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PLHA experience high self stigma and enacted stigma and stigma from health care providers associated with HIV/AIDS - A pilot study in District Kangra, Himachal Pradesh, India

KEYWORDS

HIV, stigma, discrimination, shame, PLHA/PLHIV

Rajesh K. Sood

Corresponding Author and District Epidemiologist, District Kangra, Himachal Pradesh, India

Omesh K. Bharti

Corporation Health Officer, Municipal Corporation, Shimla, India

Vidya Ramachandran

Scientist F, Deputy Director, National Institute of Epidemiology, Chennai, India

ABSTRACT Abstract

Background: Stigma associated with HIV/AIDS has been termed as the "third epidemic". Stigma is not only distressing to People Living with HIV/AIDS (PLHA/PLHIV) but represents a major obstacle to stopping the HIV/AIDS pandemic. Identification of stigma is the first step to addressing the problem; hence we undertook this study to bridge the information gap in Kangra district (North India) to estimate the prevalence of stigma & discrimination among PLHA in the year 2008.

Methods: We surveyed 45 People Living with HIV/AIDS (PLHA), 536 (87%) health care providers (HCP) & 540 community members & collected information on knowledge, stigma, attribution of blame & enacted stigma using questionnaire adapted from PLHA stigma questionnaire & USAID tools & computed proportions.

Results: Of 45 PLHA, 35 experienced enacted stigma, 34 experienced stigma from HCP, and 43 self stigma. 34 PLHIV had depression which was associated with lower Quality of life scores. 14 received no counseling. 22 PLHA had given informed consent for test. 30% HCP reported peer practices of testing without consent and 42% HCP reported disclosure to family without consent. 36% community members reported seen stigma with PLHIV. 94% community members & 84% HCP associated blame with HIV. 82% community members, 31% HCP associated shame with HIV. 75% HCP reported fear of contacting HIV from occupational exposure. 38% community members feared casual transmission. 12 PLHA & 48% community members knew that HIV and AIDS are different. 52% HCP had the misconception that HIV can be transmitted by saliva.

Conclusions: PLHA experienced high self stigma and enacted stigma which may be attributed to low awareness of community & inadequate training of HCP. There is urgent need to increase community awareness through targeted Information, Education and communication (IEC) and improve attitude of HCP through training.

Background:

One of the objectives of National AIDS Programmes is to reduce the personal and social impact of HIV infection, including discrimination against those living with or suspected of having HIV/AIDS¹. The stigma associated with HIV/AIDS is not only distressing to individuals but represents a major obstacle to stopping the HIV/AIDS pandemic.

In 1987, early in the epidemic's history, Jonathan Mann, former head of WHO's Global Program on AIDS, identified stigma as the "third epidemic," following the hidden, yet accelerating spread of HIV infection and the visible rise in AIDS cases. He recognized that stigma, discrimination, blame, and denial were potentially the most difficult aspects of HIV/AIDS to address, but also that addressing them was key to overcoming the spread of the disease.

The public reaction has been described as an "Epidemic of Stigma"². 26% of PLHA in USA perceived at least 1 of 4 types of discrimination by a health care provider³. A study revealed that 1 in 5 US people stigmatize HIV⁴. PLHA in France experienced stigma in interaction with health service providers (27%) and social interactions (24%)⁵. A multi country study of AIDS related discrimination in Asia reported that 54% experienced some form of discrimination within the health sector⁶.

Much of the stigma and discrimination associated with HIV arises from fear, shame, and blame. In many cases fears are based on irrational beliefs about HIV transmission, in

particular casual transmission. Stigma manifests in several ways, which can be broadly grouped as physical and social isolation/exclusion, verbal stigma (gossip, insults, voyeurism), loss of role (denied religious rites, loss of respect), and loss of resources (loss of job/customers/housing, given poorer quality or no healthcare).

A study in Chennai reported 26% of PLHA experienced stigma⁷. A recent study in Delhi hospitals⁸ reported that 68% had judgmental attitudes towards PLHA. Because of HIV/AIDS-related Stigma discrimination, appropriate policies and models of good practice remain undeveloped.⁹

The Fundamental Rights embodied in the Indian Constitution guarantee right to equality. Addressing stigma and discrimination is critical in preventing further infection and improving care. The identification of different forms of arbitrary discrimination, with a view to eliminate them, helps to respect, fulfill and protect human rights¹.

One of the major obstacles hampering reduction in stigma and discrimination is lack of data¹⁰. Qualitative studies in Himachal on HIV related social problems have identified instances of stigma¹¹. Studies on stigma and discrimination in Himachal are limited, resulting in an information gap on prevalence and nature of stigma and discrimination and consequently quality of life of PLHA. Hence this study was conducted.

Objectives

- To estimate the prevalence of Stigma and Discrimination experienced by people living with HIV /AIDS (PLHA) in Kangra, Himachal Pradesh.
- To describe the nature of Stigma and Discrimination experienced by PLHA
- To assess the quality of life of PLHA.
- To estimate prevalence of stigma and discrimination related to HIV/AIDS in the community
- To estimate prevalence of stigma and discrimination related to HIV/AIDS in medical care service providers.

3. Methods

3.1 Study Setting:

District Kangra is located in the western part of the north Indian state of Himachal Pradesh in the low foot hills of the Himalayas. It is a low prevalence district, with 0.25% prevalence in antenatal group. Himachal and District Kangra were a low prevalence (0.06 % and 0.25% median prevalence in antenatal group respectively) but high vulnerability district, with tourism, migration, and pastoralism¹². The district has high literacy (80%).

3.2 Study population (2008)

1. Adults living with HIV AIDS (PLHA) in District Kangra, Himachal Pradesh and willing to participate in the study constituted the study population; children were excluded from the study

2. Adult residents of District Kangra, constituted the study population for the community survey.

3. All doctors and nurses in District Kangra, Himachal Pradesh and willing to participate in the study constituted the study population of Health Care Providers (HCP).

3.3 Study design:

Cross Sectional survey of PLHA, Community members and HCP (doctors and nurses) was conducted.

3.4 Sample size and sampling:

We computed a sample size of 53 PLHA and PLHA who were willing to participate in the study were referred by doctors and counselors and local NGO.

A sample of 540 community members using cluster sampling technique (of 27 cluster with 20 community members each) was taken; and included all doctors and nurses who were willing to participate in the study.

3.5 Data collection:

PLHIV: PLHA were interviewed using an interview schedule to collect information on Demographic variables, Knowledge, Disclosure, Stigma, Blame, Discrimination, quality of life and depression. The interview schedule was adapted from the UNAIDS recommended tools¹² USAID Stigma Questionnaire¹³ UNAIDS PLHIV stigma questionnaire¹⁴ and WHO Quality of life scale- BREF¹⁵ and Beck Depression Inventory.

Community: We interviewed community members using an interview schedule to collect information on fear of casual contact, blame, shame, knowing a person who experienced stigma and discrimination due to HIV/AIDS. We adapted questionnaires from USAID questionnaire¹⁵

HCP: We gave a self administered questionnaire to health care providers to elicit information on knowledge, attitudes, training exposure, fear of casual transmission of HIV,

Values, shame, and blame, Enacted Stigma, Disclosure.

3.6 Data analysis:

Data generated were analyzed using Epi info. 3.5.1 Software as per different indicators identified. We calculated scores of Beck Depression Inventory & classified them into low (1-16), moderate (17-30) and severe (>30). We computed scores of Quality of life WHOQOL- BREF, as per the domains of Physical health, Psychological, Social Relationships and Environment & transformed scores to 100 point. We computed person correlation of QOL domains v/s other variables.

3.7 Quality assurance:

We pilot tested the questionnaires, We explained the purpose of the research and ask individuals to report actual perceptions and not what ought to do and assured the participants of confidentiality so that they could be honest about their responses. Data were collected by the author and trained female interviewer for female clients. 5% of the community questionnaires were randomly cross checked by the author. We conducted the interview one to one to avoid common responses by a group.

3.8 Bias and limitations:

As PLHIV try to maintain secrecy, they are not socially visible, only method to recruit PLHIV was through referrals; hence we were able to recruit less number of PLHIV participants. Stigma leads to shame silence and secrecy which made access difficult; there is no organization of PLHA. Female PLHA came to learn about status only when husband was terminally ill/ after death, hence less male PLHA participants.

Challenge for any study among PLHA is sample selectivity- the only way to ethically contact is through referrals, which preclude random sampling.

3.9 Protection of human subjects. The study was in accordance with the Declaration of Helsinki, ICME code of ethical guidelines for biomedical research involving human subjects. The study was submitted to and approved by the ethical committee of the National Institute of Epidemiology (ICMR). Written informed consent was obtained from participants.

3.10 Operational definitions:

Stigma: Social devaluation of a person because of a personal attribute leading to an experience of shame disgrace and social isolation.

