Geographic Distribution of HIV-Stigma Among Women Of Child-Bearing Age In Rural Kenya

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Abstract

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Background:

HIV-stigma is considered to be a major driver of the HIV/AIDS pandemic, yet there is a limited understanding of its epidemiology, especially at the structural/community level. Here we describe geographic patterns of two types of HIV-stigma in a population of women of child-bearing age: internalized-stigma (associated with shame) and externalized stigma (associated with blame), and explore whether individuals with similar attitudes towards people living with HIV are more likely to reside in the same geographic area.

Methods:

A cross-sectional sample of 405 women who gave birth within a one year period between January - December, 2010 was surveyed from the constituency of Gem, Kenya, one of three regions in the Western Kenya Health and Demographic Surveillance Area (HDSA), a 13 x 20 km region with a population of 220,000. Two forms of HIV-related stigma, self-reported HIV status, and other demographic variables were measured using a standardized, validated questionnaire. Latitude/Longitude coordinates of participants' residences were obtained with GPS devices. Residential locations of participants were compared with respect to whether or not individuals reported each form of stigma at different spatial scales using the K-function, a second order spatial data analysis used to measure spatial clustering of binary outcomes. Generalized additive models (GAMs) were used to assess whether spatial clustering of each stigma indicator occurred beyond that explained by the spatial patterns of individual-level characteristics such as age, income, education, and other socio-economic variables.

Results:

Among 373 women surveyed with complete GPS data, the median age was 25 years (IQR, 22-30 years), 12% self-reported positive HIV status, 45.5% reported at least one of three indicators of harboring internalized HIV-stigma (an indicator of shame) and 89.4% reported at least one of four indicators of harboring externalized stigma (an indicator of blame). There was strong evidence for a geographic trend in rates of externalized stigma among the respondents, with those who reported no form of externalized HIV-stigma being more likely to reside in the Southwestern portion of Gem compared to the Northeastern portion of the region, controlling for individual-level factors (p = 0.02). In contrast to blame, we did not observe spatial clustering for internalized stigma (shame) beyond that of complete spatial randomness (p = 0.36).

Conclusions:

The spatial trend observed for rates of externalized stigma compared to the random spatial distribution of internalized stigma may point to differences in the underlying social processes leading to each form of stigma. Externalized stigma may be driven more by dominant cultural beliefs disseminated within communities (i.e., churches, health facilities, or other leaders), whereas internalized stigma may be the result of individual-level characteristics outside the domain of community influence. Geographic studies of stigma can indicate higher risk areas and provide a first step in generating hypotheses as to potential community-level etiologies of stigma. Further data and hypothesis-testing is needed on community-level attributes that might promote lower rates of externalized stigma or 'high tolerance' areas. These data may inform community-level interventions to decrease HIV-related stigma.

INTRODUCTION

HIV- stigma has been a major driver of the HIV/AIDS pandemic, and the negative effects of HIV-stigma on people living with HIV/AIDS (PLWHA) are well documented [1-9]. Among PLWHA, *internalized* HIV-stigma, characterized by feelings of shame about being HIV positive, acts as a major barrier to uptake of health care, and undermines the effectiveness of prevention and treatment programs [6, 8]. The effects of HIV-stigma have been associated with increased risky sexual behavior [10], delay of HIV testing, and deferral of treatment [2], often until significant HIV progression has occurred [8]. PLWHA who report experiencing stigma tend to hide their status for fear of being ostracized, hindering their ability to receive proper treatment and care. One study, for example, found that the main reason PLWHA did not seek treatment was fear of social exclusion should the community find out their status [1].

For HIV-infected pregnant women, HIV-related stigma may be a barrier to uptake of care, and contributes to the gap between the availability of prevention-of-mother-to-child-transmission (PMTCT) services and the use of those services [11]. One cross-sectional study showed lower uptake of antiretroviral use among HIV-infected mothers in Kenya who reported feeling ashamed for their HIV status compared to those who did not [12]. Despite the recent global scale up of PMTCT services, it is estimated that only roughly half of HIV-infected pregnant women in low- and middle-income countries receive antiretroviral therapy (ART) for PMTCT. Wide disparities in PMTCT coverage exist among the countries with the greatest HIV-burden, varying from 5-10% in the Sudan and Chad to 80-90% in South Africa, Botswana, Swaziland, and Namibia [13]. In one study fear of stigmatization among pregnant women was thought to account for low rates of uptake of PMTCT services during childbirth compared to that of antenatal care (ANC) services, which are often accessed before a mother’s HIV status is known [14]. Studies on the stigmatizing behaviors of women of child-bearing age in Africa are needed, as this population continues to experience the highest incidence of HIV/AIDS and is highly vulnerable to the effects of HIV-stigma on health seeking behavior. Furthermore, women living with HIV may be more stigmatized than men due to the higher social and moral expectations on women [15].

