testing without knowledge	43	81.3
Refusal to treat on grounds of HIV status	20	37.7
H/o different treatment on grounds of HIV	41	77.4
Discrimination from health staff	40	75.5
Segregation or health controls	32	60.4
Compulsory notification	41	77.4

**Table 4: The various perceptions of PLWHA about HIV/AIDS**

STATEMENT	AGREE	DISAGREE
People who have HIV/AIDS are dirty	58(31.2)	128(68.8)
People who have HIV/AIDS are cursed	76(40.9)	110(59.1)
People who have HIV/AIDS cannot be trusted	50(26.9)	136(73.2)
People who have HIV/AIDS are like everybody else	116(62.4)	70 (37.6)
People who have HIV/AIDS should be ashamed	83(44.6)	103(55.4)
People who have HIV/AIDS have nothing to feel guilty about	75(40.3)	111(59.7)
Most people become HIV positive by being weak or foolish	63(33.9)	123(66.1)
It is safe for people who have HIV/AIDS to work with children	83(44.6)	103(55.4)
People who have HIV/AIDS should be isolated	30(16.1)	156(83.9)
People who have HIV/AIDS should not be allowed to work	7(3.8)	179(96.2)
I do not want to be friends with someone who has HIV/AIDS	47(25.3)	139(74.7)
A person with HIV/AIDS must have done something wrong and must be punished	109(58.6)	77(41.4)
I am very careful who I tell that I have HIV	175(94.1)	11(5.9)
When people learn that you have HIV they look for flaws in your character	157(84.4)	29(15.6)
I work Hard to keep my HIV a secret	171(92)	15(8)

28.49% of the subjects reported discrimination in a health care setting of which 77.36% reported discrimination at the hands of nurses, 33.74% by doctors and 18.87% by class IV and others.

Discrimination was found to be more 71.7% in hospital admitted subjects as compared to 28.3 % who had taken treatment on OPD basis only. This difference was found to be highly significant.(Table 2 )

A study by HORIZONS/ Population Council in 2002[9]also revealed similar findings wherein doctors, nurses, medical technicians and informal health care givers often exhibited stigmas about HIV/AIDS. Staff particularly nurses held exaggerated fears about the infectiousness of HIV. In another Baseline and Research Phase [10] of a study carried out by Sharan an NGO in Delhi it was seen that within the health care setting there were misconceptions about HIV transmission, negative attitude about PLWHA, inadequate training and supplies of infection control and lack of institutional policies on HIV testing and confidentiality all contributing to differential treatment of PLWHA.

From the responses mentioned PLWHA have various HIV/AIDS related stigmas associated with negative self image, personalized stigma, concerns with public attitudes towards PLWHA and concerns regarding disclosure.(Table 4 )

## CONCLUSION and RECOMMENDATION

In this study PLWHA have experienced stigma and discrimination at various levels like families and health care settings which brings out the need to have the following interventional measures at different levels

1. Among PLWHA: they need to have a greater involvement in their own care and treatment. Support groups need to be established so that stigma and discrimination can be challenged collectively.
2. Within the health care setting: Training programmes for all categories of health care providers for bringing about change in their behavior with reference to dealing with patients with HIV/ AIDS. Doctors as team leaders have to be role models and need to be vigilant to detect any form of discrimination.
3. Role of media: Media can play an important role in the disseminating and reinforcing positive messages about HIV/AIDS, thus

There is an urgent need to have more drop in centres providing care and support services through professionally trained counselors.

decreasing stigma and discrimination faced by PLWHA.

4. Care and support for PLWHA through community and faith based organizations.
5. The fact that HIV can be managed with antiretroviral drugs needs to be brought to the public's notice so as to remove fear of HIV as an incurable and deadly disease. More of ART centres need to be established so that ART is readily accessible and available to those who need it.
6. Legislation: An effective anti discrimination policy supported by a law that will ensure the protection of HIV positive people's rights should be in place. There should be effective laws for the protection of property and inheritance rights of widows and orphaned children.

These efforts need to be made at all levels on a war footing to minimize stigma and discrimination associated with HIV/AIDS, if India has to effectively tackle it's crisis of HIV infections. Failure to act now will have the severest consequences.

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