Blame, Symbolic Stigma and HIV Misconceptions are Associated with Support for Coercive Measures in Urban India

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Abstract This study was designed to examine the prevalence of stigma and its underlying factors in two large Indian cities. Cross-sectional interview data were collected from 1,076 non-HIV patients in multiple healthcare settings in Mumbai and Bengaluru, India. The vast majority of participants supported mandatory testing for marginalized groups and coercive family policies for PLHA, stating that they “deserved” their infections and “didn’t care” about infecting others. Most participants did not want to be treated at the same clinic or use the same utensils as PLHA and transmission misconceptions were common. Multiple linear regression showed that blame, transmission misconceptions, symbolic stigma and negative feelings toward PLHA were significantly associated with both stigma and discrimination. The results indicate an urgent need for continued stigma reduction efforts to reduce the suffering of PLHA and barriers to prevention and treatment. Given the high levels of blame and endorsement of coercive policies, it is crucial that such programs are shaped within a human rights framework.

Keywords AIDS stigma · Discrimination · PHLA · India

Introduction

The stigma associated with AIDS and HIV infection has long been recognized as a significant barrier in the worldwide fight against HIV/AIDS [1]. Misconceptions regarding transmission during casual social contact and pre-existing negative attitudes towards marginalized groups have been consistently associated with prejudice towards HIV-infected individuals and a willingness to restrict their civil liberties, in multiple settings [2–4].

Stigma refers to the devalued status that society attaches to a condition or attribute. Social psychologists conceptualize stigma not only as a property of a discrediting status or characteristic, but also as a set of socially constructed meanings associated with that status or characteristic. By conveying the devalued status of some identities relative to others, stigma defines social roles within interactions [4–7]. The inferior social status of stigmatized individuals means that they have less power than the non-stigmatized and less access to resources valued by society [8, 9], including health care.

Based on these considerations, AIDS stigma is used here to refer to socially shared perceptions about the devalued status of people living with HIV/AIDS (PLHA). Among individuals, it is manifested as perceptions of stigmatizing community norms, endorsement of coercive policies, personal prejudice and discrimination directed both at people perceived to have HIV and groups, such as Female Sex
Workers (FSW) and Men who have Sex with Men (MSM), who have been hardest hit by this epidemic [4, 10, 11].

Research has shown that AIDS stigma often increases pre-existing societal prejudices and inequalities, thereby disproportionately affecting those who are already socially marginalized. Although the specific marginalized groups affected by these “compounded stigmas” may vary, this phenomenon has been identified in the US, as well as in Africa and Asia [12–17]. This symbolic stigma appears to be one of the two primary factors underlying more overt behavioral manifestations of AIDS stigma. The second identified key factor is instrumental stigma (i.e., a fear of infection based on casual contact). This two-factor “theory” was elaborated on by Herek [4, 10, 18] and Pryor [19], showing that symbolic and instrumental stigma drive the behavioral manifestations of AIDS stigma in the US, including endorsement of coercive policies and active discrimination. This finding has been replicated in multiple cultures, as shown e.g., by Nyblade [20], who reviewed global stigma research and identified three “immediately actionable key causes” of community AIDS stigma. These included lack of awareness of stigma and its consequences; fear of casual contact based on transmission myths; and moral judgment due to linking PLHA to “improper” behaviors.

Across cultures, HIV stigma has repeatedly been shown not only to inflict hardship and suffering on people with HIV [21], but also to interfere with decisions to seek HIV counseling and testing [22, 23], as well as PMTCT [24–28] and to limit HIV-positive individuals’ willingness to disclose their infection to others [29–32], which can lead to sexual risk. Stigma has also been shown to deter infected individuals from seeking medical treatment for HIV-related problems in local health care facilities or in a timely fashion [33, 34] and to reduce adherence to their medication regimen, which can lead to virologic failure and the development and transmission of drug resistance. PLHA in Senegal and Indonesia reported avoiding or delaying treatment seeking for STI/HIV infections, both out of fear of public humiliation and fear of discrimination by health care workers [13, 35]. AIDS stigma in Botswana and Jamaica has been associated with delays in testing and treatment services, often resulting in presentation beyond the point of optimal drug intervention [36, 37].