Research on HIV-stigma and the implementation of anti-stigma interventions have focused primarily on the negative effects caused by stigma that result in barriers to access to HIV-care and services, with less attention towards its causes both at the individual and structural levels [7]. Qualitative studies on HIV-stigma, mostly using focus groups, point to a number of individual-level risk factors for HIV-stigma including fear, lack of HIV knowledge, and a lack of social spaces to engage in dialogue on HIV/AIDS [9, 16]. It remains unknown whether results from qualitative studies can be translated into effective community-level, anti-stigma interventions. Government-sponsored, information-based stigma-reduction and awareness campaigns targeted at dispelling myths and promoting tolerance have had minimal success [3] and anti-stigma interventions remain a low priority for HIV/AIDS programs, mainly because of the difficulty in identifying effective interventions [7]. Population-level research on structural causes of HIV-stigma, may be useful to inform how and where community-level interventions will be most effective [3, 5, 17].

We conducted a population-level study to explore the geographic distribution of two forms of HIV-stigma in recently pregnant women in rural, Western Kenya. We analyzed the geographic distribution of two types of HIV-stigma: internalized stigma, (associated with feelings of shame), and externalized stigma, (associated with blame towards PLWHA). Because stigma in communities is dependent on the cultural context in which it is manifested [3] we hypothesized that individuals of the same geographic region would harbor similar levels of HIV-related stigma due to sharing of information, social networks, influential leaders and churches, and other shared sociocultural factors. We first explored whether individuals with similar levels of HIV-stigma were more likely to reside in the same geographic area. Second, we assessed the spatial scale(s) at which community-level clustering of each form of HIV-stigma occurs. This study serves as a first step towards identifying structural-level factors associated with HIV-stigma that can motivate intervention strategies against HIV-stigma.

METHODS

Study population:

This analysis was nested in a community-based survey of women accessing maternal child health clinics (MCH) and PMTCT uptake. A random, cross-sectional sample of 405 women with unknown HIV status was selected from a comprehensive list (n = about 8,000 women) of women who were surveyed in the HDSS survey and delivered within the previous year. All subjects were sampled from within the Health and Demographic Surveillance Area (HDSA), a region that encompasses 383 villages with a population of approximately 220,000. Inclusion criteria were as follows: maternal age of 14 years and older at enrollment, resided in the HDSA catchment area, delivered a baby within a year of the 2009 HDSS survey, and willing to give written consent. Participants were asked a series of questions regarding their knowledge and attitudes about HIV. Women were also asked to self-report their HIV status. Latitude and longitude coordinates of participants' residences were obtained with GPS devices and only individuals with non-missing GPS coordinates were included in the analysis.

Survey:

Because of high stigma prevalence, we considered absence of stigma the target outcome and classified individuals without measured stigma as "cases" while those with evidence of HIV-stigma as controls. For externalized HIV-stigma, we categorized responses to questions into a binary indicator of "cases" (those who answered "disagree" to all of the following four statements) and "controls" (those who answered "agree" to any of the following questions) for externalized stigma (blame) following previous work [18]:

1) HIV is a punishment from God

2) HIV/AIDS is a punishment for bad behavior

3) Women prostitutes spread HIV in the community

4) People with HIV are promiscuous

and for internalized stigma (shame):

1. I would be ashamed if I were infected with HIV
2. I would be ashamed if a person in my family had HIV/AIDS
3. People with HIV should be ashamed of themselves

Exploratory spatial data analysis:

The residential locations of each of the 373 respondents who provided GPS coordinates were visualized in a geographic information system (GIS) using Arc View 10.0 [19]. Exploratory spatial data analysis (ESDA) methods were used to explore the spatial distribution of each type of HIV stigma indicator across the study region. All spatial data analysis was done in the R statistical package [20].

