Original Article

HIV Stigma and Specified Correlates in North India

Naresh Nebhinani, Surendra Kumar Mattoo[1], Ajay Wanchu[2]

ABSTRACT

Background: Worldwide, the stigma and discrimination impede HIV-AIDS programs across the continuum of prevention to care. We studied stigma and related issues in HIV-positive subjects. **Materials and Methods:** At a tertiary care hospital in North India, we studied 100 HIV-positive outpatients not receiving antiretroviral therapy. The subjects self-administered 'Tanzania Stigma Indicator and Community Endline-Individual Questionnaire'. Psychiatric morbidity was screened with General Health Questionnaire (GHQ-I2 Hindi) and diagnosed with Structured Clinical Interview for DSM-IV (SCID). **Results:** A typical subject was middle aged (25-44 years, 77%), school non-completer (63%), village dweller (61%), and male (59%). Only 35 subjects could differentiate between HIV and AIDS, and only 24 were aware of antiretroviral therapy. Unprotected sex, sharing injections, and blood transfusions were reported spontaneously as possible sources of transmission by 56-79% subjects each. About 80% of subjects reported no fear in touching HIV-positive subjects or their objects. Avoiding injections, being faithful to uninfected partner, avoiding blood transfusions, using condoms, and avoiding sharing razors/blades were reported spontaneously as HIV preventive measures by 40 to 26 subjects each. Half of the subjects blamed self for contracting HIV. Only 38 subjects reported others behaving differently with HIV-positive subjects. HIV status disclosure was reported by 98 subjects (73 to family or relatives). Urban subjects reported higher primary stigma and shame or blame. Psychiatric disorders, present in 45 subjects, showed no association with stigma items. **Conclusions:** The subjects had a limited knowledge, especially of treatment aspects. Stigma showed no association with psychiatric disorders. The study reflects a strong need for public health measures to enhance awareness and knowledge about HIV/AIDS.

Key words: *AIDS, blame, discrimination, HIV, shame, stigma*

INTRODUCTION

After HIV and AIDS, the third phase of this pandemic has been termed as 'stigma and discrimination'.[1] Stigma is a discrediting attribute and refers to negative feelings and behaviors toward individuals, groups, and communities. It leads to discrimination, ostracism, and denial by branding or labeling as being unworthy of inclusion in the community.[2] Incomplete and contradictory knowledge can contribute to the persistence of stigma, which may be internal or secondary. Internal stigma is the acceptance of others' stigmatizing attitudes ('we deserve it'). Secondary stigma is others' attitudes and behavior ('they deserve it'). Between or across these is the fear of stigma or being stigmatized.[3]

HIV-AIDS meets all the criteria that make an illness stigmatized: Responsibility for its occurrence, potentially serious consequences for others, outward manifestations, decreased competence, and its untreatability.[4] Also, it is believed that the stigma hurts more than the HIV-AIDS itself, and the fear

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Department of Psychiatry, Postgraduate Institute Medical Science, Rohtak, Haryana, [1]Postgraduate Institute of Medical Education and Research, Chandigarh, India, [2]Division of Arthritis and Rheumatic Diseases, Portland

Address for correspondence: Dr. Naresh Nebhinani
Department of Psychiatry, Postgraduate Institute Medical Science, Rohtak, Haryana, India. E-mail: drnaresh_pgi@yahoo.com

of being stigmatized may be a much bigger problem than the actual stigma.[3]

Worldwide, researchers have documented that people living with HIV-AIDS (PLWHA) are subjected to job loss, school expulsion, ostracism, violence, lack of care and support, labeling of hospital files and beds, and loss of property.[5] Sexual intercourse being the main route of transmission fuels the beliefs of 'unacceptable' and 'immoral' sexual behavior, and God's punishment in the form of an untreatable illness, this leads to intense blame and shame.[2]

Stigma intensifies the emotional pain and suffering of PLWHA and their families. Internal stigma and shame may lead to depression.[6] Secondary stigma is experienced in different forms within families, communities, institutions such as healthcare facilities and places of employment, in the media, and in government policies.

