

Understanding and measuring AIDS-related stigma in health care settings: A developing country perspective



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ABSTRACT

AIDS-related stigma and discrimination remain pervasive problems in health care institutions worldwide. This paper reports on stigma-related baseline findings from a study in New Delhi, India to evaluate the impact of a stigma-reduction intervention in three large hospitals. Data were collected via in-depth interviews with hospital staff and HIV-infected patients, surveys with hospital workers (884 doctors, nurses and ward staff) and observations of hospital practices. Interview findings highlighted drivers and manifestations of stigma that are important to address, and that are likely to have wider relevance for other developing country health care settings. These clustered around attitudes towards hospital practices, such as informing family members of a patient's HIV status without his/her consent, burning the linen of HIV-infected patients, charging HIV-infected patients for the cost of infection control supplies, and the use of gloves only with HIV-infected patients. These findings informed the development and evaluation of a culturally appropriate index to measure stigma in this setting. Baseline findings indicate that the stigma index is sufficiently reliable ($\alpha = 0.74$). Higher scores on the stigma index – which focuses on attitudes towards HIV-infected persons – were associated with incorrect knowledge about HIV transmission and discriminatory practices. Stigma scores also varied by type of health care providers – physicians reported the least stigmatising attitudes as compared to nursing and ward staff in the hospitals. The study findings highlight issues particular to the health care sector in limited-resource settings. To be successful, stigma-reduction interventions, and the measures used to assess changes, need to take into account the sociocultural and economic context within which stigma occurs.

Key words: Stigma, discrimination, health care worker, HIV/AIDS.

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RÉSUMÉ

La stigmatisation liée au SIDA et la discrimination restent toujours des problèmes qui se répandent partout dans des établissements de soins dans le monde entier. Cette communication porte sur des résultats de référence d'une étude liée à la stigmatisation faite à New Delhi, en Inde avec le but d'évaluer l'impact de l'intervention qui cherche à réduire la stigmatisation dans trois grands hôpitaux. Des données ont été recueillies par le biais des entretiens profonds auprès du personnel hospitalier et de patients vivants avec le VIH, des études auprès du personnel de l'hôpital (n = 884 médecins, infirmiers et personnel de services) et l'observation des habitudes hospitalières. Les résultats des entretiens ont souligné les tiges d'entraînement et des manifestations de la stigmatisation qui doivent absolument être abordés et qui pourraient avoir une pertinence étendue à d'autres situations de soins dans des pays en voie de développement. Ces derniers se sont regroupés autour des attitudes envers les habitudes hospitalières à savoir : informer la famille du patient de la séropositivité de celui-ci sans son accord, brûler les draps et les couvertures des patients séropositifs, faire payer pour les approvisionnements contre l'infection et l'utilisation des gants uniquement pour des patients du VIH. Ces résultats ont guidé le développement et l'évaluation d'un indicateur culturellement convenable afin de mesurer la stigmatisation dans ce cadre. Les résultats de référence montrent que l'indicateur de stigmatisation est suffisamment fiable ($\alpha = 0,74$). Les chiffres les plus élevés de l'indicateur de stigmatisation – qui mettent au point les attitudes envers les personnes séropositives – étaient associés à une connaissance erronée de l'infection au VIH et les habitudes discriminatoires. Les résultats de stigmatisation étaient différents suivant le type de personnel de santé – les médecins montraient des attitudes de stigmatisation les plus basses en comparaison aux infirmiers et le personnel de services dans les hôpitaux. Les résultats de cette étude soulignent des sujets du secteur de soins propre aux cadres à ressources limitées. Afin de réussir, les interventions visant la réduction de stigmatisation et les mesures utilisées pour évaluer les changements doivent prendre en considération le contexte socioculturel et économique dans lequel la stigmatisation a lieu.

Mots clés: Stigmatisation, discrimination, personnel de soins, VIH/SIDA.

INTRODUCTION

AIDS-related stigma and discrimination have serious individual and public health ramifications that contribute to a reluctance to be tested for HIV and to disclose positive test results to partners, poor treatment adherence, and increased risk of disability and drug resistance (van der Meij & Heijnders, 2004). Various studies have demonstrated that AIDS-related stigma is a common phenomenon worldwide, that occurs in a variety of contexts, including the family, community, workplace, and health care settings (e.g., Ogden & Nyblade, 2005; Parker and Aggleton, 2003; Reidpath and Chan, 2005).

