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HIV-Related Stigma, Social Norms and HIV Testing in Soweto and Vulindlela, South Africa: NIMH Project Accept (HPTN 043)

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Abstract

Objective—HIV testing is necessary to curb the increasing epidemic. However, HIV-related stigma and perceptions of low likelihood of societal HIV testing may reduce testing rates. This study aimed to explore this association in South Africa, where HIV rates are extraordinarily high.

Methods—Data were taken from the Soweto and Vulindlela, South African sites of Project Accept, a multi-national HIV prevention trial. Self-reported HIV testing, stigma, and social norms items were used to study the relationship between HIV testing, stigma, and perceptions about societal testing rates. The stigma items were broken into 3 factors: negative attitudes, negative perceptions about people living with HIV, and perceptions of fair treatment for people living with HIV (equity).

Results—Results from a univariate logistic regression suggest that past history of HIV testing was associated with decreased negative attitudes about people living with HIV/AIDS, increased perceptions that people living with HIV/AIDS experience discrimination, and increased perceptions that people with HIV should be treated equitably. Results from a multivariate logistic regression confirm these effects and suggests these differences vary according to gender and age. Compared to people who had never tested for HIV, those who had previously tested were more likely to believe that the majority of people have tested for HIV.

Conclusion—Data suggest that interventions designed to increase HIV testing in South Africa should address stigma and perceptions of societal testing. Keywords: stigma, HIV testing, South Africa, Project Accept

The global HIV epidemic commands our attention. More than 25 million people have died of AIDS worldwide, and another 33.4 million are currently living with HIV/AIDS. ¹ While cases have been reported in almost all areas, 97% of people living with HIV reside in low- and middle-income countries, particularly Sub-Saharan Africa. ² In fact, South Africa has the largest population of HIV-infected individuals, including an estimated almost 20% (approximately 5.3 million) of adult ages 15–49. ³ ⁴ Female youths have almost four times the HIV prevalence of males. ⁵

Stigma has a profound effect on people's decisions, behaviors, and outcomes. HIV-related stigma can reduce people's willingness to engage in HIV testing, treatment and prevention. 6-7 Studies have shown that stigma reduces people participation in educational meetings and counseling 8, preventive or risk reduction behaviors, 7 and participation in programs to prevent mother-to-child transmission. 9-10 Stigma has also been linked to a reduction in quality of life among people with HIV. 11-13 These studies suggest that people are reluctant to engage in HIV prevention, testing, and treatment because of the stigma related to HIV services and to a positive HIV diagnosis.

However, early diagnosis and care has been associated with improved survival rates among persons living with HIV, along with reduced rates of transmission 14-15 and studies have therefore focused on reducing stigma in order to increase testing rates. 16 For example, a study in Uganda attempting to reduce HIV-related stigma by offering home testing suggests that offering home-based testing reduces stigma and can increase testing rates up to 36% compared to standard testing. 17 Results from Project Accept found that an intervention designed to increase testing in communities by changing community norms and reducing stigma resulted in a 4-fold increase in testing rates compared to the control communities. 16 Taken together, studying the associations between HIV testing and stigma may provide information on how reducing stigma will help to increase participation in HIV prevention activities and increase people's willingness to test for HIV.

This study looks at associations between HIV testing and perceptions of stigma in South Africa because of the high rates of HIV-related stigma in South Africa. Data were collected from Project Accept, the first international multisite community-randomized, controlled multilevel structural HIV prevention intervention. 16-18 The study was designed to test an intervention aimed at the community level to increase knowledge of HIV status, change community norms related to HIV, and enhance social support for people living with HIV. While previous results from the Project Accept have demonstrated the high rates of stigma in Africa, and in particular, in South Africa, 19 this paper builds on those studies by testing whether HIV-related stigma in South Africa is associated with decreased rates of HIV testing.