Even when treatment is obtained, stigma fears can prevent individuals from following their medical regimen as illustrated by PLHA in South Africa who ground pills into powder to avoid taking them in front of others, leading to inconsistent dose amounts [38]. In our India ART adherence study, participants frequently report lying about their condition to friends and family and traveling far to get treatment or medications at clinics and pharmacies where they can be anonymous. One woman reported swallowing her pills with her children’s bathwater, since this was her only daily moment of privacy [32, 39].

Moreover, in addition to providing the cultural foundation for popular prejudice against people with HIV, stigma often affects the attitudes and behaviors of health care providers who deliver HIV-related care [33, 40]. As such, understanding stigma’s precise nature and effects on behavior is a vital step in the development of interventions to facilitate health among people living with the disease [41]. The current study was designed to examine stigma attitudes and intentions among people in health care settings; PLHA, health care professionals, and the general patient population. This paper focuses on the latter group, to better understand the attitudes and behaviors of uninfected patients toward PLHA.

The behavioral manifestations of AIDS stigma among health professionals, appear to be driven by both instrumental and symbolic stigma in Asia, Africa and Mexico [42–44]. In India, a study of hospital workers found that those who expressed greater agreement with stigmatizing statements about PLHA, were more likely to have incorrect knowledge about HIV transmission [44]. Other studies in Indian health care settings have also demonstrated that AIDS stigma is associated with moral judgment and blame [45].

The present paper describes types and levels of HIV stigma and intentions to discriminate against PLHA among individuals in outpatient clinics in Mumbai and Bengaluru, two large Indian cities located in Maharashtra and Karnataka states, respectively. Both states have been classified as “HIV high prevalence” states by the National AIDS Control Organization (NACO) of India. Understanding the dynamics of AIDS stigma in these two settings would thus have important implications for future prevention and stigma reduction programs in India.

Methods

Participants

We enrolled 1,076 participants in Bengaluru (n = 530) and Mumbai (n = 546). Participants were recruited from a range of governmental and non-governmental healthcare settings, as well as free-standing clinics. They were required to be either seeking health care services for a non-AIDS related condition or to be accompanying such an individual. In order to be eligible for participation, individuals had to be at least 18 years old, able to speak either a local language (Kannada or Tamil in Bengaluru and Hindi or Marathi in Mumbai) or English and able and willing to give informed consent. Since our focus was attitudes of the general patient population toward PLHA,
people seeking healthcare for an HIV-related condition were excluded from this sample. In addition, because healthcare workers are likely to have different levels of HIV knowledge and experiences with PLHA than members of the general public, we excluded healthcare workers from this sample. Data from these two groups were collected during a different phase of this study and will be reported elsewhere. Potential participants were also excluded if they were unable to respond to the questions asked, e.g., because of intoxication or cognitive deficits. Interested individuals were read the list of exclusion criteria and were allowed to exclude themselves without having to identify the specific reason.

Study procedures were approved by the ethics committees at the Tata Institute of Social Sciences (Mumbai), the National Institute of Mental Health and Neuro Sciences (Bengaluru), and the University of California, San Francisco’s Committee on Human Research, and received clearance from the Indian Council of Medical Research and Health Ministry Screening Committee.

Sampling procedures

This study was designed to examine AIDS stigma in urban Indian health care settings, building on previous qualitative findings, which demonstrated that families and health facilities were the two most likely settings for AIDS stigma [33, 45, 46]. To accomplish this, we selected three subgroups; PLHA, health professionals, and the general health care seeking public. This paper reports findings from the latter group.

