Stigma & Discrimination associated with HIV/AIDS - a pilot study in District Kangra, Himachal Pradesh, India, 2008

By

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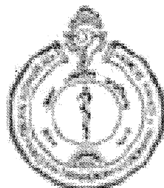
(MAE-FETP Scholar 2007-2008)

Dissertation project submitted in partial fulfillment of the requirements for the degree of Master of Applied Epidemiology (M.A.E)

of



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CERTIFICATION

This is to certify that this dissertation, entitled **'Stigma & Discrimination associated with HIV/AIDS - a pilot study in District Kangra, Himachal Pradesh, India, 2008,** submitted by Rajesh Kumar Sood, in partial fulfillment of the requirements for the degree of Master of Applied Epidemiology, is the original work done by him and has not been submitted earlier, in part or whole, for any other (Publication or degree) purpose.

Director

National Institute of Epidemiology, Chennai

(Indian Council for Medical Research)

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A

Abstract

Background: Stigma associated with HIV/AIDS has been termed as the "third epidemic". Stigma is not only distressing to individuals 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

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

Results: Of 45 PLHIV, 35 experienced enacted stigma, 34 experienced stigma from HCP, and 43 self stigma. 12/45 PLHIV knew that HIV and AIDS are different. 14 received no counselling. 10 PLHIV were tested without their knowledge/ consent. 23 PLHIV reported disclosure without consent. 34 PLHIV had depression which was associated with lower Quality of life scores.

36% community members had seen stigma occurring to PLHIV. 48% community members knew that HIV and AIDS are different. 38% community members feared casual transmission. 94% associated blame and 82% associated shame with HIV.

30% HCP reported peer practices of testing without consent and 42% reported disclosure to family without consent. 52% HCP had the misconception that HIV can be transmitted by saliva. 75% reported fear of contacting HIV from occupational exposure with HIV. 84% associated blame & 31% associated shame with HIV.

Conclusions: PLHIV experienced high self stigma and enacted stigma which may be due to low awareness of community & inadequate training of HCP. There is urgent need to increase community awareness through targeted IEC and improve attitude of HCP programmes through training, which in turn would result in reduction of stigma experienced by the PLHIV and enhance their quality of life.

Keywords: HIV, stigma, discrimination, health facilities, shame, knowledge.

1. Background - Justification

Stigma is defined as social devaluation of a person because of a personal attribute leading to an experience of shame disgrace and social isolation. 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/AIDS[1]. 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.

Since 1990, the United Nations Commission on Human Rights has also adopted a series of resolutions on human rights and HIV/AIDS. These resolutions confirm that existing international human rights standards prohibits discrimination on the basis of HIV/AIDS status[1].

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 provider[3]. A study revealed that 1 in 5 US people stigmatize HIV[4]. 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 sector[6].

A study across two continents concluded that doubts and fears *"knowing, but not quite believing"* that HIV is not transmitted casually and assumptions which associate illness with moral impropriety lead to a tendency to blame people for their HIV infection and subsequent stigma[7].

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).

Stigma in the stricter sense implies shaming[8]. A broader conceptualization that elucidates both the sociocognitive and the structural aspects of stigma and the relationship between them is given by Link and Pehlan[9], stigma exists when the following four interrelated components converge: (i) individuals distinguish and label human differences; (ii) dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes); (iii) labelled persons are placed in distinct categories to accomplish some degree of separation of 'us' from 'them'; and (iv) labeled persons experience status loss and discrimination that lead to unequal outcomes.

A study in Chennai reported 26% of PLHA experienced stigma[10]. A recent study in Delhi hospitals[11] reported that 68% had judgmental attitudes towards PLHA. Because of HIV/AIDS-related Stigma discrimination, appropriate policies and models of good practice remain undeveloped.[12].

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 eliminating them, helps to respect, fulfill and protect human rights[1].

One of the major obstacles hampering reduction in stigma and discrimination is lack of data[13]. Qualitative studies in Himachal on HIV related social problems have identified instances of stigma[14]. 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.

2. Objectives

1. To estimate the prevalence of Stigma and Discrimination experienced by people living with HIV /AIDS (PLHA) in Kangra, Himachal Pradesh.
2. To describe the nature of Stigma and Discrimination experienced by PLHA
3. To assess the quality of life of PLHA.
4. To estimate prevalence of stigma and discrimination related to HIV/AIDS in the community
5. 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 pastoralism[15]. The district has a high literacy (80%).

3.2 Study population

1. Adults living with HIV AIDS (PLHIV) 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 PLHIV, Community members and Health Care Providers (doctors and nurses) was conducted.

3.4 Sample size and sampling:

We computed a sample size of 53 PLHIV. PLHIV 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.

We included all doctors and nurses who were willing to participate in the study. Details of sample size calculation and sampling are given in Annex 2.2.

3.5 Data collection:

PLHIV: PLHIV were interviewed using an interview schedule (Annex 2.3) 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 tools[13] USAID Stigma Questionnaire[16] UNAIDS PLHIV stigma questionnaire [17] and WHO Quality of life scale- BREF [18] and Beck Depression Inventory (Annex 2.4).

Community: We interviewed community members using an interview schedule (Annex 2.5) 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 questionnaire[16]

Health Care Providers: We gave a self administered questionnaire to health care providers (Annex 2.6) 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 indicators listed in Annex 2.5. We calculated scores of Beck Depression Inventory & classified them into low (1-16), moderate (17-30) and severe (>30). (Annex 2.6) 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 (Annex 2.7). We computed Pearson correlation of Quality of Life domains v/s

other variables like education, income, employment, stigma, knowledge and depression.

3.7 Quality assurance:

We pilot tested the questionnaires. We trained the interviewers for community survey. The female interviewer was trained for interviewing the PLHIV on the questionnaire items using the manual for the questionnaire. Data were collected by the PI and trained female interviewer for female clients. 1 in 20 (5%) of the community questionnaires were randomly cross checked by the PI. We checked all forms for completeness.

3.8 Bias and limitations:

PLHIV studies have a selection bias as only those who agree to participate were included[16] in accordance with ethical guidelines.

We tried to minimize desirability bias among Health care providers by putting questions from their point of view

3.9 Definitions:

Definitions of terms used are listed in Annex 2.8.

4 Protection of 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.

4.2 Difficulties encountered in data collection & methods adopted to overcome them:

A. Informed consent:

The Ethical committee suggested that signatures/ written informed consent be obtained from all PLHIV. However, we discussed the issue that some individuals may not be willing to put their name on a written document. We requested the ethical committee that PLHIV not signing for anonymity concerns could become a barrier to participating in a study, and requested waiver of the requirement to obtain a signed consent form for PLHIV subjects. The ethical committee agreed that signatures could be replaced by attestations from researchers/ NGO that individuals have agreed for those who agree to participate but unwilling to sign their name.

During interviews, the respondents were explained the process in detail and potential benefit of the study. Inspite of this, 10 of 45 had mild apprehension before putting signature on consent form, that their identity may be disclosed by signing the form. However, when respondents were reassured of full confidentiality of records, they all agreed to sign the consent form.

Eliciting responses to sensitive questions and among depressed patients:

The interview lasted approximately for 2 hours. The initial half hour was spent building rapport and explaining that the results of the study will be used for the benefit of PLHIV, instill confidence about confidentiality protection & making the clients comfortable.

We addressed the possibility of non willingness of some PLHIV to disclose sensitive personal information; by building rapport and discussing general family conditions /

other problems with them. Female participants were interviewed by trained female interviewer who is a post graduate well versed in gender issues.

One client was depressed/ in shock and we were unable to elicit any response despite several efforts. We arranged assistance of counselor, and interviewed him after 2 months.

We gave our phone number to the PLHIV participants so that they could contact us for any assistance if needed. We received calls from 15 subjects after the study relating to various persisting problems for which we gave appropriate advice.

5 Results

Results will be described as per the outline below:

5.1 PLHIV.

5.1.1 Response Rates & Profile:

5.1.2 Profile of study PLHIV:

5.1.2 Types/ Dimensions of stigma:

- 5.1.2.1 Self Stigma
- 5.1.2.2 Enacted Stigma/ Discrimination.
- 5.1.2.3 Stigma from health care providers

5.1.3 Determinants of stigma:

- 5.1.3.1 Knowledge about HIV /AIDS.
- 5.1.3.2 Forced Testing and testing without consent
- 5.1.3.2 Disclosure without consent:
- 5.1.3.3 Support
- 5.1.3.4. QOL

5.1.4 Consequences of stigma:

- 5.1.4.1 Disclosure:
- 5.1.4.2 Health seeking behavior.
- 5.1.4.3 Depression
- 5.1.4.5 Reactions to stigma:

5.2 Community

5.2.1 Profile of study community:

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

- 5.2.2.1 Isolation Stigma:
- 5.2.2.2 Verbal Stigma:
- 5.2.2.3 Loss of Identity/Role Stigma:
- 5.2.2.4 Loss of access to resources / livelihoods

5.2.3. Determinants

5.2.3.1 Proportion of people with correct knowledge

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

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

5.2.6. Disclosure:

5.3-4 Health care providers

A Doctors

5.3.1 Response rates,

5.3.2. Sample description

5.3.3 Stigmatizing attitude:

5.3.4. Having witnessed Enacted Stigma (Discrimination)

Neglect: Differential treatment, Denial of care,

HIV testing and disclosure without consent

5.3.5. Determinants

5.3.5.1 Doctors' Knowledge about HIV/AIDS

5.3.5.2 Doctors' Fears about HIV/AIDS

5.3.5.3 Doctors' Values, shame, and blame

B Nurses

5.4.1 Response rates

5.4.2 Profile of study nurses:

5.4.3. Stigmatizing attitude among Nurses:

5.4.4 Having witnessed discrimination

Neglect: Differential treatment, Denial of care, HIV testing & disclosure without consent:

5.4.5. Determinants

5.4.5. 1 Nurses' Knowledge about HIV/AIDS

5.4.5. 2 Nurses' Fear about HIV/AIDS

5.4.5.3. Nurses' Values, shame, and blame

5.1 PLHIV.

5.1.1 Response Rates

We were able to recruit 45 PLHIV against a estimated sample size of 53. There is no network of PLHIV in the area. For confidentiality issues, we did not access their records. Indirect methods were used to recruit them through requesting local doctors and counsellors for referrals of PLHIV clients who were willing to participate in the study from the period of June to Nov 2008.

5.1.2 Profile of study PLHIV:

Of the 45 PLHIV , 30 participants were females, 20 of whom were widows of HIV positive. Eleven of the females and four males were currently married and living with partner in the household. Among the PLHIV, 24 were aged 25-34 years. 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 seven 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 [Annex 3.1-Table I]

5.1.3 Stigma

Description of stigma includes (a) various types/ dimensions of stigma experienced by the PLHIV, (b) determinants of stigma and (c) consequences of stigma experienced by the PLHIV.

5.1.3 Types/ Dimensions of stigma: This includes Self stigma, Enacted stigma (Discrimination) from family, community and health care provider. Each one is discussed in detail:

5.1.3.1 Self Stigma

A person who acquires HIV may take on the guilt and judgment they perceive society has of HIV in general and internalize it, referred to as self stigma or internal stigma. It consists of self isolation/ avoidance and fears.

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 (not mutually exclusive). Of the 37 who were reported fears, all were afraid about being gossiped about.

5.1.3.2 Enacted Stigma/ Discrimination.

Enacted stigma consists of discriminatory actions by other towards PLHIV. 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).

Of the 45 PLHIV, 35 experienced enacted stigma. Twenty six experienced verbal stigma followed by Isolation in 17. Thirteen PLHIV experienced negative effect on identity, and 7 reported lost/ decreased access to resources like health services property rights. (Annex 3.1: Table IIB).

5.1.3.3 Stigma from health care providers

34/45 PLHIV experienced stigma from Health Care Providers. (Annex 3.1-Table IIC) 23/45 reported that health care provider took extra precautions for non invasive examination *(though subjects did not have problems with it)* followed by disclosure by doctor to others without consent (12/45). The forms of stigma included health care provider refusing to attend PLHIV, PLHIV discharged too early, PLHIV made to wait longer to be attended, PLHIV being unnecessarily referred on to another, PLHIV

being told to come back later, PLHIV being denied treatment, PLHIV were tested for HIV without their informed consent, PLHIV were required to be tested for HIV before care was given or surgery scheduled, health care provider using latex gloves for performing non-invasive exams on PLHIV or took extra precautions, health care provider disclosed their HIV status to their family without consent, heath care provider gossiped about their HIV status, health care provider using derogatory language or scolded or blamed PLHIV for having HIV, their bed pans or bed clothes were not changed as often compared to other patients and PLHIV receiving less care/attention than other patients.

5.1.4 Determinants of stigma:

Self stigma:

Knowledge, Support & disclosure by others without consent

5.1.4.1 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 had no misconceptions regarding casual transmission. 18/45 felt that it is possible that one married partner is positive and the other negative. 10/45 participants had comprehensive knowledge. [Table II]

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 believed in religious/faith healing.

5.1.4.2 Testing and consent

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

Consent for HIV testing: 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 on being asked about its contents they reported that they were "*not able to read form consent, because it 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.

Reactions to learning of HIV Status: 10/45 reported grief, followed by Crying (8), Fear (8), shock (5), Denial (4), Sense of being cheated by partner (3), others described the reaction in terms of despair (2), anger towards partner (2), helplessness (1), worry (1), tension (1), shame (1), painful (1) and suicidal thoughts (1). (Not mutually exclusive)

5.1.4.3 Disclosure of HIV status without consent: 23 PLHIV reported that their status was revealed without their consent, of whom 12 stated that health care providers had disclosed their status.

5.1.4.4 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 [Annex 3.1- Table IVB]. Reaction to disclosure from in laws was gender related. Of the 10 who reported facing discrimination from in adult family members (in-laws), 9 were females.

5.1.5 Consequences of stigma:

5.1.5.1 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 [Annex 3.1-Table IVA] Overall

17 perceived disclosure to be an empowering event. 30 of the participants tried to keep their status secret from community.

5.1.5.2 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 stated 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 your HIV status, to protect confidentiality. Seven opted for paid treatment over free to assure privacy and confidentiality.

Treatment:

Of the PLHIV, 25/45 were currently taking antiretroviral treatment. 11 felt that they had access to free antiretroviral treatment, while 29 reported difficult access. HIV patients have to travel over 300 km to receive the life saving medicine "ART" at Shimla. The barriers are geographical as well as financial. Some cannot afford to travel so far and stay for a week to get tests done to get their treatment "**Free**". Even though the medicines are free, the attendants have to bring sick patients in Taxi. They were reimbursed bus fare with attendant initially, later they were given cheques which led to loss of confidentiality of patients, and clearing charges and delays. Moreover they incur out of pocket expenses on boarding and lodging for over a week till the battery of tests are done and reports are received. It is more difficult in winters when snowfall makes travel more difficult for them.

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 female PLHIV had received Nevirapine during pregnancy to decrease vertical transmission.

5.1.5.3 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.

[Annex 3.1: Table V]

5.1.5.4 Quality of life:

Description of the quality of life assessment tool and items: 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).

Distribution of scores in each domain: We studied the distribution of Quality of life scores. In physical health domain 29 subjects had scores of 41-60, followed by 16 subjects having 21-40. Mean score in this domain were 46.35. In psychological domain, 26 scored 41-60, followed by 11 who scored 61-80. Mean scores were 51.09. In Social Domain, the majority (22) scored 41-60, followed by 9 who scored 21-40. Mean QOL scores in social domain were 43.5. In the environmental domain too, the majority (22) scored 41-60, followed by 9 who scored 21-40. Mean QOL scores in environmental domain were 42.4. The mean QOL scores are depicted in Table VI

Frequency distribution of quality of life scores				
	PHYSICAL	PSYCHOLOGICAL	SOCIAL	ENVIRONMENTAL
<20	0	0	6	3
21-40	16	7	9	9
41-60	29	26	22	22
61-80	2	11	7	7
>80	0	1	1	1

The QOL domain 1 (PHYSCIAL 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, 0.009),

stigma (0.382, p=0.01), knowledge (0.378, p=0.01) and depression BDI score (-.645, p=0.000). [Table VIB]

5.1.5.5 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". The common coping mechanisms were crying in silence (8), visiting parents (8), thinking about their children (5), and others (5) reported acceptance of status.

5.2 Community

5.2.1 Profile of study community:

We had 540 respondents in the community survey, of whom 50% were males, 40% aged between 25-34 years, 45% had studied till high school, over 90% were married, about half were not gainfully employed, and one fourth were self employed. Almost all (99%) were Hindus. Of them, 24 % were general caste, 29% scheduled caste, 15% scheduled tribe and 32% other backward castes. [Annex 3.2; Table VII]

5.2.2. 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. Approximately 36% females and males reported having seen one or more of the 14 items of stigma (Annex 3.3 Table VIII)

5.2.2.1 Isolation Stigma: About 28% females and 26% males reported knowing someone with HIV or AIDS who has experienced some form of isolation stigma in the past 1 year [Section 3.2 Table XI]. 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 being isolated in household

5.2.2.2 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.

5.2.2.3 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.

5.2.2.4 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.

5.2.3. Determinants of stigma

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

5.2.3.1 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 and 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).

Education: Correct responses to the questions "There is a difference between HIV and AIDS" "A healthy looking person can have AIDS" were significantly associated with education >= 8years ([χ^2= 29.8, p=0.000]; [χ^2= 7.86, p=0.005] respectively), (Table IX B-C). Those educated more than middle school (8 years) 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 VIIIB] 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).

5.2.3.2. 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). (Table X)

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 [χ^2= 7.57, p=0.006] (Table X-B). 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 school and above stated that his/ her child could become infected by playing with a child having HIV/AIDS; this difference was statistically significant [χ^2= 7.977, p=0.005]) (Table X-C).

5.2.3.3. 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 [χ^2= 7.398, p=0.007]) (Table XI-B)

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. [Table XI]

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 [χ^2= 7.398, p=0.007]) (Table XI-C). Shame and blame were not associated with knowledge of HIV/AIDS.

5.2.6. Disclosure:

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

5.3 Health care provider

Response rates

Of the 615 health care providers in the District, 536 agreed to participate in the study, thus giving response rate of 87%. The good response rate was due to ownership by the District AIDS Programme Officer, who facilitated the process. The results are described separately for the doctors and nurses.

5.3 A Doctors

5.3.1 Response rates

Of the 293 Doctors in the district, 241 doctors agreed to participate in the study, thus giving a response rate of 82.5%.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.

5.3.2 Sample description

Among the doctors 71% were male, most (34%) were aged between 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. [Table XIII]

5.3.3. 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.

5.3.4 Having seen discrimination

Provider-level (Doctor): Witnessed Enacted Stigma

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

5.3.4.1 Neglect: 28% reported having seen PLHIV to be neglected in the past 12 months. 20% reported that HEALTH CARE PROVIDERS avoid going near PLHIV to avoid infection.

5.3.4.2 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.

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

5.3.4.4 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. [Table XVIII].

5.3.5. Determinants

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

5.3.5.1 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. [Table XIV]. Knowledge / fears and shame/ blame were not significantly associated with age, caste, or educational background.

5.3.5.2. 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. [Table XV]

5.3.5.3 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. [Table XVII]

5.4 Nurses

5.4.1 Response Rates

Of the 323 nurses in the District, 295 agreed to participate in the study, thus giving a re sponse rate of 91.3% The reasons for non response despite giving three reminders/visits were nurses being on night shift, night off, being too busy, some staff in the list on long leave or having been transferred out

5.4.2 Profile of study nurses:

Among the nurses 98% were female, 36% were aged between 25-34years; 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.

5.4.3. 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.

5.4.4 Having witnessed discrimination

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

5.4.4.1 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.

5.4.4.2 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.

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

5.4.4.4 HIV testing and disclosure without consent: 94% nurses reported practices of testing a client HIV for HIV/ disclosure of clients' HIV status without their consent. 89% nurses 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. [Table XVIII].

5.4.5. Determinants

5.4.5.1 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. [Table XIV]

5.4.5.2. 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 ware 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. [Table XV]

5.4.5.3. 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. [Table XVII]. Blame shame and judgment did not differ significantly among trained and untrained nurses.

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% HEALTH CARE PROVIDERS 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 contacting 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. Health Care Providers 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 though 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% Health Care Providers 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 Health Care Providers were untrained. Health Care Providers 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. Discussion

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

7.1 PLHIV subjects.

7.1.1 Participation rates

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.

7.1.2 Types of stigma:

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

7.1.2.1. 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.[19].

7.1.2.2 Enacted Stigma in last 12 months:

Only ten reported no stigma at all. The reported stigma in our study is much higher than in other settings, in Cape town, South Africa (Simbayi LC etal 2007, [40%])[20], PLHA in France experienced stigma in social interactions (Perretti Wattel P etal, 2005[24%]) [5] and a recent study in Chennai (Thomas BE etal, 2005) reported 26% of PLHA experienced stigma A CDC study in 2001 revealed that 1 in 5 US people stigmatize HIV[4]. Moreover our study was in community based setting rather than

ART centre based one, which may explain the differences.

7.1.2.2 Stigma from Health Care Providers 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 HEALTH CARE PROVIDERS was reported by about half participants; which is higher than 20% reported in NACER study[28].

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)[21] and 27% by PLHA in France (Perreti-Watel 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 imagined[3]. 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.

7.1.3 Determinants of stigma:

Knowledge, testing without consent, Support & disclosure by others without consent

7.1.3.1 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 (Sharma TD, 2005)[14].

6.1.3.2a 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 fifths of out study subjects were tested without knowledge/ consent which is worrisome.

7.1.3.2b Disclosure by health care provider without consent: Disclosure by a health care professional without patient's consent was found to be common in our setting. Our results are similar to findings of Chandra et al[24] (2003) in a south Indian setting who found that 35% PLHIV reported disclosure without consent. Chandra et al (2003) also observed that disclosure without the individual's consent is troubling especially because in 75% of the cases, the breach of confidentiality occurred through health professionals[24]. A multi country study of AIDS related discrimination in Asia by Paxton etal (2005) reported that 34% said that somebody else had been told of their HIV status without their consent[6]. Similar findings were noted in a recent study by Action Research Group (2006) in three districts of Maharashtra[22].

7.1.3.3 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 partner[23], Most of our subjects (40 %) were married and having regular partner living in household, which increases the chances of disclosure[23].

7.1.4 Consequences of stigma:

7.1.4.1 Disclosure: The self disclosure level in our study is similar to those seen in south India (66%)[24]. 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)[25]. 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 infection[26].

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 publically, 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 partners, 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 disclosure[27].

7.1.4.2 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 Opportunistic Infection prophylaxis, point to lack of discussion with patients on treatment options. Majority of women reported 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)[28] 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".

7.1.4.3 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%])[29]; Levine AB etal in USA, 2008(53 % having score >9)[30], Pence BW et al in outpatients in Southeast USA in a HIV clinic setting 2006 (30%)[31] ; Judd et al in Australia, 2005 (33%)[32] and Kolarić B (2006) among Croatian PLHIV (20%)[33]. 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 others[34]. The common complaint of fatigue could be associated due to depression and not the disease as found by Milkin et at[35]. However our results of high prevalence of depression need to be interpreted with caution, as depression scales that include somatic symptoms will inflate depression scores in people living with HIV infection[36].

Our finding that PLHIV having no stigma had lower mean BDI Scores, is consistent with study by Vanable etat (2006) which concluded that stigma was associated with depressive symptoms [37] and by Prachakul W et al 2007[38]

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

7.1.4.4 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)[39] . 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 Kemppainen JK (2001)[40]. The findings emphasize the importance of recognizing and treating depression in persons with HIV/AIDS.

7.1.4.5 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 etal[41] 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 positively[42]. Most did not confront stigma, which may be due to lack of association of PLHIV.

7.2 Community

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

36% of our study subjects reported witnessing any form of stigma assoicated with PLHIV, which is higher than 30% reported by Tanzania study[15].

Having witnessed isolation stigma (28% for females, 26% for males) in our study was similar to 23% in Tanzania study[16] (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 Tanzania[16] (19%); loss of identity (58% for females, 60% for males) was twelve times that found in Tanzania[16](5%). Loss of access to resources/ livelihoods seen in our study (55% for females, 59% for males) was 6 times that of Tanzania[16] (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 3[43], 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 interaction[46].

7.2.2 Determinants of stigma

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

7.2.2.1. 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 how HIV is transmitted and how to keep from getting it. The comprehensive knowledge of HIV AIDS in our study (49%) is comparable to that reported by NFHS III (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 that reported by NFHS III (62% women and 82% men) & NACO BSS 2006[44] (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 BSS[44](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)[44], (NFHS 3).

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

Fear of being infected if exposed to saliva and 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 tha 29 % of respondents in Ghana Ulasi etal (2009) [45] 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 study [16](7%). Fear were associated with low knowledge, which is similar to findings of Ulasi CI etal (Ghana 2009)[45]

7.2.2.3. 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 individuals[46]. Percentage of people who would feel shame if they associated with a PLHA (82%) is much higher than Tanzania study, 2005 (66%).

7.3 Health care provider

HIV/AIDS-related stigma and discrimination can reduce the quality of treatment and health care received [47].

7.3.1 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 HEALTH CARE PROVIDERSs in the Yunnan study were willing to treat PLWHA[48], 82% said that they would not prefer to. Our results are similar to findings of Fusilier M, (1998) who reported that 81% HEALTH CARE PROVIDERS in Mexico indicated they were willing to treat AIDS patients[49].

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 Study[11] (92%). The proportion of doctors who said that all pregnant women should be tested for HIV (97%) was higher than the Delhi Hospital study[11] (66%) while those nurses who said that all pregnant women should be tested for HIV (99%) were slightly higher than the Delhi study (92%)[11]. Similarly in Chinese settings (Weber GC, 2007), most of the Health Care Providers (94%) felt that HIV tests should be mandatory for pregnant women[48].

