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## Proximate context of HIV stigma and its association with HIV testing in Sierra Leone: a population-based study

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### Abstract

The extent to which HIV stigma at the community level remains a barrier to greater uptake is poorly understood. We used nationally representative data from the 2008 Sierra Leone Demographic and Health Survey. The primary outcome was HIV testing (past 12 months). Our explanatory variable was HIV stigmatizing attitudes (5-item scale). After multivariable adjustment, HIV testing had an inverse association with HIV stigmatizing attitudes measured at the individual (adjusted odds ratio [AOR]=0.94; 95% CI, 0.87–1.01) and community level (AOR=0.70; 95% CI, 0.58–0.85). HIV stigma had a stronger negative association with HIV testing when modeled at the community rather than individual level.

### Keywords

HIV stigma; HIV testing; sub-Saharan Africa; population-based; Sierra Leone

### Introduction

HIV testing is an important component of HIV prevention and treatment efforts worldwide [1]. People who test HIV-negative can receive counseling about risk-reduction strategies such as condom usage. In HIV-positive individuals, early initiation of ART has also become a key strategy of HIV prevention, as treatment has been shown to reduce secondary transmission risk by 96 percent [2]. Although these individual and community-wide benefits of HIV testing are well known, the stigma of HIV remains a significant barrier to greater uptake [3]. HIV remains highly stigmatized throughout sub-Saharan Africa [4], and studies have shown that individuals who perceive HIV stigma are less likely to get tested for HIV [5].

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Because these previously published studies measure stigma at the individual level, critically missing from this literature is a conceptualization of stigma as a community-level, social phenomenon. As originally described by Goffman [6], stigma is a “discrediting” attribute that, in the eyes of society, reduces someone “from a whole and usual person to a tainted, discounted one.” Extending this work, Gilmore and Somerville emphasized that stigma is best understood as a social process that involves the exercise of power by one group over another [7]. Stigmatizing beliefs should then also be conceptualized as inhering in the *proximate context*, i.e., the social environment most proximal to the person whose behavior is affected. Thus, the proximate context of stigmatizing beliefs is likely to be an important driver of HIV-related health behaviors, including HIV testing, serostatus disclosure, and HIV treatment adherence [3].

To address this gap in the literature, we used data from the 2008 Sierra Leone Demographic and Health Survey (DHS) to determine the extent to which the proximate context of HIV stigmatizing beliefs is associated with HIV testing behavior. Previously published research in social psychology has operationalized different aspects of the community environment to study their influences on wellbeing among HIV-positive and other vulnerable populations [8] We extend their work by directly modeling the proximate context of HIV stigma at the village level to understand how the environment shapes HIV testing behavior.

## Methods

### Data

We used data from the 2008 Sierra Leone DHS. The study had a stratified, two-stage cluster design and was implemented by Statistics Sierra Leone in collaboration with the Ministry of Health and Sanitation. All women age 15–49 who permanently lived in the household or slept in the household on the night before the survey were eligible to be interviewed. In one-half of the households, men age 15–59 who also had the same living situation as women were eligible to be interviewed. Overall, the response rate exceeded 92 percent. Additional information about field staff training and data collection procedures is detailed in the 2008 Sierra Leone DHS report. For reasons described below, we limited the analysis to men and women who had ever heard of HIV.

### Measures

The primary outcome was self-reported recent HIV testing behavior, defined as “having had an HIV test in the past 12 months.” Our primary explanatory variable measured HIV stigmatizing attitudes. The variable was a 5-item scale and consisted of 3 items measuring social distance and 2 items measuring negative attitudes towards people living with HIV (prejudiced attitudes). Social distance was elicited by asking whether respondents “are not willing to care for a family member with the AIDS virus in the respondent’s home,” “would not buy fresh vegetables from shopkeeper who has the AIDS virus,” and/or “say that a teacher with the AIDS virus and is not sick should not be allowed to continue teaching.” Prejudiced attitudes were elicited by asking whether people living with HIV should be “ashamed of themselves” and/or “blamed for bringing disease.” All responses were scored on a binary (yes/no) scale. The HIV stigmatizing attitudes scale was defined as the sum of

affirmative responses. The estimated Cronbach's alpha for the scale was 0.67, indicating an acceptable degree of internal consistency.

