

# The Impact of Anticipated HIV Stigma on Delays in HIV Testing Behaviors: Findings from a Community-Based Sample of Men Who Have Sex with Men and Transgender Women in New York City

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## Abstract

Treatment as prevention (TasP) is a critical component of biomedical interventions to prevent HIV transmission. However, its success is predicated on testing and identifying undiagnosed individuals to ensure linkage and retention in HIV care. Research has examined the impact of HIV-associated stigma on HIV-positive individuals, but little work has explored how *anticipated* HIV stigma—the expectation of rejection or discrimination against by others in the event of seroconversion—may serve as a barrier to HIV testing behaviors. This study examined the association between anticipated stigma and HIV testing behaviors among a sample of 305 men who have sex with men (MSM) and transgender women living in New York City. Participants' mean age was 33.0; 65.5% were racial/ethnic minority; and 50.2% earned <\$20,000 per year. Overall, 32% of participants had not had an HIV test in the past 6 months. Anticipated stigma was negatively associated with risk perception. In multivariate models, anticipated stigma, risk perception, and younger age were significant predictors of HIV testing behaviors. Anti-HIV stigma campaigns targeting HIV-negative individuals may have the potential to significantly impact social norms around HIV testing and other biomedical strategies, such as pre-exposure prophylaxis, at a critical moment for the redefinition of HIV prevention.

## Introduction

IN THE FOURTH DECADE OF THE HIV EPIDEMIC, ~2,700,000 people worldwide become newly infected each year.<sup>1</sup> In the United States (US), the epidemic is particularly stark among men who have sex with men (MSM) and transgender women, who represent 61% of new infections, and are the only groups for whom rates of HIV continue to rise.<sup>2</sup> Recent data demonstrate the critical importance of antiretroviral therapy (ART), not only in promoting optimal health for those affected by HIV, but also in preventing the spread of new infections.<sup>3</sup> One randomized controlled trial<sup>4</sup> and multiple observational studies<sup>5–8</sup> indicate that HIV-positive individuals who are virally suppressed on ART are significantly less likely to transmit the virus to their sexual partners. Often called “treatment as prevention” (TasP), the strategy of ensuring that as many HIV-infected individuals as possible are linked to care and

provided with appropriate medications is a critical component of biomedical prevention and future efforts to best combat the epidemic.<sup>9</sup>

However, the success of TasP is predicated on our ability to provide regular HIV testing to populations at high risk for infection. Estimates suggest that >20% of HIV-positive individuals living in the US are unaware of their HIV status.<sup>10</sup> These rates may be even higher among MSM; in an analysis conducted by the Centers for Disease Control (CDC), almost 44% of MSM testing positive in 21 metropolitan areas were previously unaware of their infection.<sup>11</sup> As such, both policy makers and public health officials are engaging in efforts to facilitate regular HIV testing, especially among MSM to mitigate the harm to those of unknown serostatus and reduce transmission rates.<sup>12</sup> The national HIV/AIDS strategy prioritizes HIV testing and prevention efforts for MSM,<sup>13</sup> and CDC guidelines now recommend that all sexually active MSM undergo HIV testing every 3–6 months.<sup>14</sup>

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Research suggests that many MSM do test for HIV regularly; however, a significant number do not test according to CDC guidelines every 3–6 months. Recent studies estimate that only 58% of MSM have been tested in the past year,<sup>12,15</sup> with only one third reporting testing every 6 months. Regular testing is more common among younger MSM,<sup>16,17</sup> and those who report more sexual risk behavior,<sup>18–20</sup> have health insurance,<sup>21</sup> or are employed,<sup>21</sup> as well as those with better access to testing sites.<sup>19,22</sup> Research on partnership status is equivocal; some studies suggest that MSM in a primary main partnership are more likely to test,<sup>19,23</sup> whereas others find the opposite.<sup>24</sup>