One fifths of the PLHIV in our study were tested without informing or coerced to test. This is supported by findings of evaluation by Weiser SD (2006) and review by Mahajan A etal (2008) of provider-initiated testing approach may have potential for coercion of patients to test[50,51].

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 study[11] (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 Delhi [11]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 stigmatizing[7].

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 study[11] (21%); but the proportion of nurses who believed so (34%) was higher than the Delhi hospital study[11] (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)[52].

The proportion of Health Care Providers 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 Study[11] (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 where higher than in Delhi[11] 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 study[11] (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 study[11] (which reported 79% and 44% nurses agreed). Those who felt that HIV positive women should not get pregnant (64%) were lower than Delhi hospital study [11] (71% doctors and 89% nurses).

Nurses had higher stigma than doctors which is comparable to other studies (Delhi hospital Study, Tanzania Study)[11]. Untrained persons had higher stigma than trained; which is also seen in studies in Ethiopia[53].

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 stigma[54]

7.3.2. 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 %. Health Care Providers 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 clients[55].

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 Study[16] which reported 11%. This may be due to power to delegate for senior doctors[56].

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 study[11]. 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 study[57]. Half nurses and one third doctors reported practice of disclosing client's status to family without his consent which was lower than Delhi Study baseline[11] (58%).

7.3.3. 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 etal[58] for measuring HIV stigma in Chennai, India (2008).

7.3.3.1 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)[59].

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.

7.3.3.2 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%).[16]

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 AIDS[7]

7.3.3.3 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 Study[60].

Proportion of health care providers who felt ashamed of association with HIV (16 %) was lower than the Vietnam study[60] (46%); while those who said that they would feel ashamed if they were infected with HIV (24%) was lower than Vietnam Study[60] (34%). Health Care Providers in our setting who said that people with HIV/AIDS should be ashamed of themselves (17 %) was also lower than Vietnam study[60] (44%)

Blame and Judgment: Health Care Providers who judge or blame PLHA for their illness (84%) is higher than Tanzania Study[16] (46%) and Nigeria study (20%)[52], which may be explained by cultural differences. Vance R[61] 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.

8. 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. Determiants 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 contacting HIV during providing services to patients and over one third community members expressed fear of casual transmission of HIV. People lack basic knowledge on HIV. This may be attributed to low awareness of community & inadequate training of Health Care Providers. 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.

9. Recommendations

9.1 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 HEALTH CARE PROVIDERS needs to be addressed through "PLHIV friendly hospitals". HEALTH CARE PROVIDERS 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.

9.2 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 tolerant society will thus facilitate disclosure and open discussion and thus lead to prevention of HIV transmission.

9.3 Health Care Providers

The high prevalence of stigmatizing attitudes among HEALTH CARE PROVIDERS 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[11, 62].

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 to have emphasis on confidentiality, respect for human rights, empathy. Training should be given to all Health Care Providers 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 Health Care Providers 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. This 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, which in turn will lead to interruption of transmission of HIV.

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ANNEXURES

Annex I: Review of literature Stigma and HIV AIDS

1 Stigma associated with HIV /AIDS

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/AIDS[1]. 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.

Since 1990, the United Nations Commission on Human Rights has also adopted a series of resolutions on human rights and HIV/AIDS. These resolutions confirm that existing international human rights standards prohibits discrimination on the basis of HIV/AIDS status[1]. The Fundamental Rights embodied in the Indian Constitution act as a guarantee that all Indian citizens enjoy rights such as equality and the right to constitutional remedies for the protection of civil rights. Addressing stigma and discrimination is thus critical in preventing further infection and improving care. The identification of different forms of arbitrary discrimination, with a view to eliminating them, helps to respect, fulfill and protect human rights[1].

Stigma in the stricter sense implies shaming[2]. A broader conceptualization that elucidates both the sociocognitive and the structural aspects of stigma and the relationship between them is given by Link and Pehlan[3], stigma exists when the following four interrelated components converge: (i) individuals distinguish and label human differences; (ii) dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes); (iii) labelled persons are placed in distinct categories to accomplish some degree of separation of 'us' from 'them'; and (iv) labeled persons experience status loss and discrimination that lead to unequal outcomes.

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).

2. Prevalence of Stigma

Limitations of prevalence studies: Most of the studies rely on reports rather than observations and thus suffer from a perception fallacy. Many HIV-positive adults believe that their clinicians have discriminated against them, clinicians should make efforts to address circumstances that lead patients to perceive discrimination, whether real or imagined[6] 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. Regardless of whether perceived discrimination indicates real bias, the perception of bias is

important and can have consequences that interfere with health and health-promoting behavior.

Stigma can be broadly classified as internalized, stigma, enacted stigma and stigma associated with health care settings. It can also be classified as inadvertent stigma and deliberate stigma. Structural stigma deals with institutional and legal systems that lead to stigma.

Enacted stigma:

International studies:

The public reaction has been described as an "Epidemic of Stigma"[4]. Prevalence of stigma has varied across different setteing. Simbayi (2007) reported 40% PLHIV has experienced stigma in Cape town, South Africa[5], 26% of PLHA in USA (Schuster MA et al, nationally representative sample in USA, 2005)[6]. A CDC study revealed that 1 in 5 US people stigmatize HIV [7]. 24% PLHA in France experienced stigma in social interactions (Perretti Wattel P etal, 2005)[8] A multi country study of AIDS related discrimination in Asia (Paxton G, 2005) reported that 54% experienced some form of discrimination within the health sector[9].

India

A study in Chennai reported 26% of PLHA experienced stigma(Thomas BE, 2005)[10]. A recent study in Delhi hospitals (Mahendra, 2006)[11] found that 68% had judgmental attitudes towards PLHA. Because of HIV/AIDS-related Stigma discrimination, appropriate policies and models of good practice remain undeveloped.[12].

Women and widows faced higher discrimination. Gender seems to be a strong determinant of the type of response one receives from the family (NACER) In India, widows have a very low status in the society and in spite of efforts by social

reformers, widow discrimination continues. Widows are supposed to give up all the pleasures of life, wear white clothes, and even their presence is considered inauspicious on certain occasions. The position of HIV widows is worse. They not only have to face the grief of the death of their husband and the economic repercussions, but also the stigma attached to HIV, take care of their own health and the health of children who may be positive. They have to cope with the additional financial burden on health expenditure, and in the worst cases may even have to face the death of their HIV-positive children.

Himachal Pradesh: Qualitative studies in Himachal (Sharma TD, 2005) on HIV related social problems have identified instances of stigma[13].

Self stigma:

Self stigma, a negative response by a person towards him or herself, has been reported to be high across all cultures, and is associated with shame and incomplete knowledge and association with morality. An HIV diagnosis becomes shameful because it implies association with what is widely seen as immoral behavior.

As a result, a person who acquires HIV may take on the guilt and judgment they perceive society has of HIV in general and internalize it.[14]. They may begin to believe that HIV is punishment for their (or their partner's) immoral behavior. Coming to terms with one's changed, less valued, identity lowers a person's self esteem. Women who are infected by their husband do not escape feelings of shame. As they make the transition to social outcast, they feel betrayed and victimized. Self-stigma is reflective of the broader beliefs of society and will prevail until people's rights are respected. People living with HIV must be empowered to make choices as they begin to face life carrying the virus - support and the provision of information

immediately following diagnosis is crucial, for at this time he/she is most confused and most likely to adopt negative perceptions of themselves. Self-stigma and denial may be a survival strategy to limit incidences of discrimination and to avoid being ostracized. Thomas BE, Chennai (2005) reported prevalence of self stigma among PLHIV to be 97% [10].

Reasons for stigma

A study across two continents concluded that doubts and fears *"knowing, but not quite believing"* that HIV is not transmitted casually and assumptions which associate illness with moral impropriety lead to a tendency to blame people for their HIV infection and subsequent stigma[15]. In India, as elsewhere, AIDS is perceived as a disease of "others" – of people living on the margins of society, whose lifestyles were considered "perverted" and "sinful." Stigmatization and Discrimination are the expected outcomes of such values.

Disclosure and Support

Counselling

Counseling is essential in empowering with correct knowledge, coping with HIV and can be critical in helping with disclosure to family members and significant others. Unfortunately, the majority of HIV positive people who are aware of their status have no access to regular counseling. As counseling is one of the keys to overcoming self-stigma, it must get greater priority.

Disclosure

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 infection (Sowell, 2003)[16]. In spite of the proposed benefits of disclosing one's HIV status, choosing to disclose may leave a person open to stigma and discrimination. The burden of living with any substantive secret can be regarded as detrimental to one's health. Disclosure of HIV status can therefore be an important part of helping people to come to terms with their diagnosis and learn to live positively (Health & Development Networks, 2006)[17]. Steward WT etal[18] in a study in South India (2008) concluded that disclosure avoidance leads to depression and stigma.

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 disclosure(Health & Development Networks, 2006)[19]. HIV-positive individuals must be assured that the benefits of doing so will outweigh the potential costs. The high shame and low self esteem was leading to self stigma, especially in females.

A multi country study of AIDS related discrimination in Asia (Paxton, 2005) reported that 34% said that somebody else had been told of their HIV status without their consent[9]. Chandra etal in South India (2003) reported a disclosure by 66% of PLHIV in south Indian setting. The high rate of voluntary disclosure to family members indicates the importance of families as a primary emotional and material support system in India (Chandra etal ,2003) [20]. 35% PLHIV reported HIV status disclosed without consent. Disclosure without the individual's consent is troubling especially because in 75% of the cases, the breach of confidentiality occurred through health professionals[20]. Similar findings were noted in a study by action research group in three districts of Maharashtra (2006)[21].

Deribe K, (2008) found that having regular partner increases the chances of disclosure[22]. 95% had no regrets about disclosure in a study by Serovich (2008)[23]. In Ethiopia 95% got a positive reaction to disclosure to partner (Deribe K, 2008) [22]

Effects of stigma: Depression

Numerous studies have shown that PLHIV suffering from discrimination are more likely to experience depression Vanable etat (2006) and Prachakul W et al (2007)[24] concluded that stigma was associated with depressive symptoms[25]. In turn, chronic depression among individuals with HIV hastens disease progression and mortality

Cockram etal compared the Hamilton Depression Rating Scale (HDRS), the Montgomery Asberg Depression Rating Scale (MADRS), the Beck Depression Inventory (BDI), and the Centre for Epidemiological Studies Depression Rating Scale (CES-D) and all four scales were found to be equally discriminating between depression and absence of depression(1999)[26].

Feelings of shame and guilt lead to depression and, ultimately, ill health. The common complaint of fatigue could be associated due to depression and not the disease (Milkin , 2003)[27]. High levels of Depression among PLHIV has been reported William P et al among pregnant PLHIV patients in Canada (2003,[54%])[28]; Levine AB etal in USA, 2008(53 % having score >9)[29], Pence BW et al in outpatients in Southeast USA in a HIV clinic setting 2006 (30%)[30] ; Judd et al in Australia, 2005 (33%)[31] and Kolarić B (2006) among Croatian PLHIV (20%)[32].

The findings 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. 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 infection[33].

Medical care seeking; The UNDP-NACER study (2006)[34] 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".

Quality of life: Depression has been found to be the strongest predictor of decreased quality of life in PLHIV (Kemppainen JK, 2001)[35]. QOL was found to be determined by education, income, occupation, in a study by Wig N (2006)[36]

ART /support: NACER UNDP study among PLHIV in India reported that only 17% were on ART.

3. Community

3.1 Enacted stigma (discrimination).

Percentage of people who know someone who has experienced any form of stigma in the past 1 year because they were known to, or suspected of having, HIV or AIDS: In a study in Tanzania, isolation stigma was 23% in, verbal stigma was 19%; loss of identity stigma was 5%. Loss of access to resources/ livelihoods was 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 3 A study in Mumbai and Pune revealed that among the urban middle class, 63% attributed blame to the affected individuals, 52% were not sensitive to right of PLWHA and 39% reported stigma in interaction[40].

3.2 Proportion of people with correct knowledge

Over 90% persons have heard of HIV /AIDS in Himachal Pradesh (NACO BSS 2006[37], NFHS 3). Women have lower knowledge than men on how HIV is transmitted and how to keep from getting it. Knowledge that condom use is protective in NFHS (62% women and 82% men) & NACO BSS 2006[37] (73% female and 86% male); Knowledge that being faithful to one uninfected partner can protect from HIV was 91% in NFHS 3 and 83% in BSS[37] among males. In Females the knowledge levers were lower [NFHS 3 (76%), BSS (78%)]. The comprehensive knowledge of HIV AIDS was 53% in NFHS 3.

3.3 Fear of casual contact:

Fear of being infected is exposed to saliva of PLHIV was 30% & fear of being infected is exposed to sweat of PLHIV was 14% in a study in Tanzania (USAID, 2005)[38]. Fear of being infected is exposed to excreta of PLHIV was 21%, and fear that his/her child could become infected by playing with child who has HIV/AIDS was 16% (Tanzania study, 2005). 29 % of respondents in Ghana (Ulasi etal, 2009) [39] stated that they would not allow their children to play with child having HIV/AIDS. Fear were associated with low knowledge (Ulasi CI etal, Ghana 2009).

In market of several vendors Percentage of people who NOT would buy food from PLHIV was 26 % women and 22% men in NFHS 3 and 7% in Tanzania study (2005)

3.4 Shame, blame, judgment

Percentage of people who judge or blame PLHA for their illness was 66% in Tanzania study (2005). In a recent study in Mumbai and Pune (Kaulagekar A, 2007) among the urban middle class, 63% attributed blame to the affected individuals[40].

Percentage of people who would feel shame if they associated with a PLHA was 66% in Tanzania study (2005).

HIV-related stigmatization is less a matter of individual process than a social process through social learning and social influence. Stigmatization is a cultural, political and economic phenomenon linked to law, policies, norms and prejudices HIV-related stigmatization has been viewed as an attitude toward unpopular and relatively powerless groups that, in some societies, have been disproportionately affected by the epidemic. Even if a vaccine and a cure are found, HIV/AIDS may still be linked with risk behaviour (such as unsafe sex or drug abuse) that is often regarded as shameful and embarrassing. Inaccurate beliefs and fear at the community level have a stronger, negative relationship with an individual's willingness to interact with PLWHA than with attitudes towards PLWHA[41]

4. Health care provider

HIV/AIDS-related stigma and discrimination can reduce the quality of treatment and health care received [42].

4.1 Prevalence:

Evidence of prejudicial attitudes to HIV-infected individuals amongst health workers is of concern. The enacted stigma by a health care provider is was reported to be 26% of PLHA in USA[43] and 27% by PLHA in France.

In a recent US study where 46% of skilled nursing facilities and 55% of obstetricians in Los Angeles County would not accept PLHIV clients[44].

Senior doctors have more power to delegate what they see as high-risk tasks with HIV-positive patients [45].

Practice of testing a client for HIV without their consent was reported to be 24% Tanzania [46]. 29% HCP disclosed a patient's HIV/AIDS status to colleagues in Belize[47]. 40% doctors reported practices of testing without consent and 37% disclosure to a person's family their consent in Delhi.

20% PLHIV in NACER study[34] reported unnecessary use of protective gear by hospital authorities reported.

While 62% of HCPs in the Yunnan study were willing to treat PLWHA 82% stated that they would prefer not to (Weber, 2007) [48]. 81% HCP in Mexico indicated they were willing to treat AIDS patients[49].

Proportion of health care providers who stated that patients should be tested for HIV before surgery in a study in health care settings, Delhi (Mahendra, 2006) was 79% for doctors and 92% for nurses. The proportion of doctors who said that all pregnant women should be tested for HIV was 66% while those nurses who said that all pregnant women should be tested for HIV was 92%[11]. Similarly most HCPs felt that HIV tests should be mandatory at the premarital examination (96%) or for pregnant women (94%) (Weber, 2007) [48].

The Botswana government recently implemented a policy of routine or "opt-out" HIV testing based on June 2004 by UNAIDS and the World Health Organization, recommendations to increase uptake of HIV testing and treatment, and to reduce HIV-related stigma by treating the HIV test like any other routine medical procedure. Data from Botswana indicate that some people may avoid going to the doctor out of fear of testing and women who are tested may be subject to intimate partner violence(Weiser D, 2006)[50], suggesting that prevailing stigma in the general population leads to unintended but significant consequences. Provider-initiated

approach may have the problem of the stigmatizing attitudes of healthcare providers and the potential for coercion of patients to test (Mahajan, 2008)[51].

In the Study in health care settings, Delhi (Mahendra, 2006), 60% doctors and 34% nurses felt that the need for consent is exaggerated & HIV tests should be handled like any other test[11]. 87% doctors and 98% nurses felt that when a patient tests positive the doctor should inform the patient's partner. Nurses had higher stigma than doctors [11].

HIV-related stigma data from all countries shows a gap between people's stated intentions *not* to stigmatize and their actions, which are stigmatizing (Ogden, J., & Nyblade, 2005)[15].

Attitudes towards infection control procedures:

21 % doctors and 34% nurses felt that PLHIV should be kept at distance from other. 54% doctors and 67% nurses said that clothes and linen used by HIV positive patients should be disposed off or burned. 14% doctors and 12% nurses felt that HIV infected patients should be made to pay for health staff's use of additional infection control supplies (Study in health care settings, Delhi (Mahendra, 2006))[11].

Untrained persons had higher stigma that trained; which is also seen in studies in Ethiopia[52]. A study in (Reis C, 2005) Nigeria 59% of HCP felt that patients with HIV should be kept at a distance from other patients[53].

Attitudes towards PLWHA rights

In a study in health care settings, Delhi (Mahendra, 2006), 64% and 62% respectively felt that people living with HIV should have a right to decide who should know their results 79% doctors and 44% nurses stated that PLHIV should be allowed to get married. 71% doctors and 89% nurses felt that HIV positive women should not get

pregnant[11]. In Chinese HCP, only 64% HCP believed PLWHA should be allowed to get married, while a mere 48% thought they should be permitted to have children (Weber GC)[48]

4.2 Provider-level: Knowledge and fears

Research has long attempted to establish the relationship between knowledge about HIV, fear of infection and stigma (blaming and shaming) or discrimination. Some studies find a close relationship and others do not (Deacon, 2006) [54]. 91.4% also believed that contact with an HIV-positive person (84.6%), handling belongings of an HIV positive person (87.4%), and insect bites (79%) could transmit HIV(Weber, 2006)[48]

Correct knowledge does sometimes coexist with incorrect beliefs about transmission, and there is often a lack of confidence about how HIV is *not* transmitted (Ogden, J., & Nyblade, 2005)[15]. 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 AIDS (Ogden, J., & Nyblade, 2005)

Fear: 30% of health care providers reported fear of risk of contacting HIV during contact with patients in Tanzania study.

Li et al (2007) in a study of Chinese medical service providers stated that fear of infection has been associated with stigma[55]

4.3 Values, shame, and blame:

Service providers are part of the general society, and their perceptions and attitude toward HIV/AIDS are expected to be influenced by societal norms and attitudes[56].

Shame: In a study among health care providers in Vietnam, 46% health care providers would feel shame if they associated with a person living with HIV/AIDS, 34% said that they would feel ashamed if they were infected with HIV. 44 % HCP in Vietnam said that people with HIV/AIDS should be ashamed of themselves (Oanh, 2008)[57].

Blame and Judgment: Two-thirds of the medical students in China surveyed felt that people infected with AIDS got what they deserved (Webber, G. C, 2008) [48].

The proportion of HCP who judge or blame PLHA for their illness was higher in Tanzania Study (46%) than Nigeria study (20%)[53]

Endnote:

HIV-related stigma data from all countries shows a gap between people's stated intentions *not* to stigmatize and their actions, which are stigmatizing. This 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 (Ogden, J., & Nyblade, 2005) [15].

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Annexure 2 (Methods)

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ANNEX 2.1. SAMPLE SIZE DETERMINATION

Formula for Estimating proportion[1].

$n=Z_{(1-\alpha)}^2 P(1-P)/d^2$

P = anticipated population proportion
Z = Z value corresponding to value of $1-\alpha$
$(1-\alpha)$ = Confidence interval
d= estimated precision

Category	Sampling Frame	Assumption	Sample size
10% error allowed			
PLWHA		P= 26%	
	From secondary data analysis of VCTC the pool of known HIV positive in the district is 408 (38 children; adults= 370).	Half the known numbers of PLWHA are alive	$(1.96)^2$ 26(100-26)/ 10 X10 = 53
Community members	About 10 lakh adults	P= 49 (NFHS 3)	Cluster using Software = 540
Doctor Nurse	About 555* in hospitals	RESPONSE RATE = 66%	ALL

Category	Sample	Method	Details
PLWHA	53	Referrals from counselors, NGOs and service providers	The investigator contacted service providers, NGOs and counselors and share the purpose of the research and expected benefits. The investigator requested them to discuss with HIV positive clients the possibility of participation in a research study on their problems and for those who agreed, were referred to investigator Counselor/ NGO/ service provider in contact with them arranged a meeting for conducting the interview at VCTC as per mutual agreed time.
Comm-unity members	540	27 Clusters	Of the 12 blocks in the district one area having large number of PLHA was selected. Within the block the hamlets will be selected randomly. In the sub-centre area we selected 20 by systematic random sampling.
Doctors Nurse	555*	All	Line list of staff present on day and give questionnaire to all
* Sampling frame number of service providers keeps changing due to frequent transfer postings			

[1] Lwanga SK, Lemeshow S Sample size determination in health studies, WHO Geneva 1991. pp25

Sampling procedure:

Community:

We took a representative sample of the community using cluster techniques. The area with highest number of cases in the district is Palampur. However, to avoid the fallacy of false address we confirmed with the NGOs and then select block with high burden of HIV/AIDS. Within the selected block, clusters (hamlets) were selected by simple random sampling technique by draw of lots. We prepared the line listing of houses, selected the first house by the last digit of currency note, and then sampling interval were calculated by dividing the number of houses by number of participants per cluster. One person from each house was selected by lottery method. If a particular house is locked or refusal to participate, the next house were taken.

