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## **Abstract**

**Objectives.** The purpose of this study was to assess the relationships between stigma and shame associated with seeking treatment for sexually transmitted diseases (STDs) and undergoing testing for gonorrhea and HIV.

**Methods.** Participants were 847 males and 1126 females (mean age: 24.9 years) in 7 cities. Two scales assessed STD-related stigma and STD-related shame.

**Results.** Rates of stigma and shame were higher among participants without a gonorrhea test in the past year and among those without an HIV test. Sex, age, health service use, previous suspicion of gonorrhea, and low levels of stigma were independently associated with gonorrhea testing. Age, enrollment site, use of health services, gonorrhea testing, and low levels of stigma were independently associated with HIV testing.

**Conclusions.** Shame is part of the experience of seeking STD-related care, but stigma may be a more powerful barrier to obtaining such care.

## **Disciplines**

Communication | Social and Behavioral Sciences

## **Comments**

At the time of publication, author Amy Bleakley was affiliated with Columbia University's Mailman School of Public Health. Currently, she is a faculty member at the Annenberg School for Communication at the University of Pennsylvania.

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## Relationships of Stigma and Shame to Gonorrhea and HIV Screening

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### Abstract

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Stigma and shame associated with sexually transmitted diseases (STDs) and HIV infection are important barriers to appropriate diagnostic and treatment services. For example, in one study, 59% of men who had never been tested for HIV cited fear of negative social consequences as an important reason for not seeking testing.<sup>1</sup> Stigma may influence pregnant women's refusal to be tested for HIV despite the benefits of treatment during pregnancy.<sup>2,3</sup> Similarly, 44% of the high-risk males in a study by Woods et al. stated that if name-based reporting were implemented, they would not accept HIV

testing, and they maintained this intention even after being told of the potential benefits of such reporting.<sup>4</sup> A recent Institute of Medicine report identified stigma as a key element of the “hidden epidemic” of STDs in the United States.<sup>5</sup>

Stigma and shame are related but distinct constructs. *Stigma* is defined as an attribute or label that sets a person apart from others and links the labeled person to undesirable characteristics.<sup>6</sup> Stigma related to AIDS has been defined as “the prejudice, discounting, discrediting, and discrimination that are directed at people perceived to have AIDS.”<sup>7</sup>

An additional implicit characteristic of stigma is that it represents socially shared knowledge understood even by the targets of the stigmatizing attitudes and behaviors.<sup>8</sup> Thus, shame can be an internalized reaction to stigma.<sup>6,9</sup> *Shame* is defined as a negative emotion elicited when a person experiences failure in relation to personal or social standards, feels responsible for this failure, and believes that the failure reflects self-inadequacy rather than inappropriate behavior. The term “self-stigmatization” is sometimes used synonymously with shame to reflect a person's acceptance of the negative aspects of a stigma.<sup>7</sup> Shame is clearly distinguishable, however, from the related negative affect states of guilt and embarrassment.<sup>10</sup>

The purpose of this research was to examine relationships of stigma and shame with 2 types of STD-related care: receipt of a test for gonorrhea during the past year and receipt of at least 1 HIV test in the previous year. Receipt of gonorrhea or HIV screening requires care seeking by individuals and communication with clinicians that may be affected by stigma, shame, or both. In the case of both gonorrhea and HIV, screening provides an opportunity for risk-reduction interventions among those who are not infected. Among those found to be infected, effective treatment and control strategies can reduce the risk of sequelae and limit transmission to others.<sup>11,12</sup> STD/HIV-related care could therefore be improved through a better understanding of factors such as stigma or shame that may act as barriers to appropriate screening.

## METHODS

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### Respondents

Data were collected in 1998 as part of the Gonorrhea Community Action Project, a multisite research program designed to evaluate STD-related care from the multiple perspectives of clients, providers, and health care systems. Participating sites included Prince George's County, Maryland; Denver, Colo; Los Angeles, Calif; Indianapolis, Ind; St. Louis, Mo; Central Harlem, NY; and Birmingham, Ala.

Respondents were recruited from clinics, from community-based organizations, and through street intercept in each of the 7 locations. Clinic sites were mainly primary care settings but also included STD clinics. The street intercept and community-based organization recruitment strategies targeted constituencies at high risk for gonorrhea and HIV. Administrators at each research site were asked to interview an equal number of subjects from each recruitment source. All information was collected via face-to-face interviews requiring 20 to 40 minutes to complete. No effort was made to match interviewers and respondents in regard to sex, race/ethnicity, age, or sexual preference.

