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Experiences of stigma, discrimination, care and support among people living with HIV: A four country study

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Abstract

While it is widely agreed that HIV-related stigma may impede access to treatment and support, there is little evidence describing who is most likely to experience different forms of stigma and discrimination and how these affect disclosure and access to care. This study examined experiences of interpersonal discrimination, internalized stigma, and discrimination at health care facilities among HIV-positive adults aged 18 years and older utilizing health facilities in four countries in Sub-Saharan Africa ($N=536$). Prevalence of interpersonal discrimination across all countries was 34.6%, with women significantly more likely to experience interpersonal discrimination than men. Prevalences of internalized stigma varied across countries, ranging from 9.6% (Malawi) to 45.0% (Burkina Faso). Prevalence of health care discrimination was 10.4% across all countries. In multivariate analyses, we found positive, significant, and independent associations between disclosure and interpersonal discrimination and support group utilization, and positive associations between both internalized stigma and health care discrimination and referral for medications.

Keywords

HIV/AIDS; stigma; discrimination; HIV care

Introduction

Many researchers and activists have argued that HIV/AIDS-related stigma is a persistent force reducing the effectiveness of preventive measures, discouraging those at risk of infection from HIV testing, and creating barriers to HIV-related care and support [1-4].

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No conflicts of interest are declared for any of the authors. At the time that the project was conducted, Carla Makhoul Obermeyer was a Scientist at the World Health Organization (WHO), and the project benefitted from discussions of policies and programs related to testing and counseling around the world, but the WHO did not define the project or influence data collection, analysis or interpretation.

All authors had full access to all the data and can take responsibility for the integrity of the data and the accuracy of the data analysis

There are, however, great variations in the definitions, frameworks, and tools to measure discrimination and stigma among different populations and understand its prevalence and effects among people affected by HIV. However, it is generally agreed that stigma is a product of social power structures [5]; exists at multiple levels, from within individuals to interpersonal relationships, to broader political and cultural structures [5, 6]; and affects multiple domains of an individual's life, including home life, employment, and health care [7, 8]. One means through which stigma acts on individual well-being is through increasing vulnerability to harmful, discriminatory behavior [8]. Most frameworks differentiate between experiences of discriminatory behavior (“interpersonal discrimination”) and internalized feelings of low self-worth (“felt” or “internalized” stigma) [5]. They also, implicitly or explicitly, differentiate between the experiences of discrimination among people living with HIV (PLHIV) and perceptions of stigma and stigmatizing attitudes in the community [9]. While early measures of stigma among PLHIV simultaneously assessed internalized feelings about HIV and negative experiences due to HIV [10, 11], more recent literature emphasizes the need to measure discrimination and stigma more precisely by type and domain, and to clarify their effects on the lives of people with HIV.

While many studies have investigated the prevalence of HIV-related stigma or discrimination, broadly defined, fewer studies differentiate between internalized feelings of low self-worth and experiences of externalized discrimination; they have found that 40-50% of respondents experienced discrimination and 67-78% experienced internalized stigma [12-15]. Evidence on the determinants of experiencing HIV-related stigma is mixed, with some studies finding that men more frequently report internalized stigma [15] and others that women and rural residents were more likely to experience discrimination [16, 17]. Studies of HIV-related discrimination within health facilities in the United States have found that 20-25% of HIV-positive persons have experienced discrimination, and that persons experiencing discrimination have over three times the odds of reporting low access to care [18, 19].

Few studies have assessed the effects of these specific forms of stigma and discrimination on health. However, stigma or discrimination have been identified both as important factors for individuals' decisions to disclose and as the adverse effects of disclosure [20-23], and discrimination has been linked to a variety of adverse behavioral and health outcomes among persons with HIV [15, 24-26]; and a lower likelihood of seeking health care and adhering to treatment regimens [1, 24, 27]. The causal links between stigma or discrimination and disclosure are difficult to disentangle: while a meta-analysis of stigma and disclosure found that, on average, persons experiencing greater stigma were less likely to disclose their status [28], other studies find that women and men who report “stigma-related experiences” are more likely to disclose to non-partners [24].