The health care setting is a particularly conspicuous context for HIV/AIDS-related stigma and discrimination. In this context people living with HIV or AIDS (PLWHA) often discover their status, and it is where people living with HIV have the potential to gather information about how to care for themselves and prevent transmission to others, as well as get treatment and care. Because of stigma, there have been various reports of HIV positive people receiving

inferior care or being denied care altogether (Ogden & Nyblade, 2005). For example, health care workers are influenced by the attitudes of the greater society, and prevailing negative attitudes can result in discrimination.

In India, a country with an estimated HIV/AIDS epidemic of between 2 to 3.1 million people (WHO, 2007), over 80 percent of reported AIDS cases are due to unprotected heterosexual intercourse (NACO, 2006). The epidemic remains concentrated among vulnerable and marginalised populations including sex workers, injecting drug users and men who have sex with men (UNAIDS, 2006). Here, as elsewhere, AIDS is perceived as a disease of "others" – of people living on the margins of society, whose lifestyles go against social norms and are often considered "wrong" or "sinful". Social reactions have been quite negative. For example, 36 percent of respondents in one study felt it would be better if infected individuals killed themselves, and that infected people deserved their fate (Ambati, Ambati, & Rao, 1997). Stigma and discrimination against PLWHA have also been documented in the Indian health care setting,

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including denial of care and overt labelling of their HIV-infected status (Bharat, Aggleton, & Tyrer 2001). As was found in another study with PLWHA, AIDS-related fear and anxiety, and at times denial of their status, could be traced to traumatic experiences in health care settings for a majority of those interviewed (Bharat, 1996).

While AIDS-related stigma in health facilities has become better understood over the years, it is only recently that responses are moving beyond documenting negative experiences to implementing interventions (Brown, Macintyre, & Trujillo, 2003). However, evaluation of stigma reduction interventions remains challenging, due to a lack of appropriate and validated instruments to measure stigma and discrimination (Synergy Project, 2004). One such stigma-reduction intervention was recently piloted with health care workers in health care settings in New Delhi, India by Horizons/Population Council and SHARAN, an eminent AIDS service NGO in the country (Mahendra & Gilborn, 2004). The overall objective of the intervention research was to test the effectiveness of a stigma-reduction intervention, with the goals of reducing discriminatory practices and improving quality of care for PLWHA. This paper focuses on the formative findings that informed the development of an index to measure AIDS-related stigma among health care workers, the quantitative baseline findings related to expressions of stigma, and associations between stigmatising attitudes and other key variables, such as HIV-related knowledge. It highlights the manifestations and drivers of stigma that are important to address in the low-resource Indian health care context, and that are likely to have wider relevance for other developing country settings. Finally, the paper concludes with recommendations for appropriate interventions to address stigma in this setting, and a discussion about the usefulness of the index.

The need for a stigma index for the Indian health care setting
To measure stigma and discrimination in the health care setting, appropriate tools are needed. Although tools have been developed to assess stigmatising beliefs and discriminatory practices in general, many of them have been developed in the United States. For example, of the 14 HIV-related stigma scales or indices discussed in a recent review paper by van Brakel (2006), ten were developed in the United States and

only three in developing countries. Similarly, examples of tools to measure stigma among health care workers can be found, but in general, these are for Western audiences. For example, of the six HIV-related instruments for the health care setting or health workers described in the van Brakel summary, only one had been developed in a developing country setting – Tanzania (Tanzania stigma-indicators field test group, 2005)¹. A review of the five other published scales (Blumenfield *et al.*, 1987; Dubbert, Kemppainen, & White-Taylor, 1994; Froman, Owen, & Daisy, 1992; Froman & Owen, 1997; Harrison, Fusilier, & Worley, 1994; Schondel, Shields, & Orel, 1992) reveals that the scales tend to focus on measuring (1) blaming attitudes toward people with HIV, such as that a person with HIV deserves to get the disease; (2) concerns related to casual contact, such as fears of touching people with HIV; and/or (3) general questions related to the provision of health care, such as whether the provider would be willing to offer equal quality of care to people with and without HIV. While each of these issues is important, the scales did not address a series of additional issues that may be particularly relevant in a health care setting with limited resources. The formative research (described below) highlights some of these issues.