In addition to understanding these demographic and behavioral factors, efforts to increase regular HIV testing among MSM can be informed by theory and research from social and health psychology regarding the impact of perceived stigma on health behaviors.<sup>25</sup> Research suggests that individuals sometimes act in ways that undermine their objective self-interest in order to reduce their association with a stigmatized condition.<sup>26</sup> For example, in order to differentiate themselves from high-risk groups, some individuals underestimate their risk of contracting a stigmatized illness, such as HIV or other sexually transmitted diseases.<sup>27</sup> The underestimation of perceived risk often translates into lower rates of testing and treatment for stigmatized conditions, and poses a significant barrier to preventative behaviors.<sup>28</sup> A growing body of research throughout the world indicates that greater HIV-related prejudice (i.e., “People who have AIDS are dirty” “I do not want to be friends with someone who has AIDS”) is associated with decreased HIV testing rates.<sup>29–33</sup> In a sample of former injection drug users (IDU) in the US, Earnshaw and colleagues demonstrated that perceived HIV risk mediated the relationship between HIV stereotypes (e.g., most people who are HIV are gay, prostitutes) and testing behavior, such that individuals who held more HIV stereotypes perceived themselves at lower risk for HIV and therefore tested less regularly.<sup>34</sup> Similarly, studies have illustrated that people at risk for HIV or living with the disease may delay or fail to access care, to avoid rejection by providers, families, and the general public.<sup>35–37</sup>

However, little research has examined the impact on HIV-testing of *anticipated* HIV stigma, that is, HIV-negative individuals’ expectations that they would experience HIV stigma themselves if they were infected. In the case of anticipated stigma, HIV-negative individuals may or may not endorse stigmatizing beliefs or stereotypes about HIV-positive persons themselves. However, we theorize that their knowledge of negative societal attitudes toward infected individuals may cause them to be concerned about experiencing rejection, discrimination, isolation, or shame in the event of an HIV diagnosis. This concern about future stigmatization from others may serve as a psychological barrier to finding out one’s status. In past research on the relationship between HIV stigma and testing behavior, stereotypes or other negative beliefs about persons with HIV led to distancing and reduced risk perception; that is, individuals avoided HIV testing because “people like me” aren’t at risk. In an anticipated stigma model, risk perception is not disrupted, but individuals avoid testing because they fear the negative consequences of a positive result.

The current study was designed to build on past research on the association between HIV stigma and testing behavior, to examine the role of anticipated HIV stigma in distinguishing

between MSM who report regular testing and those who do not. In contrast to past research, we hypothesized that anticipated stigma would not be associated with decreased risk perception, and that the association between anticipated stigma and testing behavior would not be mediated by individuals’ perceived risk for HIV.

## Methods

### *Participants and procedures*

Participants were recruited in New York City using a passive recruitment methods (i.e., flyers), active recruitment methods (i.e., outreach at bars, events, community-based organizations), and participant referral. Eligible individuals were born male (regardless of current gender identity), ≥18 years of age, self-reported an HIV-negative serostatus, and reported at least one act of unprotected sex with a male partner in the previous 30 days. Data for this article were collected between January 2012 and April 2013. Participants completed a self-administered survey on the computer at the research center. All procedures were reviewed and approved by the Human Research Protections Program at the City University of New York.

### *Measures*

**Demographics.** Participants were asked to report age, education, income, gender identity, race/ethnicity, relationship status, and sexual identity.

**HIV testing behavior.** Participants were asked to respond to the following item: “When was the last time you received an HIV test?” Responses were dichotomized as 1 = within the last 6 months (i.e., consistent with CDC guidelines) and 0 = more than 6 months ago.

**Anticipated HIV stigma.** Participants completed an abbreviated seven item version of our anticipated HIV stigma scale,<sup>38</sup> designed to measure the extent to which participants anticipated negative intrapersonal and interpersonal consequences were they to contract HIV in the future. Consistent with past literature, this measure included both internalization of stigma (e.g., “I would feel I were not as good a person as others if I got HIV”) and negative consequences of stigma (e.g., “If I got infected men would not want to have sex with me”). All seven items were rated on a Likert-type scale (1 = Strongly Disagree; 4 = Strongly Agree). A principal components factor analysis (conducted in SPSS version 20) was used to examine the underlying factor structure of the seven items (Kaiser–Meyer–Olson = 0.82), and supported the presence of a single factor solution, accounting for ~48.7% of total variance across the seven items. As such, items were summed to form an overall anticipated stigma score ( $\alpha = 0.82$ ), with higher values indicating greater anticipated stigma.

**Perceived risk.** Participants were asked: “How likely do you think you are to get HIV in your lifetime?” Partners were asked to respond on a visual analog scale ranging from 0 (Not at all) to 100 (I will definitely get HIV in my lifetime).