Participants were sampled from a multitude of health care settings, including government hospitals, private for-profit hospitals, not for profit non-government hospitals, and free-standing clinics. At each site, study interviewers arrived as soon as the outpatient clinics opened and remained there until closing. Following initial pilot-testing of recruitment procedures, we decided to approach everyone who was likely to have at least a 1 h wait, since the patients who were about to be seen by the doctor were not interested in participating out of fear that they would lose their place in line. It was not feasible to interrupt and resume an interview, since patients did not want to return to the interviewer following their appointments, when they were in a hurry either to obtain their prescriptions, go to the lab, or go home.

Measures

The study instrument included questions used for assessing different aspects of AIDS stigma and associated factors in previous research. These items were subsequently modified based on the qualitative findings obtained by Bharat [33, 46] and during the pilot phase of this study. The measures were administered by trained research staff in individual face-to-face interviews that took approximately 1 h. The surveys were translated into four Indian languages and back-translated into English in order to ensure semantic equivalence [47]. In Mumbai, the survey was available in Marathi (completed by 48.0% of Mumbai participants), Hindi (32.2%), and English (19.6%). In Bengaluru, the survey was available in Kannada (75.3%), Tamil (18.7%), or English (6.0%).

Demographic Information

All participants were asked about their gender, highest level of education completed, marital status, age, and monthly household income. These questions were taken from previous research by the research team in this setting and from the Indian Census questionnaire.

Feelings Toward PLHA

Participants were asked to report their feelings toward PLHA and other social groups on a scale from 0 (extremely negative feelings) to 100 (extremely positive feelings). To control for individual tendencies to assign low or high ratings in general, we used each respondent’s rating for people of his/her own gender (i.e., “women in general” or “men in general”) as an anchor, subtracting the score assigned to each social group from their gender score. Only the anchored PLHA ratings are used in this paper, with a higher score indicating more negative feelings towards PLHA [48].

Symbolic Stigma

This scale consisted of six items assessing how much their personal moral beliefs and their feelings towards different groups, including men who have sex with men, hijras, injection drug users, male and female sex workers, influence their opinions about HIV/AIDS. Response options ranged from 0 (“not at all”) to 4 (“a great deal”). An overall scale score was computed as the mean of the six items (α = 0.76), with a higher score indicating that participants perceived their values and feelings as more greatly influencing their HIV-related opinions [49, 50].

Endorsement of Coercive Policies

Participants rated three statements related to the rights of PLHA to get married and have children (e.g., “People with HIV/AIDS should not be allowed to have children”), and six statements about mandatory testing and refusal of access to education, employment, or care for PLHA (e.g.,
“All female sex workers should be required to be tested for HIV/AIDS.”). Individual items were classified as stigmatizing (“somewhat” or “strongly agree”) and non-stigmatizing responses (“somewhat” or “strongly disagree”, or “don’t know”). An index was created by summing the number of stigmatizing responses to all nine items, resulting in a possible range of 0–9, with high scores indicating greater stigma [48].

Perceptions of Responsibility

Participants indicated their agreement with four statements about who is responsible for spreading or attracting HIV/AIDS (e.g., “Men who go to prostitutes are mainly responsible for infecting their wives with HIV/AIDS.”). Number of agreements for individual items were added up for a total range of 0–4, with higher scores indicating greater responsibility [48].

Blame

Participants indicated their agreement with the statement “People who got HIV/AIDS through sex or drug use have gotten what they deserve.” with strong or moderate agreement considered endorsement of this view [48].

Intent to Discriminate Against PLHA

The intentions to discriminate against PLHA were developed during the pilot phase of this study. They assessed by three questions about hypothetical situations that involved social interactions with PLHA (e.g., “What would you do if you had a co-worker with HIV/AIDS?”) and six statements about avoiding contact with PLHA (e.g., “I would refuse to live in a house next to one occupied by a person with HIV/AIDS.”). Stigmatizing responses were those that indicated the participant would definitely or possibly avoid the PLHA in the hypothetical situations, or strongly/somewhat agreed with a statement expressing avoidance, or strongly/somewhat disagreed with a non-avoidance statement. An overall index was created by summing the number of stigmatizing responses to all nine items, resulting in a possible range of 0–9, with higher scores indicating greater stigma.