Following prior studies in this literature [9], we used these individual-level variables to measure the proximate context of HIV stigmatizing attitudes, operationalized as the level of stigma averaged across all other participants in each participant's primary sampling unit (excluding the participant). The primary sampling unit was the smallest clustering unit of analysis in the DHS and typically represents a village or cluster of villages in rural areas and a ward or residential neighborhood in urban areas. For ease of exposition in the succeeding discussion, we use the term "village" to refer to this level of analysis. Because the HIV testing and stigma questions were administered only to study participants who reported having heard of HIV, only study participants who had ever heard of HIV were included in the analyses (and only responses from those study participants who had ever heard of HIV were used to construct the village-level stigma variables). Thus, the village-level variable represents the mean level of HIV stigmatizing attitudes among other people in the participant's village.

### Statistical Analysis

We fitted multivariable logistic regression models to estimate the impacts of HIV stigma (i.e., measured at the individual level) and its proximate context (i.e., measured at the village level) on individual HIV testing behavior. In these models, individual HIV testing behavior was the binary dependent variable, and the stigma measures entered as explanatory variables. We adjusted these estimates for the following potential confounders which were selected based on their association with HIV-testing in a recent systematic review [3]: age, marital status, region of residence, educational attainment, household headship, household asset wealth, and HIV knowledge. We used the Stata software package (version 12.0, StataCorp L.P., College Station, Texas) for all analyses. We used the survey weights and clustering variables provided by ICF Macro to reweight our estimates and standard errors to be nationally representative.

### Ethics Statement

The data collection procedures for the DHS were approved by the ICF Macro Institutional Review Board and the Sierra Leone Ministry of Health. All participants verbally consented to participate in the study. Our specific analysis was reviewed by the Partners Human Research Committee and considered exempt from full review.

### Results

In total, 8,052 of 10,654 (76%) respondents had heard of HIV and were included in this analysis. The characteristics of respondents who had heard of HIV are shown in the Appendix. The average age was 30.3 (95% confidence interval [CI], 29.9–30.6), and most (68%) were married or had a partner. The majority (53%) had no education, and 18% had a low level of HIV knowledge (defined as correctly answering zero or one of five questions). Among 1,284 (15%) respondents who had ever been tested for HIV, 552 had an HIV test in the past 12 months. Most (67%) endorsed at least one item of the HIV stigmatizing attitudes

scale. The mean score on the HIV stigmatizing attitudes scale across all study participants was 2.56 (95% CI, 2.46–2.66). The study participants lived in 352 villages (mean study participants per village, 21.88; 95% CI, 0.26–43.50), and the mean score on the HIV stigmatizing attitudes scale across all villages was 2.48 (95% CI, 0.92–4.04; range, 0.47–5.00).

### Association between HIV testing and stigmatizing attitudes

In unadjusted analyses, HIV testing had an inverse association with HIV stigmatizing attitudes measured at the individual level (odds ratio [OR]=0.82; 95% CI, 0.76–0.89) and at the community level (OR=0.58; 95% CI, 0.48–0.71) (Table 1). After multivariable adjustment, the strength of the association between individual beliefs and HIV testing was reduced and no longer statistically significant (odds ratio [OR]=0.94; 95% CI, 0.87–1.01). However, community-level stigma retained a strong and statistically significant inverse association with HIV testing (OR=0.70; 95% CI, 0.58–0.85).

### Discussion

Many studies have shown that HIV stigmatizing attitudes at the individual level are a barrier to HIV testing [5]. We contribute to this literature by demonstrating that the proximate context of stigma undermines HIV testing behavior even after adjusting for individual beliefs. In the multivariable regression model, the community-level association with stigmatizing attitudes was a stronger driver of HIV testing than the individual-level association, supporting the argument made by others that addressing stigma on an individual level is not sufficient [10].