Self Stigma: negative response by a person towards him or herself; an individual's internalization of the societal attitudes s/he experiences, or anticipates, in society. Self-stigma incorporates feelings of shame, dejection, self-doubt, guilt, self-blame and inferiority. It leads to high levels of stress and anxiety, and contributes to denial

Enacted Stigma: When stigma is acted upon, the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized.

4. Results: Results are being presented in the order of PLHA, Community and Health Care Provider.

4.1 PLHA:

4.1.1 Response Rates & Profile:

There is no network of PLHA in the area. For confidentiali-

ty issues, we did not access their records. Indirect methods were used to recruit them through requesting local doctors and counsellors for referrals of PLHA clients who were willing to participate in the study from the period of June to Nov 2008. We were able to recruit 45 PLHA against a target of 53.

4.1.2 Profile of study population of PLHIV:

30 PLHIV participants were females, 20 of whom were widows of HIV positive. 11 of the females and 4 males were currently married and living with partner in the household. 24 were in the productive age group of 25-34 years. The females were significantly younger than the males, mean ages being 31.2 and 34.9 respectively (Kruksal wallis chi square =6.43, $p= 0.001$). Median education was 7 years of school and was not significantly different by gender. 44 participants were Hindu. Majority (20) belonged to general (upper) caste, followed by other backward caste (16), the rest (8) belonging to Schedules caste/ tribe.

Description of stigma includes (a) the various types/ dimensions of stigma experienced by the PLHIV (b) the determinants of stigma and (c) the consequences of stigma experienced by the PLH (Disclosure, Depression and Quality of life, health seeking behavior of PLHA).

4.1.2 Types/ Dimensions of stigma: This includes Self stigma, Enacted stigma, and stigma from health care provider. Each one is discussed in detail:

4.1.2.1 Self Stigma

43/45 subjects experienced self stigma in last 12 months (37/45 had isolation stigma and 37/45 fears, both were not mutually exclusive). (Annex 3.1-Table IIA) Of the 37 who experienced isolation stigma; 26 chose to avoid social gatherings & 22 isolated themselves from family or friends. Of the 37 who were reported fears, all were afraid about being gossiped about, while 26 said that they had chosen not to attend social gatherings

4.1.2.2 Enacted Stigma/ Discrimination.

35/45 PLHIV experienced enacted stigma. 26 experienced verbal stigma followed by Isolation in 17. 13 PLHIV experienced negative effect on identity like loss of respect, and 7 reported lost/ decreased access to resources like health services property rights. A positive finding is that 10/45 reported no stigma at all.

4.1.2.3 Stigma from health care providers

34/45 PLHIV experienced stigma from HCP. 23/45 reported that health provider took extra precautions on non invasive examination (**though subjects did not have problems with it**) followed by disclosure by doctor to others without consent (12/45)

4.1.2 Determinants of stigma: Knowledge, Support & disclosure by others without consent

4.1.2.1 Knowledge.

Only 12/45 knew that HIV and AIDS are different; 26/45 knew about prevention through condom use, and 25/45 felt that a healthy looking person can have AIDS 44/45 rejected the misconceptions regarding casual transmission. 18/45 felt that it is possible to have HIV and other married partner being negative. 10/45 participants had comprehensive knowledge.

32/45 knew that ART prolongs life, 10/45 were not aware of ART. 16/45 felt that there is a cure for AIDS, 5/45 be-

lieved in religious/faith healing.

4.1.3.2 Testing and consent

Reason for testing: Major reason for getting tested was relative testing positive (23/45). 26/45 took the decision to test themselves, 9/45 took the decision themselves but under pressure, 5/45 were coerced into the test and 5/45 tested without their knowledge.

Consent: Only 22/45 PLHIV reported that informed consent was taken. Majority (38/45) had tested in VCTC/ Government hospital. They remember putting signature on form but asked about its contents told "**not able to read form (consent), which was in English**" while 17/45 received both pre test and post test counseling, 14 received none and 14 received only pre or post test counseling.

4.1.3.2 Disclosure without consent: 23 PLHIV reported that their status was revealed without their consent of which 12 told that health care providers had disclosed their status.

4.1.3.3 Support

Subjects experiencing supportive reactions to disclosure outnumbered those facing negative reaction; parents were universally supportive, all 32 who disclosed to parents found them to be supportive. Of 35 who disclosed to partner, 19 partners were supportive and 6 discriminatory. Disclosure to in laws was gender related with 10 facing discrimination and 13 were supported.

The mean **support score** was 15.04 (SD 10.97). 17/ 45 cases had support scores higher than mean. PLHIV support score 13 items: Cornbach's alpha of support score was 0.792.

4.1.4 Consequences of stigma:

4.1.4.1 Disclosure: 30/45 subjects had disclosed HIV status to somebody themselves, of whom 19 disclosed to partner, 17 to parents and siblings, 16 to social workers/ counselors and 15 to adult family members. Overall 17 perceived disclosure to be an empowering event. 30 of the participants tried to keep their status secret from community.

4.1.4.2 Health seeking behavior.

35 sought medical care or treatment in last one year, 32 went to a government facility, 15 went to private health facility, one went to NGO for support, one took care from Pharmacy/drug Store and one went to traditional practitioner (multiple responses). 16 told that the service provider was not told their status; 24 disclosed status to service provider.

Six avoided or delayed seeking health care treatment because they were afraid of service providers' attitudes toward them. Twelve travelled to a clinic or hospital that is far away, instead of going to a nearby clinic/hospital, because of their HIV status, to protect confidentiality. Seven opted for paid treatment over free for privacy concerns.

Treatment:

25/45 were currently taking antiretroviral treatment. 33 did not have any knowledge of opportunistic infections (OI) prophylaxis. Only 4 were taking any medication to prevent or to treat (OI). Only two females had received Nevirapine during pregnancy to decrease vertical transmission.

4.1.4.3 Depression

34/45 subjects had significant depression (>17 Score). 5 had score of 1-10 which denotes normal mood disturbances, 6 had scores of 11-16 which indicates mild mood disturbance. Total 11 had low depression. 6 had score of 17-20 which denotes borderline clinical depression, 19 had scores of 21-30 which indicates moderate mood disturbance. Total 25 were classified in moderate depression category; 8 had score of 31-40 which denotes severe clinical depression, 1 had score of >30 which indicates extreme depression. Total 9/45 were classified in significant depression category.

The mean Beck Depression inventory score was 23.2. [Annex 3.1: Table V]

4.1.4.4 Quality of life:

The WHOQOL Bref consists of 26 items. Each item uses a Likert-type five-point scale. These items are distributed in four domains. The four domains of QOL are, (a) physical health and level of independence (seven items assessing areas such as presence of pain and discomfort; dependence on substances or treatments; energy and fatigue; mobility; sleep and rest; activities of daily living; perceived working capacity); (b) psychological well being (eight items assessing areas such as Affect, both positive and negative self concept, higher cognitive functions; body image and spirituality), (c) social relationships (three items assessing areas such as social contacts, family support and ability to look after family; sexual activity) and (d) environment (eight items assessing areas such as freedom; quality of home environment; physical safety and security and financial status; involvement in recreational activity; health and social care: quality and accessibility). Domain scores are scaled in a positive direction (Higher scores denote higher quality of life).

The mean scores in domain 1 and domain 2 (46.35 and 51.09) were higher than those of domain 3 and domain 4 (which were 43.5 and 42.4 respectively). [Table VI]

The QOL domain 1 (PHYSICAL HEALTH) scores were significantly correlated with age (0.398, $p=0.007$), income (0.302, $p=0.044$), employment (-0.356, $p=0.016$), depression BDI score (-0.390, $p=0.008$). The QOL domain 2 (PSYCHOLOGICAL HEALTH) scores were significantly correlated with age (0.477, $p=0.001$), income, (0.386, $p=0.009$), employment (-0.369, $p=0.013$), stigma (0.309, $p=0.039$), depression BDI score (-.348, $p=0.019$).

The QOL domain 3 (SOCIAL RELATIONSHIPS) scores were significantly correlated with, stigma (0.487, $p=0.001$) and depression BDI score (-.664, $p=0.000$). The QOL domain 4 (ENVIRONMENTAL) scores were significantly correlated with education (0.341, $p=0.022$), income (0.466, $p=0.001$), employment (-0.387, $p=0.009$), stigma (0.382, $p=0.01$), knowledge (0.378, $p=0.01$) and depression BDI score (-.645, $p=0.000$). QOL scores across the depression categories is depicted in table VI C

4.1.4.5 Reactions to stigma:

33/35 did not confront stigma and tolerated it silently, as they felt it would make resistance even worse. In the words of one participant, "... just ignore comments and live with it, if we take action, people will be openly against us and life will be difficult".