Casual Contact Transmission Misconceptions

This index was based on a previous study by Bharat [33] and consisted of six items describing forms of casual social contact through which HIV cannot be transmitted (e.g., “shaking hands with someone who is infected with HIV/AIDS,” “sharing eating utensils with someone who is infected with HIV/AIDS”). For each item, participants indicated whether, in their opinion, HIV can be transmitted through this activity (response options: 0 = “No”, 1 = “Don’t Know”, 2 = “Maybe”, 3 = “Yes”). The number of misconceptions (response options other than “No”) were summed, with higher scores indicating a greater number of misconceptions about HIV transmission.

Transmission Knowledge

We computed the percentage of correct answers to five questions regarding activities through which HIV can be transmitted (e.g., “by sharing drug injection needles used for injecting, with a person with HIV?”). The range of this index is 0–100%, with higher scores indicated greater knowledge of correct transmission routes. It was developed based on the work by Bharat [33].

Relationships with PLHA

Participants were asked whether they personally knew or had known anyone with HIV/AIDS. Responses were coded as “0” if participants had never personally known anyone with HIV, and “1” if they reported having known one or more PLHA [51].

Worry About HIV Infection

One item measured on a 0 (“not at all”) to 3 (“very”) scale how worried respondents were about getting HIV/AIDS [49, 52].

Data Analysis

Descriptive statistics were utilized to describe participants’ demographic characteristics, prevalence of stigmatizing attitudes and behavioral intentions, and knowledge of HIV/AIDS transmission routes for the full cross-site sample and by each site individually. Bivariate chi-square tests (for categorical variables) or t-tests (for continuous variables) were performed on each item as exploratory analyses of potential site differences.

Hierarchical linear regression models were employed for multivariate prediction of the Endorsement of Coercive Policies index, and the Intent to Discriminate against PLHA index. We controlled for the demographic variables Site (0 = Bengaluru, 1 = Mumbai), Gender (0 = male, 1 = female), and Education (0 = ≤10 years, 1 = >10 years). Other predictors were Relationships with PLHA, Blame, Feelings toward PLHA, Symbolic Stigma, Worry about HIV Infection, Transmission Misconceptions and Transmission Knowledge. All these predictors and covariates were entered in the first block. Then, to check for significant site differences, we added interactions between Site and all
the other predictors as a second block. Adding the block of interaction terms did not improve the model (non-significant change in $R^2$) for Intent to Discriminate, so we dropped it again for the final model reported here. For Endorsement of Coercive Policies, some significant site differences were found, and a final model was run that retained only the significant interactions. Procedures testing for problematic multicollinearity and outliers in the data were implemented, with no evidence of either. All data analyses were performed using SPSS 15.0.1 for Windows [53].

Results

As shown in Table 1, the average age of participants at the two sites was approximately 32 years and the samples included similar proportions of males and females. There was a significant site difference in the education level, with 39% of the Bengaluru sample reporting more than 10 years of formal education versus 58% of the Mumbai sample ($\chi^2 = 38.84, P < 0.001$). The average monthly household income was significantly higher in the Mumbai sample than in Bengaluru (Rs 18,523 vs. Rs 12,692, $t = -2.96$, d.f. 1027, $P < 0.01$), though the income range at each site was virtually identical.

Overall, there was a great deal of similarity in the stigma attitude patterns in the two cities (see Table 2). The vast majority of participants supported coercive testing policies for marginalized groups at high risk for HIV/AIDS (91% for MSM and 99% for FSW), while only a minority supported punitive measures such as allowing health care providers to refuse to treat PLHA (5%) and employers being able to fire PLHA (10%). A large proportion of participants at both sites supported coercive family policies for PLHA, e.g., prohibiting them from getting married (72%) and having children (76% for women and 78% for PLHA in general). Most participants also blamed PLHA for their own infections, with 82% stating that they “got what they deserved” and 71% agreeing that they did not think HIV-infected individuals care if they infect others.