This study uses comparative multi-item measures of self-reported internalized and interpersonal discrimination, and discrimination experienced at health facilities, to assess both the determinants of experiencing different forms of discrimination, and the association between these experiences and HIV status disclosure and care-seeking behavior. It answers the following questions: How are different forms of reported stigma or discrimination (interpersonal discrimination, discrimination in health care facilities, internalized stigma) distributed across the population of health facility clients by country, sex, age, educational attainment, household wealth, and type of residence? Are respondents who report different forms of discrimination more or less likely to receive a referral for medication, or join a support group?

Methods

Participants and analysis

This analysis uses a subset of data collected as part of the MATCH (Multi-country African Testing and Counseling for HIV) study, namely data on respondents who reported that they were HIV positive. For the MATCH study, trained interviewers surveyed adult clients (aged 18 years and older) at 63 health facilities in four sub-Saharan countries about their HIV testing experiences, disclosure of HIV status, and HIV care and support received. The aim of this study was to investigate the provision of testing and counseling in Burkina Faso, Kenya, Malawi, and Uganda and to understand the motivations behind clients' decisions to test or not test for HIV, and their experiences with HIV testing. The survey was implemented in 2008-2009.

Facilities to include in the survey were chosen by country research teams to represent the most common forms of HIV testing and health care provision in the capital city and one province in each country. About 20 facilities or services within larger facilities were selected for inclusion from each country. Within each facility, adult clients (aged 18 years and over) who were present at the selected facilities on the appointed days were invited to participate in the study. All respondents who agreed to discuss their experience with testing or not testing for HIV were included. Informed consent was obtained from each respondent. The study protocol included closed- and open-ended questions about socio-demographic information; attitudes towards HIV testing and counseling; a checklist on services during pre- and post-test meetings and follow-up care; questions about interactions with providers and experiences before, during and after testing, including disclosure and stigma.

The study was cleared by the Institutional Review Board of each of the four countries, and by the Ethics Review Committee of the World Health Organization. Additional information on the survey design and implementation and response rates is available elsewhere [29].

The MATCH client sample included 2,187 respondents who tested for HIV in 2007 or later and agreed to discuss their status. Of these respondents, 602 (28.4%) were HIV-positive. Respondents who had learned their HIV positive status on the date of the interview or were missing date of interview were removed from the analysis (33), as were respondents missing covariates such as age or type of place of residence (10), missing information on at least one discrimination measure (20), or reports on disclosure, medications, or use of support group (4). The final sample for this analysis included 536 HIV positive respondents.

Measures used

The items used to measure stigma and discrimination in the MATCH survey were selected on the basis of a synthesis of the literature on HIV-related discrimination and stigma and a compilation of existing instruments, conducted by the World Health Organization (WHO), as part of efforts to define key questions for operational research on HIV stigma in multiple settings. The literature review and the selection of measures were the result of several expert consultations, and while the set of questions included in the MATCH survey was not formally validated, it was based on instruments that had been field tested or validated by groups working on stigma, including the USAID-convened Interagency Stigma and Discrimination Indicators Working Group and the Population Council Horizons Program [30, 31]. The key dimensions of stigma identified in the final report of these reviews and consultations [32] included the fear of contamination from casual contact and negative judgments about people with HIV as indicators of stigma at the level of the community; discrimination experienced by people living with HIV, with special attention to discrimination in health settings; and internalized stigma. These were all included in the

MATCH survey instrument. In this analysis, we focus on internalized stigma and experiences of discrimination as reported by people living with HIV.

Three separate stigma and discrimination constructs were identified for analysis: interpersonal discrimination, which included experiencing verbal or physical abuse, exclusion, and loss of employment or housing; discrimination experienced in health care facilities; and internalized stigma, which included feeling worthless or guilty about HIV status. A list of all questions included in each measure is included in Table 1. Responses on each of these constructs were entered into factor analysis using principal components analysis and varimax orthogonal rotation. Variables with a factor loading of at least 0.4 and factors with an eigenvalue of at least 1 were retained for the final analysis [33]. To construct the final measures used in analysis, all questions retained for each factor were added into an index variable, and the index variable was dichotomized into a binary measure of no or at least one measure of discrimination reported for the interpersonal and health care measures, or agreeing with at least one statement for the internalized stigma measure. These dichotomized measures were used in the analysis to facilitate interpretation of the results; analyses conducted using the original factor scores rather than the dichotomized measures yielded similar findings in terms of direction and significance of association (data not shown).