The evidence base of interventions to reduce HIV stigma is fairly thin [11]. Our findings directly support the idea that structural interventions targeting stigma at the community level should be undertaken. The accelerated scale-up of HIV treatment in sub-Saharan Africa can be viewed as a structural intervention that diminishes people's fears about HIV, but the simple availability of treatment may not be entirely sufficient to fully eliminate the stigma of HIV [12]. Most recently, the results of the 5-country NIMH Project Accept study produced conflicting findings about the impact of a community-based intervention designed to increase access to HIV services on social and behavioral outcomes, including HIV stigma. In the qualitative report [13], a decline in stigmatizing attitudes was noted in the Tanzania and Zimbabwe study sites but not in the other 3 sites. At this time, more research on structural interventions to reduce HIV stigma is needed.

Interpretation of our findings is subject to several limitations. First, HIV stigma is a complex, multi-dimensional social process with multiple pathways [6]. We examined HIV stigmatizing attitudes but did not examine other aspects of HIV stigma, including enacted stigma or internalized stigma, which may have different patterns of associations with HIV testing behavior. Second, our study was limited to a single country. It is possible that studies conducted in countries with a greater prevalence of HIV or improved health systems resources may show different patterning in the association between stigma and HIV testing. Third, our estimates are derived from cross-sectional data, which limits our ability to draw causal inferences. It is possible that the direction of association could run the other way, i.e.,

having an HIV test reduces one's stigmatizing beliefs. This limitation could alter the interpretation of our individual-level findings; but, because it is unlikely that an individual HIV test could reduce stigma in one's village, we do not believe this limitation would undermine our findings about the community-level effects of HIV stigma. Finally, these data are more than five years old. Stigmatizing attitudes may have changed since then. Studies in other countries in sub-Saharan Africa have shown both declines and increases in HIV stigma, so it is unclear whether changes in HIV stigmatizing attitudes in Sierra Leone would have biased our estimates toward or away from the null [14].

## Conclusions

In summary, we provide new evidence that the proximate context of HIV stigmatizing attitudes can have an independent, negative effect on HIV testing. It is our hope that national programs with low HIV testing rates such as Sierra Leone will move beyond individually targeted approaches to consider structural interventions that are designed to address HIV stigma at the community level [8]. As the proximate context of HIV stigma is increasingly recognized as a viable target for interventions, we encourage rigorous evaluations of interventions so that program implementers can draw on a more diverse portfolio of strategies.

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**Table 1**

Associations between stigmatizing attitudes and HIV testing

Characteristics	Women & Men	
	Unadjusted OR (95% CI)	Adjusted for individual characteristics and effect of community AOR (95% CI)
Stigma scale (individual) <sup>¶</sup>	0.82 (0.76–0.89)	0.94 (0.87–1.01)
Stigma scale (community)	0.58 (0.48–0.71)	0.70 (0.58–0.85)
Age	0.96 (0.93–1.00)	0.91 (0.85–0.97)
Sex		
Male	Ref	Ref
Female	1.81 (1.46–2.26)	2.20 (1.65–2.94)
Marital status		
Never married	Ref	Ref
Married or partnered	1.20 (0.97–1.49)	2.62 (1.90–3.63)
Widowed or divorced	0.75 (0.48–1.18)	1.14 (0.66–1.99)
Education		
None	Ref	Ref
Primary	1.59 (1.18–2.16)	1.86 (1.31–2.65)
Secondary	2.20 (1.75–2.78)	2.58 (1.90–3.50)
Higher	5.13 (3.67–7.18)	5.49 (3.35–9.01)
Head of household	0.90 (0.71–1.15)	1.34 (0.97–1.86)
Household asset wealth <sup>†</sup>		
Poorest	Ref	Ref
Poorer	2.15 (1.39–3.34)	2.23 (1.43–3.49)
Middle	2.36 (1.42–3.94)	1.73 (0.97–3.11)
Richer	2.71 (1.63–4.48)	1.86 (1.05–3.31)
Richest	4.44 (2.69–7.33)	2.10 (1.14–3.87)
HIV knowledge <sup>§</sup>		
Low	Ref	Ref
Medium	1.42 (1.02–1.97)	1.08 (0.76–1.56)
High	2.37 (1.72–3.25)	1.44 (0.97–2.12)