Although the proportions endorsing some of the specific stigma items differed between the sites, the overall response patterns were similar.

Self-reported intent to discriminate varied depending on the type of situation presented, with the majority reporting that they would not want to be treated in the same clinic as a PLHA (56%) and 52% stating that they would refuse to eat from the same plate as an infected individual. More than a third (36%) of the participants said they were unwilling to seek services from an infected health care provider, 29% stated that they would not feed an infected person, and a quarter of the participants stated that they would not allow their child to attend the same school as an infected child. Although some of these items were endorsed more frequently in Bengaluru, the ranking order of the items was comparable across sites.

Table 1 Socio-demographic sample characteristics

|                        | Bengaluru Percent (n) | Mumbai Percent (n) | $\chi^2$ |
|------------------------|-----------------------|--------------------|----------|
| Gender                 |                       |                    |          |
| Male                   | 51.9 (275)            | 51.1 (279)         | 0.07     |
| Female                 | 48.1 (255)            | 48.9 (267)         |          |
| Religion               |                       |                    | 83.28*** |
| Hindu                  | 88.1 (467)            | 71.1 (388)         |          |
| Muslim                 | 6.6 (35)              | 11.9 (65)          |          |
| Christian              | 4.7 (25)              | 3.5 (19)           |          |
| Buddhist*              | 0.0 (0)               | 9.3 (51)           |          |
| Other                  | 0.6 (3)               | 4.2 (23)           |          |
| Highest Education      |                       |                    | 38.84*** |
| ≤10 years              | 60.8 (322)            | 41.8 (228)         |          |
| >10 years              | 39.2 (208)            | 58.2 (318)         |          |
| ≤4 years education     | 16.2 (86)             | 4.6 (25)           | 39.44*** |
| Marital status         |                       |                    | 8.62*    |
| Currently married      | 75.1 (398)            | 69.7 (380)         |          |
| Never married          | 20.4 (108)            | 27.5 (150)         |          |
| Other                  | 4.5 (24)              | 2.8 (16)           |          |
| Mean age (range)       | 32.3 (18–70)          | 32.1 (18–66)       | 0.39b    |
| Mean monthly income (range) | Rs 12,692 (500–500,000) | Rs 18,523 (700–500,000) | −2.96b** |

*a* Likely “Ambedkar Buddhists”

>b* t-Value

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$
As shown in Table 3, virtually all participants knew that HIV can be transmitted by sharing needles (96%) and having unprotected sex with an infected person (95%) and approximately two thirds of the participants knew that HIV can be transmitted by an HIV-infected mother breastfeeding her child. Half of the participants believed that HIV transmission was likely when having protected sex with an infected person and a quarter of the sample believed infection is likely when getting an injection with a sterilized syringe and needle. The mean percentages of correct responses to the knowledge questions were 77% for Bengaluru and 71% for Mumbai ($t = 5.31$, $d.f. = 1068.28$, $P \leq 0.001$). Although overall knowledge was significantly greater in Bengaluru than in Mumbai, no clear pattern of differences was evident across the individual knowledge items. For some items more Mumbai than Bengaluru participants gave correct answers for other items (breastfeeding, sterilized needles).

Misconceptions regarding casual transmission routes were common at both sites, but were held by a significantly larger proportion of participants in Bengaluru (47%) than in Mumbai (38%, $\chi^2 = 9.66$, $P < 0.01$). Despite this difference in overall rates, the response patterns were similar and a substantial proportion of participants at both sites believed that HIV transmission is likely from using a public toilet (31%), sharing a glass of drinking water (30%), or sharing eating utensils (27%) with an HIV-infected person. A smaller proportion of the sample perceived that transmission was likely when shaking hands (10%), working in the same office (10%), or sitting close (9%) to a person infected with HIV.