ANNEX2.2 PLHIV Questionnaire

Information Sheet For People living With HIV AIDS Participants

अनुसन्धान में सहभागियों के लिए सूचना पत्र

HIV/AIDS से जुड़ी लांछन एवं भेदभाव की भावना

जिला कांगड़ा, हिमाचल प्रदेश, भारत, 2008 एक पथ प्रदर्शक अध्ययन

मैं डा आर के सूद, स्वास्थ्य विभाग, जिला कांगड़ा, हिमाचल प्रदेश के लिए कार्य कर रहा हूँ। HIV/AIDS से जुड़े हुए कलंक एवं भेदभाव के कारण, इस बीमारी से ग्रस्त लोग, रोकथाम के तरीकों, जाँच एवँ अन्य उपचारों आदि सुविधाओं और सेवाओं से वंचित हैं। हम कोशिश कर रहे हैं कि उन लांछनों एवं भेदभाव की भावनाओं पर एक अध्ययन करें जो कि विभिन्न परिवेशों में जिला कांगड़ा, हि.प्र. में HIV/AIDS से जुड़ी हुई है।

उद्देश्य :

इस अध्ययन का मुख्य उद्देश्य स्वास्थ्य कार्यकर्ताओं, समुदाय एवं एडस् से ग्रसित व्यक्तियों को HIV/AIDS की कितनी जानकारी तथा क्या भावना है, उसका पता लगाना है।

इस अध्ययन से इकट्ठा की गई जानकारी HIV को फैलने से बचाने के लिए कार्यक्रम बनाने में मदद करेगी।

कार्यप्रक्रिया :

इस अध्ययन के लिए हम आपको प्रश्नों के उत्तर देने के लिए आमंत्रित करते हैं।

मैं आपको साफ साफ समझाता हूँ कि आपको क्या करना है।

अध्ययन में भाग लेने से पहले आप से अनुरोध किया जाएगा कि आप कुछ प्रश्नों के उत्तर दें। आप जैसा सोचते और समझते हैं वैसा ही उत्तर दें।

इस अध्ययन में कोई भी आक्रामक प्रक्रिया या जाँच नहीं की जाएगी। आपका नाम रिकार्ड में कहीं भी लाया नहीं जाएगा तथा सारी जानकारी गोपनीय होगी।

लाभ :

इस अध्ययन से प्राप्त की गई जानकारी ऐसे पैकेज बनाने में मदद करेगी जो कि HIV/AIDS की रोकथाम के लिए वातावरण बनाने में मदद करेंगे।

प्रोत्साहन :

अध्ययन में भाग लेने के लिए आपको किसी प्रकार का प्रोत्साहन नहीं दिया जाएगा।

गोपनीयता :

सारी जानकारी को गोपनीय रखा जाएगा। आपके द्वारा दी गई जानकारी एक ऐसी फाईल में रखी जाएगी जिसमें आपका नाम नहीं होगा।

इन्कार करने का अधिकार :

इस अध्ययन में आप केवल स्वैच्छिक सहमति से भाग लेंगे। आप किसी भी समय अध्ययन प्रक्रिया छोड़कर जा सकते हैं।

दूसरा तरीका :

यदि आप इस अध्ययन में भाग नहीं लेना चाहते तो आप ऐसा कर सकते हैं।

कृप्या संपर्क करें :

इस अध्ययन प्रस्ताव की राष्ट्रीय ज्ञानपीठ संस्थान चेन्नई–77 की संस्थागत नैतिक कमेटी द्वारा समालोचना एवं स्वीकृति की गई है। यह कमेटी देखती है कि अध्ययन में सहभागियों को किसी प्रकार की हानि न हो। यदि आप इस कमेटी के बारे में अधिक जानकारी चाहते हैं तो आप निम्नलिखित पते पर सम्पर्क कर सकते हैं।

1. निर्देशक राष्ट्रीय ज्ञानपीठ संस्थान (राष्ट्रीय चिकित्सा अनुसंधान परिषद)
R-127, 3rd Avenue, TNHB कालोनी आयापक्कम
अम्बाटूर, चेन्नई, तामिलनाडू–77

यदि आप और प्रश्न पूछना चाहते हैं तो आप अभी या फिर बाद में पूछ सकते हैं। यदि आप बाद में प्रश्न पूछना चाहें तो सम्पर्क करें :

स्थानीय मुख्य जांच कर्ता : नाम डा आर के सूद पता मुख्य चिकित्सा अधिकारी कारयालय जिला कांगड़ा, हिमाचल प्रदेश फोन नम्बर 9418064077

HIV/AIDS से जुड़ी लांछन एवं भेदभाव की भावना
जिला कांगड़ा, हिमाचल प्रदेश, भारत, 2008 एक पथ प्रदर्शक अध्ययन

प्रिय भागीदार

हम HIV/AIDS से ग्रसित व्यक्तियों द्वारा सही जाने वाली लांछन एवं भेदभाव की भावना से सम्बन्धित एक अध्ययन कर रहे हैं।

जबसे आपको यह पता चला है कि आप HIV/AIDS से ग्रसित हैं, तब से आपको दैनिक जीवन में किस प्रकार की समस्याओं का सामना करना पड़ता है उससे सम्बन्धित कुछ प्रश्न पूछेंगे।

प्रश्न पूछने में केवल 30 मिनट का समय लगेगा। इस अध्ययन से सरकार को ऐसी नीतियां बनाने में मदद मिलेगी जिनसे एड्स से ग्रसित व्यक्तियों की आवश्यकतानुसार मदद की जा सके। प्रश्नों का उत्तर देने के लिए आपको आर्थिक सहायता प्रदान नहीं की जाएगी। हम आपकी किसी प्रकार की जांच भी नहीं करेंगे।

आपके द्वारा दिए गए प्रश्नों के उत्तर पूर्ण रूप से गोपनीय रखे जाएंगे एवं किसी भी हालत में उन्हें किसी को नहीं बताया जाएगा। रिपोर्ट में कहीं भी आपके नाम का उल्लेख नहीं किया जाएगा।

यदि आपको कोई प्रश्न असुविधाजनक लगें तो आप उत्तर देने से इन्कार कर सकते हैं। अगर आप जवाब देते देते थक जाएं तो आप मुझे रूकने के लिए कह सकते हैं। आप किसी भी समय बिना कारण बताए मेरे प्रश्नो का उत्तर देने से इन्कार कर सकते हैं।

हमारा आपसे अनुरोध है कि आप इस अध्ययन में सहभागी बनने के लिए स्वैच्छिक सहमति प्रदान करें और कुछ प्रश्नों के उत्तर दें। यदि आप इस अध्यन के विषय में अधिक जानकारी चाहते हैं तो हमें आपके प्रश्नों का उत्तर देने में खुशी होगी। सर्वे के बाद भी यदि आपके मन में कुछ प्रश्न हों तो आप मुझे फोन नम्बर 9418064077 पर सम्पर्क कर सकते हैं।

घोषणा :

यह सहमति फार्म मैंने पूरा पढ़ लिया है/ इस सहमति फार्म में जो भी लिखा है उसे मुझे अपनी भाषा में पूरी तरह पढ़ कर सुनाया गया है। मेरे इस विषय में जो भी आंशकाएं थीं मुझे उनके विषय में पूछने का पूरा मौका दिया गया है और मुझे उनके उत्तरों से पूरी तरह से सन्तुष्ट किया गया है। मैं इस सर्वे में भाग लेने के लिए स्वैच्छिक सहमति प्रदान करता/करती हूँ। और समझता/समझती हूं कि बिना कारण बताए मैं कभी भी अध्ययन से अपना नाम वापिस ले सकता/सकती हूँ।

सहभागी हस्ताक्षर

गवाह हस्ताक्षर

PLHIV STIGMA QUESTIONNAIRE

SECTION 1. Respondent and Household Characteristics

No.	Questions and filters	Coding categories	
101	[SEX OF THE RESPONDENT]	Female Male	1 2
102	How old are you?	Age in years	
103	What is your religion? [RECORD RESPONSE. IF REPLY IS "HINDU," ASK "WHAT CASTE?"]	Hindu GENERAL HINDU SC HINDU ST HNDU OBC MUSLIM CHRISTIAN SIKH BUDDHIST Other (specify) _______________	1 2 3 4 5 6 7 8 9
104	How long have you been living with HIV?	• Number of Years _____Months____	
105	What is your marital status?	• Married/cohabiting & partner currently living in household • Married/cohabiting & partner currently living away from household • In relationship but not living together • Single • Divorced/ separated • Widow/ Widower	1 2 3 4 5 6
106	If currently in relationship, How long have you been in relationship?	• Years	
107	Are you sexually active	• Yes • No	1 2
108	How many people live in your house Age Relation Status 1 2 3 4	Age Relation Status 5 6 7 8	
109	HIV status of partner	• Negative • Positive and living • Positive and not living	
110	HIV status of children	• Number positive • Total children	
111	What is your employment status? [RECORD RESPONSE]	• Full time employment (employee) • Part time employment (employee) • Self employed- full time • Self employed- part time • Unemployed and not working at all	1 2 3 4 5

112	Do you belong to, or in the past belonged to any of the following categories	• Men who have sex with men • Gay or lesbian • Transgender • Sex worker • Injecting drug user • Refugee or asylum seeker • Internally displaced person • Member of an indigenous group • Migrant worker • Prisoner • None of the above	1 2 3 4 5 6 7 8 9 10 11
113	Do you have physical disability of nay kind? If yes, SPECIFY	Excluding illness due to HIV	
113	Have you ever attended school? If so, what is the highest level of school you have attended?		
114	Average Monthly income of household over the last 12 months? Rs		

No.	Questions and filters	Coding categories	
201a	From where did you first hear about HIV /AIDS When? __________		
202a	What do you understand by HIV AIDS		
202b	Is there a difference between HIV and AIDS?	No Yes Don't know	0 1 98
203	Please tell me all the ways you know of that HIV can be transmitted [CIRCLE ALL THAT APPLY]	Unprotected sex/sex without condom Sharing injections Blood transfusions Mother-to-child transmission Injecting drug use Sex with prostitutes Sex with multiple partners Kissing Mosquito bites Sharing razors/blades Sharing food/drink/eating utensils Sharing toilets Road accidents Sweat Saliva Don't know Other (specify)______________	A B C D E F G H I J K L M N O 98 95

204	How can people protect themselves from getting HIV? [CHECK ALL THAT APPLY]	Abstain from sex Use condoms Be faithful to one uninfected partner Limit number of sexual partners Avoid sex with prostitutes Avoid sex with persons who have sex with many partners Avoid sex with homosexuals Avoid sex with injecting drug users Avoid sharing razors/blades Avoid sharing needles Avoid injections Avoid kissing Avoid mosquito bites Avoid blood transfusions Don't know Other (specify)_____________	A B C D E F G H I J K L M N 98 95
205	Can the virus that causes AIDS be transmitted from a mother to her baby? [IF DEPENDS, ASK "ON WHAT?" AND RECORD ANSWER IN OPEN SPACE]	No Yes Depends__________________ Don't know	0→ 1 90→ 98
205b	In your opinion, when can the virus that causes AIDS be transmitted from a mother to her baby? Can the virus be transmitted during— [CIRCLE ALL RESPONSES GIVEN]	 During pregnancy................. During delivery.................... During breastfeeding........... Other (specify)___ ___________	Yes
206	Can a healthy looking person have HIV?	No Yes Don't know Other (specify)_______________	0 1 98 95
207	Is there a cure for AIDS?	No Yes Depends Don't know/not sure	0 → 1 3 98→
207a	If there is a cure, what kind is it? [CHECK ALL THAT APPLY]	A. Modern medicine B. Traditional medicine C. Faith healing/prayer Other (specify)______________	A B C 95
208	Do you know of treatment that can prolong the life of a PERSON LIVING WITH HIV AIDS?	No Yes Depends	0→ 1 3
208a	If yes, what treatment? [CHECK ALL THAT APPLY]	Treatment for opportunistic infection Faith healing/prayer ARV Good nutrition/ hygiene Other (specify)________________	A B C D E
209	In a married couple, is it possible for one person to have HIV and the other one not to have HIV?	No Yes Don't know	0 1 95

SECTION 3: Testing and Disclosure 3A Testing

Now I would now like to ask you some questions about your experience with learning about and disclosing your HIV status.

No.	Questions and filters	Coding categories	
301	Why WERE YOU TESTED FOR HIV? [CIRCLE ALL THAT APPLY]	Employment Pregnancy To prepare for a marriage/sexual relationship Referred by a clinic for sexually transmitted infections Referred due to suspected HIV-related symptoms (e.g. tuberculosis) Husband/wife/partner/family member tested positive Illness or the death of husband/wife/partner/family member I just wanted to know Other	A B C D E F G H I
302	Was the decision to be tested your own, or were you asked by someone else to be tested?	Yes I took the decision myself to be tested (voluntary) I took the decision but it was under pressure from others I was made to take the HIV test (coercion) I was tested without my knowledge	1 2 3 4
303	Who asked you to be tested? [CHECK ALL THAT APPLY]	Medical professional Partner Parents Employer Visa application Other (specify) ___________	A B C D E 95
304	Was your informed consent taken before you were tested? [RECORD RESPONSE]	No Yes	0 1
305	Where was the test conducted? Name of facility/place___________________ [WRITE FACILITY NAME ABOVE AND TO CODE/CLASSIFY RESPONSE, CHECK ALL THAT APPLY	Government/clinic/hospital Mission hospital/clinic Private hospital/clinic NGO-CBO VCT center Other (specify) ___________	1 2 3 4 5 95
306	Did you receive counseling before or after your blood was taken for testing? [record response. if reply is "no counseling," probe further: "what about pre-test or post-test counseling?"]	I received No counseling I received Pre-test counseling only I received Post-test counseling only I received both Pre-test & post-test counseling	0 1 2 3
307	What were your reactions on learning that you were positive?		

	SECTION 3B DISCLOSURE AND CONFIDENTIALITY		
308	Have you told anyone about your HIV HIV-status?	No Yes	0 1

309. For each of the following people or groups of people, please describe how they were first told about your HIV status, if they have been told. (Please tick your answers. Only tick more than one box in each line if the answer is different for different individuals.)

	I told them	Someone else told them WITH my consent	Someone else told them WITHOUT my consent	They don't know about my HIV status	Not Appli-Cable
Your husband/wife/partner	1	2	3	4	5
Other adult family members (in laws)	1	2	3	4	5
Parents and siblings	1	2	3	4	5
Children in your family	1	2	3	4	5
Your friends/neighbors	1	2	3	4	5
Other people living with HIV	1	2	3	4	5
People who you work with (co-workers)	1	2	3	4	5
Your employer(s)/boss (es)	1	2	3	4	5
Community leaders	1	2	3	4	5
Health care workers	1	2	3	4	5
Social workers/counselors	1	2	3	4	5
Government officials	1	2	3	4	5
The media	1	2	3	4	5

310.	How often did you feel pressure from other individuals living with HIV or from groups/networks of people living with HIV to disclose your HIV status?	Often A few times Once Never	1 2 3 4
311.	How often did you feel pressure from other individuals not living with HIV (e.g. family members, social workers, non-governmental organization employees) to disclose your HIV status?	Often A few times Once Never	1 2 3 4

312. How would you describe the reactions of these people (in general) when they first knew about your
HIV status? (Tick one box only for each category of people.)
(Tick **Not applicable** if these people do not know your HIV status or you don't know what their reaction was.)

	Very discrimi natory	Discrimin -atory	No different	Suppor tive	Very supportive	Not Applic
Your husband/wife/ partner	1	2	3	4	5	
Other adult family members (in laws)	1	2	3	4	5	
Parents and siblings	1	2	3	4	5	
Children in your family	1	2	3	4	5	
Your friends/neighbours	1	2	3	4	5	
Other people living with HIV	1	2	3	4	5	
Your co-workers	1	2	3	4	5	
Your employer(s)/boss(es)	1	2	3	4	5	
Community leaders	1	2	3	4	5	
Health care workers	1	2	3	4	5	
Social workers/counsellors	1	2	3	4	5	
Government officials	1	2	3	4	5	
The media	1	2	3	4	5	

313.	**Did you find the disclosure of your HIV status an empowering experience?** (Tick **Not applicable** if you have not disclosed your HIV status.)	Yes No Not applicable	1 2 3
314	If you have not told others about your HIV status, Why was it so? [CHECK ALL THAT APPLY]	[Because:]	
		They would tell someone else	A
		I would be gossiped about/laughed at	B
		It would become news around here	C
		I would be physically isolated	D
		I would be socially isolated	E
		I would lose respect	F
		I would lose job, housing, livelihood	G
		It would be difficult to get medical services	H
		I'd be treated differently at temple	I
		I would be afraid of being stigmatized	J
		Private matter	K
		Don't know	98
		Other (specify) ______________	95

315	Have you ever done things or behaved in a way to try and prevent people from knowing your status? [RECORD RESPONSE. IF "0" SKIP TO Q318]	No Yes	0➔ 1
316	What kinds of things have you done to avoid people knowing your status? [WRITE DOWN ALL EXAMPLES GIVEN ➔		
317	Has your HIV status ever been revealed without your consent? **Check with 313** [RECORD RESPONSE. IF "0" SKIP TO Q319]	No Yes	0➔ 1
318	Who revealed your status without your consent? [CHECK ALL THAT APPLY AND ASK: "ANYONE ELSE?"]	Partner Close Relative Distant relative Friend Neighbor Health provider/s Don't know Other (specify) ______	A B C D E F 98 95
319	Would you recommend to a person who is living with HIV, but is not showing signs/symptoms of AIDS, to keep his/her status secret, tell only family members, or share this information with the community? [RECORD RESPONSE. IF "3" SKIP TO Q319B; IF "98" SKIP TO Q320]	Tell no one Tell only family Share with community Don't know	1 2➔ 3➔ 98➔
319a	If you recommend that HIV-positive status be kept private, why? [CHECK ALL THAT APPLY]	Personal problem People act differently toward a person with HIV Person would be isolated/ neglected/avoided No one would care for person Other (specify) ______	A B C D 95
319b	If you recommend that HIV-positive status be told to gamily, why?	PLHA would not threat/infect family members PLHA needs to be isolated PLHA should get care and support of the family PLHA to encourage others to protect themselves Other (specify) ______	A B C D 95
319c	If you recommend that HIV-positive status be shared with the community, why? [CHECK ALL THAT APPLY]	To avoid community infection by PLHA PLHA can encourage/teach others do the same PLHA can create opportunity for care and support from community To reduce discrimination/ stigma against PLHA Other (specify) ______	A B C D 95

SECTION 4: INTERNAL STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) & YOUR FEARS

No.	Questions and filters	Coding categories	
401	Do people behave differently toward people suspected of having HIV/AIDS or treat PLHA differently? [RECORD RESPONSE. IF "0" OR "98" SKIP TO Q402]	No Yes Don't know	0➔ 1 98➔
401a	Can you give some examples of how people suspected of having HIV/AIDS might be treated differently? [WRITE DOWN ALL EXAMPLES GIVEN➔]		
402	**In the last 12 months, have you experienced any of the following feelings because of your HIV status?** (Tick one box for each category.)		

A	I feel ashamed	Yes	1	No	2
B	I feel guilty	Yes	1	No	2
C	I blame myself	Yes	1	No	2
D	I blame others	Yes	1	No	2
E	I have low self-esteem	Yes	1	No	2
F	I feel I should be punished	Yes	1	No	2
G	I feel suicidal	Yes	1	No	2

If "yes" When you experience this, how do you react to and cope with such feelings?

403	Are their people, groups, or organizations that you can go to for support and advice when you have such feelings? **[If "yes]** Who? [CHECK ALL THAT APPLY]	Spouse/partner Parent Sibling Other relative Friend Group for PLHA (specify)__________ Religious organization NGO Other (specify)__________	A B C D E F G H 95
404	Sometimes, having HIV changes what someone plans to do in his/her life. Would you please tell me if you have ever done any of the following because of your HIV status?		
404.1	Avoided or withdrawn from applying for school, further training, or scholarship	No Yes	0 1
404.2	Not applied for a job or promotion	No Yes	0 1
404.3	Avoided or isolated yourself from your friends or family	No Yes	0 1
404.4	Decided not to get married or have a sexual partner	No Yes	0 1
404.5	Decided not to have [more] children	No Yes	0 1
404.6	Avoided travel to another country or another area.	No Yes	0 1

404.8	Are there any [other] life goals or hopes you had that have changed because of your HIV status? Please describe. [RECORD RESPONSE AND WRITE DOWN ALL EXAMPLES GIVEN➔]	No Yes -- -- --	0 1

405.	In the last 12 months, have you done any of the following things because of your HIV status? (Tick one box for each category.)				
A	I have chosen not to attend social gathering(s)	Yes	1	No	2
B	I have isolated myself from my family and/or friends	Yes	1	No	2
C	I took the decision to stop working	Yes	1	No	2
D	I decided not to apply for a job/work or for a promotion	Yes	1	No	2
E	I withdrew from education/training or did not take up an	Yes	1	No	2
	Opportunity for education/training	Yes	1	No	2
F	I decided not to get married	Yes	1	No	2
G	I decided not to have sex	Yes	1	No	2
H	I decided not to have (more) children	Yes	1	No	2
I	I avoided going to a local clinic when I needed to	Yes	1	No	2
J	I avoided going to a hospital when I needed to	Yes	1	No	2
K	Other (specify)				

405b	In the last 12 months, have you been fearful of any of the following things happening to you – whether or not they actually have happened to you?				
	Being gossiped about	Yes	1	No	2
	Being verbally insulted, harassed and/or threatened	Yes	1	No	2
	Being physically harassed and/or threatened	Yes	1	No	2
	Being physically assaulted	Yes	1	No	2

406	In the last 12 months, have you been afraid that someone would not want to be sexually intimate with you because of your HIV-positive status?	Yes No
407	Do you know of any organizations or groups that you can go to for help if you experience stigma or discrimination?	Yes No

If the answer is **NO**, please go to question 409.

408. If yes, which kinds of organizations or groups do you know about?
(Tick more than one box if appropriate.)

People living with HIV support group	1
Network of people living with HIV	2
Local non-governmental organization	3
Faith-based organization	4
A legal practice	5
A human rights organization	6
National non-governmental organization	7
National AIDS council or committee	8
International NGO	9
UN organization	10
Other (specify).................................	11

408.	Have you sought help from any of the above organizations or groups to resolve an issue of stigma or discrimination?	Yes No
409.	If you have tried to resolve an issue of stigma and discrimination either on your own or with the assistance of others, briefly describe what the issue was about, who – if anyone – helped you, and how you and/or others tried to resolve the matter.	

WHAT was the issue of stigma and discrimination about?

If others helped you resolve the matter – **WHO** helped you

HOW did you (and, if appropriate, others) try to resolve the matter (i.e. what specifically did you and/or others do)?

411a	In the last 12 months, have you supported other people living with HIV?	Yes No	
411b	If YES, what types of support did you provide? (Tick more than one box if appropriate.)		
	Emotional support (e.g. counseling, sharing personal stories and experiences) Physical support (e.g. providing money or food, doing an errand for them) Referral to other services		**1** **2** **3**
412	Are you currently a member of a people living with HIV support group and/or network? Yes/ No		
413.	In the last 12 months, have you been involved, either as a volunteer or as an employee, in any programme or project (either government or non-governmental) that provides assistance to people living with HIV? Yes/ No		
414.	In the last 12 months have you been involved in any efforts to develop legislation, policies or guidelines related to HIV? Yes/ No		

415. Do you feel that you have the power to influence decisions in any of the following aspects?(Tick at least one box. You can tick more than one if appropriate.)

Legal/rights matters affecting people living with HIV	1
Local government policies affecting people living with HIV	2
Local projects intended to benefit people living with HIV	3
National government policies affecting people living with HIV	4
National programme/projects intended to benefit people living with HIV	5
International agreements/treaties	6
None of these things	7

SECTION 5: Enacted Stigma (Discrimination)

	501. Have you **ever** [read out options from list below] because of your HIV status? [RECORD RESPONSES BELOW]		502. **In the last year**, have you [read out options from list below left] because of your HIV status? **[If yes]** How often has this happened (never, sometimes, and often)? [record responses below]
1	Been excluded from a social gathering (wedding, funeral, party, community association group)	0. No 1. Yes	0. Never 1. Sometimes 2. Often
2	Been treated differently/shunned at a social gathering	0. No 1. Yes	0. Never 1. Sometimes 2. Often

3	Been abandoned by your spouse/partner	0. No 1. Yes	0. Never 1. Sometimes 2. Often
4	Been abandoned by your family/sent away from family	0. No 1. Yes	0. Never 1. Sometimes 2. Often
5	Been isolated in the household (made to eat alone/made to use separate eating utensils/ made to sleep alone in own room	0. No 1. Yes	0. Never 1. Sometimes 2. Often
6	Been no longer visited, or visited less by family and friends	0. No 1. Yes	0. Never 1. Sometimes 2. Often
7	Been teased, insulted, or sworn at	0. No 1. Yes	0. Never 1. Sometimes 2. Often
8	Lost customers to buy your produce/goods or lost a job	0. No 1. Yes	0. Never 1. Sometimes 2. Often
9	Been denied promotion/further training	0. No 1. Yes	0. Never 1. Sometimes 2. Often
10	Lost housing or not been able to rent housing	0. No 1. Yes	0. Never 1. Sometimes 2. Often
11	Been denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/ Not allowed to go to church/mosque	0. No 1. Yes	0. Never 1. Sometimes 2. Often
12	Been given poorer quality health services (e.g., been passed from provider to provider or not given medicines, treatment, surgery)	0. No 1. Yes	0. Never 1. Sometimes 2. Often
13	Had property (e.g., household property or land) taken away	0. No 1. Yes	0. Never 1. Sometimes 2. Often
14	Lost respect/standing within the family and/or community	0. No 1. Yes	0. Never 1. Sometimes 2. Often
15	Been gossiped about	0. No 1. Yes	0. Never 1. Sometimes 2. Often
16	Been physically assaulted / threatened with violence (i.e. hit, kicked, or punched)	0. No 1. Yes	0. Never 1. Sometimes 2. Often

503	**[If "yes" to at least one question in Q502]** How did you know it was because of your HIV status? [WRITE DOWN ALL EXAMPLES GIVEN➔]	
504	**[If "yes" to at least one question in Q502]** How did you react to and cope with the stigma and discrimination you have just told me about? [WRITE DOWN ALL EXAMPLES GIVEN➔]	
505	Have you ever been given more care and support by family/ neighbors/community because of your HIV status? Please describe. [WRITE DOWN ALL EXAMPLES GIVEN➔]	0 No, 1 yes

506	Have you ever been given special services (home based care, medical treatment, material) because of your HIV status? Please describe. [WRITE DOWN ALL EXAMPLES GIVEN➔]	0 No, 1 yes

SECTION 6. Experiences of Stigma and Discrimination in Health Settings

No.	Questions and filters	Coding categories		
601	How is your health in general? Would you say it is very poor, poor, neither poor nor good, good, or very good?	Very poor Poor Neither poor nor good Good Very good		1 2 3 4 5
602	Have you ever had HIV/AIDS-related signs/symptoms (e.g., skin rash, loss of weight, herpes) visible in your physical appearance?		No Yes	0 1
603	In the past 12 months, have you had any health concerns/worries that required medical attention?		No Yes	0➔ 1
604	In the past 12 months, when you had health problems that required medical advice or treatment, who in your household had primary responsibility to facilitate your health care?	Spouse Child Parent Sibling Other relative Other household member No one in the household		1 2 3 4 5 6 7
605	In the past 12 months, when you had these health concerns/worries, did you seek medical advice or treatment?		No Yes	0 ➔ 1
606	In the past 12 months, where did you seek medical advice/treatment? [CHECK ALL APPLY. PROBE FURTHER.]	Government health facility Private health facility NGO health facility Pharmacy/drug Store Traditional practitioner Other (specify) ___________		A B C D E 95
607	The last time you went for medical advice or treatment, did service providers at this place know your HIV status?	No Yes Not sure		0 1 2
608	How would you rate the quality of services provided to you during your last visit to a medical facility?	Poor Fair Good		1 2 3
609	In the **past 12 months**, have you had any of the following happen to you at a **health care facility** because of your HIV status?			
609.1	Health provider refused to attend you		No Yes	0 1
609.2	You were discharged too early		No Yes	0 1
609.3	You had to wait longer to be attended		No Yes	0 1

609.4	You were being unnecessarily referred on to another provider in the same facility or referred to another facility	No Yes	0 1
609.5	You were told to come back later	No Yes	0 1
609.6	You were being denied treatment—drugs, surgery—or relevant tests/investigations	No Yes	0 1
609.7	You were tested for HIV without your informed consent?	No Yes	0 1
609.8	You were required to be tested for HIV before care was given or surgery scheduled	No Yes	0 1
609.9	Health provider used latex gloves for performing non-invasive exams on you or took extra precautions.	No Yes	0 1
609.10	Health provider disclosed your HIV status to your family without your consent.	No Yes	0 1
609.11	Health provider gossiped about your HIV status	No Yes	0 1
609.12	Health provider used derogatory language or scolded or blamed you for having HIV	No Yes	0 1
609.13	Your bed pans or bed clothes were not changed as needed/as often compared to other patients	No Yes	0 1
609.14	You received less care/attention than other patients	No Yes	0 1
610	In the past 12 months, was there any other way in which you were treated differently because of your HIV status? Please describe. [WRITE DOWN ALL EXAMPLES GIVEN➔]		
611	**[If "yes" to Q609–610]** How did you know it was because of your HIV status? [WRITE DOWN ALL EXAMPLES GIVEN➔]		
612	**[If "yes" to at least one question in 401]** How did you react to and cope with the stigma and discrimination you have just told me about? [WRITE DOWN ALL EXAMPLES GIVEN➔]		
613	Have you ever avoided or delayed seeking health care treatment because you were afraid of service providers' attitudes toward you as a person with HIV? [RECORD RESPONSE]	No Yes	0 1
614	Have you ever traveled to a clinic or hospital that is far away, instead of going to a nearby clinic/hospital, because of your HIV status?	No Yes	**0➔** 1
615	**[If "yes" to Q614]** Why did you choose to go to a clinic/hospital that is farther away?		