Three measures of disclosure and utilization of care and support were used in the analysis. To measure disclosure, respondents were asked whether they had told anybody about their HIV status. Respondents were also asked if they had received a referral for clinical or medical care related to HIV, which was broadly defined to include ARVs, antibiotic prophylaxis, vitamins, or TB treatment, and if they had joined an HIV-related support group after receiving their HIV-positive test result.

Additional covariates entered into multiple regression models included sex, age in 10-year categories, urban-rural residence, and educational attainment. Age and educational attainment were self-reported by respondents. Urban-rural location was determined using the type of location of the facility in which the respondent was interviewed, with urban including both urban and peri-urban facilities.

Analysis

The analysis plan included three components. First, descriptive tables on the frequency of different forms of stigma or discrimination were generated. Next, multiple regression analysis was conducted with each discrimination measure as an outcome to identify the socioeconomic determinants of different forms of discrimination. Finally, disclosure and the two measures of care and support (prescribed medications, joined support group) were modeled as binary outcomes predicted by each form of discrimination and socio-demographic covariates. In the third set of models, disclosure was added as a predictor to models with utilization of care and support as outcomes. An additional set of models were run allowing for independent and interactive associations of multiple forms of discrimination; the results from these analyses were not substantially different from those with main associations of discrimination only, and are not reported below.

Because prevalences of discrimination, disclosing status, and obtaining care and support were relatively high, with probability greater than 10%, odds ratios estimated using logistic regression analysis would not provide an unbiased estimate of the relative prevalence of testing. For this reason we used a modified Poisson regression analysis with robust standard errors to estimate the relative risk of testing and report relative prevalences below [34]. Generalized estimating equations were used in all models to account for the clustered design of the survey. All analyses used Stata 10.1 SE for Windows [35].

Results

Description of sample

Table 1 lists the variables included in each measure and the Cronbach's alpha calculated for each measure. Cronbach's alpha is a measure of the internal consistency of the questions comprising the scale, with a value less than 0.6 indicating an unacceptable lack of consistency, between 0.6 and 0.7 acceptable, and greater than 0.7 as preferable [33]. Alpha scores for both the interpersonal discrimination and health care discrimination measures were greater than 0.8, indicating very good internal consistency reliability. The alpha score for the internalized stigma score is lower, at 0.68; while this score represents only minimally acceptable internal consistency reliability, it has been retained in the analysis because of the importance of this construct. We did not construct a composite discrimination scale because each type of discrimination represents a different experience with potentially different behavioral outcomes. The discrimination measures were weakly positively correlated, with Pearson's correlation coefficients ranging from 0.06 for interpersonal discrimination and internalized stigma to 0.16 for interpersonal and health care discrimination (analysis not shown).

Table 2 provides an overview of the sample included in the analysis. The sample was predominantly female (67.4%), reflecting the sex ratio of health facility users; nearly half (46.1%) were between the ages of 25-34 years at the time of the survey. Most respondents had disclosed their status to someone (79.9%), received a referral for HIV-related clinical or medical care (86.0%), but fewer had joined a support group (27.6%).

Prevalence of discrimination by type

Table 3 presents prevalence of interpersonal, internalized, and health care discrimination by country. The prevalence of reported interpersonal discrimination was higher in Malawi (43.0%) and Burkina Faso (40.0%), and lower in Uganda (31.2%) and Kenya (22.8%). Among the sub-measures used to calculate the interpersonal discrimination index, respondents were more likely to report that they had been made to feel badly as a result of their status (21.0%) or verbally abused (16.8%), while physical assault (2.6%), loss of employment (3.2%), loss of property (3.4%), and spousal abandonment (9.5%) were less common. Internalized stigma was most common in Burkina Faso (45.0%) and least common in Malawi (9.6%). Discrimination in health care facilities was less commonly reported than interpersonal discrimination in all countries, and was more common than interpersonal discrimination in all countries but Malawi. The most commonly reported health care discrimination sub-measure in all countries was excessive use of precautions (6.5% across all countries), and few respondents reported being denied care (3.0%) or receiving less care because of their HIV status (3.4%).

