Stigma and Access to HIV Care among HIV-Infected Women in Kolkata, West Bengal

Sharoda Dasgupta, MPH[1], **Patrick S. Sullivan, DVM, PhD**[1], **Aparajita Dasgupta, MD**[2], **Bibhuti Saha, MD**[3], and **Laura F. Salazar, PhD**[1]

[1]Department of Epidemiology, Rollins School of Public Health, Emory University, Atlanta, GA, USA

[2]All-India Institute of Hygiene and Public Health, Kolkata, India

[3]School of Tropical Medicine, Kolkata, India

Abstract

Objectives—Stigma is an important issue for marginalized HIV-infected populations. We describe stigma among HIV-infected women on antiretroviral therapy and associations with access to clinical care, demographic factors, and structural elements of support.

Methods—HIV-infected women attending a government-supported clinic in Kolkata, India, were asked about experiences with stigma. Clinical information was abstracted from medical records. We described factors associated with stigma using ordinal logistic regression.

Results—Among 198 women, higher levels of stigma were associated with lower CD4 count upon entry into care (aOR = 0.78; 95% confidence interval [CI]: [0.65, 0.94]), district of residence (aOR = 1.9; CI: [1.0, 3.4]), presence of extended family in the household (aOR = 0.57; CI: [0.32, 1.0]), and employment at the time of the interview (aOR = 0.48; CI: [0.26, 0.90]). Stigma was not associated with having missed scheduled HIV care appointments.

Conclusion—Stigma is prevalent among Indian women with HIV, should be further explored, and may be important in considering public health interventions for better access to care.

Keywords

HIV; women; stigma; compliance; clinic appointments; demographic factors; CD4

Introduction

Although the overall estimated HIV prevalence has been steadily decreasing over the last few years, recent estimates indicate that between 1.8 and 2.9 million people are still

currently living with HIV/AIDS in India.[1] West Bengal contributes about 170 000 of those individuals and has a prevalence of between 0.24% and 0.35%. Thirty-nine percent of all HIV infections in India occur in women.[2]

Of those living with HIV/AIDS in India, stigma has been reported to be more prevalent among women than men. This may be attributed to Indian women being socially disadvantaged because they often cannot negotiate their protection and have less control in sexual relationships. Further, women tend to have a lower level of education and have more subservient roles in the family, and therefore, may feel less empowered and vulnerable more. [3,4] HIV-related stigma instills a fear in Indian women that disclosure of positive HIV status to others may result in physical or mental abuse, abandonment, and loss of social and monetary support for themselves and their children.[5] However, disclosure of HIV status to health care workers is important in seeking care and is often delayed because of concerns regarding discrimination, confidentiality, and monetary issues with treatment[6,7].

As is true in epidemics in Africa and North America,[8,9] a large proportion of infections among women in India originate from the woman's husband.[3,10–12] In married couples where a husband and his wife are both infected with HIV and the man bears financial responsibility in the family, the husband generally takes precedence in receiving treatment.[13] Further, women are obligated to take care of their ill husbands and other family members, often leaving their own needs unmet.[14,15] This disproportionate access to care must be addressed to ensure that a woman and her family receive proper care and support.

HIV testing is voluntary throughout India, and the costs of testing and treatment in government-funded clinics are subsidized by the National AIDS Control Program (NACP). During implementation of the second phase of the NACP in 1999, voluntary counseling and testing centers (VCTCs) were slowly introduced throughout the country. First-line antiretroviral treatment began to be subsidized by NACP by April 2004.[1] Currently, there are 7 government-funded antiretroviral (ARV) centers in the state of West Bengal, located at the North Bengal Medical College, Medinapur Medical College, Burdwan Medical College, Islampur Subdivisional Hospital, Malda District Hospital, R.G., Kar Medical College, and the School of Tropical Medicine in Kolkata.

The government-funded clinic at the School of Tropical Medicine (STM) in Kolkata, West Bengal, offers services such as testing, treatment, and counseling to between 1000 and 1500 HIV-infected individuals per year. When patients are diagnosed with HIV at the STM clinic, they are counseled on HIV and its modes of transmission, what their test result means, treatment options, and recommended nutrition. They are advised to come in for follow-up every 3 to 6 months, depending on the status of their health. Those with CD4 counts less than 200 cells/μL are offered antiretroviral drugs, prior to which they receive counseling on how and when to take the medication and the side effects. Patients on ARV medication attend clinic appointments monthly, during which they undergo a physical examination and receive counseling on adherence to medication and overall health and nutrition.