4.2 Community

4.2.1 Profile of study community:

We had 540 respondents in the community survey. 50% were males and 50% were females. 40% were of the 25-

34 age group, 45% had studied till high school, over 90% were married, about half were not gainfully employed, and one fourth were self employed. 99% were Hindus. Of them, 24 % were general caste, 29% scheduled caste, 15% scheduled tribe and 32% other backward castes.

4.2.2. Community-level: Enacted stigma (discrimination).

We enquired about their observation or knowledge of stigma to PLHIV and in the community did not directly enquire about stigma by respondents. 36.3% females and 35.5 % males reported having seen any of the 14 items of stigma.

4.2.2.1 Isolation Stigma: 28% females and 26% males reported knowing someone with HIV or AIDS who has experienced any form of isolation stigma in the past 1 year 13.7 % females and 14.1 % males reported PLHIV being excluded from a social gathering. 12.2% females and 19% males reported PLHIV no longer visited, or visited less by family and friends. 7.8% females and 12.3% males reported PLHIV isolated in household

4.2.2.2 Verbal Stigma: 16.6% females and 22.9% males reported having witnessed verbal stigma. The major form was gossiping- 12.2 % of females and 20.4 % males reported PLHIV being gossiped about.

4.2.2.3 Loss of Identity/Role Stigma: 21.5% females, 22.2 % males reported having seen loss of identity for PLHIV. 16.7 % females and 18.1% males reported PLHIV having lost respect/standing within the family /community.

4.2.2.4 Loss of access to resources / livelihoods: 20.4% females and 21.9% males saw PLHIV suffering loss of access to resources/ livelihoods. 11.9% females and 10% males reported PLHIV were given poorer quality health services. 10% females and 10.4% males reported PLHIV having property taken away.

4.2.3. Determinants of stigma studied in the community were knowledge, fear of casual contact, and judgmental attitudes- shame, blame associated with HIV.

4.2.3.1 Proportion of people with correct knowledge (by sex, education, caste).

We enquired about the knowledge about HIV in the community to know what interventions need to be planned. 48% respondents knew that there is difference in HIV/AIDS (the knowledge was lower in women (45%) than in men (50%). 88.5 % respondents knew that AIDS can be prevented by condoms (87% women and 95% men). 87% (88.5% females & 84.8% males) said that if the mother has HIV, virus will be passed to the child. 86.5% knew that being faithful to one uninfected partner can protect from HIV (87% women and 86% men). 86% rejected the misconceptions that HIV/AIDS is transmitted through mosquito bite (88% women and 85% men). 91% did not have misconceptions that HIV/AIDS is transmitted through sharing food/utensils (91.5% women and 90.4% men).

Correct knowledge: There is a difference between HIV and AIDS [$\chi^2= 29.8$, $p=0.000$], A healthy looking person can have AIDS [$\chi^2= 7.86$, $p=0.005$] was significantly associated with education ≥ 8 years.

Those educated more than middle had higher knowledge than others. 58% of those educated more than middle standard knew that HIV and AIDS are different compared to 35% among those who studied up to 8th standard only.

[Annex 3.2: Table VIII] Similarly 33% of Scheduled castes, 35% of scheduled tribes, 55% of other backward caste and 66 % general caste persons knew that there is a difference between HIV and AIDS.

49 % had comprehensive knowledge (≥ 5 responses of 7 correct).

4.2.3.2. Community-level: Percentage of people expressing fear of contracting HIV from non-invasive contact with PLHA.

38% respondents (40% males and 37% females) expressed fear of casual contact with PLHIV. 30% were fearful of being infected if exposed to saliva of PLHIV (33% females and 27% males). 14% were fearful of being infected if exposed to sweat of PLHIV (16 %females and 13% males). 31% said that were afraid to buy food from PLHIV (35 %females and 26% males). 56% of those educated less than middle had fear for caring for a person living with HIV / AIDS, while 44% of those educated middle and above had fear; this was association with education was statistically significant [$\chi^2= 7.57, p=0.006$]. Similarly 58% of those educated less than middle had Fear that his/ her child could become infected by playing with a child having HIV/AIDS, while 42% of those educated middle and above had that his/ her child could become infected by playing with a child having HIV/AIDS; this difference was statistically significant [$\chi^2= 7.977, p=0.5005$].

4.2.3.3. Community-level: Shame, blame, judgment (Stigmatizing attitudes):

Shame: 82% community members (80 % male and 83% female) reported that they would feel shame if they associated with a person living with HIV/AIDS. 61.5 % (63% female and 60% males) stated that they would be ashamed if someone in their family had HIV/AIDS. 68.9 % (65.2 % female and 64.8 % males) said that they would feel ashamed if they were infected with HIV. 63.3 % (76% female and 68% males) said that people with HIV/AIDS should be ashamed of themselves

56% of those who were employed felt that they would be ashamed if someone in their family had HIV/ AIDS, while 44% of those who were unemployed felt so. Shame was significantly associated with being employed [$\chi^2= 7.398, p=0.007$]

Blame and Judgment: 94% people (93% female and 95% males) judge or blame PLHA for their illness. 82.2% felt that the prostitutes are responsible for spreading HIV in our community. 39% felt that HIV/AIDS is a punishment for bad behavior. 58.3% felt that people with HIV/AIDS are promiscuous. 56% of those who were employed felt that people with HIV/AIDS are promiscuous, while 44% of those who were unemployed felt so. Blame was significantly associated with being employed [$\chi^2= 7.398, p=0.007$]. Shame and blame were not associated with knowledge of HIV/AIDS.

4.2.6. Disclosure:

59% people think a person should be able to keep their HIV status private. 13% called for public disclosure. The differences across sex were not statistically different [$\chi^2= 0.64, p=0.727$].

4.3 Health care provider Response rates

There were 292 Doctors and 323 nurses in the District. Of them, 241 doctors and 323 nurses agreed to participate in the study, thus giving a response rate of 82.5% and

91.3% for doctors and nurses respectively, (and an overall response rate of 87%). The good response rate was due to ownership by the District AIDS Programme Officer, who facilitated the process. The reasons for non response despite giving three reminders/visits were doctors being too busy, some staff in the list on long leave or having been transferred out. The non responders were similar to the respondents in demographic characteristics. The results are described separately for the doctors and nurses.

4.3 A Doctors

4.3.1 Sample description and response rates

Among the doctors 71% were male, most (34%) were of the age group 25-34 years. 38% were working in medical college, 25% in Primary Health Centers, 11% in civil hospitals and 10% community health centers. 82% of the doctors were married. 37% of the doctors were general practitioners and 62% were specialists. 55 % of doctors were trained in HIV/AIDS.

4.3.2. Stigmatizing attitude:

80% felt comfortable assisting or being assisted by a colleague who is HIV infected. 65% felt comfortable performing surgical or invasive procedure on clients whose HIV status is unknown. 84% said that they felt comfortable providing health services to clients who are HIV-positive. 81% would feel comfortable sharing a bathroom with a colleague who is HIV infected. 74% felt that most frequent mode of contracting HIV among health workers is through work-related exposure. 90% stated that patients should be tested for HIV before surgery while those who said that all pregnant women should be tested for HIV were 97%.

69% doctors felt that the need for consent is exaggerated & HIV tests should be handled like any other test. 69% doctors felt that when a patient tests positive, the doctor should inform the patient's partner. 18% doctors said that patients with HIV should be kept at a distance from other patients. 35% doctors said that clothes and linen used by HIV positive patients should be disposed off or burned. 39% doctors stated that PLHIV should be allowed to get married, and 64% of doctors felt that HIV positive women should not get pregnant.

4.3.3 Having seen discrimination

Provider-level (Doctor): Witnessed Enacted Stigma

We computed percentage of doctors who reported having witnessing stigma because they were known or suspected to have HIV/AIDS: 89% doctors reported witnessing at least one type of stigma happening to PLHIV.

4.3.3.1 Neglect: 28% reported having seen PLHIV to be neglected in the past 12 months. 20% reported that HCP avoid going near PLHIV to avoid infection.

4.3.3.2 Differential treatment: 78% reported knowledge of the fact that PLHIV were treated differently in last 12 month.

59% reported witnessing that some clients were required to be tested for HIV before scheduling surgery, and 52% reported witnessing practice of using latex gloves for performing non-invasive exams on clients suspected of having HIV, and 61% reported witnessing practice of extra precautions being taken in the sterilization of instruments used on HIV-positive patients.

4.3.3.3 Denial of care: 25% reported HIV-positive clients being pushed (passed on) by a senior health care provider to a junior provider.

4.3.3.4 HIV testing and disclosure without consent: 69% reported practices of testing/disclosure a client for HIV without their consent.

60% doctors reported the practice of sharing status of patient with staff members. 31% doctors reported practice of disclosing client's status to family without his consent.