Methods

Project Accept is a community-randomized controlled trial to determine the efficacy of community-based voluntary counseling and testing. This paper is based on Project Accept baseline data from the South African sites: Soweto, an urban township of 2-3 million people located approximately 15 km south of Johannesburg, and from Vulindlela, located in the KwaZulu-Natal region with approximately 40,000 residents. The individual participants were selected by two-stage sampling. In the first stage, the participating households were chosen randomly based on a complete household enumeration. In the second stage, one participant between 18 and 32 years was selected in each participating household. The questionnaire was administered in the respondent's local language after obtaining verbal consent. More detailed information about Project Accept and the survey method may be found in previous manuscripts. 16-20

Measures

All measures were based on self-report. HIV testing was based on self-report of having ever received an HIV test. Stigma measures were based on 19 items assessing HIV-related stigma. These items and their definitions were based on the results of a previous paper 20 that consolidated stigma items into 3 stigma subscales based on: 1) negative attitudes and beliefs associated with persons living with HIV/AIDS (PLHA), including negative feelings

towards PLHA (e.g., PLHA are disgusting) and blaming PLHA for their HIV status (Q1), 2) perceived acts of discrimination (Q2), and 3) equity, or personal attitudes and beliefs related to fair treatment of PLHA (e.g., respondents were asked about their level of agreements with restrictive policies regarding PLHA) (Q3). The stigma measures were defined as sample means of responses to 19 questions (see appendix 1 for details) using 5-point Likert scales (4 = strongly agree; 3 = agree; 2 = don't know; 1 = disagree; 0 = strongly disagree). High and low levels of stigma were defined, respectively, as values exceeding the upper quartile or values lying below the lower quartile. We did not present a total stigma score (an overall score combining the subscales) because the components are related, but representing different aspects of HIV/AIDS-related stigma.²⁰ Social norms about testing were measured using the item "Most people have been tested for HIV," (rated as either strongly disagree, disagree, agree, strongly agree, or no answer). Details related to specific items used and the reliability of the stigma constructs is available in previous manuscripts ^{20, 21} and in Appendix 1.

Data analysis

All analyses were conducted with R software.²² The analysis examined the relationship between the outcome of interest (having had an HIV test), and the independent variables of stigma, discrimination, and perceptions of societal testing, controlling for age, gender and education. The analysis was conducted in a three-step process: descriptive statistics, univariate and multivariate analyses. Descriptive statistics of history of HIV testing were calculated with respect to measures of stigma and discrimination, age, gender, education, and one item related to perceptions of societal testing. Univariate logistic regression models examined the association between these variables and the history of HIV testing. Stigma measures were analyzed using both continuous and discrete scales. The statistical significance of stigma measures and age, gender, and education was tested through a multiple logistic regression model obtained by stepwise backwards model selection using Akaike's Information Criterion (AIC) considering all pairwise interactions. The pairwise interactions terms between stigma measures and other variables test whether the effect of individual stigma measures on HIV testing depends on age, gender, or education. The automatic backwards model selection is a compromise between the oversimplified model containing only six main effects and the complex model containing six main effects and all fifteen pairwise interactions.

Results

Basic descriptive statistics are given in Table 1. In a sample of 5259 people from Soweto and Vulindlela South Africa, 2130 people (40.50%) had tested and 3110 people (59.14%) had never tested. The information about HIV testing was not available for 19 people (0.36%). The observed median age of those who were tested (25 years) was higher than those who never tested (22 years). The percentage of people who had more than 11 years of education was higher among participants who had previously tested.

Table 2 displays the results of univariate logistic regressions with HIV testing as the outcome variable. Older people, females, and more educated people were more likely to have been tested. Compared to people who had never tested for HIV, those who had previously tested were significantly less likely to hold negative attitudes and beliefs about people living with HIV, more likely to believe people living with HIV/AIDS face discrimination, and more likely to hold beliefs that people living with HIV/AIDS should be treated equitably. People who tested were more likely to agree or strongly agree with the statement, "Most people have been tested for HIV".

