

## **HIV/AIDS Stigma and Knowledge among Predominantly Middle-Class High School Students in New Delhi, India**

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### **ABSTRACT**

**This study examined stigmatizing attitudes toward HIV/AIDS among predominantly middle-class adolescents in New Delhi high schools. This study was specifically designed to: 1) assess stigmatizing attitudes toward HIV/AIDS and sexuality; HIV/AIDS knowledge, and awareness of HIV-related health resources; and 2) examine whether HIV-related stigma and knowledge are related to one another and to gender, parents' education, and exposure to HIV/AIDS education.**

**In four high schools in New Delhi, 186 students completed a questionnaire assessing stigmatization of HIV/AIDS, stigmatization of sexuality, knowledge of HIV/AIDS, HIV/AIDS education and resources, and demographic characteristics.**

**Adolescents varied in how much they stigmatized persons with HIV/AIDS. They generally lacked accurate knowledge about the disease and of related health resources. However, those with greater exposure to HIV/AIDS education demonstrated significantly greater HIV/AIDS knowledge. Female adolescents demonstrated significantly less knowledge about HIV/AIDS compared with male adolescents, while the males reported significantly greater exposure to HIV/AIDS education compared with the females.**

**These results suggest a need for greater HIV/AIDS education and awareness of health resources, especially among female adolescents. Education must directly address stigmatizing attitudes about HIV/AIDS, gaps in HIV/AIDS knowledge and awareness of HIV-related health resources.**

**Keywords:** Stigma, HIV/ AIDS, sexuality, knowledge, adolescents, India

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## INTRODUCTION

Among India's population of greater than one billion people, it has been estimated that by the end of 2005, the Human Immunodeficiency Virus (HIV) seroprevalence rate had reached between 0.5% and 1.5% of all adults age 15-49.<sup>1,2</sup> It was also reported that between 3,400,000-9,400,000 people were currently living with HIV/AIDS in India, and with the epidemic described as 'the most serious public-health problem faced' by the country since Independence<sup>2</sup>. Among all countries, India is thought to currently have the greatest number of people living with HIV/AIDS<sup>1</sup>, and without considerable prevention and treatment efforts these numbers will continue to increase dramatically in the years to come. HIV infection in India is rapidly spreading from urban to rural areas and from marginalized, high-risk populations, such as sex workers, truck drivers, injection drug users and men who have sex with men into the mainstream population<sup>2,4</sup>. The majority of people being infected with HIV and dying of AIDS are between the ages of 15-34<sup>2</sup>. Also, the crippling impact of the impact of HIV on economic productivity has been a threat to the stability of many countries that are now faced with its realization.<sup>5</sup>

India has a diverse epidemic make up, with major epidemics in several states, such as Tamil Nadu in the south, where the HIV prevalence is approximately 50% among sex workers<sup>6</sup>. The epidemic is mainly concentrated in southern and western states<sup>1</sup> with lower prevalence

rates in northern states<sup>4</sup>. In northeastern states, the epidemic was primarily driven by injection drug use and has spread into the heterosexual community<sup>1</sup>. Recently UNAIDS reported that injection drug use may have played a larger role in the epidemic than previously thought. For example, 26% of injection drug users in Chennai were HIV positive and 46% reported living with a wife or regular sex partner<sup>6</sup>.

In India, UNAIDS and other HIV surveillance is generally conducted in antenatal clinics, which means that prevalence testing is mainly conducted on pregnant women. In many states, for example, Andhra Pradesh, Karnataka, Maharashtra, and Nagaland, there is a greater than 1% prevalence rate of HIV among pregnant women<sup>6,7</sup>. Women often become infected from their spouse or partner<sup>6</sup>, who rarely acknowledge extramarital relationships<sup>8</sup>. Women typically have access to fewer resources compared with men and often lack power to protect themselves<sup>9,10</sup>. Although the psychological stress on individuals with HIV in general is great, it is especially difficult and painful for women who become infected by their spouse with HIV<sup>11</sup>.

In 2002, the Indian government directed 20% of all World Bank funds towards interventions targeting people at high risk for HIV infection.<sup>12</sup> Also in 2002, the Gates Foundation donated \$100 million to increase AIDS prevention in India<sup>13</sup>. One of the most difficult aspects of this epidemic to fight, however, is that of stigma and discrimination against people

infected with HIV<sup>14,15</sup> often compounded in vulnerable groups such as women and children<sup>7,9,10,12</sup>. While sexual taboos are slowly being challenged in India,<sup>12</sup> there remains a significant portion of the population who lack correct information about the disease<sup>16-18</sup>.