Methods

Site selection

Three large hospitals in New Delhi, India were selected to participate in the intervention study. Researchers sought hospitals that reported admitting and treating HIV-infected patients and that represented a range of administrative functioning (public and private; central and state government administered). This followed a selection process wherein almost 20 hospitals representing three different administrative structures – central government, state government, and private – were identified from which six were short-listed. These six were selected because they had an in-patient capacity of over 500, employed more than 1,000 health care workers (which would allow for adequate sampling), and were treating HIV-infected patients. After reviewing the study protocol, three of the six hospitals expressed their interest and willingness to participate in the study. The study methodology was finalised in discussions with the hospital authorities.

In each of the hospitals, the researchers purposively selected four departments that were most likely to

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report treating HIV-infected patients. These four departments were medicine, STD and skin, obstetrics and gynaecology, and surgery. After receiving approval from the hospital authorities and heads of the selected departments, the research project was conducted in the in-patient wards of the four departments.

Data collection

After site selection, the researchers began the study with a period of formative research. In this phase, qualitative interviews and focus groups with a variety of respondents and observations of practices in the hospital setting were conducted. The formative phase consisted of 59 key informant interviews with hospital staff, clients receiving in-patient care, and caregivers, as well as 30 structured observations (of five hours each for a total of 150 hours of observations) of the hospital environment and of provider-patient interactions. In addition, six focus group discussions with 40 people living with HIV who were receiving services from local AIDS service organisations, as well as caregivers from various agencies were also conducted. Information was gathered about the manifestations of stigma and discrimination in the hospital setting, as well as the individual and institutional factors that fostered stigma and discrimination among health care workers. All interviews were conducted after receiving informed consent from the respondents.

Following the formative research, a baseline survey was conducted in all sites. In each hospital, three levels of health care workers who were most in contact with patients on a daily basis through providing hands-on care were recruited as survey participants. These were doctors, nurses and ward staff. Doctors and nurses provide medical care, while ward staff are responsible for the daily cleaning of the wards and departments. Using stratified random sampling, a proportional representation of the three levels of health care workers was selected from the four departments. While the private and public hospitals varied in size, the staffing size was similar in all three hospitals. Informed consent was sought from all staff for their participation in the survey. In all, a representative sample of 134 doctors, 375 nurses, and 375 ward staff, totalling 884 health care workers, were interviewed from the three hospitals at baseline. As a significant proportion of ward staff lacked basic literacy skills to read and write, all respondents were interviewed using a structured questionnaire to collect the required information.

Measures and data analysis

For this study, definitions of stigma and discrimination were based on a review of the existing literature and formative research findings. Stigma was defined as negative attitudes directed towards PLWHA because of their HIV status, and discrimination was defined as 'enacted stigma' or behaviours that stemmed from these stigmatising beliefs. The beliefs that PLWHA do not have the right to marry, that they 'get what they deserve', or that they should be kept at a distance from other patients were examples of stigmatising attitudes. The act of refusing to care for HIV-infected patients because of their status would be an example of a discriminatory behaviour.

Based on the formative research findings, items to measure HIV-related stigma in the study's health care settings were developed and tested (see description in results). Respondents were asked whether they agreed or disagreed with 21 items, and answer choices were offered on a three point Likert scale (Agree [1], Can't say [2], Disagree [3]), with a maximum total score of 63 for the 21 items. The 21 items were combined into an index. All items were coded so that a higher number always indicated greater stigma. Frequencies of stigma index items were analysed, as were characteristics of the stigma index (e.g., mean), and associations between the stigma index and key additional variables, including HIV-related knowledge and various discriminatory behaviours in the health care setting. T-tests of means, and one-way ANOVA tests were applied. All statistical analyses were conducted using the software package SPSS. Analyses of qualitative data focused on eliciting key themes related to stigma and discrimination.