Women may experience more felt and enacted stigma than men, and may have less definite financial or emotional support.[7] Religious beliefs about HIV may promote or counter the stigma. Consequently, in most communities, HIV-AIDS triggers an attitude of fear, hatred, shame, blame, and disgrace, making people reluctant to seek testing to determine their sero-status, disclose their HIV-positive status until it progresses to full-blown AIDS, which cannot be hidden, accessing treatment and rehabilitative services, changing behavior to prevent infecting others, and caring for PLHA.[8] Thus, stigma undermines the efficacy of HIV-AIDS prevention and care, increases the vulnerability to HIV for the individual, and worsens the impact of infection for the community. This impacts all aspects of the disease and presents a major challenge for all programs across the prevention to care continuum.

In India, HIV-AIDS research shows that stigma and discrimination have been perpetuated by lack of awareness, traditional beliefs, and a moralistic sexual tag (in India, HIV transmission is predominantly heterosexual). Stigma has been assessed in different populations—high school students,[9] pregnant women,[10] HIV versus leprosy,[11] rural versus urban healthcare settings,[12] and HIV-infected women.[13]

The existing literature on stigma in HIV-AIDS is predominantly from the West[6,14] and Africa.[15,16] The research from India is sparse despite the fact that India is home to nearly 2.6 million (world's third largest number) PLWHA. As part of a study on psychiatric comorbidity in HIV-positive treatment seekers,[17] the present research aimed to fill the lacuna by studying stigma and related issues in HIV-positive subjects in India using a standardized HIV-specific stigma measuring tool.

MATERIALS AND METHODS

Location, ethical clearance, and design

The study was conducted at Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh, a 1,500-bed multispecialty teaching hospital providing services to approximately 40 million people in North India. As an MD Psychiatry research thesis of the first author, the research had received institutional ethical clearance, was time bound, and involved cross-sectional design, purposive sampling procedure, and one-time assessment of each subject.

Subjects

The sample consisted of HIV-infected outpatients attending an HIV clinic and not receiving antiretroviral therapy ($n=100$). The diagnosis was based on seropositive status on enzyme-linked immunosorbent assay (ELISA) test for HIV.[18] The inclusion criteria were age 15–55 years, ability to read and write in Hindi language, and informed consent. The exclusion criteria were any serious comorbid medical disorder or receiving antiretroviral therapy. The sampling was purposive for being dependent on the availability of the first author for data collection.

Measures

Demographic proforma

Developed for the study, demographic proforma was used to record sex, age, mean years of education, occupation, sexual orientation, marital status, religion, family, and locality.

Clinical proforma

Developed for the study, clinical proforma was used to collect illness-related details: self-belief about source of infection, age at onset, duration of illness, and CD4 count at present.

General health questionnaire-12 item in Hindi

A derivative of the 60-item General Health Questionnaire (GHQ),[19] the 12-item GHQ in Hindi language (GHQ-12 Hindi)[20] is a self-administered screening tool for primary care and community settings for psychological problems including anxiety, depression, social impairment, and somatic symptoms. Each item is rated on a four-point scale—less than usual, no more than usual, rather more than usual, or much more than usual; the rating was 0 for scale points 1-2 and 1 for scale points 3-4. The Hindi language translation has been standardized and used in Hindi-speaking population in India[20] and abroad.[21] It was used to screen the psychiatric morbidity, a case being defined by a score of ≥2, a cut-off reported to be reliable.[22]

Structured clinical interview for DSM-IV clinical version

Structured clinical interview for DSM-IV clinical version (SCID-CV)[23] helps the clinician identify seven psychiatric diagnoses—mood, psychotic, substance abuse, anxiety, somatoform, eating, and adjustment disorders, as per the Diagnostic and Statistical Manual of Mental Disorders - 4th Edition (DSM-IV) of the American Psychiatric Association.