4.3.4. Determinants

The Determinants of stigma are discussed in the context of knowledge, fears and values- Blame and shame

4.3.4.1 Doctors Knowledge about HIV/AIDS

55 % of doctors were trained in HIV/AIDS. 84% (203) were aware of post exposure prophylaxis. Only 32% doctors had correct/ in-depth knowledge.

In-depth knowledge by items: 46% of doctors knew/believed that risk of HIV transmission following a needle prick or sharp injury is small, [approximately 1 in 300]. 52% of doctors felt that the risk of HIV transmission following a splash of blood to non-intact skin or mucus membrane is very small, (approximately 1 in 1,000). 67 % of doctors said that standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient.

Common Misconceptions: 54% Doctors did not have misconceptions on casual transmission. 39% of doctors had misconception that HIV/ AIDS is transmitted by saliva. 17% of doctors had the misconception that HIV/ AIDS is transmitted by sweat/tears. Knowledge / fears and shame/blame were not significantly associated with demographic characteristics like age, caste, or educational background.

4.3.4.2. Doctors` Fears about HIV/AIDS:

71% doctors reported fear of risk of contacting HIV during contact with patients.

63% doctors were afraid of conducting surgery on or suturing a person with HIV or AIDS. 61% had fear of assisting the delivery of a woman with HIV or AIDS. 50% expressed fear of dressing the wounds of a person living with HIV or AIDS. 50% reported fear of putting a drip in person with HIV or AIDS. 52% doctors had fear of drawing blood of a person with HIV or AIDS. 42% reported fear of giving an injection to a person with HIV or AIDS.

Doctors' Values, shame, and blame:

Shame: 20 % doctors would feel shame if they associated with a person living with HIV/AIDS. 18% said that people with HIV/AIDS should be ashamed of themselves, while 16 % said that they would feel ashamed if they were infected with HIV.

Blame and Judgment: 84.2% doctors judge or blame PLHA for their illness.

72% doctors felt that people with HIV/AIDS are promiscuous. 56% doctors felt that the prostitutes are responsible for spreading HIV in our community. 13% doctors felt that HIV/AIDS is a punishment for bad behavior.

4.4 Nurses

4.4.1 Profile of study nurses:

Among the nurses 98% were female, 36% were aged between 25-34 years; 40% were in posted in medical college, 14% in Primary Health Centers, 16% in civil hospitals and 10% in community health centers. 81% of the nurses were married, and 17% unmarried. 83% were general nurses

and 17% were nursing supervisors. 49 % of nurses were trained.

4.4.2. Stigmatizing attitude among Nurses:

75% nurses felt comfortable assisting or being assisted by a colleague who is HIV infected. 67% would feel comfortable (have no objection) sharing a bathroom with a HIV infected colleague.

65% of them felt comfortable performing surgical or invasive procedure on clients whose HIV status is unknown. 79% said that they felt comfortable providing health services to clients who are HIV-positive.

98% nurses stated that patients should be tested for HIV before surgery while 99% said that all pregnant women should be tested for HIV. 76% felt that the need for consent is exaggerated & HIV tests should be handled like any other test. 76% felt that when a patient tests positive, the doctor should inform the patient's partner. 34% said that patients with HIV should be kept at a distance from other patients. 56% said that clothes and linen used by HIV positive patients should be disposed off or burned.

80% felt that most frequent mode of contacting HIV among health workers is through work-related exposure. 31% stated that PLHIV should be allowed to get married, and 64% felt that HIV positive women should not get pregnant.

4.4.3 Having witnessed discrimination

98% nurses reported having witnessed at least one type of stigma to a person because he/she is PLHIV.

4.4.3.1 Neglect: 38% nurses reported having seen PLHIV to be neglected in the past 12 months. 30% nurses reported PLHIV receiving less care/attention than other patients.

4.4.3.2 Differential treatment: 97% reported knowledge of the fact that PLHIV were treated differently in last 12 month. 92% nurse reported practice of extra precautions being taken in the sterilization of instruments used on HIV-positive patients. 88 % nurses reported knowledge of requiring some clients to be tested for HIV before scheduling surgery. 85% nurses reported practice of using latex gloves for performing non-invasive exams on clients suspected of having HIV.

4.4.3.3 Denial of care: 18% nurses reported HIV-positive client being pushed by a senior health care provider to a junior provider.

4.4.3.4 HIV testing and disclosure without consent: 94% nurses reported practices of testing/disclosure a client for HIV without their consent. 89% nurse reported the practice of sharing status of patient with staff members. 51% nurses reported practice of disclosing client's status to family without his consent. 35% nurses reported practice of testing a client for HIV without their consent.

4.4.4. Determinants

4.4.4.1 Provider-level (Nurse): Knowledge

Only 51% of nurses were trained in HIV/AIDS and 78% (229) were aware of post exposure prophylaxis. 28% had correct/ in-depth knowledge.

In-depth knowledge by items: 54 % of nurses knew/believed that risk of HIV transmission following a needle prick or sharp injury small, [approximately 1 in 300]. 55 % of nurses felt that the risk of HIV transmission following a

splash of blood to non-intact skin or mucus membrane is very small, (approximately 1 in 1,000). 54 % of nurses said that standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient.

Common Misconceptions: 41% nurses did not have misconceptions on casual transmission. 55 % of nurses had misconception that HIV/ AIDS is transmitted by saliva. 30 % of nurses had the misconception that HIV/ AIDS is transmitted by sweat. 27% nurses had the misconception that HIV/AIDS is transmitted by tears.

4.4.4.2. Provider-level (Nurse): Fear

Provider-level Fear: 71% nurses reported fear of risk of contracting HIV during contact with patients. 59% nurses reported fear of giving an injection to a person with HIV or AIDS. 70% nurses had fear of assisting the delivery of a woman with HIV or AIDS. 65% nurses expressed fear of dressing the wounds of a person living with HIV or AIDS. 71% nurses were afraid of conducting surgery on or suturing a person with HIV or AIDS. 60% nurses admitted to fear of putting a drip in person with HIV or AIDS. 11% nurses were fearful of touching the sweat of a person with HIV or AIDS. 33% nurses had fear of touching the saliva of a person with HIV or AIDS. 63% nurses had fear of drawing blood of a person with HIV or AIDS.

4.4.4.3. Provider-level (Nurse): Values, shame, and blame:

Shame: 41% nurses would feel shame if they associated with a person living with HIV/AIDS. 22% nurses stated that they would be ashamed if someone in their family had HIV/AIDS. 31 % nurses said that they would feel ashamed if they were infected with HIV. 26% nurses said that people with HIV/AIDS should be ashamed of themselves. **Blame and Judgment:** 83.8% nurses judge or blame PLHA for their illness. 60% nurses felt that the prostitutes are responsible for spreading HIV in our community. 19% nurses felt that HIV/AIDS is a punishment for bad behavior. 75% nurses felt that people with HIV/AIDS are promiscuous. Blame shame and judgment did not differ significantly among trained and untrained nurses.

5. Discussion

The results from the three categories of stakeholders PLHIV, Community and Health Care Providers are discussed below:

5.1 PLHIV subjects.

The low participation was due to no network of PLHIV and our approach to protect their identity even from the researcher, so that the study does not add to their stigma through referrals and voluntary participation.

5.1.2 Types of stigma:

Stigma includes Self stigma, Enacted stigma (Discrimination), and stigma from health care provider.

5.1.2.1. Self stigma in last 12 months:

Self stigma is a negative response by a person towards himself /herself. High self stigma seen in our study is similar to findings of the study done by Thomas BE, Chennai (2005). An HIV diagnosis becomes shameful as it implies association with immoral behavior, PLHIV may take on the guilt and judgment they perceive society has of HIV in general and internalize it.¹⁶.

5.1.2.2 Enacted Stigma in last 12 months:

Only ten reported no stigma at all. The reported stigma is

much higher than in other settings, in Cape town, South Africa (Simbayi LC et al 2007, [40%])¹⁷, PLHA in France experienced stigma in social interactions (Perretti Wattel P et al, 2005[24%])⁵ and a recent study in Chennai (Thomas BE et al, 2005) reported 26% of PLHA experienced stigma. A CDC study in 2001 revealed that 1 in 5 US people stigmatize HIV⁴. Moreover our study was in community based setting rather than ART centre based one, which may explain the differences.

5.1.2.2 Stigma from HCP in last 12 months

Our finding of 40% of the PLHIV subjects avoiding visit to doctor or going to distant doctor points to lack of PLHIV friendly services in rural areas. Nearly one fourth PLHIV in our study felt that their confidentiality was not protected or were tested for HIV without informed consent, points to lack of sensitivity on part of service providers to take informed consent for testing or disclosure. Of the PLHIV reporting discrimination, unnecessary use of protective gear by HCP was reported by about half participants; which is higher than 20% reported in NACER study²⁷.