Participant characteristics

Data from the baseline survey show that doctors and ward staff were predominantly male, whereas all the nursing staff were female. Doctors had the youngest mean age (31.2 years) and ward staff the oldest (37.8 years). Nearly two-thirds (65%) of doctors were below 30 years old, compared to 49 percent of the nurses and 33 percent of the ward staff. The majority of all staff interviewed had a service tenure of less than ten years. While all doctors and nurses had advanced educational qualifications, the educational background of ward staff varied from illiteracy to post graduate degrees. Almost one-fourth of the ward staff had no schooling but reported having basic literacy skills.

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Results

Formative research findings: Hospital practices

The formative research highlighted four types of discriminatory practices carried out by health care workers in the hospital setting: testing patients for HIV without their consent, disclosing test results to relatives and other health care workers without the consent of patients, labeling of HIV-infected patients' belongings or files, and unwarranted use of precautions to prevent transmission.

Testing patients for HIV without counselling and informed consent emerged as a common practice among health care workers. According to one in-patient, "My blood was tested twice ... *No one told me why it was being tested.*"

While some doctors were aware of the procedure of obtaining a patient's consent prior to an HIV test, they chose not to use it as they felt the patient would be unable to understand the consent form:

I don't think consent matters that much. Theoretically, it is nice to talk about consent, but practically it is not possible. Many people do not know how to read or sign. In that case, consent does not really matter.

Routinely informing families about a patient's HIV status also was a common occurrence. According to a nurse, "If the result is positive, then the doctor tells the patient as well as his relatives." This practice was corroborated by patients; according to one informant, "The doctor told me that I have AIDS ... he also told my relatives ... he did not ask me before telling them."

In addition to improper disclosure of test results to family members, informants commented that health care workers frequently shared patients' status with each other. According to one nurse, "Everybody (doctors, nurses, sweepers and ward boys) who works with patients knows the status of the patient." One patient reported the following: "All the staff in the ward knows my status. The doctor tells the nurse, the nurse tells the ward staff and they tell everyone else about me."

One reason given for sharing a patient's status was to encourage health care workers to take "adequate precautions" to protect themselves while treating or handling the patient. According to one ward staff member, "When there is an HIV-infected patient in the

ward, doctors tell us to be careful and use safety measures to protect ourselves." Confidentiality of a patient's status was also breached by the use of markings or labels on beds and files. Observational data revealed that in some of the wards, use of labels such as 'High Risk', 'Barrier Precautions' and 'DANGER' were posted on top of patient's beds to indicate their HIV-infected status. Interviews with people living with HIV and their caretakers supported the observational data about labelling HIV-infected patients. According to one mother of an HIV-infected child, "Bed labels were put up for my baby. All who could read the label knew the status of my baby."

Other subtle markers reported by health workers to indicate a patient's status to other staff included placing the bed at the end of the room or next to the toilet, placing a cloth screen around the patient's bed, and placing the patient in a separate ward or room. One nurse noted: "We move the HIV positive patient outside the room into the corridor so that he is kept separately from other patients."

Another practice that indicated a patient's status was whether or not health care workers used gloves. In two of the three hospitals, the researchers observed that health workers only used gloves with patients whose beds or files were marked as HIV-positive. In the third hospital, researchers noted that nurses wore gloves during every interaction with patients, including those that involved casual contact like giving medicines to patients.

These practices of disclosing patients' HIV status to other health workers without their consent by overt and covert means were viewed by health workers as their right to know, in order to protect themselves from potential infection. According to one doctor, "You are concerned about human rights of people who are going to die soon – they are only a small fraction of patients. What about my right as a doctor – don't I have the right to survive?"

Rather than practising universal precautions, many hospital staff took inadequate precautions with the general patient population, and excessive precautions with patients they knew to be HIV-infected. One nurse commented: "You know, every time we cannot wear gloves. We take precautions while dealing with these (HIV-infected) patients."

