IJCRT.ORG ISSN : 2320-2882

INTERNATIONAL JOURNAL OF CREATIVE RESEARCH THOUGHTS (IJCRT)

An International Open Access, Peer-reviewed, Refereed Journal

HIV RELATED STIGMA AND DISCRIMINATION AMONG THE COMMUNITY MEMBERS AND HEALTH WORKERS IN UTTAR DINAJPUR DISTRICT OF WEST BENGAL

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Abstract: *Human immunodeficiency virus/Acquired immunodeficiency syndrome (HIV/AIDS) represents one of the leading global health problems. Intense negative feelings and actions directed towards People Living with HIV/AIDS (PLHA) have characterized the HIV/AIDS epidemic since its inception. Indeed, as a consequence of felt and enacted stigma, people living with HIV are marginalised and driven from the reach of prevention, treatment, care, and support services. Stigmatizing attitudes and discriminatory practices of family members and health providers prevent those infected from receiving adequate treatment, care, and support. Community members had very limited knowledge about HIV and modes of transmission, but the vast majority associated HIV with 'immoral' or 'dirty' acts that reflected the poor character of PLHA. Society sees them PLHA with disgust. Misconceptions about the modes of transmission related to HIV were very common. Stigmatized attitude of the health professionals as one of the key personnel in dealing with PLHA may result in undesirable consequences, such as dealing with fear, disgust, anger, and in some cases refusal to accept the patients. Such discriminatory treatment and inequality of personnel dealing with people with HIV versus other patients can affect the service delivered by the personnel and may deprive the patients from their minimum health rights. This can be an important incentive for people to hide their disease. Therefore, decreasing the personnel's irrational fear is important to reduce their stigmatized attitude. Perhaps this will improve the quality of services provided to patients. One of the major drivers of stigmatizing behaviours is a universal fear of HIV among medical professionals, including nurses, Health workers (ASHA/ANM), Counsellors, regarding occupational exposure to HIV. In order to improve treatment adherence and encourage optimal utilisation of services, it is imperative that the health system invest more in stigma reduction. Common manifestations of differential treatment of PLHA in the participating hospitals included delay in treatment, segregation, excessive use of barrier precautions, breaches of confidentiality, inadequate pre-and post-test counselling. Therefore, reducing HIV- related stigma and discrimination in clinical settings requires addressing not just the attitudes and practices of health care workers but also their needs for information and training.*

Key Words: *HIV/AIDS, Stigma, Discrimination, Knowledge and Attitude*

1. Overview:

Human immunodeficiency virus/Acquired immunodeficiency syndrome (HIV/AIDS) represents one of the leading global health problems. Despite progress in diagnosis, treatment, and prevention, HIV/AIDS is still a serious public health challenge. Indeed, as a consequence of felt and enacted stigma, people living with HIV are marginalised and driven from the reach of prevention, treatment, care, and support services. Their invisibility enables the denial of a problem, and leaves stigma reduction efforts low in the list of priorities. Intense negative feelings and actions directed towards People Living with HIV/AIDS (PLHA) have characterized the HIV/AIDS epidemic since its inception. PLHA have been denied employment, fired from their jobs, experienced mental and physical abuse, and ostracized from their families and communities (Herek & Glunt, 1988). Stigmatizing attitudes and discriminatory practices of family members and health providers prevent those infected from receiving adequate treatment, care, and support (van der Meij and Heijnders 2004; Brown, Macintyre and Trujillo 2003; UNAIDS 2002). Various studies have established that AIDS-related stigma is widespread and occurs in a variety of contexts, including the family, community, workplace, and the health care setting (Reidpath and Chan 2005; Nyblade et al. 2003; Horizons 2003; Bharat and Aggleton 1999; UNAIDS 2001). Such treatment can be attributed to the fact that PLHA are believed to have done something wrong to acquire HIV infection. Nowadays, social stigma could have been eliminated with the use of modern technology but something like that is far away from reality. Since stigma exists and people are marginalized, subjects afflicted with AIDS are expected to struggle harder to achieve in society, facing great difficulties while reaching occupational independence and success.