The enacted stigma by a health care provider in our study was 35/45, which is higher than 26% of PLHA in USA (Schuster MA et al, nationally representative sample in USA, 2005)¹⁸ and 27% by PLHA in France (Perretti-Wattel P et al, 2005)⁵.

Many HIV-positive adults believe that their clinicians have discriminated against them, it is not possible to ascertain whether the perceptions are real or imagined³. A patient may assume that an abrupt physician is prejudiced when he/she is actually abrupt with everyone. Similarly, a physician who refers patients to physicians with greater HIV expertise could be perceived as refusing care.

5.1.3 Determinants of stigma: Knowledge, testing without consent, Support & disclosure by others without consent

5.1.3.1 Knowledge of HIV /AIDS among PLHIV:

The low knowledge about modes of HIV transmission even after having HIV infection points to lack of proper counseling. One in five persons not being aware of ART is also a matter of concern. These support the findings of earlier case studies on lack of counseling.

5.1.3.2a Forced testing/ testing without consent

Informed consent not being taken in over half, despite majority being tested in government VCTC is matter of concern, or it was just taken as implied like other tests. One third tested without counseling may be the reason for lack of proper knowledge of the disease. Another one third received only one counseling session, thus two thirds not properly counseled may explain the exceptionally high self stigma. One fifth of our study subjects were tested without knowledge/ consent which is worrisome.

5.1.3.2b Disclosure by health care provider without consent:

Disclosure by a health care professional without patient's consent being common in our setting highlights the need for training in test related counseling and ethical aspects of HIV-related disclosure. Our results are similar to findings of Chandra et al²³ (2003) in a south Indian setting who found that 35% PLHIV reported disclosure without consent. Chandra et al (2003) in a study in south India observed that disclosure without the individual's consent is troubling especially because in 75% of the cases, the breach of confidentiality occurred through health profes-

sionals²³. A multi country study of AIDS related discrimination in Asia by Paxton et al (2005) reported that 34% said that somebody else had been told of their HIV status without their consent⁶. Similar findings were noted in a recent study by Action Research Group (2006) in three districts of Maharashtra¹⁹.

5.1.3.3 Support Over one third enjoyed high support. Subjects experiencing supportive reactions to disclosure outnumbered those facing negative reaction. Siblings and parents were overall supportive. This is similar to Studies in Ethiopia by Deribe K (2008) where 95% got a positive reaction to disclosure to partner²⁰. Most of our subjects (40 %) were married and having regular partner living in household, which increases the chances of disclosure²².

5.1.4 Consequences of stigma:

5.1.4.1 Disclosure: The self disclosure level in our study is similar to those seen in south India (66%)²¹. The high rate of voluntary disclosure to family members indicates the importance of families as a primary emotional and material support system in India. 17/30 perceived disclosure to be an empowering event. This is lower than 95% reported by Serovich (2008)²². This could be due to disclosure by others without consent. Disclosure is believed to lower stress levels and ultimately lead to better psychological health. A certain level of disclosure is necessary to access AIDS-related health care resources. Disclosure of one's HIV status to sexual partners is essential in stopping the spread of HIV infection²³.

In spite of the proposed benefits of disclosing one's HIV status, choosing to disclose may leave a person open to stigma and discrimination. Among those who did not disclose publicly, majority felt they would be gossiped about or afraid that if disclosed, scared of social isolation, loss of respects, they would tell someone else. While disclosure can have advantages for both HIV-positive individuals and their significant others, It is generally acknowledged that although wider disclosure will dispel the stigma associated with HIV, without adequate counseling, social support, and improved access to health care and medical treatment, it is difficult to encourage wider disclosure²⁴.

5.1.4.2 Health seeking behavior.

Over half (25) were currently taking antiretroviral treatment which is more than double than the NACER UNDP study among PLHIV in India. Two thirds reported difficult access, which was geographical (due to distance and terrain). Low knowledge of OI prophylaxis point to lack of discussion with patients on treatment options. Majority of women told that they were not aware of HIV testing services while pregnant, so they could not take any measures to decrease vertical transmission, which points to low awareness of services in the area.

Higher proportion seeking care in government facilities is similar to private facility is similar to other Indian studies (UNDP-NACER)²⁵ which reported "While 44 percent of the illness episodes had been treated at the government health facilities, the percentage of illness episodes for which treatment had been sought in the private facilities is lower at 37 percent".

Depression

Three - fourths of the subjects had significant depression. This is much higher than reported by William P et al among pregnant PLHIV patients in Canada (2003,[54%])²⁶; Levine AB et al in USA, 2008(53 % having score >9)²⁷,

Pence BW et al in outpatients in Southeast USA in a HIV clinic setting 2006 (30%)²⁸ ; Judd et al in Australia, 2005 (33%)²⁹ and Kolarić B (2006) among Croatian PLHIV (20%)³⁰. The results are comparable across scales as evidenced by the study of Cockram et al (1999) who compared four scales to screen for depression and found BDI to be comparable to others³¹. The common complaint of fatigue could be associated due to depression and not the disease as found by Milkin et al³². However the results need to be interpreted with caution as depression scales that include somatic symptoms will inflate depression scores in people living with HIV infection³³.

Our finding that PLHIV having no stigma had lower mean BDI Scores, is consistent with study by Vanable et al (2006) which concluded that stigma was associated with depressive symptoms³⁴ and by Prachakul W et al 2007³⁵

. Feelings of shame and guilt lead to depression and chronic depression among individuals with HIV hastens disease progression and mortality.

5.1.4.4 Quality of life:

We computed scores of WHOQOL- BREF, as per the domains of Physical health, Psychological, Social Relationships and Environment & transformed scores. We found that subjects who experienced stigma had lower mean QOL scores across all domains and higher depression scores.

QOL in present study was found to be determined by education, income, occupation, which is consistent with study by Wig N (2006)³⁶ . Individuals educated to high school or higher have greater likelihood of possessing better psychological capabilities to cope with disease. Our study is also consistent with the study on QOL and depression of life by Kempainen JK (2001)³⁷. The findings emphasize the importance of recognizing and treating depression in persons with HIV/AIDS.

5.1.4.5 Reactions to stigma:

30 /45 had tried to keep their status secret from the community as a consequence of perceived stigma, the burden of living with any substantive secret can be regarded as detrimental to one's health. Steward WT et al³⁸ in a study in South India (2008) concluded that disclosure avoidance leads to depression and stigma. Disclosure of HIV status can therefore be an important part of helping people to come to terms with their diagnosis and learn to live positively³⁹. Most did not confront stigma, which may be due to lack of association of PLHIV.

5.2 Community

.2.1. Community-level: Enacted stigma (discrimination).

36% of our study subjects reported witnessing any form of stigma associated with PLHIV, which is higher than 30% reported by Tanzania study¹⁴.

Having witnessed isolation stigma (28% for females, 26% for males) in our study was similar to 23% in Tanzania study¹⁵ (2005) by Tanzania Stigma-Indicators Field Test Group and USAID; whereas verbal Stigma (45% for females, 62% for males) in our study was much higher than Tanzania¹⁵ (19%); loss of identity (58% for females, 60% for males) was twelve times than found in Tanzania¹⁵(5%). Loss of access to resources/ livelihoods seen in our study (55% for females, 59% for males) was 6 times that of Tanzania¹⁵ (9%).

In Himachal Pradesh, the proportion of people not refusing casual contact with PLHA to HIV was 46% in females and 56% in males in NFHS 3⁴⁰, which are higher than our study. A study by Kaulagekar A (2007) in Mumbai and Pune among the urban middle class, revealed that 63% people attributed blame to the affected individuals and 39% reported stigma in interaction⁴².

5.2.2 Determinants of stigma studied in the community were knowledge, fear of casual contact, and judgmental attitudes- shame, blame associated with HIV.

5.2.2.1. Proportion of people with correct knowledge (by sex, education, caste),

Our study found that less than half knew that AIDS and HIV were different. Men had higher knowledge than women on HIV is transmitted and how to keep from getting it. The comprehensive knowledge of HIV/AIDS in our study (49%) is comparable to NFHS 53%. Those educated more than middle had higher knowledge than others. Knowledge that condom use is protective (87% women and 95% men) is higher than of NFHS (62% women and 82% men) & NACO BSS 2006⁴¹ (73% female and 86% male); three fourths knew that being faithful to one uninfected partner can protect from HIV and was higher in males than females. The response of males was higher in NFHS 3 (91%) and BSS⁴¹(83%) while that of females was lower in NFHS 3 (76%), BSS (78%). Over 90% persons have heard of HIV/AIDS in Himachal Pradesh (NACO BSS 2006)⁴¹, (NFHS 3).