616	Have you ever paid for treatment when it was available for free, because of your HIV status?	No Yes	**0➔** 1
617	Why did you choose to pay rather than seek free treatment?		
618	How would you rate your ability to work? Would you say it is very poor, poor, neither poor nor good, good, or very good?	Very poor Poor Neither poor nor good Good Very good	1 2 3 4 5
619	Has your HIV status affected your ability to work and support yourself and your family?	No Yes Not sure	**0 ➔** 1 **2 ➔**
620	**[If "yes" to Q619]** How has it been affected? [WRITE DOWN ALL EXAMPLES GIVEN➔]		
621	In the last 12 months, did you or your household receive support from any organizations to help you with basic social and economic needs (e.g., food, clothing, school fees)?	No Yes	**0 ➔** 1
622	Which organization(s)? ____________________ [WRITE FACILITY NAME ABOVE AND, TO CODE/CLASSIFY RESPONSE, CHECK ALL THAT APPLY ➔]	Government/local administration department Religious-based organization Other NGO Local/community club/society Private company Other (specify)____________	A B C D E 95
623	In the last 12 months, did you or your household receive support from any organizations to help you with basic medical care needs (e.g., home-based care, palliative care, medicine)?	No Yes Not sure	**0 ➔** 1 2
624	What organization was this? [CHECK ALL THAT APPLY]	Government Religious Based Organization Other NGO Local/community club/society Private company Other (specify) ____________	A B C D E 95
625	Are you a member of any social support group of people living with HIV/AIDS? **[If "yes"]** What group? [RECORD RESPONSE. IF "YES" WRITE DOWN NAME OF GROUP➔]	No Yes ____________________ (Name of PLHA support group)	0 1

626	Are there any major lifestyle or behavior changes you have made because of your HIV status?	No Yes	**0➔** 1
627	What lifestyle changes have you made? [WRITE DOWN ALL EXAMPLES GIVEN➔]		

SECTION 7: TREATMENT

701	**In general, how would you describe your health at the moment?** (Tick one box **only**.)	Excellent Very good Good Fair Poor	1 2 3 4 5
702a.	Are you currently taking antiretroviral treatment? (Tick one box only.)	Yes No	1 2
702b.	Do you have access* to antiretroviral treatment, even if you are not currently taking it? (Tick one box only.) * In this context access means that antiretroviral treatment is available and free or you can afford it.	Yes No Don't know Yes, but difficult	1 2 3 4
703a.	Are you currently taking any medication to prevent or to treat opportunistic infections? (Tick one box only.)	Yes No	1 2
703b.	Do you have access* to medication for opportunistic infections, even if you are not currently taking it? (Tick one box only.) In this context access means that treatment is available and free or you can afford it.	Yes No Don't know	1 2 3
704.	In the last 12 months, have you had a constructive discussion with a health care professional(s) on the subject of your HIV-related treatment options?	Yes No	1 2
705.	In the last 12 months, have you had a constructive discussion with a health care professional(s) on other subjects such as your sexual and reproductive health, sexual relationship(s),emotional well-being, drug use, etc?	Yes all Yes, some of the issues No	1 2 3
706.	Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy? (Tick one box only.)		
		Yes – I have received such treatment No – I did not know that such treatment existed No – I was refused such treatment No – I did not have access to such treatment No – I was not HIV-positive when pregnant Others – Specify	1 2 3 4 5 6

Section 8: Knowledge, Implementation, Use of Policies and Laws

No.	Questions and filters	Coding categories	
801	Do you know of any national policies against HIV stigma and discrimination in India?	No Yes	**0➔** 1
802	What does the policy say? [RECORD RESPONSE CATEGORIES TO CORRESPOND WITH RELEVANT POLICY]		
803	Do you know of any laws against discrimination?	No Yes	**0➔** 1
804	What do the laws say? [RECORD RESPONSE CATEGORIES TO CORRESPOND WITH RELEVANT LAWS]		
805	Do you know of any ways, or organizations, that you can go to for help with if you experience stigma or discrimination?	No Yes	**0➔** 1
806	What ways do you know or what organizations would you go to for help?		
807	In the past 12 months, have you sought help from any organizations to resolve an issue of discrimination?	No Yes	**0➔** 1
808	What happened?		
809	In the past 12 months, have you confronted or challenged someone who was stigmatizing or discriminating against you, or another person?	No Yes	**0➔** 1
810	What did you do or say to this person?		
811	In the past 12 months, have you participated in stigma reduction activities held by a support group?	0. No 1. Yes	**0➔** 1
812	What was your role in this group?		
813	Do you have comments or recommendations regarding HIV/AIDS?		

Section IX: Quality of life

WHOQOL For office use only

	Equations for computing domain scores	Raw score	Transformed scores*
Domain 1	(6-Q3)+(6-Q4)+Q10+Q15+Q16+Q17+Q18	=	
Domain 2	Q5+Q6+Q7+Q11+Q19+(6-Q26)	=	
Domain 3	Q20+Q21+Q22	=	
Domain 4	Q8+Q9+Q12+Q13+Q14+Q23+Q24+Q25	=	

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions**. If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

900

		Not at all	A little	A moderate amount	Very much	An extreme amount
	Do you get the kind of support from others that you need?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	An extreme amount
4 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5
6 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	An extreme amount
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8(F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for every day life?	1	2	3	4	5
11(F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12(F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13(F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14(F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15(F9.1)	How well are you able to get around?	1	2	3	4	5
16(F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17(F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
		Very poor	Poor	Neither poor nor good	Good	Very good
19(F6.3)	How satisfied are you with yourself	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
20 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24 (F19.3)	Ho w satisfied are you with your access to health services?	1	2	3	4	5
25 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26(F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Section X: Depression

(1) मनोदशा (Mood)

0. मैं गमगीन महसूस नहीं करता।
1. मैं उदास या गमगीन महसूस नहीं करता।
2. मैं हरदम उदास या गमगीन महसूस करता हूँ।

3.(A) मैं इतना गमगीन अथवा दुःखी हूँ कि यह बहुत पीड़ादायक है।

3.(B) मैं इतना गमगीन अथवा दुःखी हूँ कि मैं इसे बर्दाशत नहीं कर सकता।

(2) नैराशय (Pessimism)

0. मैं भविष्य के प्रति विशेषतः निराश नहीं हूँ।
1. भविष्य के प्रति मैं निराश महसूस करता हूँ।

2.(A) मैं महसूस करता हूँ कि मेरे भविष्य में कुछ भी नहीं है।

2.(B) मैं महसूस करता हूँ कि मेरी दिक्कत कभी दूर नहीं होगी।

3. मैं महसूस करता हूँ कि भविष्य पूर्णतः निराशाजनक है और स्थितियों में कोई सुधार नहीं हो सकता।

(3) असफलताओं का अहसास (Sense of Failure)

0. मैं ऐसा महसूस नहीं करता कि मैं असफल हूँ।
1. मैं महसूस करता हूँ कि औसत व्यक्ति से अधिक मैं असफल रहा हूँ।

2A. मैं महसूस करता हूँ कि मेरी मूल्यवान उपलब्धि बहुत कम है।

2B. मैं जब अपनी जिन्दगी पर नजर डालता हूँ तो मुझे आवश्यकताओं के अलावा और कुछ नहीं दिखता।

3. मैं महसूस करता हूँ कि मैं (पिता, माता, भाई/बहन के रूप में) पूरी तरह से असफल हूँ।

(4) संतुष्टि का अभाव (Lack of Satisfaction)

0. मैं कोई खास असंतुष्ट नहीं हूं

1A. मैं अधिकांश समय ऊबा हुआ महसूस करता हूँ।

1B. मुझे जैसे पहले जिन्दगी का मजा आता था वैसा अब नहीं आता।

2. मुझे किसी कार्य में कोई भी संतोष नहीं मिला।

3. मैं हर बात से असंतुष्ट हूँ।

(5) अपराध भृति (Guilt Feeling)

0. मैं महसूस नहीं करता हूँ कि मैं विशेष रूप से दोषी हूँ।
1. अधिकांश समय मैं ये महसूस करता हूँ कि मैं बुरा या निरर्थक हूँ।
2A. मैं अपने आप को स्पष्टतः दोषी महसूस करता हूँ।
2B. मैं अब प्रायः हर समय अपने आप को बुरा या निरर्थक महसूस करता हूँ।
3. मैं महसूस करता हूँ कि मानो मैं बहुत बुरा या निरर्थक हो जाउंगा।

(6) सजा की भावना (Sense of Punishment)

0. मैं महसूस नहीं करता कि मुझे सजा दी जा रही है।
1. मैं ऐसा महसूस करता हूँ कि मेरे साथ कुछ न कुछ बुरा होने वाला है।
2. मैं महसूस करता हूँ कि मुझे सजा दी जा रही है या दी जाने वाली है।
3A. मैं महसूस करता हूँ कि मैं सजा के लायक हूँ।
3B. मैं चाहता हूँ कि मुझे सजा मिले।

(7) आत्म घृणा (Self Hate)

0. मैं खुद से निराश महसूस नहीं करता।
1A. मैं अपने आप से निराश हूँ।
1B. मैं खुद को पसंद नहीं करता।
2. मैं अपने आप से ऊब गया हूँ। (Disgusted)
3. मैं खुद से घृणा करता हूँ।

(8) आत्मरोष (Self Accusation)

0. मैं ऐसा महसूस नहीं करता कि मैं किसी दूसरे से खराब हूँ।
1. मैं अपनी कमजोरियों या भूलों का अत्यधिक आलोचक हूँ।
2A. जो कुछ गड़बड़ होता है उस हर बात के लिए मैं अपने आपको दोषी मानता हूँ।
2B. मैं महसूस करता हूँ कि मुझमें अनेक त्रुटियां हैं।

(9) आत्म दण्डात्मक इच्छाएं(Self Punitive wishes)

0. मुझ में खुद को नुकसान पहुंचाने के विचार नहीं आते।
1. खुद को नुकसान पहुंचाने का विचार तो आता है लेकिन उसको मैं पूरा नहीं करूंगा।
2A. मैं महसूस करता हूँ कि मैं मर जाऊं तो बेहतर है।
2B. आत्महत्या करने की मेरी निश्चित योजना है।
2C. मैं महसूस करता हूँ कि मैं मर जाऊंगा तो मेरा परिवार अधिक सुखी रहेगा।
3. यदि कर सका तो मैं आत्महत्या करूंगा।

(10) चिल्लाहट के दौरे (Crying Spells)

0. मैं सामान्य से अधिक नहीं चिल्लाता।
1. मैं अब पहले से अधिक चिल्लाता हूँ।
2. मैं अब हरदम चिल्लाता रहता हूँ और मैं इसे रोक नहीं सकता।
3. मैं पहले चिल्लाया करता था लेकिन अब चाहने पर भी नहीं चिल्ला सकता।

(11) चिड़चिड़ापन (Irritability)

0. अब मैं बिलकुल चिड़चिड़ा नहीं हूँ जैसा कि पहले था।

1. अब मैं पहले की अपेक्षा जल्दी झुंझला जाता हूँ। या चिड़चिड़ा हो जाता हूँ।
2. मैं महसूस करता हूँ कि हरदम चिड़चिड़ा हूँ।
3. जिनसे मुझे चिड़चिड़ाहट होती थी उनसे अब मुझे बिलकुल चिड़चिड़ाहट नहीं होती।

(12) सामाजिक अलगाव (Social Withdrawl)

0. दूसरे लोगों में मेरी रूचि खत्म नहीं हुई है।
1. पहले की अपेक्षा दूसरे लोगों में मेरी रूचि कम है।
2. दूसरे लोगों में मेरी रूचि काफी कम हो गई है और उनसे मेरा कोई खास सरोकार नहीं है।
3. दूसरे लोगों में मेरी सारी रूचि खत्म हो गई है और उनकी मैं कोई परवाह नहीं करता।

(13) अनिर्णयकता (Indecisiveness)

0. मैं पहले जैसा निर्णय करता हूँ।
1. अब मैं अपने बारे में कम आश्वस्त हूँ और निर्णय टालने की कोशिश करता हूँ।
2. अब मैं बिना मदद के निर्णय नहीं कर सकता।
3. जब मैं बिलकुल निर्णय नहीं कर सकता।

(14) शरीर की छवि (Body Image)

0. मेरे ख्याल से मैं पहले की अपेक्षा खराब नहीं लगता।
1. मुझे चिन्ता है कि मैं बूढ़ा या अनाकर्षक लग रहा हूँ।
2. मुझे लगता है कि मेरी शक्ल सूरत में स्थायी परिवर्तन हुए हैं और उनसे मैं अनाकर्षक लगने लगा हूँ।
3. मैं महसूस करता हूँ कि मैं बदसूरत या घृणास्पद हूँ।

(15) कार्य अवरोध (Work Inhibition)

0. पहले जैंसे ही मैं काम करता हूँ।

1A. कुछ काम शुरू करने के लिए अतिरिक्त प्रयत्न करना पड़ता है।

1B. पहले जैसे अब मैं ठीक काम नहीं करता।

2. कुछ करने के लिए मुझे बड़ा जोर लगाना पड़ता है।
3. मैं कुछ भी नहीं कर सकता।

(16) नींद में रूकावट (Sleep Disturbance)

0. मुझे पहले जैसी ही अच्छी नींद आती है।
1. पहले के मुकाबले अब सुबह मैं जब उठता हूँ तब अपने आप को थका हुआ पाता हूँ।
2. पहले के मुकाबले अब मैं एक दो घण्टे पहले उठ जाता हूँ और वापस सोने में दिक्कत होती है।
3. मैं रोज जल्दी उठता हूँ। और पांच घण्टे से अधिक नहीं सो पाता।

(17) थकान (Fatiguability)

0. सामान्य से अधिक मैं नहीं थकता।
1. पहिले के मुकाबले मैं अधिक थक जाता हूँ।
2. कुछ भी करने से मैं थक जाता हूँ।
3. कुछ भी करने से मुझे भारी थकान होती है।

(18) भूख बन्द (Loss of Appetite)

0. मुझे पहले से कम भूख नहीं लगती।
1. पहले जैसी भूख मुझे अब नहीं लगती।
2. अब मेरी भूख बहुत कम हो गई है।
3. अब मुझे कतई भूख नहीं लगती।

(19) वजन में कमी (Weight Loss)

0. इधर मेरा वजन कोई खास कम नहीं हुआ।
1. मेरा वजन दो किलो से अधिक कम हो गया।
2. मेरा वजन चार किलो से अधिक कम हो गया।
3. मेरा वजन छः किलो से अधिक कम हो गया।

(20) शरीर का ख्याल (Somatic Preocupation)

0. सामान्य से अधिक मैं अपने स्वास्थ्य की चिन्ता नहीं करता।
1. दर्द या पेट की गड़बड़ी या कब्जी या शरीर संबंधी अन्य कोई दु:खदायी अनुभूति पर मैं ध्यान देता हूँ।
2. मैं कैसे और क्या महसूस करता हूँ इसकी मुझे इतनी चिन्ता है कि दूसरी बातो का विचार भी मुश्किल से कर पाता हूँ।
3. मैं पूरी तरह इसी में उलझा रहता हू। कि मैं क्या महसूस करता हूँ।

(21) काम वासना की समाप्ति (Loss of Libido)

0. यौन में मेरी रूचि में इधर कोई फर्क नहीं देखा।
1. पहले की अपेक्षा मेरी यौन में कम रूचि है।
2. अब मेरी यौन में बहुत कम रूचि है।
3. यौन में मेरी रूचि पूरी तरह खत्म हो चुकी है।

Thank you for your time

Information Sheet For Community Member Participants

अनुसन्धान में सहभागियों के लिए सूचना पत्र

HIV/AIDS से जुड़ी लांछन एवं भेदभाव की भावना
जिला कांगड़ा, हिमाचल प्रदेश, भारत, 2008 एक पथ प्रदर्शक अध्ययन

मैं डा आर के सूद, स्वास्थ्य विभाग, जिला कांगड़ा, हिमाचल प्रदेश के लिए कार्य कर रहा हूँ। भ्प्ट।प्क्ै से जुड़े हुए कलंक एवं भेदभाव के कारण, इस बीमारी से ग्रस्त लोग, रोकथाम के तरीकों, जाँच एवँ अन्य उपचारों आदि सुविधाओं और सेवाओं से वंचित हैं। हम कोशिश कर रहे हैं कि उन लांछनों एवं भेदभाव की भावनाओं पर एक अध्ययन करें जो कि विभिन्न परिवेशों में जिला कांगड़ा, हि.प्र. में भ्प्ट।प्क्ै से जुड़ी हुई है।

उद्देश्य :
इस अध्ययन का मुख्य उद्देश्य स्वास्थ्य कार्यकर्ताओं, समुदाय एवं एडस् से ग्रसित व्यक्तियों को भ्प्ट।प्क्ै की कितनी जानकारी तथा क्या भावना है, उसका पता लगाना है।
इस अध्ययन से इकट्ठा की गई जानकारी भ्प्ट को फैलने से बचाने के लिए कार्यक्रम बनाने में मदद करेगी।

कार्यप्रक्रिया :
इस अध्ययन के लिए हम आपको प्रश्नों के उत्तर देने के लिए आमंत्रित करते हैं।
मैं आपको साफ साफ समझाता हूँ कि आपको क्या करना है।
अध्ययन में भाग लेने से पहले आप से अनुरोध किया जाएगा कि आप कुछ प्रश्नों के उत्तर दें। आप जैसा सोचते और समझते हैं वैसा ही उत्तर दें।
इस अध्ययन में कोई भी <u>आक्रामक प्रक्रिया</u> या जाँच नहीं की जाएगी। आपका नाम रिकार्ड में कहीं भी लाया नहीं जाएगा तथा सारी जानकारी गोपनीय होगी।

लाभ :
इस अध्ययन से प्राप्त की गई जानकारी ऐसे पैकेज बनाने में मदद करेगी जो कि भ्प्ट।प्क्ै की रोकथाम के लिए वातावरण बनाने में मदद करेंगे।

प्रोत्साहन :
अध्ययन में भाग लेने के लिए आपको किसी प्रकार का प्रोत्साहन नहीं दिया जाएगा।

गोपनीयता :
सारी जानकारी को गोपनीय रखा जाएगा। आपके द्वारा दी गई जानकारी एक ऐसी फाईल में रखी जाएगी जिसमें आपका नाम नहीं होगा।
इस अध्ययन में आप केवल स्वैच्छिक सहमति से भाग लेंगे।

इस अध्ययन प्रस्ताव की राष्ट्रीय ज्ञानपीठ संस्थान चेन्नई–77 की संस्थागत नैतिक कमेटी द्वारा समालोचना एवं स्वीकृति की गई है। यह कमेटी देखती है कि अध्ययन में सहभागियों को किसी प्रकार की हानि न हो।
यदि आप और प्रश्न पूछना चाहते हैं तो आप अभी या फिर बाद में पूछ सकते हैं। यदि आप बाद में प्रश्न पूछना चाहें तो सम्पर्क करें :

नाम डा आर के सूद
पता मुख्य चिकित्सा अधिकारी कारयालय
जिला कांगड़ा, हिमाचल प्रदेश फोन नम्बर 9418064077

समुदाय के सदस्यों के लिए सहमति फार्म

HIV/AIDS से जुड़ी लांछन एवं भेदभाव की भावना

जिला कांगड़ा, हिमाचल प्रदेश, भारत, 2008 एक पथ प्रदर्शक अध्ययन

प्रिय भागीदार (सहभागी),

हम HIV/AIDS से ग्रसित व्यक्तियों द्वारा सही जाने वाली लांछन एवं भेदभाव की भावना से सम्बन्धित एक अध्ययन कर रहे हैं। हम आपसे HIV/AIDS से सम्बन्धित कुछ प्रश्न पूछेंगे तथा यह जानना चाहेंगे कि आप HIV/AIDS से ग्रसित व्यक्तियों के विषय में क्या सोचते हैं।

प्रश्न पूछने में केवल 15 मिनट का समय लगेगा। इस अध्ययन से सरकार को HIV/AIDS से सम्बन्धित आवश्यकताएं जानने में तथा शैक्षणिक कार्यक्रमों को बनाने में सहायता मिलेगी। प्रश्नों का उत्तर देने के लिए आपको आर्थिक सहायता प्रदान नहीं की जाएगी। हम आपकी किसी प्रकार की जांच भी नहीं करेंगे।

आपके द्वारा दिए गए प्रश्नों के उत्तर पूर्ण रूप से गोपनीय रखे जाएंगे एवं किसी भी हालत में उन्हें किसी को नहीं बताया जाएगा। रिपोर्ट में कहीं भी आपके नाम का उल्लेख नहीं किया जाएगा।

यदि आपको कोई प्रश्न असुविधाजनक लगें तो आप उत्तर देने से इन्कार कर सकते हैं। अगर आप जवाब देते देते थक जाएं तो आप मुझे रूकने के लिए कह सकते हैं। आप किसी भी समय बिना कारण बताए मेरे प्रश्नो का उत्तर देने से इन्कार कर सकते हैं।

हमारा आपसे अनुरोध है कि आप इस अध्ययन में सहभागी बनने के लिए स्वैच्छिक सहमति प्रदान करें और कुछ प्रश्नों के उत्तर दें। यदि आप इस अध्यन के विषय में अधिक जानकारी चाहते हैं तो हमें आपके प्रश्नों का उत्तर देने में खुशी होगी। सर्वे के बाद भी यदि आपके मन में कुछ प्रश्न हों तो आप मुझे फोन नम्बर 9418064077 पर सम्पर्क कर सकते हैं।

घोषणा :

यह सहमति फार्म मैंने पूरा पढ़ लिया है/ इस सहमति फार्म में जो भी लिखा है उसे मुझे अपनी भाषा में पूरी तरह पढ़ कर सुनाया गया है। मेरे इस विषय में जो भी आंशकाएं थीं मुझे उनके विषय में पूछने का पूरा मौका दिया गया है और मुझे उनके उत्तरों से पूरी तरह से सन्तुष्ट किया गया है। मैं इस सर्वे में भाग लेने के लिए स्वैच्छिक सहमति प्रदान करता/करती हूँ। और समझता/समझती हूं कि बिना कारण बताए मैं कभी भी अध्ययन से अपना नाम वापिस ले सकता/सकती हूँ।

सहभागी हस्ताक्षर

गवाह हस्ताक्षर

Annex 2.3 : COMMUNITY QUESTIONNAIRE

SECTION 1: Respondent Characteristics

No.	Questions and filters	Coding categories	
102	[RECORD SEX OF RESPONDENT]	Female Male	1 2
103	How old are you? [RECORD AGE OF RESPONDENT]	Age in years Don't know	[__I__] 98
104	Have you ever attended school? If so, what is the highest level of school you attended: Primary, middle, secondary, or higher? ____________________	None Primary Middle High School Graduation University/post secondary tertiary institutions	1 2 3 4 5 6
105	What is your marital status?	Married/cohabiting Divorced Widowed Never married	1 2 3 4
106	What is your employment status? ____________________	Unemployed Petty business Civil servant Businessperson Self-employed Peasant Other (Specify)____________	0 1 2 3 4 5 95
107	What is your religion?	HINDU BUDHISM CHRISTIANITY ISLAM Other (Specify)__ ________	1➔ 2 3 4 95
	[IF THE RESPONSE IS HINDU-ASK WHAT CASTE]	GENERAL SC ST OBC	1 2 3 4
113	Have you ever heard the word stigma?	No Yes	0➔ 1
114	What does this word mean?		