**Sexual risk behavior.** The timeline follow-back (TLFB) semistructured interview,<sup>39</sup> modified for the assessment of

sexual risk behavior,<sup>40</sup> was used to collect data for the previous 30 days. Using a calendar, interviewers asked participants to report the type of sexual activity (anal or intercourse; protected or unprotected) by partner type (main or casual) on each day of the preceding 30 days. We created a dichotomous variable of whether or not the participant had engaged in unprotected anal sex acts in the past 30 days with a casual male partner.

*Data analysis*

Descriptive statistics were obtained for all variables included in the analyses, including the distribution of scale scores, with appropriate tests for normality. We then examined associations between study variables and anticipated stigma scores. Next, bivariate analyses were conducted by fitting a series of logistic regression models to assess differences in HIV testing behaviors. Finally, we fit a hierarchical stepwise logistic regression to assess whether anticipated HIV

stigma was associated with HIV testing behaviors over and above demographic characteristics, actual risk behavior, and risk perception. Mediation of the associations between anticipated stigma and HIV testing behaviors by risk perception was assessed by examining whether previously significant anticipated stigma and HIV testing behavior associations became nonsignificant when risk perception was included in the model.<sup>41</sup> For ease of interpretability, both anticipated HIV stigma and perceived risk scores were standardized, so that parameters are expressed in terms of standard deviation change.<sup>42</sup>

**Results**

*Demographics*

Table 1 outlines the characteristics of the sample and descriptive statistics of study variables. The vast majority of the sample (97%) were MSM. The sample ranged in age from 18 to

TABLE 1. CHARACTERISTICS OF STUDY SAMPLE (N=305) AND BY ANTICIPATED STIGMA SCORES

	Total sample		Anticipated stigma scores		
	n	%	M	SD	Test statistic
Gender					n.s.
Male	295	96.7	2.57	0.61	
Female/transwoman	10	3.3	2.49	0.67	
Age					t(303) = 4.82***
< 30 years	143	46.9	2.74	0.61	
≥ 30 years	162	53.1	2.42	0.57	
Race					F(3) = 3.51*
Black	98	31.1	2.42 <sup>b</sup>	0.62	
Latino	79	25.9	2.57 <sup>ab</sup>	0.61	
White	105	34.4	2.67 <sup>a</sup>	0.59	
Other	23	7.5	2.71 <sup>a</sup>	0.52	
Education					t(303) = -3.10**
Less than Bachelor's degree	176	57.7	2.48	0.64	
Bachelor's degree or more	129	42.3	2.69	0.55	
Income					n.s.
< \$20,000 per year	152	49.8	2.58	0.63	
≥ \$20,000 per year	153	50.2	2.55	0.59	
Sexual identity					n.s.
Gay	210	68.9	2.58	0.62	
Bisexual	69	22.6	2.49	0.58	
Heterosexual	17	5.6	2.79	0.59	
Queer/other	9	2.9	2.46	0.47	
Relationship status					n.s.
Single	165	54.1	2.59	0.63	
In a relationship	140	45.9	2.54	0.59	
Sexual risk					n.s.
No UAI with casual partner	117	38.4	2.57	0.59	
≥ 1 UAI acts with casual partner	188	61.6	2.57	0.62	
HIV test in previous 6 months					t(303) = -3.99**
Yes	207	67.9	2.47	0.61	
No	98	32.1	2.77	0.56	
			M	SD	r
Risk perception			32.08	25.42	-
Anticipated stigma			2.57	0.61	-0.14*

\*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001.  
 UAI, unprotected anal intercourse.

TABLE 2. BIVARIATE LOGISTIC REGRESSION MODELS PREDICTING HIV TESTING IN THE PREVIOUS 6 MONTHS

	OR	95% CI
Younger age	1.35	0.83, 2.19
Black	1.06	0.65, 1.75
Latino	1.31	0.75, 2.31
White	0.76	0.47, 1.23
Less than Bachelors' degree	1.59	0.98, 2.58
Income < \$20,000 per year	1.05	0.65, 1.70
Gay identity	0.96	0.57, 1.62
In a relationship	0.77	0.48, 1.25
Sexual risk behavior	1.59	0.98, 2.60
Risk perception	1.35*	1.05, 1.73
Anticipated stigma	0.60**	0.46, 0.78

\* $p < 0.05$ , \*\* $p < 0.001$ .