The participants’ feelings toward sex workers were the most frequently rated reason for HIV-related opinions in both cities, followed by their feelings toward IDU and

| Table 2 Percent participants endorsing stigmatizing statements |
|---------------------|---------------------|---------------------|---------------------|
|                      | Total | BLR | MUM | $\chi^2$ |
| Endorsement of coercive policies |
| FSWs should be tested for HIV/AIDS | 98.5 | 99.1 | 98.0 | 2.12 |
| MSMs should be tested for HIV/AIDS | 91.0 | 85.1 | 96.7 | 43.82** |
| HIV+ children should not be allowed to attend school | 16.9 | 20.0 | 13.8 | 7.40** |
| PLHA should have right to choose whether or not to disclose (R) | 15.6 | 13.0 | 18.1 | 5.34* |
| Employers should be able to fire a worker who has HIV/AIDS | 9.5 | 11.3 | 7.7 | 4.05 |
| Health care workers should be able to refuse to treat a PLHA | 5.0 | 4.7 | 5.3 | 0.20 |
| People with HIV/AIDS should not be allowed to have children | 77.7 | 73.0 | 82.2 | 13.17** |
| Women with HIV/AIDS should be allowed to have children (R) | 75.5 | 71.3 | 79.7 | 10.09** |
| People with HIV/AIDS should be allowed to marry (R) | 72.3 | 71.7 | 73.0 | 0.22 |

| Perceptions of responsibility |
| FSWs are mainly responsible for infecting their wives | 95.0 | 95.9 | 94.1 | 1.65 |
| Those got HIV through sex or drug use have got what they deserved | 82.3 | 82.5 | 82.2 | 0.02 |
| Most HIV positive people don’t care if they infect others | 71.2 | 64.8 | 77.6 | 21.25** |
| FSWs are mainly responsible for spread of HIV/AIDS | 69.1 | 77.4 | 61.1 | 33.27** |

| Intent to discriminate |
| An HIV/AIDS patient was treated at same clinic as you | 55.9 | 53.2 | 58.4 | 2.97 |
| Eat from the same plate used by one with HIV/AIDS (R) | 51.7 | 52.1 | 51.4 | 0.05 |
| Not seek services from a HCW with HIV/AIDS | 35.9 | 33.7 | 38.1 | 2.13 |
| Feel comfortable feeding by hand, one with HIV/AIDS (R) | 28.7 | 33.8 | 23.9 | 12.91** |
| Your child had a classmate with HIV/AIDS | 24.9 | 28.7 | 21.2 | 7.95** |
| You had a co-worker with HIV/AIDS | 16.8 | 21.1 | 12.6 | 13.87** |
| Refuse to live next door to one with HIV/AIDS | 18.8 | 19.0 | 18.5 | 0.06 |
| Avoid visiting relative with HIV/AIDS | 14.6 | 17.3 | 12.0 | 6.36* |
| Take care of children with HIV or whose parents had HIV/AIDS (R) | 12.1 | 15.5 | 8.8 | 11.30** |
| Relationships with PLHA (Know ≥ 1 PLHA) | 27.5 | 26.2 | 28.8 | 0.86 |
| Negative feelings toward PLHA: Mean (SD) (range −90–100) | 11 (36) | 7 (38) | 16 (33) | −4.00*** |

R Reverse coded item

* $P < 0.05$, ** $P < 0.01$
MSM. However, mean scores on the 4-point symbolic stigma scale were significantly higher in Bengaluru than in Mumbai (2.5 and 2.0, respectively, $t = 8.09$, d.f. $= 947.98$, $P < 0.001$).

Table 4 reports regression analyses for stigmatizing attitudes and intentions to discriminate against PLHA. Endorsement of coercive policies was higher in Mumbai than in Bengaluru (standardized coefficient $b = 0.448$, $P = 0.001$).