A second order K-function was used to assess the scale of spatial clustering of cases relative to controls in the study area:

$$\mathrm{K(d)} = \frac{1}{\lambda}\sum_{i=1}^{n}\frac{1}{n}\sum_{j\neq i} I(d_{ij} < d),$$

Where λ is the density of points within a radius d; d_{ij} is the distance between each pair of residential locations i and j; and $d_{ij} > d$ is the indicator function, where $I(d_{ij} \leq d) = 0$ if $d_{ij} > d$ and 1 if

$d_{ij} \leq d$. Under the hypothesis of no spatial clustering, the cases and controls are independent random samples from the underlying population at risk, where $K_1(d) = K_0(d)$. The difference between K-functions, $D(d) = K_1(d) - K_0(d)$, is thus a measure of additional clustering among the cases relative to that among the controls. We plotted $D(d)$ against d to assess the degree of clustering (or dispersion) with distance between points for both cases and controls and simulated 99.9% confidence bounds (inflated to account for multiple testing) using Monte-Carlo simulations of random labeling of cases and controls to the underlying spatial distribution of the population. This approach differs from that of K-functions used to assess clustering for one set of points, where clustering at a given distance is compared to complete spatial randomness (CSR). CSR is of little interest for our purposes, as residential locations are not distributed randomly in space. Significant clustering (dispersion) occurs where the curve $D(d)$ falls above (below) the 99.9% confidence bound. For example, if cases are more spatially clustered relative to controls at certain distances then the difference in K-functions between cases and controls would be significantly positive at those distances.

Spatial regression was performed to identify clustering of "cases" (those who were found to harbor no form of HIV-stigma) relative to "controls" (those who were found to harbor any form of HIV-stigma), controlling for potential confounding by location of individual-level variables that might account for any observed spatial pattern of stigma. These variables include age, marital status, self-reported HIV status, income, number of televisions, number of cellular phones, and number of radios. Maps of adjusted odds ratios were produced using a locally weighted regression smoother in a general additive model (GAM) framework for case-control data [21] using a logistic link function and a non-parametric component for the residual spatial surface:

$$Logit(P) = \alpha_0 + \beta_1(x_1) + \beta_2(x_2) + \beta_3(x_3) + S(lat, lon)$$

Where P is the probability of reporting no stigma (i.e., the probability of being a case); x_1 is the linear combination of demographic variables (age, marital status, income, education); x_2 is the linear combination of technology variables (number of televisions, phones, and radios); x_3 is the linear combination of HIV-variables (self-reported HIV status and whether or not the individual knows someone living with HIV); and S is the smoothed term of the log odds of not reporting any stigma relative to reporting any stigma over the geographic extent of the study area. We adjusted for individual-level factors in the model to estimate the residual spatial surface and test for its significance. We then plotted the residual surface to explore the spatial clustering of cases relative to controls beyond that explained by individual-level covariates.

RESULTS

Among 405 participants surveyed, 29 had missing geographic coordinates and were dropped from the analysis. Participants were sampled over a 20 km by 13 km region in the district of Gem, encompassing 11 Kenyan Sub-locations. Among the 373 with non-missing lat/lon data, the median age was 25 years (IQR = 22 – 30 years). Of the 337 who reported an HIV-status, 41 (12%) were HIV-positive by self-report. Most of the respondents (77%) reported not knowing someone living with HIV.

Two hundred and five (54.5%) of those surveyed reported no sense of shame (“cases”) and 171 (45.5%) reported some sense of shame (“controls”). In contrast, 40 (10.6%) of those surveyed reported no sense of blame (“cases”) and 336 (89.4%) reported some sense of blame (Table 1). Individuals who reported none of the shame indicators had better sociodemographic status than those who did, specifically they were more likely to have completed primary school (51% vs. 41%, p=0.06) and less likely to be in the lowest income category (26.6% vs. 35.5%, p=0.06). Shame cases were similar to shame controls with respect to self-reported HIV-status, and more likely to know someone with HIV than shame controls (26% vs. 19%, p=0.11).