SECTION 2: Knowledge of HIV

[START WITH INTRODUCTION] Now, I would like to talk with you about HIV and AIDS

No.	Questions and filters	Coding categories	
201	Is there a difference between HIV and AIDS?	No Yes Don't know	0→ 1 98→
202	In your opinion, if a mother has HIV, would the virus always be passed on to the baby?	No Yes Sometimes/rarely Don't know Depends__________________	1 2 3 98 90
203	Please tell me all the ways you know of that HIV can be transmitted [CIRCLE ALL THAT APPLY]	Unprotected sex/sex without condom Sharing injections Blood transfusions Mother-to-child transmission Injecting drug use Sex with prostitutes Sex with multiple partners Kissing Mosquito bites Sharing razors/blades Sharing food/drink/eating utensils Sharing toilets Road accidents Sweat Saliva Don't know Other (specify)________________	A B C D E F G H I J K L M N O 98 95
204	How can people protect themselves from getting HIV? [CHECK ALL THAT APPLY]	Abstain from sex Use condoms Be faithful to one uninfected partner Limit number of sexual partners Avoid sex with prostitutes Avoid sex with persons who have sex with many partners Avoid sex with homosexuals Avoid sex with injecting drug users Avoid sharing razors/blades Avoid sharing needles Avoid injections Avoid kissing Avoid mosquito bites Avoid blood transfusions Don't know Other (specify)______________	A B C D E F G H I J K L M N 98 95

204a	Can someone prevent getting HIV by abstaining from sex?	Yes No Don't know	0 1 98
204b	Can someone prevent getting HIV by remaining faithful to a faithful partner?	Yes No Don't know	0 1 98
204c	Can someone prevent getting HIV by always using condoms correctly?	Yes No Don't know	0 1 98
205	Can the virus that causes AIDS be transmitted from a mother to her baby? [IF DEPENDS, ASK "ON WHAT?" AND RECORD ANSWER IN OPEN SPACE]	No Yes Depends__________ Don't know	0→ 1 90→ 98
205a	In your opinion, when can the virus that causes AIDS be transmitted from a mother to her baby? Can the virus be transmitted during— [CIRCLE ALL RESPONSES GIVEN]	During pregnancy................. During delivery.................... During breastfeeding........... Other (specify)___ __________	Yes 1 1 1 1
206	Can a healthy looking person have HIV?	No Yes Don't know Other (specify)__________	0 1 98 95
207	Is there a cure for AIDS?	No Yes Don't know/not sure	0 → 1 98→
207a	If there is a cure, what kind is it? [CHECK ALL THAT APPLY]	A. Modern medicine B. Traditional medicine C. Faith healing/prayer Other (specify)__________	A B C 95
208	Do you know of treatment that can prolong the life of a PERSON LIVING WITH HIV AIDS?	No Yes	0→ 1
208a	If yes, what treatment? [CHECK ALL THAT APPLY]	Treatment for opportunistic infection Faith healing/prayer ARV Good nutrition Other (specify)__________	A B C D E
209	In a married couple, is it possible for one person to have HIV and the other one not to have HIV?	No Yes Don't know	0 1 95
210	Please tell me if you are worried/have fear, or not worried about contracting HIV, in response to the following statements:		
210.1	Being exposed to the saliva of a person with HIV or AIDS	Have fear Do not have fear	1 2
210.2	Being exposed to the excreta of a person with HIV or AIDS	Have fear Do not have fear	1 2

210.3	Being exposed to the sweat of a person with HIV or AIDS	Have fear Do not have fear	1 2
210.4	Your child could become infected with HIV if they play with a child who has HIV or AIDS	Have fear Do not have fear	1 2
210.5	Caring for a person living with HIV or AIDS	Have fear Do not have fear	1 2
211	In a market of several food vendors, would you buy food from a PLHA but not showing signs/symptoms?	No Yes	0→ 1
211b	And what about if they were showing signs/symptoms?	Will still buy Will not buy	1 2

Section 3: Shame and Blame

No.	Questions and filters	Coding categories	
301	Do you agree/disagree with the following statements:		
301.1	It is the women prostitutes that spread HIV in our community	Agree Disagree	1 2
301.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree	1 2
301.3	I would be ashamed if someone in my family had HIV/AIDS	Agree Disagree	1 2
301.4	People with HIV/AIDS are promiscuous	Agree Disagree	1 2
301.5	Promiscuous men are the ones who spread HIV in our community	Agree Disagree	1 2
301.6	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2
301.7	HIV is a punishment from God	Agree Disagree	1 2
301.8	I would feel ashamed if I was infected with HIV	Agree Disagree	1 2
301.9	HIV is a punishment for bad behavior	Agree Disagree	1 2
301.10	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2

Section 4: Enacted Stigma Questions—Primary Stigma

No.	Questions and filters	Coding categories	
401	Do people in your community toward people suspected of having HIV/AIDS or treat PLHA differently?	No Yes Don't know	0 1 98
402	Do you personally know someone who in the last 12 months has had the following happen to them because they were known to have, or suspected of having, HIV or AIDS?		
402.1	Excluded from a social gathering (wedding, funeral, party, community association group)	Yes No	1 0

402.2	Treated differently/shunned at a social gathering	Yes No	1 0
402.3	Abandoned by their spouse/partner	Yes No	1 0
402.4	Abandoned by their family	Yes No	1 0
402.5	Isolated in household e.g., Made to eat alone/Made to use separate eating utensils/Made to sleep alone in own room	Yes No	1 0
402.6	No longer visited, or visited less by family and friends	Yes No	1 0
402.8	Teased, insulted, or sworn at	Yes No	1 0
402.9	Lost customers to buy their produce/goods or lost a job	Yes No	1 0
402.10	Been denied promotion/further training	Yes No	1 0
402.11	Lost housing or not been able to rent housing	Yes No	1 0
402.12	Not allowed/denied religious rites/services (marriage, social functions, cremation, prayers) /Not allowed to go to temple	Yes No	1 0
402.13	Given poorer quality health services, for example: being passed from provider to provider, not given medicines, denied treatment	Yes No	1 0
402.14	Had property (land, household goods, etc) taken away	Yes No	1 0
402.15	Lost respect/standing within the family and/or community	Yes No	1 0
402.16	Gossiped about	Yes No	1 0
402.17	Physically assaulted (i.e., hit, kicked, punched)	Yes No	1 0

SECTION 5: Disclosure

No.	Questions and filters	Coding categories	
501	In your community, in what way do people know if someone has HIV? [CHECK ALL THAT APPLY] What are some other ways?	The infected person discloses his/her status From general rumors/gossip From the HIV+ person's family From the HIV+ person's friends/neighbors From the health center/health worker where the person got tested The person looks ill and has lost a lot of weight Other (specify)________	A B C D E F G
502	Is there anyone who is currently living in this community that you know of who has HIV, but has yet to show signs and symptoms of AIDS?	No Yes	0 1

502a	Which one of the following have been ways through which you got information that someone in your community is infected with HIV? [CIRCLE "YES" OR "NO" FOR EACH ONE]	The infected person told me herself/himself Family member of infected person told me Community member told me General gossip/rumors I heard it at the clinic Other (specify)________________	Yes 1 1 1 1 1 1
503	Would you recommend to a person who is living with HIV, but is not showing signs/symptoms of AIDS, to keep his/her status secret, tell only family members, or share this information with the community?	Tell no one Tell only family Make available to the community Don't know	1 2 3➔ 98➔
503a	If you recommend that HIV-positive status be kept private, why? [CHECK ALL THAT APPLY]	Personal problem People act differently toward a person with HIV Person would be isolated/ neglected/avoided No one would care for person Other (specify) ________________	A B C D E
504	Are there people you personally know who have either disclosed their HIV positive status directly to you or publicly?	No Yes	0➔ 1

Section 6: Knowledge, Implementation, Use of Policies and Laws

No.	Questions and filters	Coding categories	
601	Do you know of any national policies/law against HIV stigma and discrimination?	No Yes	**0➔** 1
602	Describe		

THANK YOU FOR YOUR TIME AND COOPERATION

Annex 2.3 : COMMUNITY QUESTIONNAIRE

Information Sheet For Community Member Participants

अनुसन्धान में सहभागियों के लिए सूचना पत्र

HIV/AIDS से जुड़ी लांछन एवं भेदभाव की भावना
जिला कांगड़ा, हिमाचल प्रदेश, भारत, 2008 एक पथ प्रदर्शक अध्ययन

मैं डा आर के सूद, स्वास्थ्य विभाग, जिला कांगड़ा, हिमाचल प्रदेश के लिए कार्य कर रहा हूँ। भ्प्टध्।प्वै से जुड़े हुए कलंक एवं भेदभाव के कारण, इस बीमारी से ग्रस्त लोग, रोकथाम के तरीकों, जाँच एवँ अन्य उपचारों आदि सुविधाओं और सेवाओं से वंचित हैं। हम कोशिश कर रहे हैं कि उन लांछनों एवं भेदभाव की भावनाओं पर एक अध्ययन करें जो कि विभिन्न परिवेशों में जिला कांगड़ा, हि.प्र. में भ्प्टध्।प्वै से जुड़ी हुई है।

उद्देश्य :
इस अध्ययन का मुख्य उद्देश्य स्वास्थ्य कार्यकर्ताओं, समुदाय एवं एडस् से ग्रसित व्यक्तियों को भ्प्टध्।प्वै की कितनी जानकारी तथा क्या भावना है, उसका पता लगाना है।
इस अध्ययन से इकट्ठा की गई जानकारी भ्प्ट को फैलने से बचाने के लिए कार्यक्रम बनाने में मदद करेगी।

कार्यप्रक्रिया :
इस अध्ययन के लिए हम आपको प्रश्नों के उत्तर देने के लिए आमंत्रित करते हैं।
मैं आपको साफ साफ समझाता हूँ कि आपको क्या करना है।
अध्ययन में भाग लेने से पहले आप से अनुरोध किया जाएगा कि आप कुछ प्रश्नों के उत्तर दें। आप जैसा सोचते और समझते हैं वैसा ही उत्तर दें।
इस अध्ययन में कोई भी आक्रामक प्रक्रिया या जाँच नहीं की जाएगी। आपका नाम रिकार्ड में कहीं भी लाया नहीं जाएगा तथा सारी जानकारी गोपनीय होगी।

लाभ :
इस अध्ययन से प्राप्त की गई जानकारी ऐसे पैकेज बनाने में मदद करेगी जो कि भ्प्टध्।प्वै की रोकथाम के लिए वातावरण बनाने में मदद करेंगे।

प्रोत्साहन :
अध्ययन में भाग लेने के लिए आपको किसी प्रकार का प्रोत्साहन नहीं दिया जाएगा।

गोपनीयता :
सारी जानकारी को गोपनीय रखा जाएगा। आपके द्वारा दी गई जानकारी एक ऐसी फाईल में रखी जाएगी जिसमें आपका नाम नहीं होगा।
इस अध्ययन में आप केवल स्वैच्छिक सहमति से भाग लेंगे।

इस अध्ययन प्रस्ताव की राष्ट्रीय ज्ञानपीठ संस्थान चेन्नई–77 की संस्थागत नैतिक कमेटी द्वारा समालोचना एवं स्वीकृति की गई है। यह कमेटी देखती है कि अध्ययन में सहभागियों को किसी प्रकार की हानि न हो। यदि आप और प्रश्न पूछना चाहते हैं तो आप अभी या फिर बाद में पूछ सकते हैं। यदि आप बाद में प्रश्न पूछना चाहें तो सम्पर्क करें :

नाम डा आर के सूद
पता मुख्य चिकित्सा अधिकारी कारयालय
जिला कांगड़ा, हिमाचल प्रदेश फोन नम्बर 9418064077

समुदाय के सदस्यों के लिए सहमति फार्म

HIV/AIDS से जुड़ी लांछन एवं भेदभाव की भावना

जिला कांगड़ा, हिमाचल प्रदेश, भारत, 2008 एक पथ प्रदर्शक अध्ययन

प्रिय भागीदार (सहभागी),

हम HIV/AIDS से ग्रसित व्यक्तियों द्वारा सही जाने वाली लांछन एवं भेदभाव की भावना से सम्बन्धित एक अध्ययन कर रहे हैं। हम आपसे HIV/AIDS से सम्बन्धित कुछ प्रश्न पूछेंगे तथा यह जानना चाहेंगे कि आप HIV/AIDS से ग्रसित व्यक्तियों के विषय में क्या सोचते हैं।

प्रश्न पूछने में केवल 15 मिनट का समय लगेगा। इस अध्ययन से सरकार को HIV/AIDS से सम्बन्धित आवश्यकताएं जानने में तथा शैक्षणिक कार्यक्रमों को बनाने में सहायता मिलेगी। प्रश्नों का उत्तर देने के लिए आपको आर्थिक सहायता प्रदान नहीं की जाएगी। हम आपकी किसी प्रकार की जांच भी नहीं करेंगे।

आपके द्वारा दिए गए प्रश्नों के उत्तर पूर्ण रूप से गोपनीय रखे जाएंगे एवं किसी भी हालत में उन्हें किसी को नहीं बताया जाएगा। रिपोर्ट में कहीं भी आपके नाम का उल्लेख नहीं किया जाएगा।

यदि आपको कोई प्रश्न असुविधाजनक लगें तो आप उत्तर देने से इन्कार कर सकते हैं। अगर आप जवाब देते देते थक जाएं तो आप मुझे रूकने के लिए कह सकते हैं। आप किसी भी समय बिना कारण बताए मेरे प्रश्नो का उत्तर देने से इन्कार कर सकते हैं।

हमारा आपसे अनुरोध है कि आप इस अध्ययन में सहभागी बनने के लिए स्वैच्छिक सहमति प्रदान करें और कुछ प्रश्नों के उत्तर दें। यदि आप इस अध्यन के विषय में अधिक जानकारी चाहते हैं तो हमें आपके प्रश्नों का उत्तर देने में खुशी होगी। सर्वे के बाद भी यदि आपके मन में कुछ प्रश्न हों तो आप मुझे फोन नम्बर 9418064077 पर सम्पर्क कर सकते हैं।

घोषणा :

यह सहमति फार्म मैंने पूरा पढ़ लिया है/ इस सहमति फार्म में जो भी लिखा है उसे मुझे अपनी भाषा में पूरी तरह पढ़ कर सुनाया गया है। मेरे इस विषय में जो भी आंशकाएं थीं मुझे उनके विषय में पूछने का पूरा मौका दिया गया है और मुझे उनके उत्तरों से पूरी तरह से सन्तुष्ट किया गया है। मैं इस सर्वे में भाग लेने के लिए स्वैच्छिक सहमति प्रदान करता/करती हूँ। और समझता/समझती हूं कि बिना कारण बताए मैं कभी भी अध्ययन से अपना नाम वापिस ले सकता/सकती हूँ।

सहभागी हस्ताक्षर

गवाह हस्ताक्षर

COMMUNITY QUESTIONNAIRE

SECTION 1: Respondent Characteristics

No.	Questions and filters	Coding categories	
102	[RECORD SEX OF RESPONDENT]	Female Male	1 2
103	How old are you? [RECORD AGE OF RESPONDENT]	Age in years Don't know	[__|__] 98
104	Have you ever attended school? If so, what is the highest level of school you attended: Primary, middle, secondary, or higher? ______________________	None Primary Middle High School Graduation University/post secondary tertiary institutions	1 2 3 4 5 6
105	What is your marital status?	Married/cohabiting Divorced Widowed Never married	1 2 3 4
106	What is your employment status? ______________________	Unemployed Petty business Civil servant Businessperson Self-employed Peasant Other (Specify)____________	0 1 2 3 4 5 95
107	What is your religion?	HINDU BUDHISM CHRISTIANITY ISLAM Other (Specify)__ ________	1➔ 2 3 4 95
	[IF THE RESPONSE IS HINDU-ASK WHAT CASTE]	GENERAL SC ST OBC	1 2 3 4
113	Have you ever heard the word stigma?	No Yes	0➔ 1
114	What does this word mean?		

SECTION 2: Knowledge of HIV

[START WITH INTRODUCTION] Now, I would like to talk with you about HIV and AIDS

No.	Questions and filters	Coding categories	
201	Is there a difference between HIV and AIDS?	No	0➔
		Yes	1
		Don't know	98➔
202	In your opinion, if a mother has HIV, would the virus always be passed on to the baby?	No	1
		Yes	2
		Sometimes/rarely	3
		Don't know	98
		Depends________________	90
203	Please tell me all the ways you know of that HIV can be transmitted [CIRCLE ALL THAT APPLY]	Unprotected sex/sex without condom	A
		Sharing injections	B
		Blood transfusions	C
		Mother-to-child transmission	D
		Injecting drug use	E
		Sex with prostitutes	F
		Sex with multiple partners	G
		Kissing	H
		Mosquito bites	I
		Sharing razors/blades	J
		Sharing food/drink/eating utensils	K
		Sharing toilets	L
		Road accidents	M
		Sweat	N
		Saliva	O
		Don't know	98
		Other (specify)________________	95
204	How can people protect themselves from getting HIV? [CHECK ALL THAT APPLY]	Abstain from sex	A
		Use condoms	B
		Be faithful to one uninfected partner	C
		Limit number of sexual partners	D
		Avoid sex with prostitutes	E
		Avoid sex with persons who have sex with many partners	F
		Avoid sex with homosexuals	G
		Avoid sex with injecting drug users	H
		Avoid sharing razors/blades	I
		Avoid sharing needles	J
		Avoid injections	K
		Avoid kissing	L
		Avoid mosquito bites	M
		Avoid blood transfusions	N
		Don't know	98
		Other (specify)______________	95

204a	Can someone prevent getting HIV by abstaining from sex?	Yes No Don't know	0 1 98
204b	Can someone prevent getting HIV by remaining faithful to a faithful partner?	Yes No Don't know	0 1 98
204c	Can someone prevent getting HIV by always using condoms correctly?	Yes No Don't know	0 1 98
205	Can the virus that causes AIDS be transmitted from a mother to her baby? [IF DEPENDS, ASK "ON WHAT?" AND RECORD ANSWER IN OPEN SPACE]	No Yes Depends____________________ Don't know	0→ 1 90→ 98
205a	In your opinion, when can the virus that causes AIDS be transmitted from a mother to her baby? Can the virus be transmitted during— [CIRCLE ALL RESPONSES GIVEN]	During pregnancy................. During delivery.................... During breastfeeding........... Other (specify)___ ____________	Yes 1 1 1 1
206	Can a healthy looking person have HIV?	No Yes Don't know Other (specify)________________	0 1 98 95
207	Is there a cure for AIDS?	No Yes Don't know/not sure	0 → 1 98→
207a	If there is a cure, what kind is it? [CHECK ALL THAT APPLY]	A. Modern medicine B. Traditional medicine C. Faith healing/prayer Other (specify)________________	A B C 95
208	Do you know of treatment that can prolong the life of a PERSON LIVING WITH HIV AIDS?	No Yes	0→ 1
208a	If yes, what treatment? [CHECK ALL THAT APPLY]	Treatment for opportunistic infection Faith healing/prayer ARV Good nutrition Other (specify)____________________	A B C D E
209	In a married couple, is it possible for one person to have HIV and the other one not to have HIV?	No Yes Don't know	0 1 95
210	Please tell me if you are worried/have fear, or not worried about contracting HIV, in response to the following statements:		
210.1	Being exposed to the saliva of a person with HIV or AIDS	Have fear Do not have fear	1 2
210.2	Being exposed to the excreta of a person with HIV or AIDS	Have fear Do not have fear	1 2

210.3	Being exposed to the sweat of a person with HIV or AIDS	Have fear Do not have fear	1 2
210.4	Your child could become infected with HIV if they play with a child who has HIV or AIDS	Have fear Do not have fear	1 2
210.5	Caring for a person living with HIV or AIDS	Have fear Do not have fear	1 2
211	In a market of several food vendors, would you buy food from a PLHA but not showing signs/symptoms?	No Yes	0➔ 1
211b	And what about if they were showing signs/symptoms?	Will still buy Will not buy	1 2

Section 3: Shame and Blame

No.	Questions and filters	Coding categories	
301	Do you agree/disagree with the following statements:		
301.1	It is the women prostitutes that spread HIV in our community	Agree Disagree	1 2
301.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree	1 2
301.3	I would be ashamed if someone in my family had HIV/AIDS	Agree Disagree	1 2
301.4	People with HIV/AIDS are promiscuous	Agree Disagree	1 2
301.5	Promiscuous men are the ones who spread HIV in our community	Agree Disagree	1 2
301.6	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2
301.7	HIV is a punishment from God	Agree Disagree	1 2
301.8	I would feel ashamed if I was infected with HIV	Agree Disagree	1 2
301.9	HIV is a punishment for bad behavior	Agree Disagree	1 2
301.10	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2

Section 4: Enacted Stigma Questions—Primary Stigma

No.	Questions and filters	Coding categories	
401	Do people in your community toward people suspected of having HIV/AIDS or treat PLHA differently?	No Yes Don't know	0 1 98
402	Do you personally know someone who in the last 12 months has had the following happen to them because they were known to have, or suspected of having, HIV or AIDS?		
402.1	Excluded from a social gathering (wedding, funeral, party, community association group)	Yes No	1 0

402.2	Treated differently/shunned at a social gathering	Yes No	1 0
402.3	Abandoned by their spouse/partner	Yes No	1 0
402.4	Abandoned by their family	Yes No	1 0
402.5	Isolated in household e.g., Made to eat alone/Made to use separate eating utensils/Made to sleep alone in own room	Yes No	1 0
402.6	No longer visited, or visited less by family and friends	Yes No	1 0
402.8	Teased, insulted, or sworn at	Yes No	1 0
402.9	Lost customers to buy their produce/goods or lost a job	Yes No	1 0
402.10	Been denied promotion/further training	Yes No	1 0
402.11	Lost housing or not been able to rent housing	Yes No	1 0
402.12	Not allowed/denied religious rites/services (marriage, social functions, cremation, prayers) /Not allowed to go to temple	Yes No	1 0
402.13	Given poorer quality health services, for example: being passed from provider to provider, not given medicines, denied treatment	Yes No	1 0
402.14	Had property (land, household goods, etc) taken away	Yes No	1 0
402.15	Lost respect/standing within the family and/or community	Yes No	1 0
402.16	Gossiped about	Yes No	1 0
402.17	Physically assaulted (i.e., hit, kicked, punched)	Yes No	1 0

SECTION 5: Disclosure

No.	Questions and filters	Coding categories	
501	In your community, in what way do people know if someone has HIV? [CHECK ALL THAT APPLY] What are some other ways?	The infected person discloses his/her status From general rumors/gossip From the HIV+ person's family From the HIV+ person's friends/neighbors From the health center/health worker where the person got tested The person looks ill and has lost a lot of weight Other (specify)________	A B C D E F G
502	Is there anyone who is currently living in this community that you know of who has HIV, but has yet to show signs and symptoms of AIDS?	No Yes	0 1

502a	Which one of the following have been ways through which you got information that someone in your community is infected with HIV? [CIRCLE "YES" OR "NO" FOR EACH ONE]	The infected person told me herself/himself Family member of infected person told me Community member told me General gossip/rumors I heard it at the clinic Other (specify)________________	Yes 1 1 1 1 1 1
503	Would you recommend to a person who is living with HIV, but is not showing signs/symptoms of AIDS, to keep his/her status secret, tell only family members, or share this information with the community?	Tell no one Tell only family Make available to the community Don't know	1 2 3→ 98→
503a	If you recommend that HIV-positive status be kept private, why? [CHECK ALL THAT APPLY]	Personal problem People act differently toward a person with HIV Person would be isolated/ neglected/avoided No one would care for person Other (specify) ______________	A B C D E
504	Are there people you personally know who have either disclosed their HIV positive status directly to you or publicly?	No Yes	0→ 1

Section 6: Knowledge, Implementation, Use of Policies and Laws

No.	Questions and filters	Coding categories	
601	Do you know of any national policies/law against HIV stigma and discrimination?	No Yes	**0→** 1
602	Describe		

THANK YOU FOR YOUR TIME AND COOPERATION

Annex 2.4 Health care Providers Questionnaire

Information Sheet for Service Providers Participants In The Research On

Stigma and Discrimination associated with HIV/AIDS - A pilot study in District Kangra, Himachal Pradesh, India, 2008

I am Dr Rajesh Kumar Sood, Working for the HP health services presently doing my epidemiology course from NIE Chennai and posted at IDSP cell, O/O CMO Kangra at Dharamshala.

Stigma associated with HIV /AIDS is barrier to increasing access to services related to HIV AIDS prevention, testing and access to anti retro viral therapy. We are trying to study the problem of stigma, discrimination in various settings associated with HIV/AIDS in District Kangra, Himachal Pradesh.

Purpose:

The purpose of the study is to examine knowledge, perceptions of health care staff, RISK OF CONTACTING HIV AIDS DURING OCCUPATIONAL CONTACT WITH PATIENTS, community and People living with HIV/AIDS towards HIV AIDS.

The information generated through the study will assist in planning suitable interventions to reduce the transmission and impact of HIV epidemic in the area.

Procedures:

The self-administered questionnaire is attached. You are required to reply as you feel and think about the issue and as what you think should be ideal practice. SIGN ON PAGE B; AND THEN CIRCLE THE NUMBER CORRESPONDING TO THE ANSWER YOU FEEL CORRECT.

example for the first question - If you are male circle 2, if female circle 1

101	Sex of the respondent	Female Male	1 (2)	

Your name will not be mentioned on records/report and all information will be treated as confidential.

Benefits:

The information generated through the study will serve as **training needs assessment** and assist the HPSACS in planning suitable interventions to create an enabling environment to further improve the services for HIV/AIDS prevention and treatment.

Incentives:

You will not be provided with any incentive to take part in the research.

Confidentiality:

The information that we collect from this research project will be kept confidential.

Whom to contact for further information:

This proposal has been reviewed and approved by the Institutional Ethics Committee of National Institute of Epidemiology (NIE), Chennai which is a committee that makes it sure that research participants are protected from harm. If you have questions, you may contact: Principal Investigator: Dr Rajesh Kumar Sood, Medical Officer FETP, IDSP Cell, O/O CMO Kangra at Dharamshala, **Phone 9418064077**

Consent form for service providers

Stigma and Discrimination associated with HIV/AIDS - A pilot study in District Kangra, Himachal Pradesh, India, 2008

Dear Participant,

We are carrying out a study to Stigma and Discrimination faced by people living with HIV/AIDS. We will ask a few questions regarding HIV/AIDS, RISK OF CONTACTING HIV AIDS DURING OCCUPATIONAL CONTACT WITH PATIENTS and what you feel about those who are HIV positive/ AIDS patients.

It will take a total of 15 minutes before we finish asking you questions. This study will benefit in terms of a needs assessment for the government, to design appropriate educational and training programmes. There is no special financial benefit for you for answering my questions.