66 (mean=33.0, SD=10.5), with slightly >50% being  $\geq 30$  years of age. The majority of the sample identified as gay (68.9%). More than two thirds of the sample were racial/ethnic minorities (32.1% Black, 25.9% Latino, and 7.5% Other). Less than half of the sample (42.3%) had earned a college degree, and just half (50.2%) earned more >\$20,000 annually. A little less than half (45.9%) of the sample reported being in a romantic relationship. Almost two thirds of participants (61.6%) reported at least one act of unprotected anal sex with a casual male partner in the previous 30 days. A little more than two-thirds of participants (67.9%) reported having had an HIV test in the previous 6 months.

Associations between study variables and anticipated stigma scores are also presented in Table 1. Anticipated HIV stigma scores were lower among older participants, Black participants, and those with less education. Anticipated HIV stigma was not associated with our measure of sexual risk behavior, but was significantly negatively associated with risk perception. Individuals who had not been tested in the previous 6 months reported significantly higher anticipated stigma scores than did those who had had a recent HIV test.

Bivariate logistic regression models predicting HIV testing behavior are presented in Table 2. Risk perception was positively associated with the odds of having tested for HIV in the previous 6 months ( $p < 0.05$ ). As noted in previously described bivariate comparisons, anticipated HIV stigma was associated with a >60% decrease in the odds of HIV testing in the previous 6 months ( $p < 0.001$ ). No other variables were associated with HIV testing behavior.

The next step was to examine whether anticipated stigma was significantly associated with HIV testing behavior, ad-

justing for sociodemographic and behavioral factors associated with either variable in bivariate analyses. Results of hierarchical logistic regression models are presented in Table 3. In step 1, we entered age, education, Black race, and risk perception. In step 2 we added anticipated stigma, which resulted in a significant improvement in model fit (log-likelihood  $\chi^2[1]=18.41$ ,  $p < 0.001$ ). In the final model, younger age (AOR=2.10, 95% CI: 1.22, 3.62,  $p < 0.01$ ) was associated within an increased odds of having had an HIV test in the previous 6 months. Higher levels of risk perception were also associated with an increased odds of having had an HIV test in the previous 6 months (AOR=1.33, 95%CI: 1.02, 1.73,  $p < 0.05$ ). In contrast, every standard deviation increase in anticipated HIV stigma was associated with a 54% decrease in the odds of having had an HIV test in the previous 6 months (AOR=0.54, 95% CI: 0.40, 0.73,  $p < 0.001$ ). No other variables were associated with HIV testing behaviors and no evidence of mediation by risk perception was found.

## Discussion

The effectiveness of TaSP will depend upon identifying key factors associated with HIV testing behaviors, especially among populations who are disproportionately affected. Despite the CDC's recommendations that sexually active MSM receive HIV testing every 3–6 months, findings from this study and others suggest that many MSM and transgender women are not meeting these guidelines.

These data highlight the importance of addressing anticipated HIV stigma as a unique barrier to HIV testing among MSM and transgender women in the US. More than 30 years after the first case reports, HIV stigma is still rampant and widespread. To date, much of the research has focused on the ways in which stigma by HIV-uninfected people impact HIV-infected people. For people living with HIV (PLWH), HIV-related stigma has been demonstrated to result in affective consequences (i.e., negative self-image, feelings of guilt or shame, depression),<sup>43</sup> social consequences (social isolation, reluctance to disclose status),<sup>44,45</sup> healthcare consequences (decreased access to and engagement in care)<sup>46,47</sup> and behavioral consequences (increased risk behavior and poor medication adherence).<sup>48–50</sup> Our findings suggest that HIV stigma may have insidious consequences for uninfected individuals as well. In this study, higher scores on an anticipated stigma scale were associated with decreased likelihood of HIV testing according to CDC guidelines (i.e., in the previous 6 months). As was hypothesized, this association was independent of other factors that may affect testing, such as risk perception.

TABLE 3. HIERARCHAL LOGISTIC REGRESSION PREDICTING HIV TESTING IN THE PREVIOUS 6 MONTHS (N=305)

	Step 1		Step 2	
	aOR	95% CI	aOR	95% CI
Younger age	1.47	0.89, 2.42	2.10**	1.22, 3.62
Less than Bachelors' degree	1.49	0.88, 2.53	1.36	0.79, 2.34
Black	0.87	0.51, 1.50	0.73	0.41, 1.28
Risk perception	1.34*	1.04, 1.74	1.33*	1.02, 1.73
Anticipated stigma	–	–	0.54**	0.40, 0.73
	Log likelihood, $\chi^2(4)=10.23^*$		Log likelihood, $\chi^2(1)=18.41^{**}$	

\*\* $p < 0.001$ , \* $p < 0.05$ .