Individuals who reported no judgment or blame of HIV-infected individuals (blame cases) were comparable to blame controls with regard to age. Individuals with no blame/judgment indicators had better sociodemographic status than individuals who reported at least one blame/judgment indicator, specifically they were less likely than blame controls to be in the lowest income category (26% compared to 31%, p =0.47) and more likely to have completed primary school (60% compared to 45%, p= 0.07). Individuals with no blame were less likely to know someone with HIV (15% compared to 24% p=0.22) and more likely to self-report positive HIV status (16% compared to 12% p=0.47). We found a strong association between those not reporting any shame and not reporting any blame (OR = 3.77, 95% CI, 1.63 – 9.72, p < 0.001). This association depended on HIV-status, with a strong positive association among those who reported negative HIV status (OR = 4.78, 95% CI, 1.74 – 16.32, p < 0.001) and no association among those who reported positive HIV status (OR = 0.84, 95% CI, 0.10 – 7.22, p = 0.84).

The geographic distribution of cases and controls, when mapped, showed different spatial patterning by stigma indicator. Results of the differences in K-functions between cases and controls indicate significant clustering of cases relative to controls for the blame indicators but not for the shame indicator (Figure 1). For the blame indicator, on the other hand, statistically significant (α = 0.001) differences in clustering between cases and controls were observed at a radius of 0.05 - 0.07 decimal degrees, corresponding to about 5 - 7 kilometers (Figure 1). In other words, those who did not harbor any blame tended to cluster at distances between 5 – 7 kilometers relative to those who indicated any form of blame. For the blame indicator, location was associated with the log odds of being a case vs. being a control both crudely and after adjustment for individual level factors (p-value = 0.02) (Figure 2). No significant spatial structuring as modeled as a linear spline was observed for the shame indicator, after adjusting for the same individual-level covariates (Figure 2).

DISCUSSION

Despite the growing recognition that HIV-stigma plays an important role in fueling the HIV/AIDS pandemic, there is little knowledge on what causes it at the community level. Population- level anti-stigma campaigns could benefit greatly from a better understanding of the distribution, frequency, and etiology of HIV-stigma at the community level, especially in areas with high prevalence of HIV and the presence of highly vulnerable groups to both HIV acquisition and the negative effects of stigma on access to care.

In this analysis we explored the geographic distribution of HIV-stigma in a rural area of Western Kenya among a cross-sectional sample of women who recently gave birth, a group that is at high risk of contracting HIV, vulnerable to the effects of HIV-stigma, and potentially involved in promoting the spread of HIV-stigma in the community. We considered two forms of HIV-stigma: internalized stigma, the experience of shame around HIV infection, and externalized stigma, the experience of blame towards PLWHA. We hypothesized that individuals living in closer proximity to one other would hold similar levels of HIV-stigma as a result of shared cultural norms, social networks, and other community-level factors. We assessed whether, after controlling for individual-level factors such as education, income, HIV status, knowing someone with HIV, and access to technology, there remained a residual geographic pattern of each form of stigma that would implicate underlying socio-cultural factors as a driver of HIV-stigma in the community.

This is the first population-based study to our knowledge that takes a geographic approach to explore the distribution and spatial structure of HIV-stigma. Spatial analysis in health research employs unique statistical frameworks that can be used to quantitatively explore how individuals are distributed geographically with respect to important epidemiological attributes [22]. The geographic areas where individuals are more likely than not to share similar epidemiological attributes may point to underlying place-based, or cultural phenomena that drive those patterns. These areas can also elucidate spatially dependent processes where individuals influence one another with respect to shared attributes (as in the case of an infectious processes).

Our results indicate that respondents overwhelmingly hold a sense blame towards others with HIV, while less than half would experience shame if they were HIV infected (this includes those who self-reported HIV). This finding is consistent with the results of a USAID report that tested the validity of the questionnaire used here in another context [4]. We found distinct spatial patterns in respondents' attitudes towards others with HIV for each type of HIV-stigma, even after controlling for individual-level factors. The spatial distribution of individuals reporting no shame relative to any shame was no different than a random spatial distribution. On the other hand, the spatial distribution of those who reported no blame relative to any blame had significant spatial structure, with lower than expected rates of externalized HIV-stigma in the South-West and higher than expected rates in the North-East. While we originally hypothesized that that rates of blame would be highly clustered at small spatial scales – that of the size of neighborhoods – we found more of a large scale geographic trend across the study area. Results of the k-function indicated spatial clustering of individuals who report lower than expected blame towards PLWHA at a distance that spans over half the 13 x 20 km study area.