All your answers to our questions will be kept secret and will not be told to anyone at any cost. Your name will not be used in any report of the survey.

We request you to give your voluntary consent for participation in the study and answer a few questions. If you wish to know more about this survey, we will be happy to answer any question or doubt you may have. If you have any questions at a later stage, you may contact me on my phone number 9418064077.

DECLARATION:

"I have read the contents of this consent form/ the contents of this consent form have been read out to me in the language I fully understand. I have had the opportunity to ask questions about it and any questions I asked have been answered to my satisfaction. I consent voluntarily to take part in this survey and understand that I have the right to withdraw from the investigation at any time without giving any reasons."

Witness Sign
(Participant)

Sign

NAME IN CAPITAL
DESIGNATION
Place of posting

HEALTH CARE PROVIDER QUESTIONNAIRE

KINDLY **CIRCLE** THE NUMBER IN FRONT OF THE ANSWER YOU FEEL IS CORRECT

SECTION 1: HP-level: Respondent and Household Characteristics

No.	Questions	Coding categories	
101	Sex of the respondent	Female Male	1 2
102	How old are you?	Age in years	☐☐
103	What is your marital status?	Married/cohabiting Divorced Widowed Never married/single	1 2 3 4
104	What is your religion?	HINDU BUDHISM CHRISTIANITY ISLAM Other (Specify)__ ________	1 2 3 4 9 5
105	[IF THE RESPONSE IS HINDU-WHAT CASTE]	GENERAL SC ST OBC	1 2 3 4
106	Type of health facility	Medical College (Specify specialty) ____________________ Zonal Hospital Civil/ sub Divisional Hospital Community Health Center Primary Health Center Ayurvedic (Indian System Med) hospital Private Hospital ________________ Army Hospital	1 2 3 4 5 6 7 8
107	What level of pre-service training did you complete?	Post graduate Degree/ Diploma Graduate Degree (MBBS/ BAMS) Diploma/ for example Nursing Other-----------------(specify)	1 2 3 4
108	Please tell me about your work here at this facility. What is your designation?	Medical specialist Specify_________ Medical Officer/ General Duty Officer (GDO)/ Ward sister Nurse	1 2 3 4
109	How long have you been working in job/ private practice?	YEARS----------- MONTHS......... Y ☐☐	☐
110	Have you received any in-service training specifically on HIV and AIDS?	No Yes	0 1

111	Please tell me about that training.	When? How long? Where? ____________	

SECTION 2: HP-level: In-Depth Knowledge of HIV and AIDS

No.	Questions	Coding categories	
201	Can the HIV virus live in the open air (outside the human body)?	Yes No Depends Don't know Other	1 0 90 98 95
202	It is required to wear latex gloves whenever performing ANY task related to examining a patient who may be HIV positive.	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
203	The risk of HIV transmission following needle prick or sharps injuries is **small**, approximately 1 in 300.	True False Don't know	1 0 98
204	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.	True False Don't know	1 0 98
205	Standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient. NO EXTRA STERLIZATION NEEDED FOR INSTRUMENTS USED ON HIV POSITIVE	True False Don't know	1 0 98
206	To prevent transmission of HIV and other blood-borne infections in the health care setting, staff should wear latex gloves for every client contact for any procedure**, including taking vital signs.**	True False Don't know	1 0 98
207	Which body fluids have high enough concentrations of HIV to transmit the virus? [CIRCLE ALL RESPONSES- MORE THAN ONE CAN BE CORRECT]	Semen Blood Vaginal fluid Breast milk Other bodily fluids containing blood Saliva Sweat Tears Don't know Other specify_____	A B C D E F G H 98 95

208	Which body fluids do NOT have high enough concentrations of HIV to transmit the virus? [CIRCLE ALL RESPONSES- MORE THAN ONE CAN BE CORRECT]	Semen Blood Vaginal fluid Breast milk Other bodily fluids containing blood Saliva Sweat Tears Don't know Other (specify)____	A B C D E F G H 98 95

SECTION 3A: Health Provider -level: Fear of Casual Transmission of HIV and Refusal of Contact with People Living with HIV /AIDS PLHA

No.	Questions	Coding categories	
301	In response to the following situations, please tell me if you have fear of HIV transmission, do not have fear of HIV transmission to yourself, or don't know/not sure:		
301.1	Giving an injection to a person with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.2	Assisting the delivery of a woman with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.3	Dressing the wounds of a person living with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.4	Conducting surgery on or suturing a person with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.5	Putting a drip in person with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.6	Touching the sweat of a person with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.7	Touching the saliva of a person with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.8	Drawing blood of a person with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3
301.9	Caring for a person living with HIV or AIDS	Have fear of infection to self Do not have fear Don't know/ not sure	1 2 3

302	In response to the following situations, please tell me if you strongly agree, agree, disagree, or strongly disagree.		
302.1	I am comfortable assisting or being assisted by a colleague who is HIV infected	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
302.2	I am comfortable performing surgical or invasive procedure on clients whose HIV status is unknown	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
302.3	I am comfortable providing health services to clients who are HIV-positive	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
302.4	I am comfortable sharing a bathroom with a colleague who is HIV infected	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
302.5	Most frequent mode of contracting HIV among health workers is through work-related exposure	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
302.6	Most HIV-positive health care workers get infected at work	Strongly agree Agree Disagree Strongly disagree	1 2 3 4

SECTION 3B: HP-level: Attitudes towards practices in health care settings

For the following statements, kindly tick if you agree or disagree

303	Patients should be tested for HIV before surgery	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
304	All pregnant women should be tested for HIV	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
305	The need for consent is exaggerated. HIV tests should be handled like any other test	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
306	Patients blood should never be tested for HIV without their consent	Strongly agree Agree Disagree Strongly disagree	1 2 3 4

307	Patients who test positive have the right to decide if or not their relatives should be informed	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
308	When a patient tests positive, the doctor should inform the patient's partner	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
309	Patients with HIV should be kept at a distance from other patients	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
310	Clothes and linen used by HIV positive patients should be disposed off or burned	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
311	HIV infected patients should be made to pay for health staff's use of additional infection control supplies- gloves etc	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
312	People living with HIV should have a right to decide who should know their results	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
313	People with HIV should be allowed to get married	Strongly agree Agree Disagree Strongly disagree	1 2 3 4
314	HIV positive women should not get pregnant	Strongly agree Agree Disagree Strongly disagree	1 2 3 4

401	Do you agree or disagree with the following statements?		
401.1	It is the prostitutes that spread HIV in our community	Agree Disagree	1 2
401.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree Depends	1 2 3
401.3	I would feel ashamed if someone in my family had HIV/AIDS	Agree Disagree Depends	1 2 3
401.4	Promiscuous (having multiple partners) men are the ones who spread HIV in our community	Agree Disagree	1 2
401.5	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2

401.6	HIV is a punishment from God	Agree Disagree	1 2
401.7	I would feel ashamed if I was infected with HIV	Agree Disagree Depends	1 2 3
401.8	HIV is a punishment for bad behavior	Agree Disagree	1 2
401.9	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2

SECTION 5: HP-level: Enacted Stigma

No.	Questions	Coding categories	
501	**In the past 12 months, have you seen or observed the following happen in this health care facility because a client was known or suspected of having HIV/AIDS?**		
501.1	Testing a client for HIV without their consent/ informing	Yes No	1 2
501.2	Requiring some clients to be tested for HIV before scheduling surgery	Yes No	1 2
501.3	Using latex gloves for performing noninvasive examination on clients suspected of HIV.	Yes No	1 2
501.4	Extra precautions being taken in the sterilization of instruments used on HIV-positive patients.	Yes No	1 2
501.5	Health providers share status of patient with staff members (tell other staff that XX patient is HIV positive)	Yes No	1 2
501.6	Because a patient is HIV-positive a senior health provider pushing the client to a junior provider	Yes No	1 2
501.7	HIV positive patients Receiving less care/attention than other patients	Yes No	1 2
501.8	To protect themselves from HIV infection, avoid going near HIV infected patients	Yes No	1 2
501.9	To protect themselves from HIV infection, avoid touching HIV infected patients	Yes No	1 2
501.10	Inform family members about the HIV positive result	Yes No	1 2
501.11	Did not obtain consent of patients before informing family	Yes No	1 2
501.12	Always use gloves to examine patient/ give food or medicines for HIV positive patients and not for HIV negative patients	Yes No	1 2
501.13	Mark the file of HIV positive with red ink as HIV positive	Yes No	1 2
501.14	Don't keep HIV positive patient. We refer the patient	Yes No	1 2

SECTION 5: HP-level: Enacted Stigma

No.	Questions	Coding categories	
503	Have you ever heard the word stigma/ discrimination? कलंक एवं भेदभाव	No Yes	0→ 1
502	Where does Stigma wrt HIV /AIDS occur? कलंक एवं भेदभाव [CIRCLE ALL RESPONSES- MORE THAN ONE CAN BE CORRECT]	Health facilities Household/family Community Workplace Places of worship Others (specify)_______________	A B C D E 95
504	Does HIV stigma occur in health facilities कलंक एवं भेदभाव	No Yes Not sure Don't know	0→ 1 2→ 98→
505	Please give me some examples of HIV related stigma in the health facilities. कलंक एवं भेदभाव		
506	Does HIV related stigma occur outside health facilities (Family/ community etc) कलंक एवं भेदभाव	No Yes Not sure Don't know	0→ 1 2→ 98→
507	Please give me some examples of HIV related stigma that occur outside health facilities. कलंक एवं भेदभाव		
508	If you ever saw any of the above (types of enacted stigma) happening to a client because s/he is HIV positive, would you be willing to report to higher authority?	Yes No Depends Don't know	0 1 95 98

SECTION 6: HP-level: Disclosure

No.	Questions	Coding categories	
601	If a person learns that he/she is HIV positive, but is not yet showing signs and symptoms of AIDS, should this fact remain a personal secret, a family secret, or should it be known to the community?	Be kept a personal secret Be kept a family secret Should be known to the community Don't know Other (specify)_______________	1→ 2→ 3→ 98→ 95→
601.a	If it should be kept a personal secret, why? [CIRCLE ALL THAT APPLY]	It is a personal/private issue Person would be treated differently Person would be isolated/neglected/avoided Other (specify) _______________	A B C 95

601.b	If it should be known to the family, why? [CIRCLE ALL THAT APPLY]	S/He would not threat/infect others S/He needs to be isolated S/He should get care and support of the family S/He to encourage others to protect themselves Other (specify) ____________	A B C D 95
601.b	If it should be known to the community, why? [CIRCLE ALL THAT APPLY]	S/He would not threat/infect others S/He needs to be isolated S/He should get care and support of the community S/He to encourage others to protect themselves Other (specify) ____________	A B C D 95
602	Is there anyone you know who has HIV, but has yet to show signs and symptoms of AIDS? HAVE YOU SEEN OR HEARD ABOUT A HIV POSITIVE PATIENT IN YOUR HOSPITAL?	Yes No	0 1

602a	How did you find out that he/she is infected with HIV?		NO	YES
		The infected person told me her/himself	0	1
		Family member of infected person told me	0	1
		Community member told me	0	1
		General gossip/rumors	0	1
		From other health care provider	0	1
		Read from his/her hospital file	0	1
		Other (specify)__________	0	1

603	Are there people you personally know, but not as a patient, that have disclosed their HIV-positive status directly to you?	Yes No	0 1

SECTION 7: Awareness of Laws and Policies to Protect PLHA from Stigma & Discrimination

No.	Questions	Coding categories	
701	Should the health facility have a policy to protect HIV positive patients from discrimination by protecting patients' rights and providing recourse?	Yes No	1 2
702	Are you aware of any policies to protect People living with HIV /AIDS at your health facility?	Yes No	1 2
702A	If yes, kindly specify what is the policy for protecting People living with HIV /AIDS from discrimination		
702a	Are these policies enforced?	Yes No Don't know	0 1 98
750	Are you aware that if accidental exposure to HIV, occurs to health staff, medicine (post exposure prophylaxis- PEP) is provided to health care staff?	Yes No	0 1
750A	If yes, where is PEP Available		
799	Any other comments		

THANK YOU FOR YOUR TIME AND CO-OPERATION

Annex 2.5: **Indicators**

A. PLHIV level

1. Knowledge.

   Proportions of subjects having comprehensive knowledge of HIV/ AIDS

2. Self Stigma

   Proportion of subjects experiencing self stigma in last 12 months

3. Enacted Stigma.

   Proportion of subjects experiencing enacted stigma

   - Proportion who have been socially isolated
   - proportion physically isolated
   - proportion experienced verbal stigma
   - proportion experienced negative effect on identity
   - proportion lost access to resources

4. Hospital associated stigma

   - Proportion of subjects experiencing stigma from health care providers

5. Disclosure:

   - Proportion who disclosed HIV status
   - Proportion whose HIV status was disclosed without their consent
   - Proportion of subjects experiencing supportive reactions to disclosure.
   - Proportion receiving support for stigma and discrimination.
   - Proportion challenging someone stigmatizing respondent

B. **Community Level**

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

- There is difference in HIV AIDS
- Knowledge that AIDS can be prevented by condoms
- If the mother has HIV, can the virus be passed to the child
- Knowledge that being faithful to one unifected partner can protect from HIV
- Reject the misconceptions that HIV/AIDS is transmitted through mosquito bite
- Reject the misconceptions that HIV/AIDS is transmitted through sharing food/ utensils
- Comprehensive Knowledge (all of the above)

2. Community-level: Percentage of people expressing fear of contracting HIV

- from non-invasive contact with PLHA.
- Fearful of being infected is exposed to saliva of PLHIV
- Fearful of being infected is exposed to sweat of PLHIV
- Fearful of being infected is exposed to excreta of PLHIV
- Fear that his/her child could become infected by playing with child who has HIV/AIDS
- In market of several vendors Percentage of people who NOT would buy food from PLHIV
- Any of the above (Fear)

3. Community-level: Shame, blame, judgment (Stigmatising attitudes): Percent of people who would feel shame if they associated with a person living with HIV/AIDS

- Percentage of people who judge or blame PLHA for their illness,

- Percentage of people who would feel shame if they associated with a PLHA

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

   Percentage of people who personally know someone who has experienced any form of stigma in the past 1 year because they were known to, or suspected of having, HIV or AIDS;

   - Isolation,
   - Verbal Stigma,
   - loss of identity,
   - Loss of access to resources/ livelihoods

5. Disclosure:

   - Proportion of people who think a person should be able to keep their HIV status private, percentage of people who would want a family member's HIV-positive status to be kept secret, and proportion calling for public disclosure.

C. Health care Provider level

Knowledge

- Proportion of service providers trained
- Proportion with correct/ indepth knowledge
- Proportion who reject common misconceptions on transmission
- Proportion of heath care providers aware of post exposure prophylaxis.

Provider-level: Proportion of doctors, nurses report fear of risk of contacting HIV

- o (a) providing medical care on patients with HIV/AIDS
- o (b) casual contact with PLHA.

Percent of people working in institutions/facilities (e.g., doctors, nurses) who:

- o (a) were uncomfortable working with or treating PLHA,

- (b) perceive work-related HIV exposure to be high,
- (c) report negative attitudes toward PLHA,

Provider-level: Values, shame, and blame:

Percent of people working in institutions/facilities (e.g., doctors, nurses) who report:

- negative attitudes/judgment of PLHA,
- negative attitudes/blame toward PLHA,
- negative attitudes/shame toward PLHA.

Provider-level: Enacted Stigma

Percent of doctors, nurses who personally know patients who were in the past 12 months because they were known or suspected to have HIV/AIDS:

- neglected,
- treated differently,
- denied care,
- verbally abused, or
- tested for HIV/sero-status disclosed without consent

Provider-level: Disclosure:

- Percent of people who think a person should be able to keep their HIV status private.

Attitudes towards PLHIV were measured through a summary stigma score: (Annex 2.8)

Annex 2.6: Scoring the Beck Depression Inventory

After the patient has completed the test, add up the score for each of the 21 questions and obtain the total score. The highest score for each of the twenty-one questions is three, the highest possible total for the whole test would be

sixty-three if the patient marked number 3 on all the questions. The lowest score for each question is zero, so the lowest possible score for the test would be zero if the patient marked zero on each question. The following chart indicates the relationship between total score and level of depression.

Clasification	**Total Score**	**Level of Depression**
Low	1-10	These ups and downs are considered normal
	11-16	Mild mood disturbance
Moderate	17-20	Borderline clinical depression
	21-30	Moderate depression
Significant	31-40	Severe depression
	Over 40	Extreme depression

A persistent score of 17 or above indicates you may need professional treatment.

Annex 2.7: Quality of life and Method for converting raw scores to transformed scores WHO QOL BREF WHO/MSA/MNH/PSF/97.4

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). There are also two items that were examined separately: one which asked about the individual's overall perception of QOL and the other which asked about the individual's overall perception of his or her health. Domain scores are scaled in a positive direction (Higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain scores compatible with the scores used in WHOQOL-100 and subsequently transformed to a 0-100 scale using the following formulas:

DOMAIN 1		
Raw Score	Transformed scores	
	4-20	0-100
7	4	0
8	5	6
9	5	6
10	6	13
11	6	13
12	7	19
13	7	19
14	8	25
15	9	31
16	9	31
17	10	38
18	10	38
19	11	44
20	11	44
21	12	50
22	13	56
23	13	56
24	14	63
25	14	63
26	15	69
27	15	69
28	16	75
29	17	81
30	17	81
32	18	88
33	19	94
34	19	94
35	20	100

DOMAIN 2		
Raw Score	Transformed scores	
	4-20	0-100
6	4	0
7	5	6
8	5	6
9	6	13
10	7	19
11	7	19
12	8	25
13	9	31
14	9	31
15	10	38
16	11	44
17	11	44
18	12	50
19	13	56
20	13	56
21	14	63
22	15	69
23	15	69
24	16	75
25	17	81
26	17	81
27	18	88
28	19	94
29	19	94
30	20	100

DOMAIN 3		
Raw Score	Transformed scores	
	4-20	0-100
3	4	0
4	5	6
5	7	19
6	8	25
7	9	31
8	11	44
9	12	50
10	13	56
11	15	69
12	16	75
13	17	81
14	19	94
15	20	100

DOMAIN 4		
Raw Score	Transformed scores	
	4-20	0-100
8	4	0
9	5	6
10	5	6
11	6	13
12	6	13
13	7	19
14	7	19
15	8	25
16	8	25
17	9	31
18	9	31
19	10	38
20	10	38
21	11	44
22	11	44
23	12	50
24	12	50
25	13	56
26	13	56
27	14	63
28	14	63
29	15	69
30	15	69
31	16	75
32	16	75
33	17	81
34	17	81
35	18	88
36	18	88
37	19	94
38	19	94
39	20	100
40	20	100

Reverse 3 negatively phrased items (Q3 Q4 Q26)

Programme on mental health, world health organization geneva WHOQOL-BREF introduction, administration, scoring and generic version of the assessment. December 1996

Annex 2.8: Definitions of terms used

Person Living with HIV/AIDS (**PLHIV**) is a person who has been tested HIV positive

Stigma: Stigma has been described as a dynamic process of devaluation that 'significantly discredits' an individual in the eyes of others. HIV-related stigma refers to all unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities. Patterns of prejudice, which include devaluing, discounting, discrediting, and discriminating against these groups of people, play into and strengthen existing social inequalities--especially those of gender, sexuality, and race--that are at the root of HIV-related stigma. HIV infection fits the profile of a condition that carries a high level of stigmatization.

Discrimination /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. Discrimination, as defined by UNAIDS (2000) in the *Protocol for Identification of Discrimination Against People Living with HIV,* refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of HIV and AIDS, a person's confirmed or suspected HIV-positive status—irrespective of whether or not there is any justification for these measures.

Any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV sero status or state of health (UNAIDS, 2000)

Self stigma

Self-stigma can be defined as negative response by a person towards him or herself; an individual's internalisation 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. An HIV diagnosis becomes shameful because it implies association with what is widely seen as immoral behavior. As a result, a person who acquires HIV may take on the guilt and judgment they perceive society has of HIV in general and internalize it. They may begin to believe that HIV is punishment for their (or their partner's) immoral behavior. On discovering their HIV-positive sero-status some people withdraw from society and stop participating in social activities because of their lowered self-esteem and sense of self-worth. There is often a reluctance to disclose one's status to others because of the fear of how they will respond.

Hospital associated stigma

HIV/AIDS is a highly stigmatized health condition—people living with HIV/AIDS (PLWHA) are more likely to be discriminated against than patients with most other health conditions. Thus, even where HIV-positive people have access to health care, they may not experience We asked respondents if they agreed, disagreed, or were neutral to seven attitudinal statements capturing better health and quality of life as a result

Shame

We asked respondents if they agreed, disagreed, or were neutral to three attitudinal statements capturing shame. These were:

- I would feel ashamed if I was infected with HIV
- People with HIV/AIDS should be ashamed of themselves
- I would be ashamed if someone in my family had HIV/AIDS

From these individual items, we calculated two summary measures agreement with at least one of three shame statements.

Quality of life:

Quality of life is a multi-dimensional concept, and is conceptualized in terms of "an absence of pain or an ability to function in day to day life". Several researchers described Quality of life as a "fighting spirit" associated with longer survival time for individuals. "Quality of life relates both to adequacy of material circumstances and to personal feelings about these circumstances. It includes "overall subjective feelings of well being that are closely related to morale,

happiness and satisfaction". Further as health is generally cited as one of the most important determinants of overall quality of life, it has been suggested that quality of life may be uniquely affected by specific disease process such as AIDS

Blame and Judgment:

We asked respondents if they agreed, disagreed, or were neutral to four attitudinal statements capturing blame *and Judgment.* These were:

- It is the women prostitutes that spread HIV in our community
- HIV is a punishment for bad behavior
- People with HIV/AIDS are promiscuous
- HIV is a punishment from God

From these individual items, we calculated summary measures agreement with at least one four blame statements.

Indepth knowledge (Community): Proportion who give correct response on **≥5** of the following 7 questions:

- There is difference between HIV and AIDS
- Know that HIV/ AIDS can be prevented by condoms?
- If a mother has HIV, can the virus be passed on to the baby?
- Know that Being faithful to one uninfected partner can protect from AIDS
- Know that a healthy looking person can have AIDS (Q 206)
- Reject the misconception that HIV/ AIDS IS TRANSMISTTED by mosquito bites
- Reject the misconception that HIV/AIDS is transmitted by sharing utensils/ food/ drinks

In-depth Knowledge (Health care providers): Proportion who give correct response on ALL of the following 3 questions:

- The risk of HIV transmission following a needle prick or sharp injury small, approximately 1 in 300
- 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.

- Standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient

Fear (Health Care Providers): We asked respondents if they feared HIV infection through 8 specific means

1. Giving an injection to a person with HIV or AIDS*
2. Assisting the delivery of a woman with HIV or AIDS
3. Dressing the wounds of a person living with HIV or AIDS*
4. Conducting surgery on or suturing a person with HIV or AIDS
5. Putting a drip in person with HIV or AIDS
6. Touching the sweat of a person with HIV or AIDS
7. Touching the saliva of a person with HIV or AIDS
8. Drawing blood of a person with HIV or AIDS

From these individual items, we calculated summary measures agreement with at least one eight fear statements

Fear (Community): We asked respondents if they feared HIV infection through 5 specific means:

- If you touch the saliva of a person with HIV or AIDS
- If you touch the sweat of a person with HIV or AIDS
- If you touch the excreta of a person with HIV or AIDS
- [That your child would become infected with HIV] if they play with a child who has HIV or AIDS
- Afraid to buy food forma PLHIV

From these individual items, we calculated summary measures agreement with at least one four blame statements.

PLHIV Self stigma (15 items)

- I have chosen not to attend social gathering(s)
- I have isolated myself from my family and/or friends
- I took the decision to stop working
- I decided not to apply for a job/work or for a promotion
- I withdrew from education/training or did not take up an Opportunity for education/training
- I decided not to get married
- I decided not to have sex
- I decided not to have (more) children
- I avoided going to a local clinic when I needed to
- I avoided going to a hospital when I needed to
- I made other changes to protect myself
- I was afraid of being gossiped about
- I was afraid of being verbally insulted, harassed and/or threatened
- I was afraid of being physically harassed and/or threatened
- I was afraid of being physically assaulted

PLHIV Enacted stigma (14 items)

- Q502.1 Excluded From social gathering due to HIV
- Q502.2 Treated differently due to HIV
- Q502.3 Abandoned by spouse due to HIV
- Q502.4 Abandoned by family due to HIV
- Q502.5 Isolated in household due to HIV
- Q502.6 No longer visited due to HIV
- Q502.7 Teased due to HIV
- Q502.10 Lost Housing due to HIV
- Q502.11 Denied religious rites due to HIV
- Q502.12 Given poor quality Health Services due to HIV
- Q502.13 Had property taken away
- Q502.14 Lost Respect

- Q502.15 Been gossiped about
- Q502.16 Physically assaulted

Stigma By Health Care Providers (14 items):

- Health provider refused to attend you
- You were discharged too early
- You had to wait longer to be attended
- You were being unnecessarily referred on to another provider in the same facility or referred to another facility
- You were told to come back later
- You were being denied treatment—drugs, surgery—or relevant tests/investigations
- You were tested for HIV without your informed consent?
- You were required to be tested for HIV before care was given or surgery scheduled
- Health provider used latex gloves for performing non-invasive exams on you or took extra precautions.
- Health provider disclosed your HIV status to your family without your consent.
- Health provider gossiped about your HIV status
- Health provider used derogatory language or scolded or blamed you for having HIV
- Your bed pans or bed clothes were not changed as needed/as often compared to other patients
- You received less care/attention than other patients

The sum of yes responses (yes=1) on the 43 items was added to give stigma score. The mean was computed and those with scores above mean were classified as high stigma.