The study protocol was approved by the institutional review boards of the participating sites as well as the institutional review board of the Centers for Disease Control and Prevention. Written informed consent was obtained from each participant.

### Measures

Two dependent variables were chosen: gonorrhea testing and HIV testing. Respondents were asked, “In the past 12 months, how often have you been to a doctor, hospital, or clinic to get tested for gonorrhea?” A similarly phrased question assessed HIV testing in the past year. Responses to each item were recoded to represent either “no test in the previous year” or “any (gonorrhea or HIV) test in the previous year.”

STD-related stigma and STD-related shame were measured via items developed for the current research. A larger set of items was developed to assess personal reactions to STD and STD-related testing as well as perceptions of others' responses to these issues. Participants responded on a 5-point Likert scale ranging from *strongly disagree* to *strongly agree*. Pilot tests involving 100 volunteers were conducted to assess factor structure and scale reliability. Items that had factor loadings (i.e., correlations with their underlying factor) of .50 and contributed to overall scale reliability were retained. All factor cross loadings (i.e., correlations with nonunderlying factors) were less than .50. *STD-related stigma* (5 items;  $\alpha = .77$ ) reflected the participant's expectation of isolation and adverse social judgment associated with STD. *STD-related shame* (6 items;  $\alpha = .80$ ) reflected the participant's sense of shame and contamination associated with STD (Table 1▶).

**TABLE 1—  
Stigma and Shame Measures**

Stigma ( $\alpha = .77$ )	Shame ( $\alpha = .80$ )
I would feel dirty if a doctor examined me for sexually transmitted diseases	People with sexually transmitted disease have been hanging with the wrong crowd
Getting a sexually transmitted disease would make me feel lonely	Getting a sexually transmitted disease means I don't keep myself clean
Getting examined for a sexually transmitted disease makes people think I have poor morals	People with sexually transmitted diseases should be ashamed of themselves
Most people I know think that a sexually transmitted disease is a sign of a weak character	Getting a sexually transmitted disease means a person is dirty
Getting a sexually transmitted disease means I have poor morals	Getting a sexually transmitted disease means I don't take care of myself
	Getting examined for a sexually transmitted disease means I'm not clean

Items in each scale were summed to create scale scores, with higher scores reflecting greater stigma or shame. The stigma and shame scales were moderately correlated ( $r = 0.54$ ), suggesting that they measured separate but related constructs. Scale scores below the 75th percentile were reclassified as “low,” and scores above the 75th percentile were reclassified as “high.”

Additional predictor measures included sex, age (14–19, 20–29, 30–39, 40–49, or 50–59 years), enrollment site (community/health care facility), health service use in the past year (no/yes), and suspicion of gonorrhea in the past year (no/yes). These variables were selected to control for potential demographic differences in STD-related care seeking as well as influences of general use of health care or STD-related symptoms. With 2 exceptions, similar models were evaluated for each outcome. For

gonorrhea testing, previous suspicion of gonorrhea was included to control for symptom-motivated care seeking. For HIV testing, receipt of a gonorrhea test in the past year was entered to control for routine HIV testing associated with STD-related visits.

Logistic regression (with 95% confidence intervals for each odds ratio) was used in conducting statistical analyses. Predictors were entered in a single block. Level of statistical significance was set at  $P < .05$ .

## RESULTS

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The original sample included 2020 individuals aged 12 to 83 years. Data on sex or age were missing for 10 participants, and these individuals were excluded from subsequent analyses. In addition, we restricted the sample to those aged 14 to 59 years to focus on the groups at greatest STD/HIV risk. The final sample included 1973 respondents (Table 2▶). Missing data reduced the available sample for some analyses. The majority of participants of both sexes were younger than 39 years. Sixty percent of the participants were enrolled from health care facilities.

TABLE 2—

**Sample Characteristics, by Sex (n = 1973): Gonorrhea Community Action Project, 1998**

	Males (n = 847), No. (%)	Females (n = 1126), No. (%)
Age, y		
14–19	281 (33)	445 (40)
20–29	320 (38)	402 (36)
30–39	167 (20)	205 (18)
40–49	60 (7)	57 (5)
50–59	19 (2)	17 (2)
Previous suspicion of gonorrhea*		
No	541 (65)	820 (74)
Yes	291 (35)	290 (26)
Enrollment site		
Community	344 (41)	448 (40)
Health facility	500 (59)	675 (60)
Gonorrhea test, past year*		
No	422 (50)	433 (39)
Yes	424 (50)	693 (61)
HIV test, past year*		
No	322 (39)	383 (35)
Yes	497 (61)	714 (65)
STD-related stigma		
Low	621 (73)	852 (76)
High	226 (27)	274 (24)
STD-related shame*		
Low	546 (64)	862 (77)
High	301 (36)	264 (23)

Note. STD = sexually transmitted disease.