AOR, adjusted odds ratio; OR, odds ratio

<sup>¶</sup>The HIV stigmatizing attitudes scale was generated by summing the total number of responses to five questions about persons with HIV, with responses indicating a negative view of persons with HIV coded to equal “1”. The scale ranges from 0–5, with higher values indicating a greater degree of stigma.

<sup>†</sup>The household asset wealth index is calculated by applying principal components analysis to a set of household possessions and housing characteristics. The index is then defined as the first principal component extracted from the principal components analysis and used to categorize participants into quintiles of household asset wealth. Further details on the construction of the asset index can be found in Filmer D, Pritchett LH. *Demog* 2011;38:115–132.

<sup>§</sup>The HIV knowledge score was generated by summing the total number of correct responses to a series of 5 questions about HIV transmission. Participants who had 0–1 correct responses were classified as having “low” HIV knowledge, 2–3 correct responses were classified as having “medium” HIV knowledge, and 4–5 correct responses were classified as having “high” HIV knowledge.

## Appendix

### Summary statistics for respondents who had heard of HIV (n=8,052)

	N (%) <sup>*</sup> or mean (95% CI)
<b>HIV testing</b>	
Ever been tested for HIV	1,284 (15.3)
Had an HIV test in the past 12 months	552 (6.7)
<b>Characteristics</b>	
Age (in years)	30.3 (29.9–30.6)
Current marital status	
Never married	2,208 (25.9)
Married or partnered	5,353 (68.2)
Widowed, divorced, or separated	491 (5.9)
Highest educational level	
No education	3,966 (52.5)
Primary	1,206 (14.3)
Secondary	2,491 (28.7)
Higher	389 (4.4)
Interviewed household head	2,105 (26.4)
Wealth index <sup>†</sup>	
Poorest	1,127 (15.2)
Poorer	1,092 (15.8)
Middle	1,269 (16.8)
Richer	1,881 (21.9)
Richest	2,683 (30.3)
HIV knowledge (3 categories) <sup>§</sup>	
Low	1,432 (18.2)
Medium	2,855 (36.4)
High	3,630 (45.4)
<b>HIV stigmatizing attitudes</b>	
Endorsed at least one stigmatizing attitude	5,406 (67.1)
Mean score of HIV stigmatizing attitudes scale <sup>¶</sup>	2.56 (2.46–2.66)
Willing to care for relative with HIV	2,543 (33.6)
Person with HIV allowed to continue teaching	4,054 (52.2)
Would buy vegetables from vendor with HIV	5,361 (68.6)
People with HIV should be ashamed of themselves	4,346 (55.7)
People with HIV should be blamed for bringing disease	3,585 (45.9)

<sup>\*</sup> N refers to the raw number of observations, while the % refers to the survey-weighted percentage (not the raw percentage)

<sup>†</sup> The household asset wealth index is calculated by applying principal components analysis to a set of household possessions and housing characteristics. The index is then defined as the first principal component extracted from the principal components analysis and used to categorize participants into quintiles of household asset wealth. Further details on the construction of the asset index can be found in Filmer D, Pritchett LH. *Demog* 2011;38:115–132.



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<sup>¶</sup>The HIV stigmatizing attitudes scale was generated by summing the total number of responses to five questions about persons with HIV, with responses indicating a negative view of persons with HIV coded to equal “1”. The scale ranges from 0–5, with higher values indicating a greater degree of stigma.

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