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The reason for selective use of universal precautions with HIV-infected patients was explained by the lack of availability of supplies, such as gloves, running water, etc, necessary for the practice of infection control in health care settings. Staff mentioned that if they were told of an HIV-infected patient's status beforehand, it helped them protect themselves from potential infection. According to one nurse, *'Precautions taken by us are not adequate, therefore once we know the status of the case we can prepare ourselves to take precautions in advance.'*

Waste management practices also varied on the basis of a patient's disease status, with extreme steps being reported for HIV-infected patients. According to one ward staff, *"We burn the linen of the patient. Even utensils of HIV-infected patients are thrown away."* Sometimes, the patients were asked to bring their own supplies to the hospital so that they could be either returned or disposed off to avoid using them for other patients. A nurse commented, *"All disposable items such as gloves, masks, etc. and AIDS kits are purchased by the patient or his/her family...after use they are disposed off."*

Formative research findings: Health worker attitudes toward people living with HIV/AIDS

In a second major theme, interviews with health workers also revealed that many held judgmental and prejudiced attitudes toward people living with HIV, and blamed their infection on specific attributes, such as their social class, occupational status or behavioural practices. According to one doctor, *"HIV can spread only through errors of human behaviour."* Another doctor commented, *"High risk population means lower class people – they live in slums in unhygienic conditions. These people sleep with anybody. In this class of people, extramarital affairs are common and also drug users and sex workers come in this category."*

Once infected, some health workers felt that PLWHA should not lead a normal healthy life by marrying and procreating. They also mentioned that an HIV-infected woman should terminate a pregnancy rather than give birth to a child who could be born with HIV infection.

The people living with HIV whom we interviewed reported confronting judgmental attitudes of health care workers. According to one patient, some staff members were rude and overly inquisitive about how he got infected with HIV. *"They asked me, 'how did you*

get this, what all did you do, where has it come from?' I feel that they are only concerned about how I got the disease."

Another patient mentioned that a doctor told his pregnant wife *"just drop (terminate) the child"* rather than giving birth to a child who may be born with HIV infection.

Designing and evaluating the stigma index

The formative research findings helped identify important dimensions of stigma and discrimination against PLWHA in health care settings in India. The researchers then conducted a review of available national and international literature on stigma reduction interventions and measures, to supplement and finalise a list of candidate items (50 items). These items were then reviewed by a team of specialists in India with HIV stigma-related experience.

After review, ten items were rejected and this revised list of 40 items was then translated and pre-tested in the participating study hospitals, with 45 respondents selected from departments other than the four selected for the study. Based on this pre-test, eight other items were removed – due to lack of clarity, etc. – and a list of 32 items was short-listed for use in the baseline survey. Twenty-one items were worded as statements and 11 were worded as questions. These 32 items address the main issues that emerged from the formative research, including attitudes of blame towards some groups of PLWHA, attitudes about personal contact with PLWHA in society, and attitudes related to hospital practices and policies towards PLWHA.

Following a review of baseline survey responses, it was determined that some questions were unclear to respondents, or where they answered 100% in one direction or another, they were removed from the index list. After a final consultation, 21 items were retained in the index. A higher score denotes a higher level of stigma. The internal consistency reliability for this index in the baseline survey was good at 0.742 (Cronbach's alpha).

Responses to items on the stigma index

Attitudes towards PLWHA

Some statements assessed attitudes about casual contact with HIV-infected people in the social setting in which health workers lived and worked (See Table 1). There was a great deal of fear of casual contact with PLWHA: when health workers were asked if they

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TABLE 1. STIGMA ITEMS: ATTITUDES TOWARDS PEOPLE LIVING WITH HIV (N=884)

| Attitudes about personal contact | % yes |
|---|----------|
| Would you be willing to share a meal with an HIV-infected person? | 41 |
| If you knew that a foodseller had HIV/AIDS would you buy food from him? | 52 |
| Would you be willing to move into a home if the neighbour was HIV-infected? | 72 |
| If you found out that a co-worker has HIV would you be willing to work with him/her? | 87 |
| Blaming and judgmental attitudes | % agreed |
| HIV/AIDS spreads due to immoral behavior. | 68 |
| Men who get HIV/AIDS get what they deserve. | 37 |
| Sex workers are the only women who have to worry about getting HIV. | 43 |
| Men who go to sex workers or use drugs are the only men who have to worry about getting HIV | 44 |
| A woman who gets HIV gets what she deserves. | 29 |

would share a meal with an HIV-infected person, less than half (41%) would be willing to do so. At the same time, health workers had a more supportive attitude toward working with a colleague who was HIV-infected, as 87 percent of respondents would be willing to work with an HIV-infected colleague.