Tanzania stigma indicator and community endline-individual questionnaire

It is an HIV-specific self-administered instrument with five sections: Respondent and household characteristics, Knowledge and misconceptions, Indicators regarding transmission and treatment, Shame and blame, Enacted stigma questions – primary stigma and disclosure. The questions used to assess stigmatizing attitudes and behaviors in this questionnaire were derived from the HIV-stigma field test[24] conducted in Tanzania in 2004-2005 (http://www.icrw.org/).[25] We excluded the first section as the relevant information was collected by our demographic proforma and remaining four sections were translated in Hindi as per World Health Organization (WHO) methodology.[26]

Procedure

The consenting subjects meeting the inclusion and exclusion criteria were administered the Demographic and Clinical proformas, Tanzania Stigma Indicator and Community Endline –Individual Questionnaire and GHQ; those with GHQ score ≥2 were then administered the SCID-CV. On average, a time of 75-90 minutes was required for administering all instruments, including the SCID-CV.

Statistical analysis

The data were analyzed using SPSS version 14.0 for Windows (Chicago, Illinois, USA). Descriptive data were analyzed by percentage, mean, and standard deviation. The subjects with or without shame or blame, and primary stigma were compared for demographic and clinical variables including presence of psychiatric disorder, with the continuous normally distributed variables by independent t test, and the discrete variables by Chi-square test. Binomial logistic regression analysis was used to find out the predictors of shame or blame and primary stigma.

RESULTS

Demographic profile

A typical subject was heterosexual (98% vs 1%, each homo-/bi-sexual), currently working (90% including 39% housewives, 29% un-/semi-/skilled workers, 15% clerical/shopkeepers/farmers, and 7% semi-/professionals; and 3% retired), married (73%), nuclear family (68%), school non-completer (63%; mean years of education for the whole sample being 7.66±3.67), village dweller (61%), middle aged (77% were aged 25-44 years; for the whole sample mean age was 33.57±7.71, and age range was 15-51 years), Hindu (52%), and male (59%). For the whole sample, the mean age at HIV diagnosis was 32.53±7.75 years and mean duration of HIV infection (based on seropositive status on ELISA test for HIV) (Kasper *et al.*, 2005) was 12.95±20.68 months. The mean CD4 count at intake into the study (N=63) was 278.98.

Psychiatric morbidity

The prevalence of GHQ-positive cases (score ≥2) was 52%. The rate of SCID-CV psychiatric disorders was 45%. The disorders were mood disorder (24%, including major depressive disorder in 19%), substance use disorders (17%), adjustment disorders (7%), and anxiety and psychotic disorders (2% total, 1% each).

The past psychiatric illness was present in 18% of subjects: alcohol dependence/abuse (8.5%); alcohol dependence+opioid dependence (3%); nicotine dependence and cannabis abuse (2% each); and alcohol and nicotine dependence, opioid dependence, and adjustment disorder (1% each).

Knowledge and misconception of HIV

The most common belief about the source of HIV infection was sexual contact (58%, equally distributed for men and women); 35% subjects did not report any suspected source; and injecting drugs, blood products, and artificial insemination were suspected only in 2%, 4%, and 1% subjects each [Table 1].

Only 35% subjects were aware of HIV and AIDS being different; half of them mentioned HIV as a virus and AIDS as a disease. Of the spontaneously reported means of HIV transmission, the most common were unprotected sex (79%), sharing injections (67%), and blood transfusion (56%), followed by mother-to-child (25%), sex with prostitutes (12%), and sharing blades (11%); the least common means were sex with multiple partners, road accidents, and mosquito bites (2% each), and injecting illegal drugs (1%). While 56% subjects believed that there could be mother-to-child transmission of AIDS, only 7% and 5% respectively believed the transmission to happen 'always' or 'depends'. The transmission was believed to occur during pregnancy (44%), breastfeeding (26%), or delivery (20%). While 84% subjects believed a healthy looking person could have HIV, 81% believed only one of the married partners could have HIV infection.