Women were less likely to endorse coercive policies ($b = -0.068$, $P < 0.05$), as were more educated respondents, but in Mumbai only (main effect of education, which reflects Bengaluru if interaction with site is included: $b = 0.049$, n.s.; interaction Site x Education, $b = -0.184$, $P < 0.001$). Endorsement of coercive policies was positively associated with the belief that people who became infected through sex or drugs got what they deserved ($b = 0.136$, $P < 0.001$), having negative feelings toward PLHA ($b = 0.116$, $P < 0.001$), a higher level of symbolic stigma ($b = 0.098$, $P < 0.01$), worrying about getting infected ($b = 0.073$, $P < 0.05$), and having misconceptions about casual transmission of HIV ($b = 0.192$, $P < 0.001$), the effect of which was stronger in Mumbai than in Bengaluru (interaction $b = 0.089$, $P < 0.05$). Correct transmission knowledge was positively associated with endorsement of coercive policies in Bengaluru ($b = 0.090$, $P < 0.05$), but negatively in Mumbai (interaction $b = -0.265$, $P < 0.05$).

Intent to discriminate against PLHA was significantly lower in Mumbai than in Bengaluru ($b = -0.101$, $P < 0.01$), but it was associated with the same factors at both sites, as indicated by the lack of significant interactions between site and other predictors. As with endorsement of coercive policies, respondents expressed a significantly greater intent to discriminate the higher their blame score ($b = 0.067$, $P < 0.01$), their negative their feelings toward PLHA ($b = 0.177$, $P < 0.001$), their symbolic stigma ($b = 0.060$, $P < 0.05$), their worries about HIV infection ($b = 0.241$, $P < 0.001$), and their number of misconceptions ($b = 0.445$, $P < 0.001$). But those with higher knowledge of correct transmission routes showed less intent to discriminate against PLHA ($b = -0.074$, $P < 0.01$).

**Discussion**

This study represents the first large scale attempt to quantify different dimensions of individual manifestations of AIDS-related stigma in urban India. The results reveal a high prevalence of stigma attitudes and intent to discriminate in both cities, suggesting that AIDS stigma is not a region-specific phenomenon in India. The vast majority of participants appeared to blame PLHA for their condition, with more than 80% stating that HIV-infected individuals “got
what they deserved’’ and between two-thirds and three-quarters of participants agreeing with the statement that PLHA do not care if they infect others. More than half of the participants said they would refuse to use the same plate as an infected person (25%), by a health care provider (36%), or if they had an infected child (25%). In contrast, participants said they would refuse to eat food prepared by an infected person and that they would not accept treatment at a clinic that serves PLHA. In addition, a substantial portion did not want to use the same plate as an infected person (29%), be treated at a clinic that serves PLHA, or allow their child to attend the same school as an infected child (25%).

These data provide support for the findings from previous qualitative research on stigma in India [33] and suggest that efforts made thus far to educate the population may have had only a limited impact on AIDS stigma. Although the recent emphasis on AIDS education in Bengaluru appears to have improved knowledge levels, more needs to be done to simultaneously address transmission misconceptions. Mumbai has a longer history of providing AIDS education to the general public, especially in the earlier days of the epidemic, when billboards were common. In spite of this, knowledge levels in the Mumbai sample were found to be poorer than in Bengaluru, which may be due to the steady influx of migrants and ever changing population profile of this city. This suggests that there is a need for sustained education interventions, preferably at multiple levels to ensure that new citizens are informed. Addressing AIDS stigma therefore must continue to remain a priority for the national AIDS program, even in regions that have a long history of AIDS education efforts.

Given that approximately three-quarters of the participants endorsed coercive family policies, there appears to be a pervasive lack of support for the rights of PLHA. Not only do these coercive attitudes about marriage and family impose a hardship on PLHA, but they are also unwarranted from a public health perspective. This highlights the need for a rights based approach to addressing stigma in future intervention programs and through the national AIDS control program to safeguard and uphold PLHA rights to marriage and having a family.