Other statements in the baseline survey assessed blaming or judgmental attitudes towards PLWHA. The majority of health workers seemed to associate HIV with negative or immoral behaviours, as for example, over two-thirds (68%) of respondents indicated that HIV is spread by immoral behaviours. HIV was also associated with populations at higher risk of exposure, for example, almost one half (43%) of respondents indicated that the only women who were at risk for HIV infection were sex workers. A substantial proportion of respondents expressed explicit blaming attitudes; almost 40 percent indicated that men with HIV deserved to be infected and ill.

A series of items were also included to assess health workers' attitudes towards safeguarding human rights of PLWHA (Table 2). Health workers gave mixed responses about supporting the rights of infected individuals. While over three-quarters of health workers agreed that HIV-infected people had the right to decide who should know their status, an equally large proportion endorsed the view that HIV-infected women should not get pregnant and have children. Also, a majority (60%) did not agree that PLWHA

should have the right to marry.

Attitudes towards practices in health care settings

A series of items were included regarding attitudes towards different hospital practices (See Table 2). Based on formative research, mandatory HIV testing appeared to be commonly practised in the participating hospitals. As per Indian national guidelines, mandatory HIV testing is considered a violation of patients' rights, and voluntary counselling and testing is promoted as the appropriate practice. In the baseline survey, almost 90 percent of health workers endorsed the practice of conducting mandatory HIV testing prior to surgery. More than half of the respondents (61%) also disagreed with the need for seeking patient's informed consent prior to testing. Furthermore, over three-quarters of the respondents (79%) agreed that all pregnant women should be tested for HIV.

Regarding disclosure of HIV test results, over half of the respondents (57%) agreed that the patient had the right to decide about disclosing his/her HIV test results to relatives. However, there was almost unanimous agreement (94%) with the statement that doctors should inform the patient's partner.

A majority of health workers (55%) agreed that patients should be distanced from other patients. Also, there was great support for infection control measures that would be unnecessary to prevent HIV infection. For example, two-thirds of respondents (67%) agreed that clothes and linen should be destroyed after HIV positive patients used them.

Stigma index scores and key associations

The responses to all of the 21 items in the stigma index were combined into one score. The mean score for the full group of health workers (N = 884) was 42.79, with individual scores ranging from a minimum of 23 to a maximum of 61. The difference among the three groups of health care workers was significant (one-way ANOVA test p value of .000), with the ward staff having the highest mean stigma score of 47.80, followed by nurses (39.99) and then doctors who had the lowest score of 36.60.

HIV-related knowledge and stigma

As part of the baseline survey, information about health staff's knowledge about HIV transmission was collected – addressing general transmission and transmission in health care settings. Responses to the knowledge

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TABLE 2. STIGMA ITEMS: HEALTH WORKER ATTITUDES TOWARDS PRACTICES IN HEALTH CARE SETTINGS (N=884)

| Attitudes about HIV testing, informed consent and disclosure | % agreed |
|---|----------|
| Patients should be tested for HIV before surgery. | 86 |
| All pregnant women should be tested for HIV. | 79 |
| The need for consent is exaggerated. HIV tests should be handled like any other blood test. | 50 |
| Patient's blood should never be tested for HIV without their consent. | 39 |
| Patients who test positive have the right to decide whether their relatives should be informed. | 57 |
| When a person tests positive, the doctor should inform the patient's partner. | 94 |
| Attitudes towards infection control procedures | % agreed |
| Patients with HIV should be kept at a distance from other patients. | 55 |
| Clothes and linen used by HIV-infected patients should be disposed of or burned. | 67 |
| HIV-infected patients should be made to pay for health workers' use of additional infection control supplies. | 10 |
| Attitudes towards PLWHA rights | % agreed |
| People living with HIV should have a right to decide who should know about their status. | 78 |
| People with HIV should be allowed to get married. | 39 |
| HIV positive women should not get pregnant. | 80 |

questions were then compared with the staff's scores on the stigma index. Consistently, health workers who had misconceptions about HIV transmission scored significantly higher on the stigma index than those with correct knowledge (see Table 3). For example, those who believed that being close to an HIV-infected patient could result in HIV transmission were significantly more likely to hold stigmatising attitudes.