Results of this exploratory analysis suggest that the two forms of HIV-stigma explored here do not follow similar geographic distributions in this population. While further investigation will be needed to confirm this observation, the differences in geographic distributions of each form of HIV-stigma have certain implications for community-level interventions. Externalized (blame) stigma may be driven more by dominant cultural beliefs disseminated within communities, (i.e., churches, health facilities, or influential leaders), whereas internalized (shame) stigma may be the result of individual-level characteristics outside the domain of community influence. The observed spatial trend observed for the blame indicator begs further study into what community-level risk factors might drive high vs. low rates of externalized stigma in a population. Religious institutions are thought to heavily influence community-level attitudes towards PLWHA [5], though no formal evaluation of the influence of religious institutions on HIV-stigma has been done. As this analysis was exploratory in nature, the spatial structure and scale of clustering observed for the blame indicator should be confirmed in further study through hypothesis-driven analysis. Further study could also explore whether lower levels of externalizing stigma tend to be concentrated in areas known to promote tolerance towards PLWHA and/or in areas where stigma-reduction interventions are currently being implemented at the community level.

There are several limitations to using the methods presented here. First, the standardized questionnaires used in the study may not capture an individual's actual attitudes and values towards PLWHA. Second, whether the two forms of HIV-stigma ascertained in this study reflect actual levels of overt discrimination towards PLWHA at the community-level has not been tested, nor whether these forms of stigma are associated with negative outcomes among PLWHA at the individual-level. Thus, the forms of stigma used here may not necessarily correspond to those forms of stigma that act as barriers to health seeking behavior or negative health outcomes among PLWHA. Third, this study only measures HIV-stigma among women who recently gave birth, ignoring other demographic groups, namely men and women-of-non-child-bearing-age, in the community who may play an important role in perpetuating (or working against) stigmatizing attitudes. Finally, some of the questions may be considered ambiguous as to what underlying cause of the stigmatizing behavior is being measured, or whether answering "no" to a question in the stigma survey necessarily indicates the absence of stigma [5]. We attempted to overcome this limitation by conservatively categorizing individuals into the "no stigma" category only if they answered "no" to every question. In light of the difficulty in accurately measuring levels of stigma in individuals [5], which has resulted in a limited literature on the causes of stigma [7], it will be important to refine the stigma measurement tools we already have and to test those tools in a variety of settings.

For PLWHA, the benefits of seeking HIV-services are often weighed against the social costs of accessing care [23]. This is especially true for women living with HIV who are both highly vulnerable to being stigmatized and are more at risk to the negative sequelae associated with stigma. Thus, the extent to which communities reduce levels of stigma while also increasing the availability and accessibility of HIV-services, may improve the effectiveness of HIV-programs in treating PLWHA and preventing new infections. In order to this, more research is needed to identify attributes of communities that promote high (and low) levels of stigma (and tolerance) towards PLWHA, and to turn those lessons into effective community-level interventions.

	Shame (internalized stigma)				Blame (externalized stigma)			
	No reported shame indicator		At least one reported shame indicator		No reported blame indicator		At least one reported blame indicator	
	n = 205 (54.5%)		n = 171 (45.5%)		n=40 (10.6%)		n=336 (89.4%)	
	(Number/ Median)	(percent/ IQR)	(Number/ Median)	(percent/ IQR)	(Number/ Median)	(percent/ IQR)	(Number/ Median)	(percent/ IQR)
Age (median/IQR)	27.0	(22 - 31)	26.0	(22 - 30)	26.5	(23 - 30)	26.6	(22 –30)
Household Income(KSH)								
0-2000	54	(26.6)	60	(35.5)	10	(25.6)	104	(31.2)
2001-5000	26	(12.8)	27	(16.0)	4	(10.3)	49	(14.7)
5001-10,000	8	(3.9)	5	(3.0)	3	(7.7)	10	(3.0)
10,0001-20,000	0	(0.0)	3	(1.8)	0	(0.0)	3	(0.9)
21,000-30,000	1	(0.5)	0	(0.0)	0	(0.0)	1	(0.3)
Don't Know	114	(56.2)	74	(43.8)	22	(56.4)	166	(49.9)
Highest Level of Education								
None	7	(3.4)	3	(1.7)	0	(0.0)	10	(3.0)
Some Primary	93	(45.6)	97	(57.1)	16	(40)	174	(52.1)
Completed Primary	81	(39.7)	47	(27.7)	14	(35.0)	114	(34.1)
Some Secondary	16	(7.8)	17	(10.0)	6	(15)	27	(8.08)
Completed Secondary	6	(2.9)	4	(2.4)	4	(10.0)	6	(1.8)
College	1	(0.5)	2	(1.2)	0	(0)	3	(0.9)
Occupation								
Housewife	89	(43.6)	58.0	(33.9)	18	(45.0)	129	(38.5)
Salaried job	4	(2.0)	2.0	(1.2)	2	(5.0)	4	(1.2)
Self-employed/small business	79	(38.7)	75.0	(43.9)	14	(35.0)	140	(41.8)
Unemployed	32	(15.69)	36.0	(21.1)	6	(15.0)	62	(18.5)
Number of Mobile Phones in Household								
None	56	(27.5)	51	(29.8)	6	(15.0)	101	(30.2)*
1	91	(44.6)	85	(49.7)	17	(42.5)	159	(47.5)
2+	57	(27.9)	35	(20.5)	17	(42.5)	75	(22.4)**
Self-reported HIV status								
HIV-Positive	22	(11.6)	19	(12.8)	6	(15.8)	35	(11.7)
Knows someone with HIV								
Answered "yes"	53	(25.9)	32	(18.8)	6	(15.0)	79	(23.6)