Young people are particularly vulnerable to HIV infection<sup>2,19</sup>, and often their access to adequate health information and services is restricted. The complex sexual taboos in Indian culture may be compounded by adult censorship of sex education and acknowledgment of children's sexual activity and interest for fear of encouraging early sexual experimentation.<sup>20</sup> There is an intensifying need to demystify HIV globally, and specifically in India<sup>14, 21</sup>, which means not only talking about the disease but opening up a dialogue around one of the primary modes of transmission sexual behavior.

### ***Stigma and Discrimination***

HIV/AIDS-related stigma can be understood within the more general context of social stigma. Stigma is a complex, multi-faceted phenomenon felt and manifested both subtly and overtly. Stigma can be subjectively experienced in multiple ways, depending on the nature of the stigmatizing condition, as well as the social stature and circumstances of the particular individual being stigmatized against and perpetrating the stigmatizing action.<sup>22</sup> The power of stigma lies in the fact that it excludes, marginalizes, and creates social boundaries<sup>23</sup> between "normals" and "outsiders".

Understanding stigmatization in terms of social exclusion provides a useful framework for conceptualizing stigma and examining the consequences of HIV/AIDS-related stigma more specifically. Individuals living with HIV/AIDS may be socially ostracized or discriminated against based on whether they: 1) pose a threat to others' health or safety; 2) deviate largely from group standards; 3) fail to contribute sufficiently to the welfare of the social group to which they belong, and; 4) elicit negative emotional reactions from others<sup>24</sup>.

Individuals may hesitate to interact with persons who are known to have HIV or AIDS because it is contagious, life threatening, and presently incurable. HIV infection is also often associated with individuals who are viewed as deviant and immoral, such as sex workers, gay men and intravenous drug users<sup>25</sup>, despite the fact that the majority of women currently living with HIV contracted it from their husbands<sup>7,12</sup>. Another aspect of HIV/AIDS stigma results from responses to the perceived blemishes and flaws in individual character<sup>26</sup>. People living with HIV or AIDS can be stigmatized because they may not be able to meet occupational, family, and social obligations as they had previously, and may no longer be seen as contributing to the well being of the overall social group. Finally, many individuals react to people living with HIV/AIDS by experiencing feelings of discomfort, awkwardness, and depression, which can create a stressful and unpleasant encounter for both parties<sup>25</sup>.

HIV/AIDS-related stigma takes on a new dimension in India, with its unique history of institutionalized stigma in the caste system<sup>26</sup>. While the explicit practice of castes has been legally banned, its legacy still affects Indian society and culture today, with people living with HIV/AIDS becoming the 'new untouchables'<sup>12</sup>. In India, as in many other developing countries, many believe that HIV-related illnesses solely affect the 'sinful and perverted'<sup>27</sup>. This stigmatization of HIV/AIDS is firmly rooted in the dominant notions of what constitutes good and bad, and right and wrong which serve to strengthen existing social inequalities, particularly those with respect to gender, sexuality, race and social class<sup>27</sup>.

Previous research conducted in India regarding social responses to HIV/AIDS has documented negative reactions by the public toward this epidemic. A 1997 study found that 36% of adolescents felt individuals with HIV or AIDS should kill themselves, while 20% stated that AIDS was a punishment by God<sup>28</sup>. In the same study, 34% of participants said they would not associate with people with AIDS and a staggering 90% of individuals endorsed at least one hostile view towards HIV/AIDS infected individuals<sup>28</sup>.

A lack of correct knowledge of HIV/AIDS and its transmission is compounded by sexual taboos and stigmatization of the disease that present serious barriers to young people in protecting themselves from high risk situations in which they may be

increasingly likely to contract HIV<sup>29</sup>. It also may influence them to focus on prevention methods that are ineffective in protecting against HIV. For example, in one study among an illiterate population in New Delhi, 45% of participants erroneously thought that HIV is transmitted via mosquito bites<sup>30</sup>.

Research is needed on HIV/AIDS stigma and discrimination in India, especially among high school aged adolescents. This study examines attitudes toward HIV/AIDS held by students attending high school in New Delhi, India. This study was specifically designed to: 1) assess stigmatizing attitudes toward HIV/AIDS and sexuality; HIV/AIDS knowledge, and awareness of HIV-related health resources; and 2) examine whether HIV-related stigma and knowledge are related to one another and whether they differ by gender or parents' level of education.