Willingness to treat: We asked respondents if they were wiling to treat PLHIV through 4 specific means

- Comfortable assisting or being assisted by a colleague who is HIV- infected
- Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown
- Comfortable to providing health services to clients who are HIV-positive
- Comfortable sharing a bathroom with a colleague who is HIV- infected

Stigma in Community:

Proportion of people who have seen at least one of the following 14 items happen to person because of HIV status or being suspected of being positive in last 12 months.

- Excluded from a social gathering
- Abandoned by spouse/partner
- Abandoned by family/sent away to the village
- No longer visited, or visited less by family and friends
- Isolated in household (made to eat alone/ made to use separate eating utensils/ made to sleep alone in separate room)
- Teased, insulted, or sworn at
- Gossiped about
- Lost respect/standing within the family and/or community
- Denied religious rites/services (marriage, communion, cremation)/Not allowed to go to temple
- Lost customers to buy produce/goods / lost job
- Denied promotion/further training
- Lost housing or not able to rent housing
- Given poorer quality health services
- Had property taken away

Annex 3.1 Results 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**	Kruksal 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**	Kruksal 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**	Kruksal 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)	1. Excluded from a social gathering (wedding, funeral, party, community association group) **501.1**	7	17
		2. Been treated differently at a social gathering **501.2**	3	
		3. Abandoned by your spouse/partner **501.3**	2	
		4. Abandoned by your family/sent away to the village **501.4**	2	
		5. No longer visited, or visited less by family and friends **501.6**	12	
		6. Isolated in your household **501.5**	10	
		7. Physically assaulted (e.g., hit, kicked, punched) **501.16**	1	
	2. Verbal stigma)	1. Teased, insulted, or sworn at **501.7**	5	26
		2. Gossiped about **501.15**	26	
	3. Loss of identity/role	1. Lose respect/standing within the family/community **501.14**	13	13
		2. Denied religious rites/services **501.11**	1	
	4. Loss of access to resources and livelihoods (housing, employment)	1. Lost customers to buy produce/goods or lost a job **501.8**	**0**	7
		2. Denied promotion/further training **501.9**	**0**	
		3. Lose housing or not be able to rent housing **501.10**	0	
		4. Given poorer quality health services **501.12**	7	
		5. 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.			
Indicator	**Item/ Question**	**Percent experiencing (n=45)**	**Percent experiencing 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

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
	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 knowledge of HIV/AIDS?	All of the above: 7 item score	8	2	10

Table IVa Disclosure by relative indicator, items, and frequencies

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 Applica ble
	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

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**	11	**13**
	Parents and siblings	32	**0**	8	**24**
	Children	8	**0**	3	**5**
	Friends	12	**6**	1	**5**
	Other PLHIV	12	**0**	2	**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**	5	**9**
	Social workers/ Counselors	24	**1**	13	**10**
	Govt Officials	20	**0**	5	**15**
	Media	3	**1**	1	**1**

Table V: Depression among PLHIV				
Classi-fication	**Total Score**	**Level of Depression**	**N=45**	
Low	1-10	These ups and downs are considered 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 PLHIV

	Description	**Mean**	**SD**	**Range**
WHO QOL Bref (26) Scores (Transformed to 100 scale) across domains				
Domain 1	Physical health	46.35	9.15	31-69
Domain 2	Psychological	51.09	12.88	25-81
Domain 3	Social Relationships	43.51	19.24	0-81
Domain 4	Environment	42.36	15.12	6-75

Table VI B Frequency distribution of quality of life scores

	PHYSICAL	**PSYCHOLOGICAL**	**SOCIAL**	**ENVIRONMENTAL**
<20	0	0	6	3
21-40	16	7	9	9
41-60	29	26	22	22
61-80	2	11	7	7
>80	0	1	1	1

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	-.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).

Annex 3.2: Qualitative findings of PLHIV study

Narratives of the discussion with PLHIV:

Most of them identified HIV and AIDS synonymously and in terms of **"infection", "Disease", Dirty**". Only 2 were able to distinguish that HIV is the earlier stage and AIDS later stage of infection. Less than half of them (21) had heard about HIV beforehand from NGOs/ TV/ Media or health worker, the rest learnt from the doctor only after their family member or they themselves had some illness and tested positive. The initial reaction to learning of HIV status ranged from despair, grief and crying, shock, and very painful to fear of death. **"I don't eat food, remain sad, blame mother for marrying me to HIV positive drug addict**" The subjects especially women felt ashamed, and worried for their children's future and male initially denied. Helplessness and sense of being cheated by the partner was a common reaction. One participant told "**I felt shocked, I felt so bad that my husband did not disclose to me though I was life partner, I worry about children, what is their fault**?" Another widow narrated "**Sir, I feel to ashamed, Got this very dirty disease, cannot tell anybody**". Self blame and self stigma was expressed in terms of "**Is is our own mistake**" even by the innocent widows who got the infection from their husbands. Confidentiality protection and desire for privacy was high with most lying about disease to inquisitive neighbors or relatives as other disease like "**Cancer**", "**TB**" "**Alcohol induced**" or "**healthy**". When going for ART they told others that they are visiting a relative or parent's home. Their reactions were frame by perceptions of community "**Village people think that AIDS is = wrong character. We should not suffer in silence.** (*Ghut Ghut kar na mar jayen)*". Some reported self isolation from community. However in case of widows there is a custom of not going outside the house to social functions etc for one year, but the self isolation was superimposed as they stopped taking to close friends for fear of rebuke.

Disclosure of status by another person without consent took place from neighbours, relatives visiting reading hospital file or test reports, or by relatives telling others. However, they put up a brave face despite breach of confidentiality "**every body already knew from my husband's brother, It is**

better that rather than other person asking about it, I my self face the situation and tell". The lifestyle change made to cope was becoming introvert "**don't talk too much now**" One who had not disclosed to anybody weighing the pros and cons of disclosure felt "**for treatment I will need help, now have to disclose that I am HIV positve, I will have to do some job, but nobody will give me job due to this disease (HIV/AIDS)**"

One had child turned away from school, "**Children were expelled from DAV School Dehra due to suspicion of HIV, 3 months ago, then we got test done at Shimla and then readmission on showing report of negative**". Other included children not being sent to play with children of PLHIV, family members practiced untouchability, asked them to keep their utensils separate, pass judgmental remarks, call "**Promiscous**", they felt distancing and a sense of isolation, "**relations get cold**". An educated participant inferred that "**they (community) are afraid of us as if coming near us they will get AIDS, so they try to avoid us**". They did not confront stigma as they felt it would make resistance even worse. "**We just ignore comments and live with it, if we take action, people will be openly against us and life will be difficult**". Most said they cry in solitude, tolerate silently, go to parents home and get over it when faced with blue moods, which happened quite often. Some stated that in laws were hostile but all stated parents or partners as supportive and source of support (financial and moral). They were definitely clear that discrimination in family was due to HIV and not other cause like property dispute "**in laws never used to behave like this with me before HIV**".

An educated participant tried to engage other colleagues "**I tell other people that this disease is not untouchable, do tell me if you feel uncomfortable. I myself do take care**" and got good support, however she was spared of stigma due to needle prick being as mode of transmission and living in closed urban community, than due to speaking up. Some widows reported attempts to snatch property rights but they managed to resist till date (for the sake of their children). "**Husband's sister wants to sell off property and grab everything**" Two participants got support from NGO –FXB which works for the cause of AIDS orphans, and Human Rights Law Network, India local team.

There was definite gender disparity in the stigma, men did not report much problems but women had to shoulder all the blame. "**People blamed me for bringing disease to family, witchcraft. I had fever, doctors gave medicines but refused test admissions, the doctors knew my status. if I did not have house and property, I would have left the village when I went to hospital for treatment, people said that she goes around enjoying**". Another whose husband was alive told that her husband is driver at Hoshiarpur, denies that he is postive (tells cancer), "**blames me instead, refuses divorce, used to beat me**". He got ill six months after marriage "**He wanted to sell my jewellery.**"

Another reported domestic problems –" **In laws used to blame me for not taking care of family. In laws did not support for medical care etc- going to Shimla for tests**." HIV patients have to travel over 300 km from different parts of the state to receive the life saving medicine "ART" at Shimla..

Some cannot afford to travel so far and stay for a week to get tests done to get their treatment "**Free**". Even though the medicines are free, the attendants have to bring sick patients in Taxi. They were reimbursed bus fare with attendant initially, later they were given cheques which led to loss of confidentiality of patients, and clearing charges and delays. Now they have stopped getting cheques even. "**I went to ART centre at Shimla, was prescribed tests, these would take 1 week, I requested for admission as I had no place to stay, refused admission, out of pocket expenses were rs 2000, have no income and need assistance**". "**It is even more difficult to go to Shimla in winters and snowfall**" told a patient who had a fall in the snow when she went last winter. Due to tourist season, she did not get accommodation to stay and had to lie on the corridor of hospital. Already weakened, and travel in night bus not possible told brother of a participant who took his brother from village to Shimla twice in taxi.

Weakness and tiredness which also impaired their daily activities was the predominant symptom, which could have been due to disease itself or superimposed depression. "**Weakness, I can't go to the forest to chop firewood for the kitchen**", "**I cant work full day in the farms**".

Interaction with health care system was mixed. Two reported avoiding the local health staff as they were poking and insisting on disclosure of status.

They were not very clear about consent being taken in the counseling process They remember putting signature on form but asked about its contents told "**not able to read form (consent), which was in English**."

They retrospectively felt that had they be given PPMTC services earlier, they could have saved the child "**everybody should take precautions and protect himself. when I went for checkup in pregnancy, nobody told me about HIV test, else I would test timely and not had second child**."

Some had bad experiences "**When I tested positive I was month pregnant, Took medicines, at time of delivery no doctor was ready to do operation, referred, after repeated requests by mother, other doctor agreed, after surgery in the ward nurses stigmatized, were afraid to do dressing, isolated me from others, asked to use own bed sheets etc, after surgery I was discharged before removing stitches,** I refused to go, and stayed over."

Refusal to draw blood sample was seen in many "**I was tested in pvt lab, then got confirmation done at VCTC. When I went for CD4 test to ART centre, the Lab technicians refused to take my blood sample and asked me to bring gloves, then I was made to wait till the end and each of them saying to the other to take sample**."

Community resistance to one who applied for job of anganwari worker was seen "**37 people signed an application/ petition to Child Development Project Officer to not keep me as anganwari worker**."

Some also reported <u>POSITIVE REACTIONS</u> to the disease, "**Sub Divisional Magistrate who was in the selection committee supported me for the job despite all odds**". "**Doctor brought food from his home for us**"; "**Parents help, they send food grains from their farm produce. Got job after being HIV +**" A nurse living with HIV told "**colleagues gave motional support, though no relaxation in work**". Positive living was coping strategy which distinguished the women. Though men left job and came home, women took up family responsibilities "**took exams of class 10 after being positive, employed as water carrier in primary school**" Some have found a new purpose in life, with spirituality, or to raise their children and survive long enough for their children to be independent.

Annex 3.3 Results: Community Survey

Table VII. Background Characteristics of Community Sample

Background characteristics	n	Percent
Sex		
Female	270	50.0
Male	270	50.0
Age		
15–24	57	10.6
25–34	220	40.7
35–44	168	31.1
>44	95	17.6
Education		
No formal	28	5.2
Primary	101	18.7
Middle	113	20.9
High School	244	45.2
Graduate	43	8.0
University/ Higher	11	2.0
Marital Status		
Married	495	91.7
Divorced	7	1.3
Widowed	12	2.2
Never married	26	4.8
Occupation		
Not gainfully employed	262	48.5
Government Servant	51	9.4
Self Employed	134	24.8
Farmer	33	6.1
Other	60	11.1
Religion		
Hindu Gen	130	24.1
Hindu SC	156	28.9
Hindu ST	79	14.6
Hindu OBC	172	31.7
Others	3	0.7

Table VIII. Forms of stigma and their items

Modified forms of stigma	Item	% (n= 270 each)		Percent witnessing at least one item per group	
		M	F	M	F
1. Isolation (physical and social exclusion)	1. Excluded from a social gathering (wedding, funeral, party, community association group)	38(14.1)	37(13.7)	69 (25.6)	75(27.8)
	2. Abandoned by spouse/partner	26(9.7)	24(8.9)		
	3. Abandoned by family/sent away to the village	26(9.7)	22(8.1)		
	4. No longer visited, or visited less by family and friends	51(19.0)	33(12.2)		
	5. Isolated in household (made to eat alone/ made to use separate eating utensils/ made to sleep alone in separate room)	33(12.3)	21(7.8)		
2. Verbal stigma (gossip, voyeurism, taunting)	1. Teased, insulted, or sworn at	14(5.2)	20(7.4)	62 (22.9)	45 (16.7)
	2. Gossiped about	55(20.4)	33(22.2)		
3. Loss of identity/role	1. Lost respect/standing within the family and/or community	49(18.1)	45(16.7)	60 (22.2)	58 (21.5)
	2. Denied religious rites/services (marriage, communion, cremation)/Not allowed to go to temple	38(14.1)	37(13.8)		
4. Loss of access to resources & livelihoods (housing, employment)	1. Lost customers to buy produce/goods / lost job	21(7.8)	17(6.3)	59 (21.9)	55 (20.4)
	2. Denied promotion/further training	38(14.1)	27(10.0)		
	3. Lost housing or not able to rent housing	28(8.9)	38(11.9)		
	4. Given poorer quality health services	27(10.0)	32(11.9)		
	5. Had property taken away	23(10.4)	27(10.0)		
Percent reporting some form of stigma for any of the above				**96 (35.5)**	**98 (36.3)**

TABLE IXa: COMPREHENSIVE KNOWLEDGE BY SEX

Indicators	Questions in survey corresponding to indicator(s)	Male N =270 (%)	Females N =270 (%)	Total N =540 (%)
1. Percent of people who know that :	There is difference between HIV and AIDS (Q 201)	136 (50.4)	121 (44.8)	257 (47.6)
	Know that HIV/ AIDS can be prevented by condoms? (Q 204c)	228 (84.8)	249 (92.2)	477 (88.5)
	If a mother has HIV, can the virus be passed on to the baby? (Q 205)	233 (86.3)	237 (87.8)	470 (87.5)
	Know that Being faithful to one uninfected partner can protect from AIDS (Q 204 b)	229 (84.8)	239 (88.5)	468 (86.7)
	Know that a healthy looking person can have AIDS (Q 206)	172 (63.7)	190 (70.4)	362 (67.0)
	Reject the misconception that HIV/ AIDS IS TRANSMISTTED by mosquito bites (Q 203i=0) *	229(84.8)	237(87.8)	466(86.3)
	Reject the misconception that HIV/AIDS is transmitted by sharing utensils/ food/ drinks (Q 203k=0)	244 (90.4)	247 (91.5)	491 (90.9)
Comprehensive knowledge of HIV/AIDS?	≥5 OF THE ABOVE CORRECT	127 (47.0)	136 (50.4)	263(48.7)

Table IXb: KNOWLEDGE BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		Is there a difference between HIV and AIDS?						
		YES		NO		Total		χ^2 (P)
		N=257	%	N=283	%	N=540	%	
Age group	15-24	30	11.7	27	9.5	57	10.6	1.45
	25-34	107	41.6	113	39.9	220	40.7	
	35-44	79	30.7	89	31.4	168	31.1	(0.695)
	>=45	41	16.0	54	19.1	95	17.6	
SEX	F	121	47.1	149	52.7	270	50.0	1.67
	M	136	52.9	134	47.3	270	50.0	(0.196)
Literacy	<=8	84	32.7	158	55.8	242	44.8	29.18
	>8	173	67.3	125	44.2	298	55.2	(0.000)
Occupation	Unemployed	116	45.1	146	51.6	262	48.5	2.25
	Employed	141	54.9	137	48.4	278	51.5	(0.134)
CASTE	Gen	83	32.3	50	17.7	133	24.6	34.29
	SC	51	19.8	105	37.1	156	28.9	
	ST	28	10.9	51	18.0	79	14.6	(0.000)
	OBC	95	37.0	77	27.2	172	31.9	

Table IXc KNOWLEDGE BY DEMOGRAPHIC CHARACTESRISTIS

KNOWLEDGE BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		Can a healthy looking person have HIV?						
		YES		NO		Total		χ^2 (P)
		N=362		N= 178		N=540		
Age group	15-24	39	10.8	18	10.1	57	10.6	0.07
	25-34	147	40.6	73	41.0	220	40.7	(0.995)
	35-44	112	30.9	56	31.5	168	31.1	
	>=45	64	17.7	31	17.4	95	17.6	
SEX	F	190	52.5	80	44.9	270	50.0	2.72
	M	172	47.5	98	55.1	270	50.0	(0.099)
Literacy	<=8	147	40.6	95	53.4	242	44.8	7.86
	>8	215	59.4	83	46.6	298	55.2	(0.005)
Occupation	Unemployed	173	47.8	89	50.0	262	48.5	0.233
	Employed	189	52.2	89	50.0	278	51.5	(0.629)
CASTE	Gen	96	26.5	37	20.8	133	24.6	25.33
	SC	80	22.1	76	42.7	156	28.9	(0.000)
	ST	56	15.5	23	12.9	79	14.6	
	OBC	130	35.9	42	23.6	172	31.9	

Table X. Fear of casual contact: indicators, items, and frequencies

Indicators	Questions in survey corresponding to indicator(s)	Percent		
1. Percent of people expressing fear of contracting HIV from non-invasive contact with PLHA	**Please tell me if you have fear, do not have fear, or do not know in response to the following statements:**	**Male N=270**	**Female N=270**	**Total N=540**
	Fearful/Afraid that you could become infected with HIV if you are exposed to the saliva of a person with HIV or AIDS (210.1)	90 (33.3)	72 (26.7)	162 (30.0)
	Fearful/Afraid that you could become infected with HIV if you are exposed to the sweat of a person with HIV or AIDS (210.3)	42(15.6)	36(13.3)	78 (14.4)
	Fearful/Afraid that you could become infected with HIV if you are exposed to the excreta of someone with HIV or AIDS (210.2)	65(24.1)	57(21.1)	122(22.6)
	Fearful/Afraid that your child could become infected with HIV if they play with a child who has HIV or AIDS (210.4)	53(19.6)	44(16.3)	97(18.0)
	Fearful/Afraid to care for a person living with HIV or AIDS (210.5)*	69(25.6)	51(18.9)	120(22.2)
	In a market of several food vendors, would NOT buy food from a PLHA but not showing signs/symptoms? (211)*	94(57.0)	71(26.3)	165(36.6)
	Any of the above	109 (40.4)	99(36.7)	208(38.5)

Table X B: FEAR BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		Fear of caring for a person living with HIV or AIDS						
		FEAR		NO FEAR		Total		χ^2 (P)
Age group	15-24	9	7.5	48	11.4	57	10.6	8.602
	25-34	41	34.2	179	42.6	220	40.7	(0.035)
	35-44	50	41.7	118	28.1	168	31.1	
	>=45	20	16.7	75	17.9	95	17.6	
SEX	F	69	57.5	201	47.9	270	50.0	3.471
	M	51	42.5	219	52.1	270	50.0	(0.062)
Literacy	<=8	67	55.8	175	41.7	242	44.8	7.574
	>8	53	44.2	245	58.3	298	55.2	(0.006)
Occupation	Unemployed	59	49.2	203	48.3	262	48.5	.026
	Employed	61	50.8	217	51.7	278	51.5	(0.872)
CASTE	Gen	24	20.0	109	26.0	133	24.6	4.945
	SC	44	36.7	112	26.7	156	28.9	(0.176)
	ST	17	14.2	62	14.8	79	14.6	
	OBC	35	29.2	137	32.6	172	31.9	

Table X C: FEAR BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		Your child could become infected with HIV if they play with a child who has HIV or AIDS						
		FEAR		NO FEAR		Total		χ^2 (P)
		N=97	%	N=443	%	N=540	%	
Age group	15-24	11	11.3	46	10.4	57	10.6	5.398
	25-34	30	30.9	190	42.9	220	40.7	(0.313)
	35-44	38	39.2	130	29.3	168	31.1	
	>=45	18	18.6	77	17.4	95	17.6	
SEX	F	53	54.6	217	49.0	270	50.0	1.018
	M	44	45.4	226	51.0	270	50.0	(0.313)
Literacy	<=8	56	57.7	186	42.0	242	44.8	7.977
	>8	41	42.3	257	58.0	298	55.2	(0.005)
Occupation	Unemployed	49	50.5	213	48.1	262	48.5	0.189
	Employed	48	49.5	230	51.9	278	51.5	(0.664)
CASTE	Gen	19	19.6	114	25.7	133	24.6	4.967
	SC	34	35.1	122	27.5	156	28.9	(0.174)
	ST	18	18.6	61	13.8	79	14.6	
	OBC	26	26.8	146	33.0	172	31.9	

Table X D: FEAR BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		Fear of being exposed to the saliva of a person with HIV or AIDS						
		FEAR		NO FEAR		Total		χ^2 (P)
		N=162	%	N=378	%	N=540	%	
Age group	15-24	19	11.7	38	10.1	57	10.6	4.174
	25-34	56	34.6	164	43.4	220	40.7	
	35-44	53	32.7	115	30.4	168	31.1	(0.243)
	>=45	34	21.0	61	16.1	95	17.6	
SEX	F	90	55.6	180	47.6	270	50.0	2.857
	M	72	44.4	198	52.4	270	50.0	(0.291)
Literacy	<=8	89	54.9	153	40.5	242	44.8	9.590
	>8	73	45.1	225	59.5	298	55.2	(0.002)
Occupation	Unemployed	93	57.4	169	44.7	262	48.5	7.321
	Employed	69	42.6	209	55.3	278	51.5	(0.007)
CASTE	Gen	31	19.1	102	27.0	133	24.6	11.105
	SC	58	35.8	98	25.9	156	28.9	
	ST	30	18.5	49	13.0	79	14.6	(0.011)
	OBC	43	26.5	129	34.1	172	31.9	

Table XI. Shame, blame, and judgment: Indicators, items, and frequencies				
Shame and Blame Indicators	**Questions in survey corresponding to indicator(s)**	**Percent**		
Statements related to shame, blame, and judgment		**M** **N =270**	**F** **N =270**	**T** **N= 540**
1. Percent of people who would feel shame if they associated with a person living with HIV/AIDS	**Do you agree/disagree with the following statements?**			
	I would be ashamed if someone in my family had HIV/AIDS (301.3)	162(60.0)	170(63.0)	332(61.5)
	I would feel ashamed if I were infected with HIV (301.8)	175 (64.8)	176(65.2)	342(63.3)
	People with HIV/AIDS should be ashamed of themselves (301.2).	183(67.7)	189(70.0)	372(68.9)
	Percent of respondents who agree with at least one stigmatizing "shame" statement	**224(83.0)**	**217(80.4)**	**441(81.7)**
2. Percent of people who judge or blame persons living with HIV/AIDS for their illness	**Do you agree/disagree with the following statements?**			
	It is the women prostitutes who spread HIV in our community.	220(81.5)	224(83.0)	444(82.2)
	HIV/AIDS is a punishment for bad behavior.	99(46.9)	112(41.5)	211(39.1)
	People with HIV/AIDS are promiscuous.	160(59.3)	155(57.4)	315(58.3)
	HIV/AIDS is a punishment from God.	49(18.3)	31(11.5)	80(14.5)
	Percent of respondents who agree with at least one stigmatizing "blame and judgment" statement	**256(94.8)**	**251(93.0)**	**507(93.9)**

TABLE XIB. SHAME BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		I would be ashamed if someone in my family had HIV/AIDS						
		YES		NO		Total		χ^2 (P)
		N=332	%	N=204	%	N=540	%	
Age group	15-24	29	8.7	28	13.7	57	10.6	17.427
	25-34	121	36.4	97	47.5	218	40.4	
	35-44	109	32.8	58	28.4	167	30.9	(0.001)
	>=45	73	22.0	21	10.3	94	17.4	
SEX	F	162	48.8	106	52.0	268	49.6	.506
	M	170	51.2	98	48.0	268	49.6	(0.477)
Literacy	<=8	161	48.5	81	39.7	242	44.8	3.941
	>8	171	51.5	123	60.3	294	54.4	(0.471)
Occupation	Unemployed	147	44.3	115	56.4	262	48.5	7.398
	Employed	185	55.7	89	43.6	274	50.7	(0.007)
CASTE	Gen	79	23.8	54	26.5	133	24.6	5.945
	SC	85	25.6	68	33.3	153	28.3	
	ST	53	16.0	26	12.7	79	14.6	(0.114)
	OBC	115	34.6	56	27.5	171	31.7	

TABLE XI C: BLAME BY DEMOGRAPHIC CHARACTERISTICS COMMUNITY MEMBERS

		People with HIV/AIDS are promiscuous						
		YES		NO		Total		χ^2 (P)
		N=315	%	N=220	%	N=540	%	
Age group	15-24	33	10.5	23	10.5	56	10.4	.757
	25-34	129	41.0	90	40.9	219	40.6	
	35-44	101	32.1	65	29.5	166	30.7	(0.860)
	>=45	52	16.5	42	19.1	94	17.4	
SEX	F	160	50.8	107	48.6	267	49.4	.241
	M	155	49.2	113	51.4	268	49.6	(0.623)
Literacy	<=8	137	43.5	103	46.8	240	44.4	.579
	>8	178	56.5	117	53.2	295	54.6	(0.447)
Occupation	Unemployed	139	44.1	122	55.5	261	48.3	6.652
	Employed	176	55.9	98	44.5	274	50.7	(0.010)
CASTE	Gen	61	19.4	72	32.7	133	24.6	21.039
	SC	85	27.0	68	30.9	153	28.3	
	ST	47	14.9	31	14.1	78	14.4	(0.000)
	OBC	122	38.7	49	22.3	171	31.7	