Table 1. Characteristics of individuals reporting vs. not reporting shame or blame indicators.
* p-value = 0.04
**p-value = 0.01

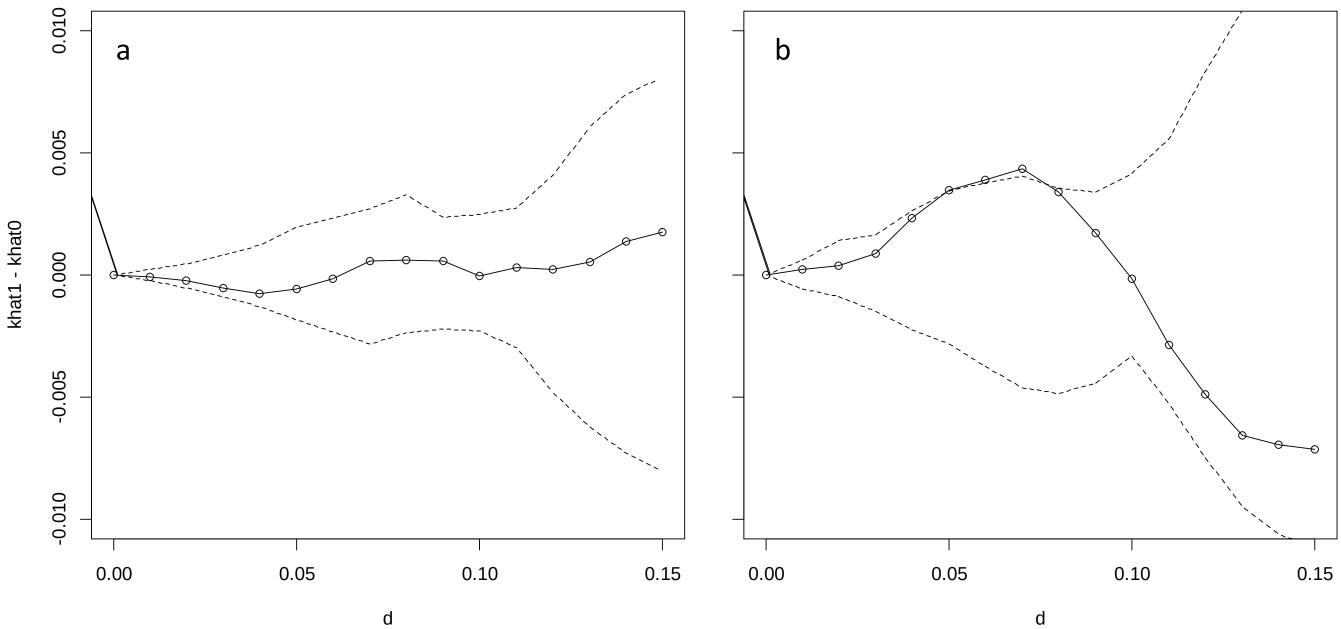

Figure 1 Differences in K-functions of cases and controls for both (a) shame, and (b) blame indicators, with 99.9% confidence bounds (dashed lines) derived from permuting cases and controls under complete spatial randomness. Significant clustering of residential locations of those who did not harbor stigma relative to those who did is indicated where the solid line is positive and outside of the confidence bounds.