## **MATERIALS AND METHODS**

### *Participants*

Questionnaires were distributed to a convenience sample of students from 11<sup>th</sup> and 12<sup>th</sup> grade classrooms in four high schools in New Delhi. The schools were chosen based on ease of logistics, with schools chosen based on their concurrent participation in other health-related studies undertaken by Maulana Azad Medical College in New Delhi, as well as on the interest and willingness of school administrators to participate in the study. This study was approved by the institutional review boards of Maulana Azad Medical college in New Delhi, India

and Stanford University, in Palo Alto, California, USA.

Participating schools were similar to one another in demographic characteristics and were generally representative of New Delhi area. All schools were in an urban setting (New Delhi City proper), and the students were from a lower-to-middle socioeconomic background, with the predominance of students coming from middle-class families. All participants were between 18 to 20 years old. Students were informed that participation in this study was voluntary, and those who were willing to participate read a consent form and verbally agreed to participate. A total of 203 consent forms and surveys were distributed in classrooms, with 186 completed surveys returned, resulting in a 91.6% response rate. There did not appear to be any overall difference with regards to SE between those who responded and did not respond.

Participants were fairly evenly distributed by gender, (49.2% male and 50.8% female). Thirty-nine per cent of students' parents had completed a high school education or less, and another 61% of participants' parents had a university education.

### **Measures**

All measures were provided in English. Basic demographic information was collected from each participant, including gender, age, and parents' education. Five scales were administered, including: Endorsing Stigmatization of HIV/AIDS (9 items);

Refuting Stigmatization of HIV/AIDS (6 items); Endorsing Stigmatization of Sexuality (7 items); Knowledge of HIV/AIDS (7 items); and Exposure to HIV/AIDS Education (5 items). All items included in the attitude scales provided 'Yes' (= 1) or 'No' (= 0) responses, and scales scores were derived by summing item responses, after reverse-scoring items worded in the opposite direction. The sum of correct responses on the Knowledge of HIV/AIDS was converted to a percentage correct score. Three additional items were also included in the questionnaire asking whether HIV/AIDS education should be given in schools and universities, whether it is society's duty to educate people about HIV/AIDS, and whether the respondent would be willing to be tested for HIV infection.

### **Procedure**

For each participating classroom, one of the study investigators (SP) provided an overview of the purpose and importance of the study. The voluntary nature of participation was emphasized and it was stressed that there were no "right or wrong" answers to the survey items assessing attitudes. Students were told the questionnaire would take approximately 30 minutes to complete and that if a particular question was not clear, to ask for clarification.

### **Statistical analysis**

Descriptive statistics were computed to summarize the results of the survey, including the means and standard deviations on each scale and the percentages of adolescents endorsing

each item. The Mann-Whitney test examined for possible differences by gender and differences in parents' education (university education versus none) on each scale. Spearman's rank-order correlations were used to assess the relationships among the five scales. It is important to note that there is no widely accepted approach for assessing and identifying a level of stigma that would have a negative impact with reference to people affected with HIV/AIDS.

Given that there may be some reservations in interacting with people with any disease, endorsing any single item avoiding persons with HIV/AIDS might not reflect this stigma. Therefore, students' endorsements of stigmatization were dichotomized at two or more endorsements, to provide an indication of a level of stigmatizing that might be likely to negatively affect people living with HIV/AIDS. This designation of stigma versus no stigma was analyzed by gender and parents' education level using chi

square tests and by knowledge of HIV using a t-test.

## RESULTS

Table 1 presents the descriptive statistics for each scale. There was considerable variability across items on all scales, indicating a range of knowledge and understanding among this student population. The students who met the cut-off criterion of endorsing at least two of the HIV stigmatization items comprised 43.2% of the sample. This binary designation of stigma versus no stigma was not significantly associated with gender, parents' education level, knowledge of HIV/AIDS, or exposure to HIV/AIDS education. Knowledge of HIV/AIDS was significantly correlated with exposure to HIV/AIDS education ( $r = 0.15, p = .05$ ), such that the greater the exposure to HIV/AIDS education, the greater the knowledge of HIV/AIDS. Statistically significant gender differences were found in which the female respondents reported less exposure to HIV/AIDS education than did the male respondents (Mann-Whitney  $U = 3319, p = .05$ ). No other significant differences were found.