2. Study Area:

The Government of India estimates that about 2.40 million Indians are living with HIV, while new infections have emerged from West Bengal, Gujarat, Bihar and Uttar Pradesh which estimated to have more than 100,000 PLHA each and together account for another 22% of HIV infections in India (NACO, 2015). As per the HIV estimation in India 2015, estimated number of 1.29 lakhs PLHIV, 6% of the total PLHAs of the country, live in West Bengal. Estimated adult (15-49 years) HIV prevalence is 0.21% in West Bengal. The state is categorized as a low prevalence state and declining trends in adult HIV prevalence sustained in West Bengal. Still there are some pockets of high prevalence mainly driven by sub-populations that have higher risk of exposure to HIV. On the basis of data available to support the above statement, Uttar Dinajpur district among them is more vulnerable to HIV. The reason for this is partly due to widespread failure to respond adequately to stigma and discrimination.

3. Sample size, Sampling process and Data Collection:

We conducted semi structured, in-depth interviews with healthcare personnel, as well as community members accessing care at health facilities. Participants were approached while they were waiting to seek services, informed about the study and asked whether they would be interested in participating. All interviews took place in a private area of the health facility, away from other patients.

In-depth interviews were conducted with health staff who provide some level of care to PLHA, which included nurses, health workers (like ANM/ASHA) and counsellors from Integrated Counselling and Testing Centres (ICTC) in government hospitals. There were no other specific eligibility criteria for these participants. All respondents were interviewed on a one-to-one basis. Finally, the study aimed to gauge the attitudes of community members towards PLHA. As a result, community members who were over the age of 18 and accessing general OPD services were also recruited for in-depth interviews. Besides this, they (1) did not identify as a PLHA (self-reported) and (2) did not have a family member with HIV (self-reported). The rationale behind this selection criteria was to try and obtain insights from a group of participants who may not otherwise interact with PLHA on a routine basis.

In order to conduct the study following sample size was estimated:

General Population		Health Workers/Nurses	Counsellors	
Male	Female		Male	Female
55	42	30	2	8

4. Result and Discussion:

4.1 Basic Information of Respondents:

As shown in Table 1, 137 participants were interviewed, which includes 97 community members (non PLHA group) and 40 healthcare providers like nurses, ASHA/ANM and Counsellors. Out of total respondents, 57 were male, and 80 were female, with respondents ranging in age from 24 to 40 years. 54% of the respondents had secondary level of education. Among Health Care Workers, 10 were nurse and 10 were counsellor at government hospitals by profession. 30 respondents in this group worked as an ASHA/ANM at different health centres at the study area. 31% of the respondents particularly among community members engaged as Non-Agricultural Wage labour. 64% of the female respondent among community members were housewife.

Table 1: Socio demographic Characteristics

Characteristics	No. of Respondents	Percentage (%)
Gender		
Male	57	42
Female	80	58
Age Group of Respondent		
18-25	42	31
26-40	95	69
Educational Status		
Illiterate	18	13
Primary	41	30
Secondary	54	39
Higher-Secondary and above	24	18
Profession		
Nurse	10	7
Health Care Worker (ASHA/ANM)	20	14
Counsellor	10	7
Non-Agricultural wage Labour	42	31
Housewife	27	20
Business	16	12
Service	12	9

Source: Field data

4.2 Enacted Stigma at Community level about the concept of HIV:

Community members had very limited knowledge about HIV and modes of transmission, but the vast majority associated HIV with 'immoral' or 'dirty' acts that reflected the poor character of PLHA. Society sees them PLHA with disgust. That he is not a good person, or he is a morally incorrect man and does not behave well. They see the family from a bad lens. Women are viewed even more negatively in comparison to men. Misconceptions about the modes of transmission related to HIV were very common. Many community members reported that food and drinks should not be shared with PLHA: 'you get AIDS from sharing food as well…they should stay a little far away' (M6, Male, Age 34). Others mentioned that they would not buy vegetables from PLHA, or eat food prepared by PLHA. While some people understood that HIV is spread through direct contact with blood, many generalised this fear and expressed that they would have to 'stay at least a little far away from PLHA. Even if it is a close friend, I will have to stay a little far away' (M4, Male, Age 32). It was commonly perceived by community members that HIV was a dangerous, life-threatening illness with no cure: 'the only thing I have heard about HIV/AIDS, is like wrong injections, wrong relations between people…it is a life-threatening illness due to these behaviours. It is a life-threatening illness coming from these factors' (F4, Female, Age 30). Responses related to Knowledge and Awareness of community members were recorded below:

Table 2: Knowledge and Attitude of Community Members related to HIV: (n=97)

Sl. No.	Questions on Knowledge and Awareness	Answer Option	
		Yes	No
	Knowledge		
1	Do you know someone living with HIV	12	85
2	Does HIV transmit through infected person cough/sneeze?	52	45
3	Does HIV transmit through sharing food utensils with an infected person?	74	23
4	Does HIV transmit through mosquito's bites?	63	34
5	Does HIV transmit through touching the blood of an infected person?	65	32
6	Does HIV transmit from infected mother to her unborn/new born baby?	32	65
7	Does HIV transmit through sexual relations with infected person more than 90% of the time?	77	20
8	Is there available medication for HIV patients so they can live an ordinary life?	24	73
	Attitude		
9	Do you accept that a relative would marry an HIV patient?	16	81
10	Do you accept to live with an HIV patient?	12	85
11	Do you think HIV patients should be isolated from the community?	36	61
	Personal Stigma Indicators		
12	PLHA people do not deserve any support	11	86
13	People with HIV should feel ashamed of themselves	31	66
14	Do you feel ashamed, if you became HIV positive	37	60
15	If a family member has HIV, would you keep it secret?	69	28
16	If you test positive, would you share your results with anyone?	25	72

Source: Field data

The knowledge of the respondents varies according to gender as well as their level of education. Knowledge about the spread of HIV is quite prominent among the respondents having graduate or post graduate degree as compared to the respondents having primary level education. The knowledge was also very high among those who have a friend or family member living with HIV as compared to those who do not know anyone with HIV.

Less than half of the respondents (12/97, 12 %) said that they would live with a friend or relative who has HIV, and only 16 participants (17%) said that they would accept a relative to marry someone with HIV. A total of 36 (37%) respondents indicated that they think HIV patients should be isolated from the community. More people between 24 and 30 years of age would agree to live with someone with HIV compared to the other age groups. More respondents with higher education would agree to live with an HIV positive person compared to those without a university degree. Male respondents were more likely to accept a relative marrying someone with HIV than their female counterparts. This is due to level of education was higher among male respondent

as compared to female. Also, male respondents were more connected with social media/newspaper/TV as a source of knowledge. Older participants were less likely to accept a relative marrying someone with HIV than their male counterpart.

The section on personal stigma looks at how the respondents perceive those people living with HIV in the congregation. This domain encompasses items on judgment, shame and blame for the responsibility for HIV infection on the HIV-positive individual. It also entails labelling, and devaluing of PLHA. 11 percent disagreed with the statement that PLHA do not deserve any support. 32 percent indicated that PLHA should feel ashamed of themselves and 38 percent would feel ashamed it they contract HIV. But 29 percent would not feel ashamed if they have a family member who is HIV positive. 68 percent assign blame on PLHA for contracting the virus. On disclosure, respondents provided a Yes or No answer to the question whether they would keep it a secret if a family member has HIV. 28.9 percent would not keep it a secret, while 71.1 percent would not reveal. 25.7 percent would share the test results if they test positive. 74.3 percent would not disclose their results to anyone.