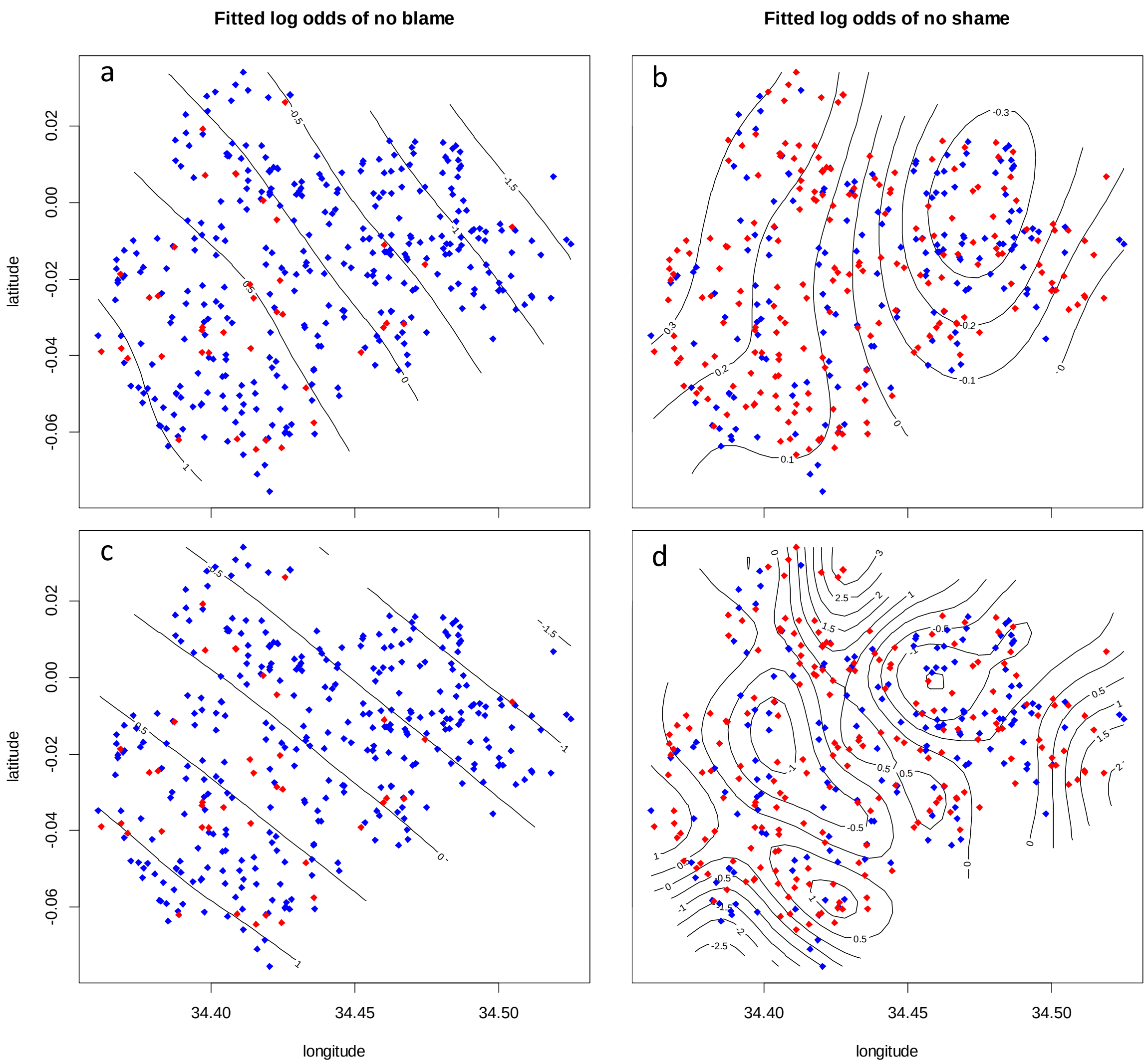

Figure 2 Fitted log odds ratios from the Generalized Additive Model (GAM) of reporting no stigma (red points) relative to reporting any form of stigma (blue points) for a) blame and b) shame, both unadjusted for co-variates and for c) blame and d) shame, both adjusted for age, income, education, marital status, self-reported HIV status, knowing someone with HIV, number of televisions, number of cellular phones, and number of radios. In contrast to the shame indicator which is randomly clustered there is a linear gradient for blame, indicating higher rates of tolerance than expected in the southwest portion of the study area.

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