Table.2 presents the adolescents(%) who endorsed the items assessing stigmatization of HIV/AIDS. Greater than a third of participants endorsed the statement that HIV/AIDS is a punishment from God to those who have multiple sexual partners, and nearly a third agreed that: "People who have HIV/AIDS deserve it." In contrast, few adolescents endorsed statements that only bad or poor people get

**Table 1: Mean Score, Standard Deviation, and the Range on Each Scale.**

Scale	Mean	S. D.	Range
Endorsing HIV Stigmatization	1.6	1.6	0 - 8
Refuting HIV Stigmatization	4.2	1.0	0 - 6
Stigmatization of Sexuality	3.5	1.1	1 - 6
Knowledge of HIV/AIDS (%)	57.6	18.7	0 85.7
Exposure to HIV/AIDS Education	1.9	1.1	0 - 5

**Table 2. Responses Endorsing Stigmatization of HIV/AIDS**

Responses	Yes response	
	n	%
HIV/AIDS is a punishment by God to those who have multiple sexual partners	68	37.4
People who have HIV/AIDS deserve it	52	30.2
Is HIV/AIDS related to morality?	49	29.3
People who have HIV/AIDS are immoral	25	14.0
Only bad people get HIV/AIDS	26	14.4
People with HIV/AIDS should be quarantined from the rest of society	23	3.1
People with HIV are not true members of society	20	11.2
Only the uneducated people get HIV	14	7.8
Only poor people have HIV/AIDS	5	2.7

HIV/AIDS.

The percent of adolescents endorsing statements refuting stigma toward HIV/AIDS are presented in Table 3. Interestingly, most adolescents said they would be willing to talk to or work with someone with HIV/AIDS, although few said they would be willing to shake hands with a person with HIV/AIDS.

Table 4 presents the percentages of adolescents endorsing items assessing the stigmatization of sexuality. Over two-thirds of adolescents endorsed statements that sex outside of marriage and homosexuality are wrong.

However, the majority of adolescents supported open discussion of sexuality and the discussion of sexuality on the television or radio.

As adolescents ranged in their knowledge of HIV/AIDS, and they showed greater knowledge of some important aspects than others. On one hand, for example, the adolescents scored at chance level on the item stating that only homosexuals can get the disease. Also, most adolescents erroneously thought that HIV/AIDS can be transmitted through saliva. On the other hand, nearly all of the students knew that HIV/AIDS is becoming a serious problem in India (Table 5).

**Table 3. Responses to Refuting Stigmatization of HIV/AIDS**

Responses	Yes response	
	n	%
I would be willing to talk to or work with someone with HIV/AIDS.	151	83.9
People with HIV/AIDS should be able to have contact with others.	151	83.0
Should doctors treat individuals with HIV/AIDS?	141	82.9
It is appropriate for HIV to be discussed in casual conversation?	139	82.2
If someone with HIV needed help physically, I would help	139	78.1
I would be comfortable shaking hands with a person with HIV/AIDS.	22	12.0

**Table 4. Responses to Endorsing Stigmatization of Sexuality**

Responses	Yes response	
	n	%
Sex education should only be given to those who are going to be married.	33	18.2
Thinking about sex is wrong.	42	23.3
Sex education should be restricted to the home.	50	27.6
Open discussion of sexuality is acceptable. <sup>1</sup>	115	65.0
Homosexuality is wrong.	116	69.5
Sex outside marriage is wrong.	128	73.6
Should sex be discussed on television or radio? <sup>1</sup>	134	74.0

<sup>1</sup>All values shown are the frequencies and percentages of affirmative responses; however, these footnoted items were reverse-scored for computing the scale score.

The responses to items assessing exposure to HIV/AIDS education showed that nearly half of the students had heard someone speak about HIV/AIDS publicly, while almost a quarter of adolescents did not know where to go to find information on HIV/AIDS and very few adolescents knew where there were HIV/AIDS counseling agencies (Table 6).

In response to three additional questions, nearly all adolescents (94.5%) agreed with the statement that HIV/AIDS education should be given in schools and universities, and 91% agreed that it was society's duty to educate people about HIV/AIDS. However, about half (49.2%) said they would not get tested for HIV.

## DISCUSSION

In general these results suggest that stigma towards HIV and sexuality may be endorsed by these predominantly middle-class students living in New Delhi, India. However, the variability in endorsement of stigmatizing views toward HIV and sexuality suggests that other factors are at play in influencing such views. It is important to view these findings as raising questions about stigma, rather than satisfactorily resolving these questions. One major

**Table 5: Correct Responses to Assessing Knowledge of HIV/AIDS**

Responses	Yes response	
	n	%
HIV/AIDS is becoming a serious problem in India.	176	94.6
Can AIDS kill people?	150	80.6
HIV/AIDS is only transmitted through sex.	136	73.1
HIV/AIDS can affect anyone.	128	68.8
Is HIV/AIDS preventable?	126	67.7
Only homosexuals get HIV/AIDS.	95	51.1
HIV/AIDS can be transmitted by saliva.	65	34.9