Table 3 contains effects of the three stigma measures, controlling for age, gender, and education and pairwise interactions selected by the stepwise backwards selection procedure. The effects of gender, age, and education are statistically significant and similar to the effects shown in Table 2. Additionally, we observed significant interactions between gender and age, and gender and education, such that older people (p-value 0.0141) and females (p-value 0.0078) were more likely to have been tested but the effect of gender was less strong for older and more educated females. People with negative attitudes were less likely to have received an HIV test (p-value 0.0049). No significant effect was found for perceived discrimination but the interaction between perceived discrimination and age was significant (p-value 0.0001) indicating that the effect of perceived discrimination significantly increases with age. Similarly, the effect of equity (Q3) was not statistically significant (p-value 0.2371) but the effect is significantly different for males and females (p-value 0.0009). The interaction between perceived discrimination (Q2) and equity (Q3) was not statistically significant (p-value 0.0902).

Discussion

The present study suggests a link between HIV testing, stigma, and social norms such that decreasing HIV-related stigma may help to increase testing. Results from a univariate logistic regression suggest that compared to those who have never tested, people who tested were significantly less likely to hold negative attitudes and beliefs about people living with HIV, more likely to believe people living with HIV/AIDS face discrimination, more likely to hold beliefs that people living with HIV/AIDS should be treated equitably, and more likely to believe that most people have previously tested for HIV. Results from a multivariate logistic regression confirm these results and show a more intricate story that these effects vary according gender and age. People with negative attitudes were significantly less likely to have received an HIV test. The interaction between perceived discrimination and age was significant indicating a stronger relationship between HIV testing and perceived discrimination for older people (compared to younger people). The significant interaction between gender and perceptions of equity indicates that women who have tested (compared to men) were more likely to feel that people who have HIV should be treated equitably. These results suggest that interventions that are designed to decrease stigma (such as by increasing HIV-related conversations, increasing rates of HIV prevention behaviors, and changing social norms around perceptions of HIV stigma) may help to increase HIV testing. Because stigma can differ by demographics and culture, interventions that are culturally and demographically tailored toward populations of interest might prove to be more effective in decreasing stigma and increasing testing.

Finding ways to increase HIV testing in South Africa may help to prevent the spread of HIV by increasing acceptance for HIV prevention behaviors and HIV treatment. 18, 23, 24 However, the high rates of stigma in South Africa might be contributing to the low rates of testing. 7, 25, 26 In the United States, Stall et al., 27 reported that two out of three men who have sex with men who were unaware of their HIV status said that HIV-related stigma affected their testing decisions. In a separate U.S. study, Herek et al., 28 found that 38% of adults would be very concerned about HIV stigma if they tested positive, and 44% said that stigma influences their testing decisions. South African studies confirm these U.S. studies. For example, South Africans who have not tested for HIV have been shown to hold more negative views about HIV. 7 Results from the 2002 South African survey indicate that 18% of respondents were unwilling to sleep in the same room with someone with HIV/AIDS, 26% were unwilling to share a meal with someone with HIV/AIDS, and 6% would not talk to someone who they knew had HIV/AIDS. 25 These stigmatizing views are significant barriers to effective HIV prevention and treatment. 5 Taken together, these studies show the importance of addressing stigma in order to increase testing rates. The present analysis

suggests that South Africa is no exception; interventions that reduce HIV stigma might help to increase testing rates.

Study limitations are based on the self-report measurements used in the analysis. HIV testing was based on participant reports of previously having tested, rather than actual HIV testing behavior. However, past studies have used self-reported measures of HIV testing both in South African and internationally. 7, 29 Additionally, the stigma measures were also self-reports and it is possible that participants were motivated to underreport negative attitudes related to HIV because of social desirability biases. Finally, it is possible that reports of stigma in other countries may not be associated with HIV testing to the same extent as in South Africa. However, we believe this is unlikely as studies suggest that stigma is associated with reductions in HIV testing. 7, 25, 26 Nevertheless, addressing the association between stigma and HIV testing in South Africa is important in order to develop interventions to increase HIV testing.