Discriminatory practices and stigmatising attitudes

Associations between stigma index scores and discriminatory practices were also examined (See Table 4). Some questions relating to general hospital practices were asked of all staff, while other questions that were relevant to only certain cadres of health workers were asked of that particular subgroup. For example, only doctors were asked about their experiences providing HIV counselling and testing services, and all health workers were asked about whether they intentionally avoided touching HIV positive patients. Associations were tested between the behavior of the relevant group and the stigma scores for the subgroup in question.

TABLE 3. ASSOCIATION BETWEEN HEALTH WORKERS KNOWLEDGE AND STIGMA SCORES

| Knowledge about HIV transmission (general and in hospital setting) | Staff response and mean stigma index scores (higher score = greater stigma) | | Significance * (t-test for equality of means at levels below 0.05) |
|--|---|-------|--|
| | Yes | No | |
| HIV can be transmitted by | | | |
| Touching PLWHA | 50.28 | 42.20 | * |
| Breath of PLWHA | 48.48 | 41.79 | * |
| Saliva/sputum of PLWHA | 44.14 | 41.54 | * |
| Mosquito bite | 45.94 | 40.93 | * |
| In hospital setting, HIV can be transmitted by | | | |
| Handling dry linen without gloves | 47.76 | 41.73 | * |
| Blood splash on intact skin | 47.36 | 40.97 | * |
| Serving food to HIV-infected patient | 45.83 | 42.63 | NS |
| Coming close to HIV-infected patient | 49.77 | 42.25 | * |

The analysis determined that staff members who had scored higher on the stigma index were more likely to report discriminatory practices. Examples of these behaviours included: (1) avoiding going near HIV-infected patients, (2) sharing the patient's HIV status with non-treating staff or with staff who did not directly interact with the patient, and (3) the inappropriate use of gloves during casual contact with HIV positive patients.

DISCUSSION

The formative data revealed important dimensions of stigma and discrimination particular to the health care setting in India, and possibly to other resource-limited developing world settings. These clustered around support for certain hospital practices, which when carried out by enough health workers, could contribute to the establishment of a normative environment that perpetuates discriminatory behaviours among health care workers. Examples of these hospital practices are the burning of linen of HIV-infected patients and charging HIV-infected patients for the cost of infection control supplies.

The inappropriate use of gloves and the misinterpretation of Universal Precautions, widely found in this study, is one particularly challenging issue for resource-limited health care settings. The National AIDS Control Organisation (NACO) has guidelines

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TABLE 4. DISCRIMINATORY PRACTICES AND ASSOCIATION WITH STIGMA MEAN SCORE

| Discriminatory practices | Mean stigma index scores (higher score = higher stigma) | | Significance* (t-test value below 0.05) |
|---|--|-------|--|
| | Yes | No | |
| Reported practices of all health workers | | | |
| To protect themselves from HIV infection while working in the hospital, staff report they try to | | | |
| Avoid going near HIV-infected patients (N=884) | 45.40 | 42.53 | * |
| Avoid touching HIV-infected patients (N=884) | 46.18 | 42.46 | * |
| Reported practices of doctors and nurses | | | |
| Share HIV-infected status of patient with ward staff (N=509) | 39.73 | 35.43 | * |
| Reported practices of doctors | | | |
| Of those doctors who (N=48) received an HIV-infected test result for a patient, informed family members | 36.14 | 34.90 | NS |
| Of the doctors who informed family members (N=28), did not obtain patient's consent prior to informing family | 36.94 | 35.08 | NS |
| Reported practices and nurses | | | |
| Wear gloves to give medicines to HIV-infected patients (N=364) | 41.67 | 39.22 | * |
| Always inform relatives about patients HIV status (N=336) | 41.29 | 39.51 | * |
| Reported practices of ward staff | | | |
| Wears gloves to transport HIV-infected patients and not for HIV negative patients (N=209) | 49.09 | 46.09 | * |
| Wears gloves for delivering food to HIV-infected patients and not for HIV negative patients (N=46) | 47.20 | 42.60 | * |