5.2.2.2. Community-level: Percentage of people expressing fear of contracting HIV from non-invasive contact with PLHA.

Fear of being infected is exposed to saliva of PLHIV & fear of being infected is exposed to sweat of PLHIV was which was similar to Tanzania study (30% and 14% respectively). Fear of being infected if exposed to excreta of PLHIV (23%) and fear that his/her child could become infected by playing with child who has HIV/AIDS (18%) was higher than Tanzania study by 2 percentage points. However this is lower than 29% of respondents in Ghana Ulasi et al (2009)⁴² who stated that they would not allow their children to play with child having HIV/AIDS. Proportion of people who reported that they would NOT buy food from PLHIV vendors in market of several vendors (31%) is much higher than NFHS (26% women and 22% men) and Tanzania study¹⁵(7%). Fear were associated with low knowledge, which is similar to findings of Ulasi CI et al (Ghana 2009)⁴⁵

5.2.2.3. Community-level: Shame, blame, judgment (Stigmatizing attitudes):

Percentage of people who judge or blame PLHA for their illness (94%) is much higher than Tanzania study (66%) and recent study by Kaulagekar A (2007) in Mumbai and Pune which revealed that among the urban middle class, 63% attributed blame to the affected individuals⁴³. Percentage of people who would feel shame if they associated with a PLHA (82%) is much higher than Tanzania study, 2005 (66%).

Health care provider

HIV/AIDS-related stigma and discrimination can reduce the quality of treatment and health care received⁴⁴.

5.3.1 Stigmatizing (Negative) attitude:

It is encouraging that three fourths of the health care providers felt comfortable with PLHIV, which is higher than Chinese studies reviewed by Weber GC who noted that

while 62% of HCPs in the Yunnan study were willing to treat PLWHA⁴⁵, 82% said that they would not prefer to. Our results are similar to findings of Fusilier M, (1998) who reported that 81% HCP in Mexico indicated they were willing to treat AIDS patients⁴⁶.

Attitudes about HIV testing, informed consent and disclosure:

The proportion of health care providers (90% doctors and 98% nurses) stated that patients should be tested for HIV before surgery was higher than Delhi Hospital study (79%) while that of nurses was comparable to the Delhi Study¹⁰ (92%). The proportion of doctors who said that all pregnant women should be tested for HIV (97%) was higher than the Delhi Hospital study¹⁰ (66%) while those nurses who said that all pregnant women should be tested for HIV (99%) were slightly higher than the Delhi study (92%)¹⁰. Similarly in Chinese settings (Weber GC, 2007), most of the HCPs (94%) felt that HIV tests should be mandatory for pregnant women⁴⁴.

1/5 of the PLHIV in our study were tested without informing or coerced to take the test. This is supported by findings of evaluation by Weiser SD (2006) and review by Mahajan A et al (2008) of provider-initiated testing approach may have potential for coercion of patients to test^{47,48}.

The proportion of participants who felt that the need for consent is exaggerated & HIV tests should be handled like any other test (69% doctors and 76% nurses) is much higher than Delhi hospital study¹⁰ (60% doctors and 34% nurses). However the proportion who felt that when a patient tests positive, the doctor should inform the patient's partner (69% doctors and 76% nurses) was lower than the Delhi¹⁰ hospital study (87% doctors and 98% nurses).

Evidence of prejudicial attitudes to HIV-infected individuals amongst health workers is of concern. However, as three fourths were comfortable with PLHIV, the stigma appears to be inadvertent with a desire to protect themselves, than to actually deny service. This is similar to findings from all countries (Ogden J & Nyblade L, 2005) which show a gap between people's stated intentions *not* to stigmatize and their actions, which are stigmatizing⁷.

Attitudes towards infection control procedures:

The doctors in our study who felt that PLHIV should be kept at distance from other (18%) was lower than Delhi study¹⁰ (21%); but the proportion of nurses who believed so (34%) was higher than the Delhi hospital study¹⁰ (29%). 27% of our participants (18% doctors and 34% nurses) said that patients with HIV should be kept at a distance from other patients; which is much lower than that 59% seen in Nigeria Study (Reis C, 2005)⁴⁹.

The proportion of HCP in our study who said that clothes and linen used by HIV positive patients should be disposed off or burned (35% doctors and 56% nurses) were lower than the Delhi Study¹⁰ (54% and 67% respectively). Participants in our study (17% doctors and 38% nurses) who felt that HIV infected patients should be made to pay for health staff's use of additional infection control supplies were higher than in Delhi¹⁰ hospital study (14% doctors and 12% nurses).

Attitudes towards PLWHA rights

Participants who felt that people living with HIV should have a right to decide who should know their results (71%

doctors and 80% nurses) were higher than Delhi hospital study¹⁰ (64% and 62% respectively). Proportion of participants who stated that PLHIV should be allowed to get married (39% doctors and 31% nurses) is much lower than Delhi hospital study¹⁰ (which reported 79% and 44% nurses agreed). Those who felt that HIV positive women should not get pregnant (64%) were lower than Delhi hospital study¹⁰ (71% doctors and 89% nurses).

Nurses had higher stigma than doctors which is comparable to other studies (Delhi hospital Study, Tanzania Study)¹⁰. Untrained persons had higher stigma than trained; which is also seen in studies in Ethiopia⁵⁰.

Those having in-depth knowledge had significantly lower stigma than others and having fear of casual contact had higher stigma. This is similar to findings of Li *et al* (2007) in Chinese medical service providers that fear of infection has been associated with stigma⁵¹.

5.3.2. Perceived Discriminatory Behaviours by Peers Provider-level: Enacted Stigma

In our study, 30% health providers reported having seen PLHIV to be neglected in the past 12 months. 15 % HCP reported that some service providers avoid going near HIV infected patients to protect themselves from HIV infection 88% health care providers reported that PLHIV were treated differently in last 12 month. This is lower than the recent US study by Sears B (2006) where 46% of skilled nursing facilities and 55% of obstetricians in Los Angeles County would not accept PLHIV clients⁵².

One in five health care providers (18% nurses and 25% doctors) reported HIV-positive client being pushed by a senior health care provider to a junior provider, which is higher than the Tanzania Study¹⁵ which reported 11%. This may be due to power to delegate for senior doctors⁵³.

83% health care providers (94% nurses and 69% doctors) reported practices of testing/disclosure a client for HIV without their consent which is higher than Delhi Hospital study¹⁰. This may be due to lack of training in ethics or a measure for self protection due to fear from not following universal precautions.

Practice of testing a client for HIV without their consent (35% nurses and 23% doctors) is higher than 24% in Tanzania study⁵⁴. Half nurses and one third doctors reported practice of disclosing client's status to family without his consent which was lower than Delhi Study baseline¹⁰ (58%).

5.3.3. Determinants of Stigma

The determinants of stigma studied were knowledge, fear, and values- blame and shame. These are similar to the domains identified in a Scale by Zelaya *et al*⁵⁵ for measuring HIV stigma in Chennai, India (2008).

5.3.3.1 Provider-level: Knowledge

Half the service providers were not trained is a matter of concern, moreover higher proportion of nurses were untrained compared to doctors. With just half having received a formal training, the proportion of misconception was high. One fifth were not aware of post exposure prophylaxis. In China, knowledge of HIV and negative attitudes among nurses were inversely correlated; 50% of nurses reported anxiety about becoming infected with HIV in the workplace, and 49% said they avoided contact with HIV-positive patients altogether (Chen, Han, and Holzemer 2004)⁵⁶.

The in-depth knowledge was much less than required. Nurses having lesser knowledge and higher misconception than doctors on casual transmission may due to training differences.

5.3.3.2 Provider-level: Fear: Three fourths of health care providers reported fear of risk of contacting HIV during contact with patients, which is more than twice that seen in Tanzania study (30%).¹⁵

However, correct knowledge does sometimes coexist with incorrect beliefs about transmission, and there is often a lack of confidence about how HIV is *not* transmitted. Having only partial information can lead to incorrect conclusions about the risk posed by casual transmission. This, in turn, may lead to actions that, while perceived simply as preventive, in fact result in stigmatizing behaviors, such as minimizing or restricting contact with people living with HIV and AIDS⁷.

5.3.3.3 Provider-level: Values, shame, and blame: Shame: 31% health care providers would feel shame if they associated with a person living with HIV/AIDS, which is lower than the results of Vitenam Study⁵⁷.

Proportion of health care providers who felt ashamed of association with HIV (16 %) was lower than the Vietnam study⁵⁴ (46%); while those who said that they would feel ashamed if they were infected with HIV (24%) was lower than Vietnam Study⁵⁴ (34%). HCP in our setting who said that people with HIV/AIDS should be ashamed of themselves (17 %) was also lower than Vietnam study⁵⁴ (44%)

Blame and Judgment: HCP who judge or blame PLHA for their illness (84%) is higher than Tanzania Study¹⁵ (46%) and Nigeria study (20%)⁴⁷, which may be explained by cultural differences. Vance R⁵⁸ *et al* in a recent review (2008) have concluded that Nurses need to be encouraged to sincerely examine personal values and reflect on personal bias that might conflict with professional responsibilities.