The present analysis builds on the results of previous research on stigma and testing and suggests that stigma is associated with people's HIV testing behavior in Soweto and Vulindlela, South Africa. As HIV rates in South Africa continue to climb, it becomes imperative that studies aimed to increase HIV testing and treatment in South Africa address ways to reduce stigma.

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Table 1

Descriptive statistics of demographic variables and perceptions of stigma based on previous history of HIV testing in Soweto and Vulindlela, South Africa

	Never tested (n=3110)	Tested previously (n=2130)	Total (n=5259)
Age: median (IQR)			
	22 (7)	25 (8)	23 (8)
Male: n (%)			
	1737 (41.45%)	537 (45.36%)	2284 (43.43%)
Education: n (%)			
< 5 years	63 (2.03%)	32 (1.51%)	96 (1.83%)
5–10 years	905 (29.22%)	509 (23.96%)	1422 (27.15%)
11–12 years	1904 (61.48%)	1357 (63.89%)	3268 (62.39%)
13+ years	225 (7.27%)	226 (10.64%)	452 (8.63%)
Q1 (negative attitudes): mean (sd)			
	0.88 (0.47)	0.78 (0.47)	0.84 (0.47)
Categorized Q1: n (%)			
Low Q1	592 (19.04%)	540 (25.42%)	1134 (21.64%)
Medium Q1	1793 (57.67%)	1196 (56.31%)	2991 (57.08%)
High Q1	724 (23.29%)	388 (18.27%)	1115 (21.28%)
Q2 (perceived discrimination): mean (sd)			
	1.88 (0.72)	1.93 (0.78)	1.9 (0.75)
Categorized Q2: n (%)			
Low Q2	584 (18.78%)	409 (19.26%)	994 (18.97%)
Medium Q2	1891 (60.82%)	1175 (55.32%)	3068 (58.55%)
High Q2	634 (20.39%)	540 (25.42%)	1178 (22.48%)
Q3 (equity): mean (sd)			
	0.88 (0.56)	0.78 (0.56)	0.84 (0.56)
Categorized Q3: n (%)			
Low Q3	618 (19.88%)	584 (27.50%)	1203 (22.96%)
Medium Q3	1932 (62.14%)	1248 (58.76%)	3185 (60.78%)
High Q3	559 (17.98%)	292 (13.75%)	852 (16.26%)
Most people have been tested for HIV): n (%)			
Strongly agree	58 (1.87%)	44 (2.07%)	102 (1.95%)
Agree	592 (19.05%)	452 (21.29%)	1046 (19.97%)
Disagree	1102 (35.46%)	677 (31.89%)	1781 (34.00%)
Strongly disagree	221 (7.11%)	160 (7.54%)	382 (7.29%)
Don't know	1135 (36.52%)	790 (37.21%)	1927 (36.79%)

Table 2

Univariate logistic regressions of associations with past history of HIV testing among people in Soweto and Vulindlela, South Africa