4.3 Stigmatizing Attitudes and Practices Among Health Care Workers:

Stigmatized attitude of the health professionals as one of the key personnel in dealing with PLHA may result in undesirable consequences, such as dealing with fear, disgust, anger, and in some cases refusal to accept the patients. Such discriminatory treatment and inequality of personnel dealing with people with HIV versus other patients can affect the service delivered by the personnel and may deprive the patients from their minimum health rights. This can be an important incentive for people to hide their disease. Therefore, decreasing the personnel's irrational fear is important to reduce their stigmatized attitude. Perhaps this will improve the quality of services provided to patients (Pulerwitz J, Michaelis AP, Lippman SA, et al.). One of the major drivers of stigmatizing behaviours is a universal fear of HIV among medical professionals, including nurses, Health workers (ASHA/ANM), Counsellors, regarding occupational exposure to HIV. One nurse described this fear as: "Have you seen an advanced HIV patient? The way his body wastes away, his gaunt appearance, his papules everywhere…it is a truly scary sight. Have you worked with them? When you see a patient like this, you are truly scared". Another Health Care worker stated that 'There is no permanent cure for HIV. And the taboo of AIDS in society is very scary. So, HIV is more dangerous". This often translates into indirect refusals to provide service to HIV positive people or directly interact with the positive patient at hospital.

Associations between stigma and reported stigmatizing or discriminatory practices by health care workers were also examined. Some questions relating to general hospital-wide practices were asked to health care workers as well as the counsellors. Respondents were more likely to report stigmatizing or discriminatory practices, such as avoiding going near HIV-positive patients, sharing the patient's HIV status with family members, or inappropriately using gloves during casual contact with HIV-positive patients. Denial of service or direct interaction with the positive patient was also noticed in certain cases. The table below recorded the responses of health care workers towards HIV positive people at hospitals:

Table 3: Stigmatizing Behaviour of Health Care Workers

Indicators related to discriminatory practices of Health Workers/Counsellors	Yes (Response in %)	No (Response in %)
Reported practices of all health care workers/counsellors (n=40)		
To protect themselves from HIV infection while working in the hospital,		
staff avoid going near HIV-positive patients	55	45
staff avoid touching HIV-positive patients	65	35
Unwilling to provide service to HIV positive people	65	35
Isolated the HIV positive patient	85	15
Of those health care workers/counsellors who received an HIV-positive test result for a patient (n = 40), informed family members	65	35
Of those health care workers/counsellors who informed family members (n = 40), did not obtain patient's consent prior to informing family	70	30
Wear gloves to give medicines to HIV-positive patients	85	15
Only wear gloves to transport HIV-positive patients	92	8
Only wear gloves for delivering food to HIV-positive	84	16
Attitude Practices by Counsellors (n=10)		
Is there any need of proper counselling after get infected by HIV virus	70	30
Is HIV patient treat separately for any opportunistic infections (if caused)	50	50
Is it necessary to counsel the family members of HIV positive patient	60	40
Do the HIV positive people feel ashamed on themselves	50	50
Is support group is necessary for HIV positive people to cope up with the situation	30	70

Source: Field Data

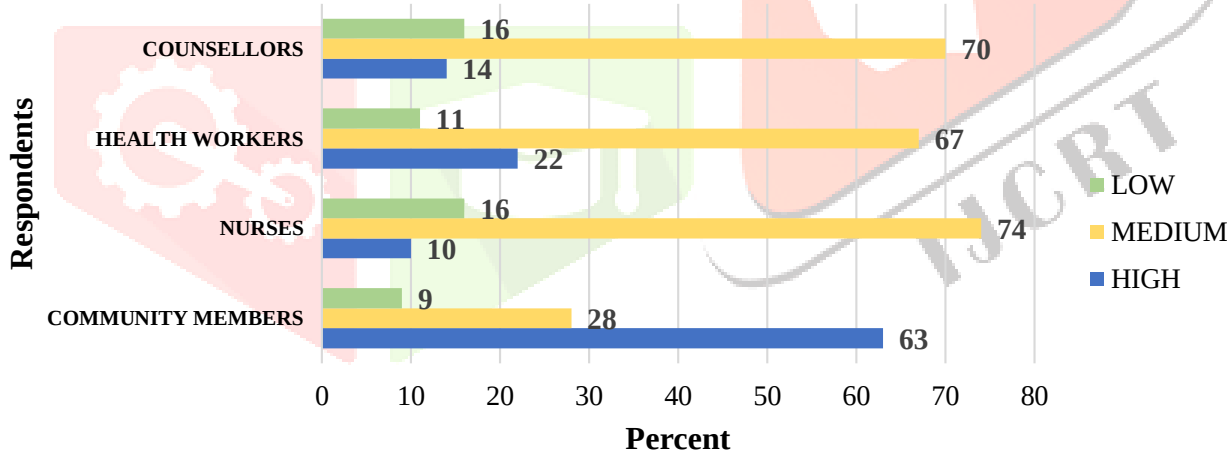
In the medical field, discrimination and stigma have engendered serious and even tragic consequences, denying the people living with HIV/AIDS access to care and testing, which can in turn increase the likelihood of patients concealing their HIV status. In addition, stigma and discrimination have been extensively reported in medical settings worldwide, most of which involved discriminatory attitudes among medical workers, with a few cases of discriminatory behaviour. In our study, we found that almost 65% of the health care staffs avoid touching HIV infected persons as a fear of getting infected. Not only that, they also unwilling to provide any services to infected patient who came for treatment at hospital. 85 % among them stated that HIV infected patient should get treatment separately. Administering HIV tests report of patients without his or her consent was the act of discrimination. Still, 70 % of healthcare providers indicated that they had disclosed patient's HIV status to their family members without any consent of the patient. PLHA routinely experienced disclosure without their informed consent, which not only made them uncomfortable, but also led to worries of anticipated stigma in future encounters given past experiences of enacted stigma. 70% among the counsellors, supports that PLHA need moral support about how to lead a healthy life after the detection. But when the question arises about the treatment of HIV positive patient with the normal patient at hospital for any opportunistic infections, the responses divide into 50-50.