that state that 'low risk' activities such as touching HIV positive patients, transporting patients from one location to another, and injections and related activities do not require glove use; and these guidelines were reflected in the policies of the study hospitals. Thus, when health workers reported using gloves for these activities only with HIV positive patients, it was both indicative of discriminatory practices and potentially problematic in an environment where gloves were sometimes unavailable for needed procedures. Many of these findings correspond with findings from

a large qualitative study conducted in health care settings in Mumbai and Bangalore, India. Drawing on key informant interviews, in-depth interviews, and focus group discussions, Bharat, Aggleton and Tyrer (2001) found that disclosure of HIV test results to family members of people living with HIV/AIDS, without consent from the person in question, was a fairly common practice. Other examples of stigmatising and discriminatory acts included denial of care, overt labelling of HIV-infected status on files and beds, and excessive use of barrier precautions by health workers.

There was a relatively high level of support for discriminatory behaviours in these hospital settings across all cadres of health workers. However, based on stigma index scores, attitudes varied substantially by category of worker. Physicians reported the least stigmatising attitudes, followed by nurses. Ward staff reported the most stigmatising attitudes. All of these health workers regularly interacted with HIV-infected patients. This finding highlights the importance of providing sufficient HIV-related education and stigma-reduction activities to all health workers who interact with PLWHA patients, and not only to professional staff, such as nurses, who are often the main recipients of training and interventions. It is important to include all staff whenever possible in stigma-reduction activities.

Findings from the literature review and the formative research also highlighted the need to develop a tool tailored to measure AIDS-related stigma among health workers in a limited resource setting such as India. Existing tools that were reviewed focused on fear of casual contact with, and judgmental attitudes toward, people living with HIV. While these topics were found to be relevant among the study population as well, and were reflected in the stigma index that was developed, other topics specific to the health care setting in a low-resource setting such as India also emerged as very important.

Study findings indicate that the index was sufficiently reliable ($\alpha = 0.74$). Furthermore, stigma was associated with other key variables hypothesised to be related to stigma. For example, a growing body of data suggests that people with better knowledge tend to exhibit less stigmatising attitudes towards PLWHA. According to Lau, Tsui and Chan (2003), for example, stigmatising attitudes of youth were reduced after

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exposure to an educational intervention. This study supported these findings, as those health workers who scored higher on the stigma index were more likely to have less knowledge about HIV transmission, such as knowledge that HIV cannot be transmitted by touching an HIV positive patient or by handling dry linen. Discriminatory behaviours were considered another set of key variables, as more stigmatising attitudes would theoretically lead to more discriminatory behaviours. This supposition was also borne out, as respondents with higher stigma scores were more likely to carry out discriminatory behaviours, such as avoiding any contact with HIV-infected patients or sharing the HIV status of a patient with staff who did not treat or directly interact with the patient, due to unnecessary concerns about safety.

The baseline findings helped guide the development of an intervention. They highlighted that a stigma reduction intervention in the hospital setting needed to include activities at the individual and institutional levels. As a result of discussing the findings with hospital managers, a multi-level intervention that included participatory self-assessment, sensitisation training, development of posters reinforcing infection control procedures and policy reform was implemented. The findings from the intervention evaluation will be reported in a separate paper.

The findings reported on in this paper highlight that stigmatising attitudes and discriminatory behaviours towards people living with HIV/AIDS are big challenges in hospitals in India, and that there are particular issues in this limited resource setting that are often not taken into account in global discussions about HIV-related stigma in the health care sector. To be successful in this context and in other resource-limited settings, stigma-reduction interventions need to take into account the sociocultural and economic context within which stigma occurs.

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Footnotes

¹This index had resulted out of collaboration between a number of institutions, led by the International Centre of Research on Women, Muhimbili University, and the Synergy Project/TvT Associates, and one of the authors of the current paper (Dr. Pulerwitz) had provided input into the development of the index.

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