\* $P < .05$  (for sex difference).

There were no differences between male and female participants in regard to age or enrollment location (Table 2). Males were more likely than females to have suspected gonorrhea in the past, but females were more likely than males to have received a gonorrhea or HIV test in the past year. A significantly higher proportion of males were classified in the “high shame” group.

Multiple logistic regression analysis showed that gonorrhea testing was independently related to female sex, younger age, enrollment from a health facility, health service use in the past year, suspicion of gonorrhea, and low levels of STD-related stigma (Table 3). HIV testing was related to older age, health service use, gonorrhea testing, and low levels of STD-related stigma. STD-related shame was not related to gonorrhea testing or HIV testing.

TABLE 3—

**Predictors of Gonorrhea Testing or HIV Testing in the Past Year (Multiple Logistic Regression): Gonorrhea Community Action Project, 1998**

	Gonorrhea Testing, <sup>a</sup>	HIV Testing, <sup>b</sup>
	OR (95% CI)	OR (95% CI)
Female (vs male)	1.6 (1.3, 1.9)	0.94 (0.75, 1.2)
Age (in decades)	0.86 (0.78, 0.95)	1.3 (1.1, 1.4)
Clinic (vs community)	1.6 (1.3, 2.0)	1.2 (0.99, 1.5)
Health service use, past year (vs no use)	2.5 (2.0, 3.2)	1.6 (1.2, 2.0)
Gonorrhea history (vs no history)	2.3 (1.9, 2.9)	...
Gonorrhea test, past year (vs no test)	...	8.5 (6.8, 10.6)
High stigma (vs low)	0.77 (0.67, 0.97)	0.66 (0.51, 0.86)
High shame (vs low)	1.1 (0.90, 1.4)	1.2 (0.92, 1.6)

Note. OR = odds ratio; CI = confidence interval.

<sup>a</sup>Sample for logistic regression was 1929 owing to listwise deletion of missing data; model  $\chi^2 = 190.0$ ;  $P < .05$ .

<sup>b</sup>Sample for logistic regression was 1903 owing to listwise deletion of missing data; model  $\chi^2 = 501.2$ ;  $P < .05$ .

## DISCUSSION

We found that STD-related stigma was associated with a decreased likelihood of being tested for gonorrhea or HIV during the past year. This association was independent of other factors that may affect testing, such as sex, age, and suspicion of gonorrhea. STD-related shame was not associated with receipt of STD-related care. This is not to say that negative emotions associated with STD/HIV-related care are an unimportant element of people's health care experiences.<sup>13</sup> Rather, the perception that others confer negative attributes to those with STD is associated with less than optimal STD/HIV-related care.

Our findings are consistent with widely held assumptions about the role of stigma as a barrier to STD-related care. Our finding that stigma, rather than shame, may be a barrier to STD-related care seeking highlights the potential difficulties facing interventions designed to improve STD-related care seeking. Increasing knowledge or health care access may not address the barriers posed by STD-related stigma.<sup>4</sup> Communitywide interventions, advocacy, and education might be expected to achieve some gains,



although the (not uncommon) opinion that acknowledgment and discussion of issues such as STD/HIV prevention connote approval of proscribed sexual behaviors makes such approaches difficult to implement.<sup>14</sup>

Lay health advisors have been suggested as an excellent means for promotion of community norms of healthy sexuality and STD-related care.<sup>15</sup> However, a substantial body of social psychological research demonstrates the resistance to change of social stereotypes, especially in regard to conditions judged to be associated with irresponsible behavior.<sup>16</sup> As long as at-risk people perceive adverse judgments associated with STD, stigma is likely to remain an important barrier to appropriate care.

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## Notes

J. D. Fortenberry and M. McFarlane contributed to study conception and design, data collection and analysis, and manuscript preparation. A. Bleakley, S. Bull, M. Fishbein, D. M. Grimley, C. K. Malotte, and B. P. Stoner each contributed to study design, data collection, and manuscript preparation.

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