Determinants of reporting discrimination

Model results estimating the determinants of reporting different forms of discrimination are presented in table 4. After adjustment for multiple covariates, women were significantly more likely to experience interpersonal discrimination (APR: 1.414, 95% CI: 1.028, 1.945). Respondents in Malawi were substantially less likely to report interpersonal discrimination (APR: 0.226, 95% CI: 0.152, 0.336). There were no significant differences in respondent discrimination by age, educational attainment, or type of place of residence.

Discrimination, disclosure, and utilization of care and services

Table 5 presents model results estimating the association of different forms of discrimination with disclosure, prescription of medications for HIV, and membership in an HIV support group. After adjustment for individual-level covariates, no form of

discrimination significantly predicted whether or not a respondent had disclosed their status, though experiences of interpersonal discrimination tended to have a positive association, and experiences of internalized stigma a negative association with disclosure. Women (APR: 1.172, 95% CI: 0.994, 1.383) and persons aged 45 years and older (APR: 1.185, 95% CI: 0.998, 1.407) were more likely to disclose their status than were other respondents. Respondents reporting either internalized stigma or discrimination in health care facilities were more likely to have received clinical or medical care for HIV (APR for internalized stigma: 1.090, 95% CI: 1.031, 1.285); APR for health care discrimination: 1.084, 95% CI: 1.032, 1.139). Respondents reporting interpersonal stigma were nearly 90% more likely to participate in an HIV support group (APR: 1.860, 95% CI: 1.439, 2.404). Respondents reporting internalized stigma were less likely to participate in these groups, though this difference was not significant after adjustment for individual covariates (APR: 0.855, 95% CI: 0.666, 1.098).

Because disclosure may affect an individual's capacity to access care and support services, we also estimated models with disclosure as a predictor of receiving medication and joining a support group. After adjusting for covariates, disclosure was not a significant predictor of receiving a referral for HIV-related care (APR: 1.018, 95% CI: 0.902, 1.150). After adjustment for disclosure status, both internalized stigma and health care discrimination remained positively associated with receiving a referral for clinical or medical care (internalized stigma APR: 1.091, 95% CI: 1.033, 1.153; health care discrimination APR: 1.084, 95% CI: 1.033, 1.139). Disclosure was significantly and positively associated with joining an HIV support group: respondents who had disclosed their status were 71% more likely to join a support group after adjustment for experiences of discrimination and other covariates (APR: 1.715, 95% CI: 1.001, 2.939). As in the models excluding disclosure as a predictor, experiences of interpersonal discrimination were substantially and positively associated with joining a support group (APR: 1.805, 95% CI: 1.389, 2.346).

Discussion

Prevalences of interpersonal discrimination that we found in the four countries, ranging from 22.8% (Kenya) to 43.0% (Malawi), were similar to those found in a study of urban PLHIV in South Africa [15]. While experiences of verbal abuse and being made to feel badly by others were relatively common across countries (16.8% and 21.0% respectively), more severe forms of interpersonal discrimination were less common, with physical assault occurring in 2.6% of respondents (3.8% of women, 0.6% men [data not shown]). Reviews of studies of the consequences of HIV disclosure found that between 3% and 15% percent of HIV-positive women in Africa and Asia experience violence after disclosure [22, 23], and that about 4% of HIV-positive women experienced violence after disclosure in a United States-based sample [36]. The results presented above, collected much later and after increased investment in HIV testing and treatment in these areas, are thus at the lower end of prevalences of violent discrimination. This is consistent with the notion that increased availability of treatment and other community resources for assisting PLHIV may have reduced, though not eliminated, HIV-based stigma and discrimination [37, 38]

Prevalences of internalized stigma ranged from 9.6% (Malawi) to 45.0% (Burkina Faso), and are generally lower than reported in a sample of HIV+ urban residents in South Africa, where prevalence of internalized stigma sub-measures ranged from 33% to 66% among men and 23% to 61% among women [15]. Internalized stigma was noticeably less common in Malawi, and this difference persisted after differences in age, sex, educational attainment, and type of residence were accounted for using multiple regression analysis. There are several possible explanations for this disparity in internalized stigma. First, studies have documented an inverse association between stigma or negative attitudes toward persons with