**Table 6. Responses to Assessing Exposure to HIV/AIDS Education**

Responses	Yes response	
	n	%
I know where are HIV/AIDS counseling agencies	17	9.3
If I need to find information on HIV/AIDS, I know where to go	48	26.5
HIV/AIDS was discussed in my school/ university	50	27.6
I have heard people publicly discussing the issue of HIV/AIDS	93	51.1
(I have read) about HIV/AIDS <sup>1</sup>	140	76.9

<sup>1</sup>This item has been reworded from "Have you read about HIV/AIDS?" to provide a structure consistent with the other items in this Table.

question raised is "At what point does endorsing the attitudes deemed as stigmatizing actually negatively impact people living with HIV/AIDS?" In this study, many students endorsed two or more of these items. Whereas one item might be endorsed for reasons other than stigma, this finding raises the question of whether endorsement of two items can be interpreted to be likely to reflect a more systematic bias toward persons living with HIV/AIDS that might negatively affect them. Compared to using endorsement of a single stigma item, using a cut-off of endorsement of at least two items would make it more likely that a person exhibits a harmful level of stigma, but non-stigma related explanations for such responses could still be possible. Further research is

certainly needed to resolve such questions.

The finding that adolescents who endorsed the most stigmatizing views toward HIV and sexuality were not necessarily those with less knowledge of HIV/AIDS suggests that education about the biology of HIV/AIDS in itself may not be sufficient for tackling the underlying issue of HIV stigma. As the insidious and subtle problem of stigma continues to fuel HIV epidemics globally, these results suggest that HIV must be addressed by education that recognizes the social context of attitudes toward sexuality and toward HIV. These are delicate issues to address however, because studies suggest that teachers often have an aversion to teaching sex education, discussing sex and/or talking about HIV.<sup>31,32</sup> An earlier study in New Delhi, found that 75% of teachers had never discussed AIDS with their students<sup>34</sup>, consistent with the results of this study.

Models are needed for providing such education by using approaches that are sensitive to the norms and context of Indian culture. One such model of an HIV/AIDS prevention program that brought HIV education to the classroom in India used highly trained and motivated outreach workers to teach sex education in high school classrooms. This has been piloted in Gujarat, India and has shown promising results.<sup>33</sup>

Programs to help young people to prevent HIV infection must provide more general education about sex and reproductive health to prevent other sexually transmitted diseases that

increase the risk of HIV infection.<sup>17,18</sup> The need for additional education is particularly important for young women, who in this study demonstrated less knowledge about HIV than their male counterparts. This is problematic because women are particularly vulnerable to the harmful effects of stigmatization. In this context, it is encouraging that most of the adolescents endorsed the open discussion of sexuality and its discussion in the media.

As for all studies, there were methodological limitations that should be considered in interpreting this study's findings. This study's sample of high school students in New Delhi were not randomly selected, and therefore their responses may not be representative of those of all high school students between 18-20 years of age in the city or in other regions of India. They may also not be representative of youths their age who are not in school, as research has shown that in general people who are more educated have better knowledge of HIV/AIDS.<sup>30</sup> Also, the use of self-report measures in this study may have yielded different results than would be yielded by more behavioral measures, such as observational measures of attitudes toward persons with HIV infection.

Despite its limitations, this study provides important information about HIV-related knowledge and stigma in this young population. Such information is particularly needed now that the HIV sero-prevalence rate is increased manifold during 1993 to 2000.<sup>34</sup> Another study conducted in New Delhi found a

45% sero-positivity rate among injection drug users.<sup>35</sup> Furthermore, specific cases of HIV/AIDS discrimination and maltreatment of individuals living with HIV have been documented in New Delhi.<sup>36</sup> As with other regions in India, cities such as New Delhi are likely to follow similar trends. Mobility between urban and rural areas has helped disseminate HIV throughout the country.<sup>1</sup> HIV/AIDS is not limited only to the poor,<sup>3</sup> the uneducated or the immoral, requiring examination of deeply held values which contribute to the perpetuation of HIV-related stigma.<sup>37</sup>

The Indian government has responded to the ongoing need to address treatment and prevention of HIV by announcing the provision of free anti-retroviral therapy to all HIV infected individuals living in the six states with the highest prevalence rates.<sup>1</sup> More specific interventions also are needed to reduce stigma and increase awareness and education of HIV. Future research should evaluate the impact of prevention efforts in India that question stigmatization of people living with HIV.

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