Table 1: Knowledge and misconceptions of HIV

Question asked	Responses	Frequency/%
Is there a difference between HIV and AIDS?	Yes	35
	No	17
	Don't know	48
What's the difference?	HIV refers to the virus	14
	AIDS is the disease	16
What are the ways you know of that HIV can be transmitted? (Spontaneous reply)	Unprotected sex/sex without condom	79
	Sharing injections	67
	Blood transfusions	56
	Mother to child transmission	25
	Sex with prostitutes	12
	Sharing razors/blades	11
	Sex with multiple partners	2
	Road accidents	2
	Mosquito bites	2
	Injecting illegal drugs	1
Can the virus that causes AIDS be transmitted from a mother to her baby?	Yes	56
	No	7
	Depends	8
	Don't know	29
When can the virus that causes AIDS be transmitted from a mother to her baby?	During pregnancy	44
	During delivery	20
	During breastfeeding	26
If a mother has HIV, would the virus always be passed on to the baby?	Yes	7
	Sometimes/rarely	19
	Don't know	30
	Depends	5
Can a healthy looking person have HIV?	Yes	84
	No	4
	Don't know	11
	Depends	1
In a married couple, is it possible for one person to have HIV and the other one not to have HIV?	No	14
	Yes	81
	Don't know	5

The majority reported no fear of getting infected on touching saliva or other body secretions of HIV positive subjects or on sharing with them belongings such as room or utensils, or on cleaning their excreta, beds, etc.

Indicators regarding HIV transmission and treatment

Nearly a quarter to one-third of the subjects spontaneously reported the following ways to protect people from getting HIV infection: avoiding injections, being faithful to one uninfected partner, avoiding blood transfusions, using condoms, and not sharing razors/blades. More than half agreed for the protective value of remaining faithful to a faithful partner and using condoms correctly, on specific query. Less than half were aware of any treatment available to prolong the life of PLWHA. On open questioning, a majority reported that they would buy food from PLWHA, or share a utensil with them [Table 2].

Shame and blame

A majority (60%) agreed with at least one stigmatizing 'shame' statement. Half of them were ashamed of themselves or family for being HIV infected. A majority (87%) also agreed with at least one stigmatizing 'blame and judgment' statement. Lastly, a majority (60%) blamed promiscuous men or women for spreading HIV in community and considered HIV as punishment for bad behavior [Table 3].

Enacted stigma

One-third of the subjects mentioned that people behave differently toward people suspected of having HIV/AIDS. Stigmatizing behavior reportedly observed in the community more commonly were isolation and verbal stigma [Table 4].

Disclosure

Self-disclosure remained the most common method of knowing about one's HIV status. Nearly half had seen individuals dying from AIDS. A majority had revealed their HIV status to the family members.

Correlates of stigma

On analysis of association of demographic and

clinical variables and shame, blame judgment, or primary/enacted stigma, urban subjects were found to have significantly higher primary stigma (item: Do people behave differently with PLWHA?) (53.8% vs. 27.8%, χ^2=6.81, *P*=0.009) and shame or blame statement (97.4% vs. 83.6%, χ^2=4.64, *P*=0.031) compared to rural subjects. There was no association between the presence of psychiatric disorder and shame, blame judgment, or primary/enacted stigma.

Simple binary logistic regression analysis with enter method was used to study the relationship among independent variables, which were more frequently present in subjects with primary/enacted stigma. Living in urban locality was the only significant predictor for enacted stigma with odds ratio of 3.02 (β=1.1, SE=0.43, wald=8.6, *P*=0.010).