HIV and community prevalence of HIV [39, 40]; this pattern is seen in the MATCH study for internalized stigma only, with Malawi, the country with the highest HIV prevalence having significantly lower rates of discrimination and Burkina Faso, the country with lowest HIV prevalence, having the highest rate. Other comparative literature on HIV has identified country-level differences in perceptions of HIV risk, whereby respondents who believe that risk of infection is ubiquitous are less likely to assign blame for infection [37], and a qualitative study of perceptions of HIV in Malawi found that, at least among married women, risk of HIV infection through a husband's infidelity was seen to be common [41]. This suggests that the Malawian context may be somewhat different from the other three sites, with both HIV prevalence and perceived risk of HIV relatively high, leading to lower self-blame for HIV infection. This conclusion is speculative, however, and points to the need to further integrate measures of the social and cultural context of HIV-positive persons in understanding how they manage HIV and seek care.

Relatively few respondents in any country reported experiencing health care discrimination, with prevalences ranging from 7.0% in Burkina Faso to 12.7% in Malawi. These rates are similar to findings from a recent facility-based study in Nigeria, which found that 13% of respondents experienced unnecessary use of protective equipment and 4% received poorer quality care [42]. These results underscore both the progress that has been made in providing care for those with HIV, and the need for continued efforts to eliminate discrimination in health settings.

Women were substantially more likely to experience interpersonal discrimination than were men, but these gender differences were not found for internalized or health care discrimination. There are few studies comparing the experiences of HIV-positive men and women, in part because many facility-based studies of discrimination among HIV-positive persons in sub-Saharan Africa are implemented in prenatal care centers and include women only [22, 36, 43]. However, a study in South Africa found that men had higher levels of internalized stigma than did women [15], and a study in Burkina Faso found that similar percentages of women and men had been hurt by the words or behaviors of others as a result of their HIV status [44]. Of note, other measures of community environment and SES were not significantly associated with any form of discrimination, contrary to earlier findings suggesting that rural residents are more likely to experience discrimination [16].

The directions of the associations between receiving care, support, and the different forms of discrimination were mixed. Those experiencing internalized stigma were less likely to disclose their status or join a support group, although these differences were not significant. In contrast, there were positive, significant, and independent associations between disclosure and interpersonal discrimination on support group utilization. Other studies have also suggested that support group participation may be a coping mechanism for HIV-positive people [1, 45], and have identified positive associations between disclosure and the availability of social support [21, 43]. However, it is possible that attendance at support groups heightens the sensitivity of those participating in the group to discriminatory behavior, thereby increasing the number of discriminatory encounters reported. By estimating independent associations between internalized and interpersonal discrimination and care and support outcomes, this analysis illustrates the different impacts through which these constructs may affect the behavior of persons with HIV, and highlights the particular vulnerability of those experiencing internalized stigma to isolation and psychological distress.

This study has several weaknesses and strengths. It was conducted in a facility-based population, and while the sampling frame was developed to incorporate different types of facilities and different types of locations within each country, these findings cannot be

generalized to the entire population of HIV-positive individuals in these countries. Moreover, because respondents were interviewed at a health facility, it is possible that respondents underreported their negative experiences of discrimination at health facilities.

This study is cross-sectional, with both discrimination and care outcomes reported simultaneously. While this design is appropriate for identifying associations, it is not suitable for exploring causal pathways. This is particularly problematic for this study, given the strong interrelationships among care, discrimination, social support, and status disclosure and the possibility of multiple causal pathways between discrimination and status disclosure. While this analysis provides a descriptive summary of how these constructs interrelate, future research could incorporate longitudinal data to more fully understand the trajectories through which HIV-positive persons negotiate care and social support and decide when and to whom to disclose status. Additionally, the measure of internalized stigma is not strongly reliable, with a Cronbach's alpha value of 0.68; while this suggests that prevalences of internalized stigma should be interpreted cautiously, the similarities between our results in three countries and other findings using a more detailed measure of internalized stigma suggest that our findings are reasonably valid. The measure of discrimination in health care facilities relies on respondents' own understandings of what care should be provided to them. Perceived discrimination within health care facilities may be driven by respondents' prior experiences receiving health care or other factors unrelated to HIV status, leading to potential confounding by unmeasured factors. More broadly, some authors have suggested that self-reports of stigma and discrimination are not reliable for measuring discrimination at the structural or social level [46].