In our study, fear of occupational exposure was a key factor in the occurrence of medical discrimination. Therefore, reducing fear is also an urgent problem to be addressed. From the aspects of medical staff members, HIV-related training should be conducted to address unnecessary fears about the risk of infection with HIV after casual contact.

Following the survey (which included 97 community members, 40 nurses, health workers and counsellors) and a review of the responses to the stigma items (related to their knowledge), which address the main domains that emerged from the formative research and included both stigmatizing and non-stigmatizing statements. Scoring was done on a three-point Likert scale (agree, can't say, disagree), ranging from 1 to 3, with a maximum total score of 63 for the 21 items. For scoring, each of the statements was weighted as negative (stigmatizing statements) or positive (non-stigmatizing statement), and scored accordingly. For example, those who responded as 'agree' to a stigmatizing (or negative) statement were scored as 3 and to a non-stigmatizing (or positive) statement as 1. Similarly, those who disagreed with a positive statement were scored as 3 and to a negative statement as 1. Those respondents who were unable to agree or disagree with the statements were scored as 2. Thus, a higher score on the index denotes a higher level of stigma.

According to stigma score, nearly 39 percent fell into the moderate stigma category and 49 percent were in the high stigma category. Only 12 percent were classified in the low category (Figure 1).

Figure 1: Level of Stigmatizing attitudes of Respondents (in %)



These findings indicate that respondents with higher stigma scores were more likely to carry out stigmatizing or discriminatory behaviours, such as avoiding casual contact with HIV-positive patients or sharing the HIV status of a patient with staff that do not treat or directly interact with the patient.

5. Conclusion:

The continued presence of discriminatory and stigmatising attitudes towards PLHA is deeply concerning, and negatively impacts both disclosure of HIV status as well as access to care and treatment. It is likely that this universal discrimination may result in poorer outcomes for these patients, and may be implicated in the relatively high HIV-related mortality rate in Uttar Dinajpur. In order to improve treatment adherence and encourage optimal utilisation of services, it is imperative that the health system invest more in stigma reduction. Common manifestations of differential treatment of PLHA in the participating hospitals included delay in treatment, segregation, excessive use of barrier precautions, breaches of confidentiality, inadequate pre-and post-test counselling. The study also found that many health care workers lacked adequate knowledge and training in the basics of HIV transmission, infection control, and clinical management of HIV/AIDS. Therefore, reducing HIV- related stigma and discrimination in clinical settings requires addressing not just the attitudes and practices of health care workers but also their needs for information and training. The study also showed that all cadres of health care workers, including nurses, ANM/ASHA workers, or Counsellors carry out discriminatory practices.

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