Although site differences emerged on individual HIV knowledge items, substantial knowledge gaps were found in both cities, with a tendency for participants to overestimate the risk of HIV transmission through numerous routes. This pattern highlights the need to step up ongoing HIV education programs and to expand efforts for reaching the general population at multiple venues, including communities, workplaces, healthcare settings, and educational institutions.

Although the data show an overall trend that can help shape national policies, the existence of regional and sociodemographic differences points to the need for adopting an approach to educational interventions that includes flexibility and collaboration with local and regional stakeholders.

The results from this study demonstrate for the first time quantitatively, that the factors underlying AIDS stigma in India are similar to those in the West [4, 9, 10].
regression analyses show that AIDS stigma attitudes and intent to discriminate against PLHA are driven primarily by HIV transmission misconceptions, blame and negative feelings towards people living with HIV/AIDS, highlighting the importance of addressing these factors in future programs. Most participants reported that they did not personally know anyone infected with HIV. However, our previous research [32] indicates that most PLHA in this population do not voluntarily disclose their HIV status to others. Thus, many members of the present sample may have HIV-infected friends and relatives, but may be unaware of this fact.

The generalizability of the present findings is limited by our reliance on an opportunistic sample. The 2001 census, which is the most recent one for which such data are available, shows that although the slum residents may have been under-represented in Mumbai, the demographic characteristics of our sample are roughly comparable to those of the general population of these cities [54, 55]. Study participants were somewhat more likely to be Hindu (88 and 71% in Bengaluru and Mumbai, respectively, compared to 80 and 68% in the 2001 census), and less likely to be Muslim (7 and 12%, compared to 13 and 19% in the census), compared to the 2001 Indian census for these settings. The urban illiteracy rate for India was approximately 20% in the 2001 census. While our study does not have reliable data on literacy, 16% of participants in Bengaluru and 5% of those in Mumbai reported receiving four years or less of education.

We made every effort to recruit participants from a wide range of clinics and hospitals, in order to be as representative as possible of health care settings that are accessible to the general population in these cities. While government hospitals and some not-for profit catholic hospitals tend to treat those who are lower to middle income and provide care on a sliding scale, higher income patients are over-represented at the private for-profit hospitals. However, our sample did not include individuals in these cities who do not seek any form of health care or who seek care only at non-allopathic institutions. Thus, the only healthcare-seeking individuals who were not sampled in this study were those who seek only non-allopathic care, such as homeopathy, siddha, unani, and ayurveda.

Finally, our rural subsample was too small to enable reliable subgroup analyses. Thus, the extent to which the present results are applicable to individuals in this group is unknown and we are unable to generalize our findings to individuals who seek care only in rural clinics. We note, however, that anecdotal reports suggest that AIDS stigma is prevalent in rural areas, making them an important setting for future research.

The findings reported here suggest that there is an urgent need for continued stigma reduction efforts in India. Such efforts are needed to reduce the suffering of those who are infected with and directly affected by HIV, as well as to reduce barriers to accessing prevention and treatment programs. Given the high levels of blame and endorsement of coercive policies reported here, future programs may benefit from involving PLHA in co-facilitating such programs to personalize and humanize the epidemic. It is also important to note that sometimes HIV educational interventions targeting the general public inadvertently bolster blame and negative feelings toward PLHA in the participants. Thus, it is crucial to ensure that programs are shaped within a human rights framework.

For maximum impact, future programs need to target the general population in multiple venues. As this study demonstrated, health care settings may be a feasible site for such efforts. Patients and their friends and families often spend up to several hours sitting in clinic waiting rooms before they see a doctor and many are willing to participate in other programs during this time, provided that it does not prolong their wait time. It may thus be feasible to use these waiting areas for the delivery of innovative stigma education efforts as well.

Finally, given the paucity of rigorously evaluated interventions that explicitly target AIDS stigma and discrimination as outcomes [3], it is crucial that future stigma reduction efforts incorporate well designed evaluations to examine their efficacy in various populations. Identifying strategies that effectively reduce AIDS stigma is crucial both to alleviate suffering and to facilitate global AIDS prevention and treatment efforts.

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