Finally, there are limitations to the disclosure, support and clinical care measures used in the analysis. The disclosure variable is broadly defined as disclosure to anyone; a follow-up question in the survey revealed that most respondents had disclosed only to spouses or partners, family members, or close friends. However, the lack of specificity in this measure makes it difficult to pinpoint whether disclosure within a particular relationship was associated with stigma or experiences of discrimination. The support measure used above includes only support group attendance, which is only one of several possible options for receiving emotional or instrumental support. The clinical and medical care variable includes both antiretroviral therapies (ART), and treatments suggested prior to commencing ART. This measure is thus a proxy for receiving a referral to additional care, but is not a marker for the availability or utilization of ARTs in the study population.

Strengths of the analysis include the breadth of population surveyed, the use of multi-item measures of specific forms of discrimination or stigma, and the incorporation of both medical care and support group utilization as outcomes. While other studies have collected data on experiences of discrimination in multiple countries in sub-Saharan Africa, these studies are primarily qualitative or, if quantitative, have not differentiated between types of discrimination [1, 37, 45, 47]. Consequently, we believe that the results presented above represent an important addition to our knowledge of HIV discrimination and stigma in sub-Saharan Africa, and may provide benchmark data for future quantitative assessments of HIV discrimination. Moreover, by examining the associations between each form of discrimination and care outcomes, this analysis clarifies the different mechanisms through which discrimination affects the well-being of persons with HIV.

This analysis suggests that future analyses and programs addressing HIV-related discrimination and stigma should consider how experiencing different forms of these constructs may affect access to social support and health care. Internalized stigma, in particular, appears to be inversely associated with both status disclosure and utilization of support groups, suggesting that respondents experiencing internalized stigma may be less

able to access broader social support networks and may consequently experience difficulty in coping with HIV. Additional consideration of the determinants and effects of internalized stigma, and interventions designed to reduce its effects, are important next steps in improving treatment and promoting health for PLHIV.

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Table 1
List of variables included and Cronbach's alpha for discrimination indices

Scale 1. Interpersonal discrimination *

Variables

- 1 Have you personally ever been made to feel bad because of things people did or said to you on account of your HIV status?
- 2 Some people I know avoid touching me once they know I have HIV
- 3 People seem uncomfortable with me once they learn I have HIV
- 4 People have told me that getting HIV is what I deserve for how I live my life
- 5 Excluded from social events because of HIV status
- 6 Abandoned by spouse/partner/family because of HIV status
- 7 Verbally abused or ridiculed because of HIV status
- 8 Physically assaulted because of HIV status
- 9 Fired from work because of HIV status
- 10 Expelled from place of living because of HIV status
- 11 Had property taken away because of HIV status

Cronbach's alpha 0.8261

Scale 2. Internalized stigma

Variable

- 1 I sometimes feel worthless because I am HIV positive
- 2 I feel guilty because I have HIV

Cronbach's alpha 0.6794

Scale 3. Discrimination in health care facilities

Variable

- 1 Some of the staff ignored you
- 2 You were denied care that you should have received?
- 3 You received less care, or worse care
- 4 The staff were uncomfortable with you
- 5 The staff use more precautions when treating you
- 6 You were treated with disrespect or abused

Cronbach's alpha 0.8439

*Note: two factors, rotated using orthogonal varimax

Table 2
Frequencies of respondents by sex, age, educational attainment, duration HIV status known, disclosure, referral to medication, and use of support group, by country