DISCUSSION

Stigma is dynamic in that more knowledge changes the attitude toward HIV-AIDS. However, despite educational campaigns, knowledge remains low and stigmatizing attitudes and behaviors toward PLWHA remain a problem. One way to make health education effective is to make people identify their health problems and discuss them openly. Interventions to reduce AIDS stigma should address the role of stigma within families, be sensitive to the prevailing sociocultural and economic environment to promote better HIV prevention, treatment, and care, as well as to engage PLWHA in active life in the community, to help them cope with the internalized and perceived stigma.[15]

In India, a survey among teenage students in Delhi showed HIV-AIDS education leading to greater

Table 2: Indicators regarding HIV transmission and treatment

Question asked	Responses	Frequency/%
Tell me all the ways you know of that people protect themselves from getting HIV infection (Spontaneous reporting)	Avoid injections	40
	Be faithful to one uninfected partner	39
	Avoid blood transfusions	37
	Use condoms	26
	Avoid sharing razors/blades	25
	Abstain from sex	13
	Avoid sex with prostitutes	8
	Avoid sex with IDUs	4
	Limit number of sexual partners	2
	Avoid sex with persons having multiple sexual partners	1
	Avoid sex with homosexuals	1
	Avoid kissing	1
	Other-quite wrong response	12
	Don't know	25
Can someone prevent getting HIV by abstaining from sex?	No	23
	Yes	37
	Don't know	40
Can someone prevent getting HIV by remaining faithful to a faithful partner?	No	18
	Yes	58
	Don't know	31
Can someone prevent getting HIV by always using condoms correctly?	No	6
	Yes	70
	Don't know	24
Indicators regarding treatment of HIV/AIDS		
Is there a cure for AIDS?	No	48
	Yes	19
	Don't know/not sure	33
IF YES, then what kind of cure is it? (Spontaneous reporting)	Modern medicine	20
	Traditional medicine	3
	Faith healing/prayer	2
Do you know of treatment that can prolong the life of people living with HIV/AIDS?	No	57
	Yes	43
On asking further	Local herbs	4
	Faith healing/prayer	4
	ARV	24

IDU - Injection drug users

Table 3: Shame and blame – Tell me if you agree/disagree with these statements or are indifferent

	Agree	Indifferent	Disagree
Shame			
I feel ashamed as I am infected with HIV	54	20	26
I feel ashamed if someone in my family had HIV	49	19	32
People with HIV should be ashamed	45	27	28
I feel ashamed on seeing in public with an HIV-positive friend	38	15	47
Percentage of subjects who agree with at least one stigmatizing 'shame' statement	60	–	–
Blame and judgment			
Promiscuous women are spreading HIV in community	52	42	6
HIV is a punishment for bad behavior	51	28	21
Women prostitute spread HIV in our community	46	41	13
People with HIV should bear consequences of their bad behavior	45	30	25
HIV is punishment from God	44	24	32
People with HIV are promiscuous	39	46	15
Men could not control sexual urges so not to be blamed on getting HIV by promiscuous behavior	12	23	65
People with HIV are to be blamed for bringing HIV in community	48	38	14
Promiscuous men are spreading HIV in community	61	27	12
Women could not control sexual urges so not to be blamed on getting HIV by promiscuous behavior	6	37	57
In a married couple woman to be blamed for HIV	5	82	13
People with HIV got what they deserved	22	40	38
In a married couple man to be blamed for HIV	9	76	15
People with HIV to be blamed for their infection	39	40	21
Percentage of subjects who agree with at least one stigmatizing 'blame and judgment' statement	87	–	–
Percentage of subjects who agree with at least one stigmatizing 'shame' or 'blame' statement	89	–	–

Table 4: Enacted stigma questions – primary stigma

Question	Item	Frequency/%
Do people behave differently toward people suspected of having HIV/AIDS?	No	46
	Yes	38
	Don't know	16
Do you personally know someone within your community who in the last 12 months has had the following happen to them because they were known to have, or suspected of having, HIV/AIDS?		
Form of stigma		**Frequency/%**
Any sort of stigmatizing behavior observed in community		16
Isolation	No longer visited, or visited less by family/friends	6
	Excluded from a social gathering	1
	Isolated in household	1
Verbal stigma	Gossiped about	4
Loss of identity/role	Lost respect within the family/community	3
Loss of access to resources and livelihood	Been denied promotion/further training	2
	Given poorer quality health services	1

HIV-AIDS knowledge, and females to have less knowledge.[9] In coastal Karnataka, one-third of the population believed that one could get infected by merely touching an HIV-positive individual, and respondents with less than secondary school education had a more discriminatory attitude toward HIV-positive people,[27] while in our study, 20% subjects reported fear in touching HIV-positive subjects or their objects.