6. Summary

6.1 Stigma:

Prevalence of stigma was high with 43/ 45 PLHIV having experienced self stigma, 35 experienced enacted stigma (of which 26 had experienced verbal stigma, 17 isolation stigma, 13 experienced negative effect on identity, and 7 lost access to resources). The perceived stigma by PLHIV

Among the community, 28% males and 26% females reported knowing PLHIV who experienced isolation stigma, while those reported verbal stigma for PLHIV were 17% and 23 % respectively. 22% reported loss of identity stigma, and 21% reported loss of access to resources for PLHIV.

Among Health Care Providers (HCP), 28% doctors and 38% nurses reported peers to be neglecting PLHIV. 88% reported PLHIV to be treated differently, 21% reported denial of care (PLHIV being pushed by senior to junior staff). Nurses had higher stigma than doctors.

Thus the results of PLHIV study are corroborated by the survey of community and Health care providers.

This may be inadvertent, rather than intention to stigmatise as 77% HCP stated that they felt comfortable treating PLHIV. A patient may assume that an abrupt physician is prejudiced when he/she is actually abrupt with everyone

(We did not observe the health care providers' behavior with other patients). Similarly, a physician who refers patients to physicians with greater HIV expertise could be perceived as refusing care.

6.2 Confidentiality:

Rights of patients to confidentiality and consent were not respected. Only 22 PLHIV reported informed consent being taken; only 14 received no counseling at all. 23 reported status being disclosed to others without their consent, most by medical professionals.

More than 95% of health care providers felt that all patient before surgery and pregnant women should be tested for HIV. 69% doctors and 76% nurses felt that the need for consent is exaggerated and HIV should be handled like any other test and an equal proportion felt that the doctors should inform the partner.

94% doctors and 69% nurses reported peer practices of testing without consent/ disclosure to family without consent.

6.3 Fear:

Three fourths of health care providers reported fear of contracting HIV during providing services to patients and 38% community members expressed fear of casual transmission of HIV. 19% doctors and 33% nurses said they were not comfortable sharing a bathroom with a colleague who was HIV infected. HCP expressing fear had higher stigma.

6.4 Knowledge:

Too many people lack basic knowledge on HIV. Only 12/45 PLHIV knew that HIV and AIDS are different. 10 were not aware of ART.

Among community members, 45% women and 50% men knew that HIV and AIDS are different; (8% said that it could be transmitted through sharing toilets, 9% felt that HIV can be spread through sharing food/ utensils, while 11% and 13% felt that it is spread by kissing and mosquito bite). High education was associated with better knowledge. High knowledge existed along with misconceptions.

19% HCP were not aware of PEP. 32% doctors and 28% nurses had in-depth knowledge on AIDS. 13% doctors and 30% nurses had the misconception that HIV is spread through sweat. 39% of doctors and 55% nurses had the misconception that HIV can be spread by saliva. Half the HCP were untrained. HCP having higher knowledge had lower stigma.

Believing that HIV may be spread casually, may lead to actions that, while perceived simply as preventive, in fact result in stigmatizing behaviors, such as minimizing or restricting contact with people living with HIV and AIDS.

6.5 Shame, Blame & Judgement (Prejudice):

94% people judge and blame PLHIV for their illness. 80% community members associated shame with HIV/AIDS.

84% health care providers blamed the PLHIV for their illness. 20% doctors and 41% nurses would feel shame if they had HIV or were associated with PLHIV. Blame and shame were associated with higher stigma. Assumptions which associate illness with moral impropriety lead to a tendency to blame people for their HIV infection and subsequent stigma

6.6 Consequence of Stigma:

6 avoided or delayed seeking treatment due to fear of service provider's attitudes; 12 travelled to far off clinic and 7 opted for paid treatment over free for medical care due to confidentiality concerns. 34 PLHIV had significant depression and lower QOL.

7. Conclusions

PLHIV experienced high self stigma and enacted stigma and stigma from health care providers. As a consequence, PLHIV avoided disclosure, many avoided seeking health care locally, ¾ had depression and lower QOL. Determinants of stigma were common practices of testing without consent/counseling, disclosure of HIV status without their consent, most by medical professionals were common; High blame and shame associated with HIV in the community and high fear perception. Three fourths of health care providers reported fear of contracting HIV during providing services to patients and over one third community members expressed fear of casual transmission of HIV. This high proportion of stigma reported by PLHIV was corroborated by high proportion of community members reporting and expressing stigma towards those suspected of or having HIV infection.

People lack basic knowledge on HIV. This may be attributed to low awareness of community & inadequate training of HCP.

8. Recommendations

PLHIV study:

PLHIV had high self stigma. Counseling and support services for PLHIV need strengthening and regular counseling to help them cope with self stigma. NGOs could also be involved to improve access to counseling. As those who disclosed to family, had high positive reactions, HIV-positive individuals should be encouraged to disclose status and assured that the benefits of disclosure will outweigh the potential costs.

The findings of high depression among PLHIV associated with low QOL, emphasize the importance of recognizing and treating depression in persons with HIV/AIDS and suggest the potential benefit of routine integration of mental health identification and treatment into HIV service sites.

High enacted stigma and stigma from HCP needs to be addressed through "PLHIV friendly hospitals". HCP need to be trained and educated to improve attitudes towards PLHIV (with focus on confidentiality, consent and patient rights, non-judgmental attitudes). Community needs to be sensitized to stigma issues.

Community study:

To address the low awareness and misconceptions, community members need to be educated/ counseled about non casual transmission and judgmental attitudes and fears dispelled through infotainment. An enabling environment and compassionate attitude of society will thus facilitate disclosure and open discussion and thus lead to prevention of HIV transmission.

HCP:

The high prevalence of stigmatizing attitudes among HCP calls for intervention for by addressing the and needs and rights of both health care workers and PLHIV through "PLHIV friendly hospitals". Less in-depth knowledge and fear perceptions need to be addressed through trainings as such interventions in India have been proven to be effective.

tive^{10, 59}.

This training needs assessment will pave the way for more meaningful and relevant trainings towards a PLHIV-friendly health care service. The training curriculum needs comprehensive revision with emphasis on confidentiality, respect for human rights, empathy. Training should be given to all HCP with focus on real life situations rather than facts, as it will take extra efforts to unlearn the blame, shame and judgmental attitudes learnt over a lifetime.

High proportion of HCP reporting willingness to treat PLHIV, and high stigma coexisting suggests a gap between people's stated intentions *not* to stigmatize and their actions, which are stigmatizing; which indicates a lack of recognition of what stigma actually is. Creation of improved awareness of what stigma is and fostering an understanding of how stigma is harmful would help stop this inadvertent stigma from occurring

This study assumes importance in the context that HIV is an emerging disease in the state, and we need to address these issues at an early stage, so that a proper attitude is fostered, which will enable the PLHIV to seek and access services, and have better interruption of transmission of HIV.

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Tables:

PLHIV				
Table I. Background characteristics of PLHIV sample				
	Female (n=30)	Male (n=15)	Total (n=45)	Comparison of means
Age				
<25	3	1	4	Kruskal Wallis test (equivalent to chi square) =6.4269 (p=0.00112)
25-34	19	5	24	
>=35	8	9	17	
Mean Age in years(SD)	31.23 (5.03)	34.86(5.27)	32.44	
Education				
No formal education	5	1	6	Kruskal Wallis test (equivalent to chi square) = 0.6517 (p=0.4195)
Elementary (Standard 1-8)	13	10	23	
Post Elementary 8-12	11	4	15	
College/University 13 +	1	0	1	
Mean years of education (SD)	7.2 (4.03)	7.00(2.54)	7.13 (3.57)	
Marital status				
Married/cohabiting & partner living in household	7	11	18	
Married/cohabiting & partner not living in household	2	2	4	
Widowed/ Widower	20	1	21	
Divorced/ Single	1	1	2	
Length of Time Knowing HIV Status				
Less than 6 months	11	10	21	Kruskal Wallis test (equivalent to chi square) =8.7395 (p=0.0031)
7 -12 months	4	5	9	
>12 months	15	0	15	
Mean duration living with HIV in months (SD)	27.5 (32.64)	4.33 (3.83)	19.8 (28.79)	
Religion/ Caste				
Hindu Gen	10	10	20	
Hindu SC/ST	6	2	8	
Hindu OBC	13	13	16	
Other (Sikh)	1	0	1	