Table XII. Disclosure, Indicators, items, and frequencies

Indicators	Questions in survey corresponding to indicator(s) (n = if not stated)	Response Category	Percent		
			M	F	T
1. Percent of people who think a person should be able to keep their HIV status private.	If a person learns that he/she is infected with the virus that causes AIDS, should this information remain this person's secret or should this information be available to the community?	Private	154 (57.5)	162 (60.5)	316 (59.1)
		Community	34 (12.7)	33 (12.4)	67 (12.5)
		Don't know	80 (29.9)	72 (27.0)	152 (28.0)

Annex 3.4 Results- Health Care Providers

Table XIII. Background Characteristics of health care providers Sample

Background characteristics	Doctor n=241		Nurse =295		Total N= 536	Percent
Female	69	28.6%	290	98.3%	177	67.0%
Male	172	71.4%	5	1.7%	359	33.0%
Age						
15–24	11	4.6%	20	6.8%	31	5.8 %
25–34	82	34.%	109	36.9%	191	35.6 %
35–44	75	31.1%	83	28.1%	158	29.5 %
>44	73	30.3%	83	28.1%	156	29.1 %
Type of health facility						
Medical College	93	38.6%	121	41.0%	214	39.9%
Zonal Hospital	17	7.1%	39	13.2%	56	10.4%
Civil/ sub Divisional Hospital	26	10.8%	60	20.3%	86	16.0%
Community Health Center	24	10.0%	32	10.8%	56	10.4%
Primary Health Center	61	25.3%	15	5.1%	76	14.2%
Private Hospital	2	0.8%	2	0.7%	4	0.7%
Army Hospital	11	4.6%	11	3.7%	22	4.1%
Marital Status						
Married	197	81.7%	235	79.7%	431	80.6 %
Divorced	0	0.0%	2	0.7%	2	0.4 %
Widowed	1	0.4%	5	1.7%	6	1.1 %
Never married	42	17.4%	50	16.9%	92	17.2 %
Other/ unspecified	1	0.4%	3	1.0%	4	0.8 %
Qualification						
Doctors Specialist	91	37.8%	--	--	91	17.0%
Doctors Gen	150	62.2%	--	--	150	28.0%
Nurses	--	--	295	100%	295	55.0%
Religion						
Hindu Gen	198	82.2%	190	64.4%	388	72.4%
Hindu SC	16	6.6%	37	12.5%	53	9.9%
Hindu ST	5	2.1%	4	1.4%	9	1.7%
Hindu OBC	4	1.7%	41	13.9%	45	8.4%
Others	18	7.5%	23	7.8%	41	7.6%
Training status						
Trained	132	54.8%	145	49.2%	277	51.7%
Untrained	109	45.2%	150	50.8%	259	48.3%

TABLE XIV. **Forms of stigma and their items**

Indicators	Modified Forms of Stigma	Item	Percent		Percent who saw or observed at least one item per group	
			DOCTOR N= 241	**NURSE N=295**	**DOCTOR**	**NURSE**
1. Percent of people working in institutions/facilities who personally know patients who were because they were known or suspected to have HIV/AIDS (a) Neglected (b) treated differently (c) tested for HIV/sero-status disclosed without consent	1. Neglect	Receiving less care/attention than other patients **(501.6)**	45 (18.9)	88 (29.8)	68 (28.2)	113 (38.3)
		To protect themselves from HIV infection, avoid going near HIV infected patients (501.8)	35 (14.5)	45 (15.3)		
		To protect themselves from HIV infection, avoid touching HIV infected patients (501.9)	49 (20.3)	43 (14.6)		
	2. Differential treatment/ forced to test	Requiring some clients to be tested for HIV before scheduling surgery (501.2)**	142 (58.9)	259 (87.8)	187 (77.6)	286 (96.9%)
		Using latex gloves for performing non-invasive exams on clients suspected of having HIV (501.3)**	126 (52.3)	251 (85.1)		
		Extra precautions being taken in the sterilization of instruments used on HIV-positive patients (501.4)**	147 (61.0)	271 (91.9)		
	3. Denied care/ un necessary referral	Because a patient is HIV-positive, a senior health care provider pushed the client to a junior provider (501.7)	59 (24.5)	53 (18.0)	*Tot*	*112 (20.9)*
	4. HIV testing & disclosure without consent	Testing a client for HIV without their consent (501.1)**	56 (23.2)	103(34.9)	165 (68.5%)	276 (93.6%)
		Share status of patient with staff members (501.5)**	139 (59.7)	262 (88.8)		
		Disclosing client's HIV status to their family without client's consent (501.11)	72 (29.9)	150 (50.8)		
	ANY OF THE ABOVE ITEMS				215 (89.2)	289 (97.9)

Table XV: Stigmatising attitude of Health care providers								
Stigmatisng Attitudes			DOCTORS		NURSES		TOTAL	
I am comfortable assisting or being assisted by a colleague who is HIV infected	302.1	Agree	192	79.7%	221	74.9%	413	77.1%
		Disagree	49	**20.3**%	74	**25.1**%	123	22.9%
I am comfortable performing surgical or invasive procedure on clients whose HIV status is	302.2	Agree	157	65.1%	193	65.4%	350	65.3%
		Disagree	84	**34.9**%	102	**34.6**%	186	34.7%
I am comfortable providing health services to clients who are HIV-positive	302.3	Agree	203	84.2%	234	79.3%	437	81.5%
		Disagree	38	**15.8**%	61	**20.7**%	99	18.5%
I am comfortable sharing a bathroom with a colleague who is HIV infected	302.4	Agree	195	80.9%	198	67.1%	393	73.3%
		Disagree	46	**19.1**%	97	**32.9**%	143	26.7%
Most frequent mode of contracting HIV among health workers is through work-related exposure	302.5	Agree	178	**73.9**%	236	**80.0**%	414	77.2%
		Disagree	63	26.1%	59	20.0%	122	22.8%
Patients should be tested for HIV before surgery	303.0	Agree	217	**90.0**%	290	**98.3**%	507	94.6%
		Disagree	24	10.0%	5	1.7%	29	5.4%
All pregnant women should be tested for HIV	304.0	Agree	233	**96.7**%	292	**99.0**%	525	97.9%
		Disagree	8	3.3%	3	1.0%	11	2.1%
The need for consent is exaggerated. HIV tests should be handled like any other test	305.0	Agree	166	**68.9**%	223	**75.6**%	389	72.6%
		Disagree	75	31.1%	72	24.4%	147	27.4%
When a patient tests positive, the doctor should inform the patient's partner	308.0	Agree	166	**68.9**%	223	**75.6**%	389	72.6%
		Disagree	75	31.1%	72	24.4%	147	27.4%
Patients with HIV should be kept at a distance from other patients	309.0	Agree	44	**18.3**%	100	**33.9**%	144	26.9%
		Disagree	197	81.7%	195	66.1%	392	73.1%
Clothes and linen used by HIV positive patients should be disposed off or burned	310.0	Agree	85	**35.3**%	166	**56.3**%	251	46.8%
		Disagree	156	64.7%	129	43.7%	285	53.2%
HIV infected patients should be made to pay for health staff's use of additional infection control	311.0	Agree	41	**17.0**%	113	**38.3**%	154	28.7%
		Disagree	200	83.0%	182	61.7%	382	71.3%
People living with HIV should have a right to decide who should know their results	312.0	Agree	172	71.4%	236	80.0%	408	76.1%
		Disagree	69	**28.6**%	59	**20.0**%	128	23.9%
People with HIV should be allowed to get married	313.0	Agree	95	39.4%	91	30.8%	186	34.7%
		Disagree	146	**60.6**%	204	**69.2**%	350	65.3%
HIV positive women should not get pregnant	314.0	Agree	155	**64.3**%	189	**64.1**%	344	64.2%
		Disagree	86	35.7%	106	35.9%	192	35.8%

Table XVI: In-depth Knowledge of HIV/AIDS among health care providers

Existing Selected Indicators	Questions in survey corresponding to indicator	DOCTOR N= 241(%)	NURSE N=295 (%)	Total N= 536 (%)
1. Percent of people who know that :	The risk of HIV transmission following a needle prick or sharp injury **small**, approximately 1 in 300 [Q203]	150 (45.6)	179 (54.4)	329 (61.4)
	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. [Q204]	124 (51.5)	162 (54.9)	286(53.4)
	Standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient [Q205]	161 (66.8)	159(53.9)	320 (59.7)
1A In-depth knowledge of HIV/AIDS	All of the above: 3 item score (In depth Knowledge)*	78(32.4)	72 (21.4)	150 (28.0)
2. Percent of people who reject the common Misconceptions on HIV Transmission	Reject the misconception that HIV/ AIDS IS ** TRANSMISTTED by saliva (Q 208 f=1)	148(61.4)	133(45.1)	281(52.4)
	Reject the misconception that HIV/ AIDS IS ** TRANSMISTTED by sweat (Q 208 g=1)	212 (88.0)	206 (69.8)	418 (78.0)
	Reject the misconception that HIV/AIDS is transmitted by tears (Q 208 h=1) **	201 (83.4)	206(69.8)	407 (75.9)
2A No misconceptions	All of the above: 3 item score**	131 (54.4)	120 (40.7)	251(46.8)

* (p<.05) ** (P<.001)

Table XVII	Fear of HIV transmission among health care providers							
Indicators	**Questions in survey corresponding to indicator(s)**							
1. Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear: (a) providing invasive medical care to patients with HIV/AIDS (b) contact with non-blood bodily fluids of patients with HIV/AIDS (c) casual contact with PLHA	**In response to the following situations, please tell me if you have fear of HIV transmission, have no fear of HIV transmission, or do not know:**		**DOCTOR N= 241(%)**		**NURSE N=295 (%)**		**Total N= 536 (%)**	
	Giving an injection to a person with HIV or AIDS*	Have fear	102	42.3	175	59.3	277	51.7
		No Fear	134	55.6	110	37.3	244	45.5
		Don't Know	5	2.1	10	3.4	15	2.8
	Assisting the delivery of a woman with HIV or AIDS	Have fear	148	61.4	205	69.5	353	65.9
		No Fear	82	34.0	83	28.1	165	30.8
		Don't Know	11	4.6	7	2.4	18	3.4
	Dressing the wounds of a person living with HIV or AIDS*	Have fear	121	50.2	192	65.1	313	58.4
		No Fear	115	47.7	97	32.9	212	39.6
		Don't Know	5	2.1	6	2.0	11	2.1
	Conducting surgery on or suturing a person with HIV or AIDS	Have fear	152	63.1	210	71.2	362	67.5
		No Fear	85	35.3	81	27.5	266	49.6
		Don't Know	4	1.7	4	1.4	8	1.5
	Putting a drip in person with HIV or AIDS	Have fear	119	49.4	179	60.7	298	55.6
		No Fear	119	49.4	111	37.6	230	42.9
		Don't Know	3	1.2	5	1.7	8	1.5
	Touching the sweat of a person with HIV or AIDS	Have fear	21	8.7	32	10.8	52	9.7
		No Fear	209	86.7	249	84.4	458	85.4
		Don't Know	11	4.6	15	5.1	26	4.9
	Touching the saliva of a person with HIV or AIDS	Have fear	59	24.5	98	33.2	157	29.3
		No Fear	169	70.1	186	63.1	311	58.0
		Don't Know	113	46.9	102	34.6	215	40.1
	Drawing blood of a person with HIV or AIDS	Have fear	125	51.9	186	63.1	311	58.0
		No Fear	113	46.9	102	34.6	215	40.1
		Don't Know	3	1.2	7	2.4	10	1.9
	Any of the above 8 items	Have fear	173 (71.7)		228 (77.3)		401(74.8)	

Table XVIII. Willingness to provide medical care to PLHA: Indicators, items, and frequencies

Indicators	Questions in survey corresponding to indicator(s)		Percent					
3. Percent of people working in institutions/facilities (e.g., managers, health care workers) who are uncomfortable working with and treating PLHA	**Do you agree or disagree with the following statements:**							
	Comfort working with and treating PLHA		**DOCTOR** N= 241(%)		**NURSE** N=295 (%)		**Total** N= 536 (%)	
	Comfortable assisting or being assisted by a colleague who is HIV- infected	Agree	195	80.9	218	73.9	413	77.1
		Disagree	48	19.9	75	25.4	123	22.9
	Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown	Agree	157	65.1	193	65.4	350	65.3
		Disagree	86	35.7	100	33.9	186	34.7
	Comfortable to providing health services to clients who are HIV-positive**	Agree	205	85.1	232	78.6	437	81.5
		Disagree	38	15.8	61	20.7	99	18.5
	Comfortable sharing a bathroom with a colleague who is HIV-infected **	Agree	198	82.2	195	66.1	393	73.3
		Disagree	45	18.7	98	33.2	143	26.7
	Percent reporting one or more stigmatizing responses:		**121 (51.6)**		**171 (57.9)**			
4. Percent of people working in institutions/facilities (e.g., managers, health care workers) who perceive work-related HIV exposure to be high	*High work-related HIV exposure*							
	Most frequent mode of contracting HIV among health care workers is through work-related exposure.	Agree	179	74.3	235	79.7	414	77.2
		Disagree	64	26.6	58	19.7	122	22.8
	Most HIV-positive health care workers get infected at work.	Agree	158	65.6	243	82.4	401	74.8
		Disagree	85	35.3	50	16.9	135	25.2
	Percent reporting one or more stigmatizing responses:							

TABLE XIX . Shame, blame, and judgment: Indicators, items, and frequencies

Shame and Blame Indicators	Questions in survey corresponding to indicator(s)	Percent		
Statements related to shame, blame, and judgment				
		DOCTOR N= 241	**NURSE N=295 (%)**	**Total N= 536 (%)**
1. Percent of people who would feel shame if they associated with a person living with HIV/AIDS	**Do you agree/disagree with the following statements?**			
	I would be ashamed if someone in my family had HIV/AIDS. (401.3)**	22 (9.1)	65 (22.0)	87 (16.2)
	I would feel ashamed if I were infected with HIV. (401.7)**	38 (15.8)	91 (30.8)	129 (24.1)
	People with HIV/AIDS should be ashamed of themselves. (401.2)**	17 (18.3)	76 (25.8)	93 (17.4)
	Percent of respondents who agree with at least one stigmatizing "shame" statement**	48 (19.0)	120 (41.7)	168 (31.3)
2. Percent of people who judge or blame persons living with HIV/AIDS for their illness	**Do you agree/disagree with the following statements?**			
	It is the women prostitutes who spread HIV in our community. (401.1)	135 (56.0)	187 (63.4)	322 (60.1)
	HIV/AIDS is a punishment for bad behavior. (401.8)	32 (13.3)	56 (19.0)	88 (16.4)
	People with HIV/AIDS are promiscuous. (401.4)	**173(71.8)**	**221(74.9)**	**394(73.5)**
	HIV/AIDS is a punishment from God. (401.6)	9 (3.7)	19 (6.4)	28 (5.2)
	Percent of respondents who agree with at least one stigmatizing "blame and judgment" statement**	203 (84.2)	246 (83.4)	449 (83.8)

Table XIX B: Shame And Blame By Demographic Characteristics							
		SHAME				Ch Square (p)	Ch Square (p)
		DCOTORS		NURSES		DCOTORS	NURSES
		NO	YES	NO	YES		
AGEGP	<35	73	20	76	53	0.24 (0.62)	0.02 (0.90)
	>=35	120	28	99	67		
CASTE	Gen	160	38	110	80	0.37 (0.54)	0.45 (0.50)
	Others	33	10	65	40		
Q108_DESIG	Specialist	66	25	29	21	5.23 (0.02)	0.04 (0.83)
	Gen	127	23	146	99		
INDEPTHKNO	No	133	30	132	91	0.72 (0.39)	0.01 (0.94
	Yes	60	18	43	29		
BLAME3	No	33	5	35	14	1.29 (0.25)	3.57 (0.058)
	Yes	160	43	140	106		

		BLAME					
		DCOTORS		NURSES		Ch Square (p)	Ch Square (p)
		NO	YES	NO	YES	DCOTORS	NURSES
AGEGP3	<35	18	75	20	109	1.47 (0.22)	0.20 (0.65)
	>=35	20	128	29	137		
Q105_CASTE	Gen	32	166	30	160	0.13 (0.71)	0.26 (0.61)
	Others	6	37	19	86		
Q108_DESIG	Specialist	17	74	15	35	0.93 (0.33)	7.79 (0.005)
	Gen	21	129	34	211		
INDEPTHKNO	No	26	137	40	183	0.01 (0.91)	1.16 (0.28)
	Yes	12	66	9	63		

DR. RAJENDRA PRASAD GOVERNMENT MEDICAL COLLEGE,
KANGRA AT TANDA.

NO: HFW-H (DRPGMC)-PA/2008- Dated:

CIRCULAR

All the HODs of Dr. Rajendra Prasad Govt. Medical College, Kangra at Tanda alongwith HOD, Microbiology, HOD Pathology, HOD Biochemistry Incharge Blood Bank & Incharge Casualty are requested to extend full cooperation in study on training needs assessment on HIV and stigma associated with HIV by Dr. R.K. Sood for the health Deptt. and also direct the doctors in your departments complete the questionnaire and deposit the completed forms with incharge ICTC-cum-HOD Microbiology within seven days positively.

The information will be kept confidential and participants are required to sign consent form on page-B. The name or signature should not be written anywhere else on the form. The information will be utilized to plan future HIV trainings and CME.

-sd-
Principal
Dr. R.P. Govt. Medical College
Kangra at Tanda.

Endst. No. As above- Dated:

Copy to:

1. All concerned HODs, Dr. RPGMC Hospital, Kangra at Tanda for information and necessary action please.
2. The DAPO-cum-Nodal Officer training (HIV) w.r.t. his letter No. ICTC / Dharamshala/- 230 dt. 13.5.08.
3. Dr. R.K. Sood, FETP Scholar, o/o CMO Kangra at Dharamsala for information
4. Dr Kamlesh HOD Microbiology and Incharge ICTC for information and n/a.

-sd-
Principal
Dr. R.P. Govt. Medical College
Kangra at Tanda.

REMINDER

DR. RAJENDRA PRASAD GOVERNMENT MEDICAL COLLEGE,
KANGRA AT TANDA.

NO: HFW-H (DRPGMC)-PA/2008- Dated:

CIRCULAR

In continuation of this office circular No. 15397 to 421 dt. 17.5.2008 regarding study on HIV and associated stigma (copy attached). All the doctors who have not filled the questioner already sent to the Deptts. may be requested to send the fill forms to Mr. Govind (Male Counselor ICTC, Room No. 324 Deptt. of Microbiology, Dr. RPGMC, Tanda within seven days positively.

-sd-
Principal
Dr. R.P. Govt. Medical College
Kangra at Tanda.

Endst. No. As above- Dated:

Copy to:

5. All concerned HODs, Dr. RPGMC Hospital, Kangra at Tanda for information and necessary action please.
6. Dr. R.K. Sood, FETP Scholar, o/o CMO Kangra at Dharamsala for information
7. Mr. Govind (Male Counselor ICTC, Room No. 324 Deptt. of Microbiology, Dr. RPGMC, Tanda for information and n/a.

-sd-
Principal
Dr. R.P. Govt. Medical College
Kangra at Tanda.

No.ICTC/Dharamshala/- Dated:

O/o DAPO Kangra at Dharamshala

Dr XXX, Block Medical Officer,
Block XXX, District Kangra

Subject: Filling Forms for medical officers and nurses for Training Needs assessment on HIV and study on stigma associated with HIV

Dear Sir,

I am to intimate that a baseline assessment of knowledge, attitudes of service providers to care of HIV positive patients is being undertaken as part of training needs assessment. Dr RK Sood, FETP Scholar has been designated as investigator for the project.

You are requested to extend full cooperation and get forms filled from all doctors and nurses and send the completed forms through special messenger to the undersigned at Room No 402 D, with one week. You are requested to collect all and prepare a consolidated list with the filled forms on the form below. This will be helpful in planning the activities under National AIDS Programme Activities.

The proforma consists of a 12 page self administered questionnaire which will take 10-15 minutes to complete. The participants will sign only at page B and do not need to write their name anywhere else. In case of any clarification kindly call Dr RK Sood at 9418064077.

Thanking you,

Dr Surinder Singh
DAPO Cum nodal officer Trainings (HIV)
District Kangra (HP).

Encl. 1. Questionnairres for MO And Nurses (Nos)
2. Checklist

2. Forwarding Checklist of consolidated form of HIV survey doctors and nurses Block XXX

S NO	Name of Institution	Name of doctor/ nurse	Form No

Date (Signature) Name of BMO /SMO

Office of the Chief Medical Officer, Kangra at Dharamshala
District Kangra, Himachal Pradesh

No. HFW/KGR /FETP/2008- Dated the 2008

To

The SMO I/C ICTC Palampur/ Dehra/ Kangra/ ZH Dharamshala
District Kangra.

Subject: Referral of HIV positive clients for study on HIV stigma & discrimination.

Dear Doctors,

Fear of stigma and discrimination is a barrier to improving access to free HIV counseling and testing and ART services. A study is being undertaken by Dr RK Sood on the topic. You are requested to refer HIV positive clients to him for assessment of their social problems and identification of areas in which policy can be made to create an enabling environment to stop HIV AIDS. You are also requested to direct the counselors to refer the positive clients for the assessment on mobile number is 9418064077 to Dr Sood.

The study is being conducted in accordance with ethical guidelines and confidentiality of identity of clients will be maintained. The interview takes about 90 minutes and clients are reimbursed bus fare from the place of residence to Dharamshala after the interview.

Kindly treat the matter as most urgent.

-sd-

Chief Medical Officer,
Kangra at Dharamshala

Endst. No as above

Copy to Dr RK Sood for information and perusal and he is directed to submit the feedback and report within a fortnight to the undersigned.

-sd-
Chief Medical Officer,
Kangra at Dharamshala

Office of the Chief Medical Officer, Kangra at Dharamshala
District Kangra, Himachal Pradesh

No. HFW/KGR /FETP/2008- Dated the 2008.

OFFICE ORDER

Dr. Rajesh Kumar Sood, MAE FETP Scholar, posted in the office of the Chief Medical Officer Kangra for his field assignments of MAE FETP degree course is hereby accorded permission to conduct the following studies:
1. Stigma and discrimination associated with HIV/AIDS in Kangra district of Himachal Pradesh. 2. Evaluation of Revised National Tuberculosis Control Programme in Kangra district of Himachal Pradesh. 3. Evaluation of Integrated Disease Surveillance Programme with special emphasis on Tuberculosis in Kangra district of Himachal Pradesh.
All assistance may kindly be provided to him in completing these projects as in turn it will help to document the baseline status of the programmes and identify training needs and design other appropriate interventions based on feedback, suggestions, problems in the field and knowledge of factors associated with better performance.

Chief Medical Officer,
Kangra at Dharamsala

Endst. No.: as above Dated the 2008

Copy to:
District AIDS Programme Officer (DAPO) Kangra, for needful and assistance to the scholar.
District Surveillance Officer (IDSP) Kangra, for needful and assistance to the scholar.
District Tuberculosis Officer, Kangra for needful and assistance to the scholar.
Dr. Rajesh Kumar Sood, FETP Scholar with the directions to submit feedback and share the findings of report with the undersigned within six months.

-Sd-

Chief Medical Officer,
Kangra at Dharamsala

Office of the Chief Medical Officer, Kangra at Dharamshala
District Kangra, Himachal Pradesh

No. HFW/KGR /FETP/2008- Dated the 2008

To

The All MO/BMO/SMO
in District Kangra,

Subject:- Regarding submission of completed Questionnaires for IDSP Evaluation RNTCP Evaluation and HIV Stigma Studies.

Memo,

The following three operational research studies are being undertaken in the district to improve understanding of problems in implementing health programmes and get your feedback. 1. Stigma and discrimination associated with HIV/AIDS in Kangra district of Himachal Pradesh. 2. Evaluation of Revised National Tuberculosis Control Programme in Kangra district of Himachal Pradesh. 3. Evaluation of Integrated Disease Surveillance Programme with special emphasis on Tuberculosis in Kangra district of Himachal Pradesh.

The proformas for data collection have been circulated to you earlier. All assistance may kindly be provided to Dr RK Sood (Nodal Officer) for the research projects in completing these projects as in turn it will help to document the baseline status of the programmes and identify training needs and design other appropriate interventions based on feedback, suggestions, problems in the field and knowledge of factors associated with better performance.

Reminder is issued for the following Proformas- Kindly ensure submission of filled proformas

MOs.	Stigma and discrimination on **HIV** AIDS; **IDSP** Questionnaire for MO/BMO; **RNTCP**- MO PHI/ DMC/ MOTC Questionnaires.
Nursing staff	Stigma and discrimination on **HIV** AIDS
Lab /tech	**IDSP** LT Questionnaires; **TB** questionnaires for LT (DMC/ TU)
MPW	**IDSP** MPW Questionnairres
STS/STLS	**TB** Questionnaires

You are further directed to complete the questionnaires and ask your subordinate staff to fill the questionnaires and deposit the completed forms in IDSP Cell of this office within 10 days positively. In case proformas are not received, or if you need any clarifications on the questionnaire you may contact your Block Medical Officer or Dr RK Sood on Mobile No 9418064077.

-sd-

Chief Medical Officer,
Kangra at Dharamshala

Endst No As above

Copy to Dr RK Sood for information and perusal and he is directed to submit the feedback ad report within a fortnight to the undersigned.

-sd-
Chief Medical Officer,
Kangra at Dharamshala