Although many studies report on HIV-AIDS stigma, the use of vastly different instruments/interview schedules makes a comparison difficult and forces us to compare our data largely with Tanzania study,[24] as basically the same instrument was used by both. Similar to Tanzania study, our study subjects were predominantly male, school non-completers, and middle aged (25-45 years), though married subjects predominated in our study (73% vs 16%). In Tanzania study, over 90% of both rural and urban respondents had heard of HIV and AIDS, while all our subjects knew about their HIV-positive status.[24]

Similar to our findings, the Tanzania study reported awareness of HIV transmission by route of mother-to-child in 60% of the respondents and unprotected sex or sex with multiple partners in 70% of the respondents.[24] A majority of respondents mentioned preventive approaches by avoiding premarital and multiple-partner sex, and sharing sharpened tools such as razors or needles with others.[24]

The Tanzania study reported HIV transmission belief ranging from 30% for mosquito bite, 15% for kissing, 10% for sharing food, and 7% for sharing toilet,[24] while comparative figures were reported much less in our study.

Similar to our finding, most respondents in Tanzania study knew of no life-prolonging measure or any cure for AIDS. Similar to our study in Tanzania study, 42% respondents blamed PLWHA for their disease and 73% considered that having HIV was shameful.[24]

Compared to isolation being the most common form of stigma in our study, verbal forms were the most common in Tanzania study.[24] Compared to only 16% PLWHA reporting any stigmatizing behavior in our study, 63% women and 50% men in Tanzania study had experienced stigma, and 59% of health providers reported observing stigma at their workplace.[24] These differences may be due to our subjects (HIV-positive outpatients not on antiretroviral therapy (ART)) being in the early phase of illness and largely functional. On further exploration, subjects reported less perceived stigma when they knew of many other HIV-positive subjects, indicating stigma decreasing with increased prevalence and disclosure of HIV. Our study did not find higher HIV stigma among women subjects as reported in earlier studies.[10,11,24] These multiple forms of stigma make people reluctant to disclose an HIV-positive status, even though most people believe that HIV status should be disclosed to family, friends, and community members in general, as opined by 82% respondents in the Tanzania study.[24]

Contrary to earlier studies reporting stigma to be more common among poorer, less-educated, and rural subjects,[16,24] our study reported higher primary stigma and shame or blame statement among urban subjects; though actual disclosure rate was somewhat higher in our study (97% vs. 81%) compared to that in the Tanzania study.[24]

Our study could not establish any of the associations reported by earlier studies such as higher felt stigma and lesser adherence to ART being associated with avoidant coping[28] and with low CD4 count, extended family, and being employed in HIV-infected women in India;[13] association between presence of psychiatric illness and shame/blame statements or primary stigma.[6]

The results of our study may be generalized only within its limitations. The time-bound nature of the study enforced a small sample size. The sample came from the outpatient service of an urban multispecialty hospital. The use of self-administered psychological assessment tools forced the exclusion of illiterates and semi-literates. There was no control group to compare our findings with.

In summary, our study subjects had a fair knowledge about the sources of and preventive measures for HIV transmission, but few subjects were aware of ART; the observed stigma was low and disclosure rate high; urban subjects reported higher primary stigma and shame or blame; prevalence of psychiatric disorders was high but not associated with stigma or shame or blame statements. The limited knowledge of HIV-AIDS, especially for treatment aspects, reflects a strong need for public health measures to enhance awareness and knowledge about HIV-AIDS so as to overcome the associated misconception and stigma.

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