In this study, we describe stigma among women attending this clinic who are on antiretroviral therapy (ART), and how this measure relates to access to HIV care. We

hypothesize that women who experience higher levels of stigma have less access to care. HIV care was measured using 2 markers: CD4 count upon entry to care (indicates promptness of diagnosis and when patients sought care with respect to progression of disease[16]) and number of missed scheduled appointments.

Methods

Study Population

We conducted a cross-sectional study in which women attending the ARV clinic were recruited to participate from June 2008 to August 2008. Eligible women were over 18 years of age, had HIV-infection, were taking ARV medication provided by the STM clinic, spoke English or Bengali, gave verbal informed consent, and were healthy enough to participate in a short interview. Though the study was restricted to women who spoke Bengali or English, there was no exclusion criterion related to racial or ethnic group. The study population was mostly ethnically homogeneous and over 90% of the women attending the clinic spoke either English or Bengali. After patients consented to participating in the study and were interviewed, specific demographic and clinical information was abstracted from their medical charts. The protocol was approved by Emory University Institutional Review Board and the Institutional Ethical Committee at the School of Tropical Medicine.

Measures

The questionnaire addressed stigma through a scale that combined elements of previously validated scales used primarily in the United States.[17,18] The authors familiar with the study population (AD, BS) chose elements from previously validated scales thought to be culturally relevant and appropriate to use in the study. The scale used to measure stigma was derived from the Berger scale, which was originally administered and validated using a 4-point Likert scale (strongly disagree, disagree, agree, strongly agree).[18] However, we modified the response options to 'Yes,' 'No,' and 'Don't know' because we felt that the multiple responses to questions might be difficult for women to answer, given their level of education and state of health. Because the elements of the scales and the response categories for each question had been changed from their original forms, they were reassessed for reliability in this study using Cronbach's α coefficients.[19] One item in the modified stigma scale was removed during reliability testing, which resulted in a Cronbach's α of .60 (for elements included in the final scale, see Table 1). Components from the final scale were weighted equally and summed for each respondent to obtain composite scores for stigma, ranging from 0 to 4.

Demographic information, such as presence of extended family members in the household, whether the individual was employed at the time of the interview, religious affiliation, and marital status, was collected and considered in our analysis based on prior reports.[13,16,20–22] Data on CD4 count, missed HIV care visits, and additional demographic information, such as age, ethnic group, and level of education were abstracted from medical records. However, because information on education was not recorded in the medical records in a standardized manner, it could not be included in the analysis. We conducted ordinal logistic regression models with stigma as the primary outcome of interest. In addition to the main exposure of

interest relating to access to care, age, district of residence (used as a proxy for distance from the patient's residence to the clinic), marital status, religion, total number of children, presence of extended family members in the household, initial CD4 (measured per 100 cell count) upon entry to the clinic, and whether the respondent worked at the time of the interview were eligible to be included in the model. Our secondary outcome of interest was missed appointments for HIV care in the 12 months before the interview; the data on missed visits were from medical records, and other putative explanatory variables were as described above.

Statistical Analysis

Bivariate analyses—Because all continuous covariates had nonnormal distributions, the Wilcoxon rank-sum test was used to assess whether there were significant crude associations between continuous variables and the outcomes. The chi-square test evaluated bivariate relationships between categorical variables and the primary outcomes of interest. In this exploratory analysis, all variables having a P value of less than or equal to .25 were eligible for possible inclusion in the multivariable model.

Model building—We used similar methods for the analyses of factors associated with stigma and with missed clinic visits. We used backward selection to determine which covariates should be included in our multivariable ordinal logistic regression model for factors associated with stigma. After the final main effects were chosen, all possible 2-way interactions between the retained first-order regressors were evaluated, also using backward selection. Interaction terms with a P value of less than .05 were eligible to stay in the model. The model was then evaluated for collinearity using condition indices, where a value of 30 signaled the possibility for collinearity.[23] Because this was an exploratory analysis, confounding and precision were not assessed for any of the models in this study.

Results

A total of 217 women were approached for recruitment into the study, and 215 (99%) provided informed consent. Out of the 215 who were interviewed, medical charts were available for abstraction for 198 (91% of interviewed) women.