	Burkina Faso (n=100)		Kenya (n=130)		Malawi (n=166)		Uganda (n=140)		Total (n=536)	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Sex of the respondent										
Female	81	81	64	49.2	123	74.1	93	66.4	361	67.4
Male	19	19	66	50.8	43	25.9	47	33.6	175	32.6
Age (10-yr cats)										
18-24	7	7	9	6.9	16	9.6	30	21.4	62	11.6
25-34	43	43	72	55.4	78	47	54	38.6	247	46.1
35-44	33	33	33	25.4	47	28.3	38	27.1	151	28.2
45+	17	17	16	12.3	25	15.1	18	12.9	76	14.2
Education (3 cats)										
No formal education	36	36	2	1.5	41	24.7	12	8.6	91	17
Primary incomplete/complete	37	37	55	42.3	91	54.8	59	42.1	242	45.1
Secondary or more	27	27	73	56.2	34	20.5	69	49.3	203	37.9
Urban/rural location										
Rural	0	0	42	32.3	122	73.5	32	22.9	196	36.6
Urban/perri-urban	100	100	88	67.7	44	26.5	108	77.1	340	63.4
Duration HIV status known										
1 - 30 days	11	11	22	16.9	16	9.6	57	40.7	106	19.8
30 days to one year	64	64	58	44.6	96	57.8	46	32.9	264	49.3
More than one year	25	25	50	38.5	54	32.5	37	26.4	166	31
Disclose status to anyone										
No	12	12	42	32.3	14	8.4	40	28.6	108	20.1
Yes	88	88	88	67.7	152	91.6	100	71.4	428	79.9
Join a support group										
No	57	57	118	90.8	91	54.8	122	87.1	388	72.4
Yes	43	43	12	9.2	75	45.2	18	12.9	148	27.6
Receive referral for medication										
No	31	31	14	10.8	22	13.3	8	5.7	75	14

	Burkina Faso (n=100)		Kenya (n=130)		Malawi (n=166)		Uganda (n=140)		Total (n=536)	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Yes	69	69	116	89.2	144	86.7	132	94.3	461	86

Table 3
Frequencies of discrimination indices and sub-measures by country

	Burkina Faso (n=100)		Kenya (n=130)		Malawi (n=166)		Uganda (n=140)		Total (n=536)	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Interpersonal - all measures										
No on all measures	60	60	98	77.2	98	57	95	68.8	351	65.4
Yes on at least 1 measure	40	40	29	22.8	74	43	43	31.2	186	34.6
Interpersonal - sub-measures										
Made to feel badly	28	28	18	13.8	44	26.7	22	15.9	112	21
Some avoid touching me	13	13	4	3.1	31	18.7	10	7.1	58	10.8
Some uncomfortable around me	15	15	9	7	33	19.9	16	11.4	73	13.6
Been told HIV is what I deserve	14	14	3	2.3	35	21.1	16	11.4	68	12.7
Excluded from social events	1	1	7	5.5	23	13.9	2	1.4	33	6.2
Abandoned by spouse	6	6	11	8.5	21	12.7	13	9.3	51	9.5
Verbally abused or ridiculed	15	15	23	17.8	29	17.5	23	16.4	90	16.8
Physically assaulted	3	3	4	3.1	4	2.4	3	2.1	14	2.6
Fired from work	2	2	5	3.9	5	3	5	3.6	17	3.2
Expelled from place of living	0	0	5	3.9	5	3	5	3.6	15	2.8
Property taken away	3	3	5	3.9	5	3	5	3.6	18	3.4
Internalized - all measures										
Disagree on all measures	55	55	88	67.7	150	90.4	99	70.7	392	73.1
Agree on one or more measures	45	45	42	32.3	16	9.6	41	29.3	144	26.9
Internalized - sub-measures										
Feel worthless - strongly agree/agree	41	41	36	27.7	8	4.8	30	21.7	115	21.5
Feel guilty - Strongly agree/agree	9	9	27	20.8	14	8.4	24	17.8	74	13.9
Health care - all measures										
No on all measures	93	93	117	90	145	87.3	125	89.3	480	89.6
Yes on at least 1 measure	7	7	13	10	21	12.7	15	10.7	56	10.4
Health care - sub-measures										
Staff avoided caring for you	1	1	5	3.8	10	6	1	0.7	17	3.2
Denied care that you should have received	0	0	5	3.8	9	5.4	2	1.4	16	3