	odds	95% confidence interval	p-value
Intercept (Age=18)	0.410	(0.372, 0.452)	
Age	1.085	(1.072, 1.099)	0.0000
Intercept (Male)	0.309	(0.280, 0.340)	
Female	3.753	(3.328, 4.237)	0.0000
Intercept (Education<5years)	0.508	(0.328, 0.771)	
5–10	1.107	(0.719, 1.736)	0.6492
11–12	1.403	(0.919, 2.184)	0.1236
13+	1.977	(1.252, 3.175)	0.0040
Negative attitudes, Q1			
Intercept (Q1)	1.003	(0.896, 1.123)	
Q1	0.630	(0.558, 0.710)	0.0000
Categorized Q1			
Intercept (Medium Q1)	0.667	(0.620, 0.718)	
Low Q1	1.367	(1.192, 1.569)	0.0000
High Q1	0.803	(0.696, 0.927)	0.0028
Perceived discrimination, Q2			
Intercept (Q2)	0.566	(0.486, 0.658)	
Q2	1.104	(1.025, 1.189)	0.0086
Categorized Q2			
Intercept (Medium Q2)	0.621	(0.578, 0.668)	
Low Q2	1.127	(0.974, 1.304)	0.1078
High Q2	1.371	(1.196, 1.570)	0.0000
Equity, Q3			
Intercept (Q3)	0.902	(0.817, 0.997)	
Q3	0.715	(0.646, 0.791)	0.0000
Categorized Q3			
Intercept (Medium Q3)	0.646	(0.601, 0.693)	
Low Q3	1.463	(1.280, 1.672)	0.0000
High Q3	0.809	(0.690, 0.947)	0.0086
Most people have been tested for HIV)			
Intercept (strongly agree & agree)	0.763	(0.679, 0.857)	
Don't know	0.912	(0.787, 1.058)	0.2233
Disagree & strongly disagree	0.829	(0.717, 0.959)	0.0115

Table 3

Multiple logistic regression of associations with past history of HIV testing among people in Soweto and Vulindlela, South Africa

	odds	95% confidence interval	p-value
(Intercept)	0.180	(0.068, 0.432)	
Male	1.000		
Female	4.237	(1.504, 12.776)	0.0078
Age = 18 years	1.000		
Age	1.053	(1.010, 1.097)	0.0141
Age:Female	0.941	(0.915, 0.969)	0.0000
Education < 5 years	1.000		
Education 5–10 years	1.379	(0.648, 3.298)	0.4334
Education 11–12 years	1.893	(0.904, 4.470)	0.1128
Education 13+ years	3.826	(1.737, 9.385)	0.0016
Female:Education 5–10 years	0.931	(0.328, 2.453)	0.8887
Female:Education 11–12 years	0.632	(0.226, 1.634)	0.3598
Female: Education 13+ years	0.313	(0.106, 0.865)	0.0292
Q1 (Negative attitudes)	0.796	(0.679, 0.933)	0.0049
Q2 (Perceived discrimination)	0.855	(0.694, 1.053)	0.1417
Q2:Female	1.184	(0.997, 1.407)	0.0549
Q2:Age	1.035	(1.018, 1.054)	0.0001
Q3 (Equity)	0.847	(0.640, 1.111)	0.2371
Q3:Female	1.487	(1.179, 1.882)	0.0009
Q2:Q3	0.896	(0.789, 1.017)	0.0902

Appendix 1

Definition of HIV/AIDS stigma and discrimination measures

Item	Negative attitudes (Q1)	Perceived discrimination (Q2)	Equity (Q3)
Families of people living with HIV/AIDS should be ashamed.	*		
People living with HIV/AIDS should be ashamed.	*		
People who have HIV/AIDS are cursed.	*		
People who have AIDS are disgusting.	*		
People living with HIV/AIDS deserve to be punished.	*		
It is reasonable for an employer to fire people who have AIDS.	*		
People with AIDS should be isolated from other people.	*		
People with HIV/AIDS should not have the same freedoms as other people.	*		
People living with HIV/AIDS in this community face rejection from their peers.		*	
People who have HIV/AIDS in this community face verbal abuse or teasing.		*	
People living with HIV/AIDS in this community face ejection from their homes by their families.		*	
People living with HIV/AIDS in this community face neglect from their family.		*	
People who are suspected of having HIV/AIDS lose respect in the community.		*	
People living with HIV/AIDS in this community face physical abuse.		*	
Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS.		*	
People with AIDS should be treated similarly by health care professionals as people with other illnesses.			*
People with HIV should be allowed to fully participate in social events in this community.			*
A person with AIDS should be allowed to work with other people.			*
People who have HIV/AIDS should be treated the same as everyone else.			*

* The last four items (addressing equity) were reverse-coded.