Demographic Characteristics

Table 2 summarizes demographic and clinical characteristics of our respondents. The median age of the study participants was 31 years and most (67%) were between 25 and 36 years of age. A majority of the women were either married or widowed, and most women identified themselves as Hindu or Muslim. About a quarter of the participants were employed at the time of the interview.

Stigma

Reported stigma among the interviewed women ranged from 0 to 4, with a median of 2. Out of the 198 respondents included in the analysis, 162 (82%) had a nonzero score: 30 (15%) had a score of 1, 49 (25%) had a score of 2, 57 (29%) had a score of 3, and 26 (13%) had a score of 4.

Table 3 describes the unadjusted and adjusted associations between stigma score and demographic and clinical factors. In the multivariable model, higher stigma scores were associated with lower CD4 T-lymphocyte count at entry to care and living outside of Kolkata, versus in Kolkata. Being employed at the time of the interview and having extended family members in the household were associated with decreased odds of higher stigma. Age, number of children, and religion were not associated with level of stigma and were not significantly associated with stigma and were therefore removed from the model.

We also used ordinal logistic regression to model the number of missed appointments over the last year as the outcome to find significant associations with any of the covariates listed earlier. Tertiles of missed visits were used to represent the outcome. Only being employed at the time of the interview was significantly associated with missing appointments (OR: 2.5; 90% CI: [1.3, 4.6]). Stigma was not significantly associated with missed appointments ($P = .9397$).

Discussion

Most studies about stigma in India have either focused on other at-risk groups, such as homosexual men, or described results within a general population. Therefore, HIV-related stigma among Indian women has not been well-characterized.[7,24] Our results indicate high levels of stigma among these women (82% of women reported non-zero stigma scores), and identifying factors associated with stigma may inform programs on how to improve access to HIV care and support retention in care.

According to the results, a lower initial CD4 count at first care, which is indicative of later diagnosis and presentation to care, was associated with higher odds of stigma. This suggests that women who reported more stigma at the time of interview entered care at later stages of HIV disease. Although the causality of this relationship is not clear from our data, we should consider that stigma may operate to delay entry into care, perhaps because women who perceive more stigma disclosed their status to fewer people, and therefore, tended to seek care later.[7,25] In order to fully understand this relationship, it would be important to conduct follow-up qualitative studies to understand the relationship between stigma and care-seeking, and to conduct prospective studies to document the temporal relationship between self-reported stigma and care-seeking behaviors.

District of residence was also shown to be associated with higher stigma. Although there are other clinics in the state of West Bengal, women who attended the STM clinic but lived outside the district may have attended care in Kolkata because they lived in a more rural area and the Kolkata clinic was the nearest one or because they preferred to travel from their own city to Kolkata to attend care more confidentially. Thus, non-Kolkata residence may be a marker for higher self-reported stigma, because women who perceived more stigma in the city of residence chose to travel to seek care away from home. Alternatively, there may be differences in stigma between rural and urban settings. However, because urbanicity of residence was not collected in this study, we were unable to distinguish between possible reasons for the association of district of residence and stigma.

Our data show an association between lower odds of stigma and having extended family members living in the household. Studies have shown that extended family members often provide monetary assistance for ARV medications for patients [12] and can provide emotional support as well.[26] Therefore, we speculate that the women in this study who lived in joint families were more likely to receive more monetary and emotional support than those living in nuclear families, and therefore, reported lower levels of stigma due to their HIV status.

Literature shows that Indian women are reluctant to seek employment after their diagnosis because they are afraid of the stigma and discrimination they may face in the work place.[3,7] However, our data indicate that women who worked at the time of the interview reported less stigma than those who did not work. In our qualitative discussions with participants, many women reported that they did not disclose their HIV status to their employer because of fear of discrimination in the work-place. There were several limitations in our study. The first is that this was a cross-sectional study, and therefore, the temporal relationship between the exposures and outcomes were unclear. Further, because the medical records were not in electronic format, some of them were not available for review; this decreased the effective sample size. The reliability score of the stigma scale, as measured by Cronbach's α, was marginally acceptable; however, no previous reports of validated stigma scales had been published for this population, and our scale adaptation produced reasonable measures of reliability. There is a possibility of uncontrolled confounding, because there may be unmeasured factors that were not taken into account in the analyses. There may have also been social desirability bias and misclassification in our study, because some of the respondents may have denied feeling stigma. Finally, study participants were not representative of all the women in care for HIV infection in India, because the study was conducted at one government-supported clinic. The associations in this study are not applicable for women who are infected but undiagnosed, those diagnosed but not seeking care, or those attending private or other government-subsidized clinics in West Bengal. Further, although number of missed appointments can indicate access to HIV care, CD4 count may have some limitations in quantifying this measure. Specifically, if a patient is not diagnosed with HIV until progression into the later stages of disease, CD4 count may not be an accurate marker for access to care. We did not evaluate dates of initial diagnosis of HIV infection and interval to care.