Table IIA. Self stigma: Indicators, items, and frequencies

Existing Selected Indicators	Form of Stigma	Item	Percent experiencing (n=45)	
1. Percent of PLHA reporting experiencing self stigma or discrimination in the past 12 months	1. Isolation (physical exclusion, social exclusion)	I have chosen not to attend social gathering(s)	26	
		I have isolated myself from my family and/or friends	22	
		I took the decision to stop working	9	
		I decided not to apply for a job/work or for a promotion	2	
		I withdrew from education/training or did not take up an Opportunity for education/training	2	
		I decided not to get married	11	
		I decided not to have sex	13	
		I decided not to have (more) children	12	
		I avoided going to a local clinic when I needed to	9	
		I avoided going to a hospital when I needed to	9	
	2. Fears	Being gossiped about	37	
		Being verbally insulted, harassed and/or threatened	12	
		Being physically harassed and/or threatened	4	
		Being physically assaulted	2	
	Percent experiencing at least one of the above 16 items			43

Table IIB. Enacted stigma: Indicators, items, and frequencies

Existing Selected Indicators	Form of Stigma	Item	Percent experiencing (n=45)	Percent experiencing at least 1 Item
1. Percent of PLHA reporting experiencing stigma or discrimination ever, and in the past 12 months	1. Isolation (physical exclusion, social exclusion)	Excluded from a social gathering (wedding, funeral, party, community association group) 501.1	7	17
		Been treated differently at a social gathering 501.2	3	
		Abandoned by your spouse/partner 501.3	2	
		Abandoned by your family/sent away to the village 501.4	2	
		No longer visited, or visited less by family and friends 501.6	12	
		Isolated in your household 501.5	10	
		Physically assaulted (e.g., hit, kicked, punched) 501.16	1	
	2. Verbal stigma)	Teased, insulted, or sworn at 501.7	5	26
		Gossiped about 501.15	26	
	3. Loss of identity/role	Lose respect/standing within the family/community 501.14	13	13
		Denied religious rites/services 501.11	1	
	4. Loss of access to resources and livelihoods (housing, employment)	Lost customers to buy produce/goods or lost a job 501.8	0	7
		Denied promotion/further training 501.9	0	
		Lose housing or not be able to rent housing 501.10	0	
		Given poorer quality health services 501.12	7	
	Someone tried to take property away 501.13	6		
Percent experiencing at least one of the above items			35	

Table IIC: Hospital Associated Stigma, Indicator, Items and frequencies in PLHA

Indicator	Item/ Question	Percent experi-encing (n=45)	Percent experi-encing at least 1 Item
1. Percent of PLHA reporting experiencing stigma in health settings in the past 12 months	Health provider refused to attend you	6	34
	You were discharged too early	5	
	You had to wait longer to be attended	5	
	You were being unnecessarily referred on to another provider in the same facility or referred to another facility	8	
	You were told to come back later	4	
	You were being denied treatment—drugs, surgery—or relevant tests/ investigations	6	
	You were tested for HIV without your informed consent?	11	
	You were required to be tested for HIV before care was given or surgery scheduled	5	
	Health provider used latex gloves for performing non-invasive exams on you or took extra precautions.	23	
	Health provider disclosed your HIV status to your family without your consent.	12	
	Health provider gossiped about your HIV status	6	
	Health provider used derogatory language or scolded or blamed you for having HIV	2	
	Your bed pans or bed clothes were not changed as needed/as often compared to other patients	1	
	You received less care/attention than other patients	7	

Table III: Knowledge of HIV /AIDS in PLHA

Selected Indicators	Questions in survey corresponding to indicator(s)	Female N=30	Male N =15	Total N =45
1. Percent of people living with HIV/AIDS who know that :	There is difference between HIV and AIDS (Q 202b)	10	2	12
	Know that HIV/ AIDS can be prevented by condoms? (Q 204b)	14	12	26
	If a mother has HIV, can the virus be passed on to the baby? (Q 205)	23	11	34
	Know that Being faithful to one uninfected partner can protect from AIDS (Q 204 c)	14	3	17
	Know that a healthy looking person can have AIDS (Q 206)	18	7	25
Comprehensive knowl- edge of HIV/AIDS?	Reject the misconception that HIV/ AIDS IS TRANSMISTTED by mosquito bites (Q 203 k=1)	29	15	44
	Reject the misconception that HIV/AIDS is transmitted by sharing utensils/ food/ drinks (Q 203i=1)	30	15	45
Comprehensive knowl- edge of HIV/AIDS?	All of the above: 7 item score	8	2	10

Table IVa Disclosure by relative indicator, items, and frequencies in PLHA

Existing Selected Indicators		Questions in survey corresponding to indicator(s)	(n=45)			
1. Percent of persons living with HIV/AIDS who have disclosed their sero-status to anyone		Have you told anyone about your HIV status?	30			
	Has someone else disclosed you HIV Status?		23			
2. Percent of PLHA who have disclosed their sero-status to various key people (Working Group)		How were the following told about HIV status? N=45				
		Self	Someone told with consent	Someone told without my consent	Don't Know status	Not Applicable
Partner		19	9	7	7	3
Adult Family members (In laws)		15	6	13	10	1
Parents and siblings		17	7	8	12	1
Children		4	0	4	27	10
Friends		4	0	8	30	3
Other PLHIV		10	1	1	29	4
People working with you		2	0	4	22	17
Employer		4	0	1	23	17
Community Leaders		2	1	4	31	7
Health care provider		11	4	3	23	4
Social workers/ Counselors		16	7	1	16	5
Govt Officials		13	5	2	21	4
Media		0	2	1	31	11

Table IVb Effect of disclosure by relative indicator, items, and frequencies PLHA

Indicator		Questions in survey corresponding to indicator(s)	(n=45)		
		Have you told anyone about your HIV status?	15 Self	15 self + others	
	Has someone else disclosed you HIV Status without your consent?		15 Self + Others	8 Others	
2. Reaction to disclosure- PLHA who have disclosed their sero-status to various key people		What was the reaction of the following to knowing your HIV status?			
		Those who know status N	Discriminatory	Indifferent	Supportive
	Partner	35	6	10	19
	Adult Family members (In laws)	34	10	8	13
	Parents and siblings	32	0	4	24
	Children	8	0	1	5
	Friends	12	6	0	5
	Other PLHIV	12	0	1	10
	People working with you	6	0	3	3
	Employer	5	1	1	3
	Community Leaders	7	1	5	1
	Health care provider	18	4	4	9
	Social workers/ Counselors	24	1	2	10
	Govt Officials	20	0	3	15
	Media	3	1	0	1

Table VI: Depression among PLHA

Classi- fication	Total Score	Level of Depression	N=45	
Low	1-10	These ups and downs are onsidered normal	5	11
	11-16	Mild mood disturbance	6	
Moderate	17-20	Borderline clinical depression	11	17
	21-30	Moderate depression	6	
Significant	31-40	Severe depression	8	9
	Over 40	Extreme depression	1	

Table VI. Quality of life among PLHA

	Description	Mean	SD
WHO QOL Bref (26) Scores (Transformed to 100 scale) across domains			
Domain 1	Physical health	46.35	9.15
Domain 2	Psychological	51.09	12.88
Domain 3	Social Relationships	43.51	19.24
Domain 4	Environment	42.36	15.12

Table VI B:
WHO Quality Of Life BREF Pearson Correlation coefficients

	Domain 1	Domain 2	Domain 3	Domain 4
AGE	.398**	.477**	-0.056	0.149
	0.007	0.001	0.716	0.33
	45	45	45	45
EDUCATION	0.152	-0.088	0.121	.341*
	0.318	0.564	0.43	0.022
	45	45	45	45
INCOME	.302*	.386**	0.059	.466**
	0.044	0.009	0.701	0.001
	45	45	45	45
EMPLOYMENT	-.356*	-.369*	-0.183	-.387**
	0.016	0.013	0.229	0.009
	45	45	45	45
STIGMA FROM HCP	-0.082	-0.067	-.323*	-0.147
	0.591	0.661	0.03	0.335
	45	45	45	45
TOTAL STIGMA	-0.161	-0.283	-.461**	-.362*
	0.292	0.059	0.001	0.015
	45	45	45	45
STIGMA	0.294	.309*	.487**	.382**
	0.05	0.039	0.001	0.01
	45	45	45	45
DEPRESSION	.475**	.333*	.602**	.637**
	0.001	0.025	0	0
	45	45	45	45
BECK SOCRE SUM	-.390**	-.348*	-.664**	-.645**

	0.008	0.019	0	0
	45	45	45	45
KNOWLEDGE DISCHOTOMISED	-0.088	-0.181	-0.19	-0.326*
	0.567	0.233	0.212	0.029
	45	45	45	45
*. Correlation is significant at the 0.05 level (2-tailed).				
**. Correlation is significant at the 0.01 level (2-tailed).				

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