Consistent with findings from previous stigma research, there was a negative correlation between anticipated stigma and risk perception; individuals who believe they would experience greater stigma were they to become positive also perceive themselves to be at lower risk for contracting HIV. This association is consistent with past research on individuals' distancing themselves from stigmatized conditions, thereby underestimating their risk. However, in contrast with past research, the association between anticipated stigma and testing behavior was not mediated through risk perception. Although there was a slight negative correlation between anticipated stigma and risk perception at the bivariate level, the multivariate model indicated that each variable was independently associated with HIV testing. Not surprisingly, participants who perceived themselves to be at higher risk for HIV were more likely to have tested in the previous 6 months. But as anticipated stigma scores increased, participants' likelihood of testing decreased. This finding suggests that anticipated stigma may be an important barrier to testing behavior.

Gay and bisexual men, MSM, and transgender women may avoid testing because they are aware of the social and psychological costs associated with a positive result. This awareness may result from knowing, identifying, or having a close relationship with someone who is HIV positive, witnessing the effects of societal stigma on individuals living with HIV,<sup>51</sup> or endorsing stereotypes and prejudice about people living with HIV.<sup>34</sup> Many studies have documented associations between stigma, discrimination, delays in seeking care when testing HIV positive, and poor HIV treatment adherence.<sup>52-54</sup> One of potential reasons that people may not take an HIV test result is fear. This fear is not surprising, as there are real social consequences of acquiring HIV, such as rejection by, and isolation and discrimination from significant others and providers.<sup>37,55</sup> Fear-based public health campaigns have produced mixed results, whereby some individuals may internalize stigmatizing messages and engage in avoidance coping strategies to alleviate those feelings. Our study did not assess individuals' stereotypes and prejudice about persons living with HIV. As such, future research is warranted to examine how their attitudes and emotions about people living with HIV are associated with the anticipation of HIV stigma, coping strategies, and, consequently, HIV testing behaviors.

The only significant demographic factor to emerge within our sample was that younger age was associated with a twofold increase in the odds of having had an HIV test in the previous 6 months. These findings are encouraging, as they suggest that young MSM may be receiving health promotion messages and engaging in preventative behaviors. It is critical to continue to promote testing practices among young MSM, as the number of new infections among MSM ages 13-24 increased 22% from 2008 to 2010.<sup>56</sup> However, it is important to note that the largest number of new infections among white and Latino MSM in this time period occurred among men ages 25-34, and the number of individuals  $\geq 50$  years of age living with HIV is steadily increasing. It is imperative to develop and promote messages that encourage HIV testing among MSM and transgender women across the lifespan.

Several limitations must be noted when interpreting our findings. This study relies on self-report data, which may be subject to social desirability. Our study was cross-sectional in nature; therefore, casual claims cannot be drawn from these

data. Although our sample was diverse in terms of race/ethnicity, age, and socioeconomic status, the limited number of transgender women in our sample limits our findings for this group. Therefore, future research is warranted with and for transgender women to understand HIV stigma to guide implementation efforts in these communities. Additionally, participants were not asked questions about HIV-related stereotypes or stigma based on gender expression, sexual identity, and/or race/ethnicity.<sup>57</sup> As such, there is no way to make inferences between anticipated HIV stigma and multiple forms of stigma. Finally, the participants in this study resided in New York City where there are many lesbian, gay, bisexual, and transgender (LGBT) sexual health services, which restrict our ability to generalize these results to other MSM and transgender women in different regions.

Despite these limitations, our findings underscore the importance of directly addressing HIV stigma in the development of strategies for new prevention programs. The effectiveness of TaSP will not be possible without attending to social inequities and stigma. Past social media campaigns have been effective at raising AIDS awareness and reducing HIV stigma.<sup>58</sup> Anti-stigma campaigns have the potential to create positive environments that foster policies to protect human rights of people living with HIV.<sup>48</sup> Taken together, these findings suggest that focused anti-HIV stigma campaigns targeting HIV-negative individuals may also have the potential to significantly impact social norms around HIV testing and other biomedical strategies, such as pre-exposure prophylaxis, at a critical moment for the redefinition of HIV prevention.

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### Author Disclosure Statement

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