The results show that factors associated with stigma should be further explored and may be important in considering public health interventions to improve clinic care and treatment of HIV-infected women in India. For instance, offering more counseling and encouraging the patients to seek out support groups may provide emotional support for those battling HIV-associated stigma. Our observation that women who worked were more likely to miss appointments suggests that providing extended operating hours may also be helpful to encourage care for women who have work responsibilities.

Acknowledgments

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Table 1

Questionnaire Components for Stigma Measure Administered to Women Attending Government-Supported HIV Clinic, Kolkata, India, 2008.

Construct	Item[a]
Stigma	In your opinion, if a person has HIV/AIDS but is not sick, should he/she be allowed to continue with his or her occupation?[b]
	I feel guilty because I have HIV.
	Telling someone I have HIV is risky.
	I work hard to keep my HIV a secret.
	I feel set apart, isolated from the rest of the world.

[a]Possible responses included 'Yes,' 'No,' 'Don't know,' and 'Refused.'

[b]These scale items were not included in the final scale.

Table 2

Demographics and Clinical Characteristics of HIV-Infected Women Attending a Government-Supported HIV Clinic, Kolkata, India, 2008.

Variable	Median (IQR)	N[a,b]
Continuous variables		
Age at time of interview (years)[b]	31 (27, 36)	
Total # children[c]	1 (1, 2)	
CD4 count at first clinic visit per 100 cell[c] count (cells/μL)	166.5 (112, 210)	
Categorical variables		
District of residence[c]		
Kolkata		130 (61)
Surrounding district		60 (28)
Missing		25 (12)
Marital status		
Married/remarried		95 (44)
Widowed		72 (34)
Divorced		24 (11)
Single		22 (10)
Missing		2 (1)
Religion[c]		
Hindu		153 (71)
Muslim		24 (11)
Christian		5 (2)
Sikh		5 (2)
Missing		28 (13)
History of commercial sex work		
Yes		13 (6)
No		202 (94)
Presence of extended family in household[c]		
Yes		108 (51)
No		105 (49)
Works (currently)[c]		
Yes		58 (27)
No		157 (73)

[a] Total number of women consenting to interview ($n = 215$) were included in the table. However, for CD4 count and age at time of interview, only women whose medical records were available were included ($n = 198$). Numbers may not sum up to total because of missing values.

[b] Whole percentages may not add up to 100 due to rounding.

[c] Factors significant in bivariate analysis with stigma level as outcome ($\alpha = .25$).

Table 3

Results of an Ordinal Logistic Regression Model of Stigma Score among HIV-Infected Women Receiving Antiretroviral Treatment in a Government-Supported HIV Clinic, Kolkata, India, 2008.

Variable	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)	P Value
Current age per 10 years	1.2 (0.85, 1.7)	–	
Initial CD4 per 100 cell count (cells/µL)	0.71 (0.60, 0.85)	0.78 (0.65, 0.94)	.01
Total number of children	0.64 (0.42, 0.97)	–	
Religion			
Hindu	Referent	–	
Non-Hindu	1.8 (0.94, 3.6)	–	
District of residence			.04
Kolkata	Referent	Referent	
Outside of Kolkata	1.4 (0.80, 2.4)	1.9 (1.0, 3.4)	
Presence of extended family in household			.05
Yes	0.58 (0.36, 0.95)	0.57 (0.32, 1.0)	
No	Referent	Referent	
Respondent currently works			.02
Yes	0.44 (0.25, 0.76)	0.48 (0.26, 0.90)	
No	Referent	Referent	

Note: The 198 women who consented to interview and whose medical records were available were included in analysis.