	Burkina Faso (n=100)		Kenya (n=130)		Malawi (n=166)		Uganda (n=140)		Total (n=536)	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Received less care	0	0	6	4.6	9	5.4	3	2.2	18	3.4
Staff made you uncomfortable	0	0	7	5.4	4	2.4	0	0	11	2.1
Staff uses excessive precautions	6	6	6	4.6	11	6.7	11	7.9	34	6.4
Treated with disrespect or abused	0	0	4	3.1	10	6.1	3	2.1	17	3.2

Table 4
Adjusted prevalence ratios comparing risk of reporting different forms of discrimination
by sex, age, educational attainment, urban/rural location, and country*

	Interpersonal Adj. PR	Internalized Adj. PR	Health care Adj. PR
Female	1.414 (1.028, 1.945) p=0.033	0.887 (0.645, 1.221) p=0.463	0.804 (0.43, 1.501) p=0.493
Age 25-34 years	1.028 (0.687, 1.537) p=0.894	1.305 (0.923, 1.844) p=0.132	1.583 (0.79, 3.174) p=0.196
Age 35-44 years	1.106 (0.771, 1.585) p=0.585	0.834 (0.528, 1.317) p=0.436	0.842 (0.333, 2.13) p=0.717
Age 45 years and higher	1.091 (0.698, 1.705) p=0.703	1.081 (0.688, 1.698) p=0.735	1.024 (0.399, 2.628) p=0.961
Primary education complete	1.085 (0.811, 1.451) p=0.582	1.025 (0.638, 1.647) p=0.919	0.816 (0.419, 1.592) p=0.552
Secondary and higher education	0.939 (0.697, 1.265) p=0.679	0.755 (0.453, 1.258) p=0.281	0.98 (0.456, 2.109) p=0.959
Urban location	0.965 (0.621, 1.498) p=0.873	1.154 (0.817, 1.63) p=0.417	0.78 (0.38, 1.598) p=0.497
Kenya	0.666 (0.421, 1.052) p=0.081	0.75 (0.55, 1.024) p=0.07	1.156 (0.55, 2.432) p=0.701
Malawi	1.032 (0.672, 1.586) p=0.886	0.226 (0.152, 0.338) p<0.001	1.488 (0.611, 3.625) p=0.381
Uganda	0.812 (0.556, 1.186) p=0.281	0.705 (0.49, 1.015) p=0.06	1.431 (0.63, 3.249) p=0.392
Constant	0.289 (0.135, 0.619) p=0.001	0.419 (0.209, 0.842) p=0.015	0.096 (0.029, 0.317) p=0
N	536	536	536

* Reference: male, no primary education, urban resident, in Burkina Faso. Adjusted for clustered sample design using GEE.

Table 5
Mutually adjusted associations between discrimination on disclosure of status, medication referral, and support group membership*

	Disclosed status		Referred for medication		Joined support group	
	Discrimination measures only	Individual-level covariates	Discrimination measures only	Individual-level covariates	Discrimination measures only	Individual-level covariates
	Adj. PR	Adj. PR	Adj. PR	Adj. PR	Adj. PR	Adj. PR
Interpersonal measure	1.119 (1.014, 1.236)	1.057 (0.969, 1.153)	1.023 (0.953, 1.098)	1.032 (0.96, 1.109)	2.377 (1.735, 3.256)	1.86 (1.439, 2.404)
Internalized measure	p=0.026 0.899	p=0.211 0.928	p=0.532 1.051	p=0.392 1.09	p=0 0.711	p=0 0.855
Health care measure	p=0.033 0.975	(0.837, 1.029) p=0.154 0.993	(0.981, 1.127) p=0.158 1.102	(1.031, 1.153) p=0.003 1.084	(0.488, 1.036) p=0.076 0.908	(0.666, 1.098) p=0.218 1
Female	(0.859, 1.107) p=0.696	(0.855, 1.155) p=0.931 1.172	(1.021, 1.188) p=0.012	(1.032, 1.139) p=0.001 1.045	(0.642, 1.285) p=0.586	(0.709, 1.409) p=0.998 1.158
Age 25-34 years		(0.994, 1.383) p=0.059		(0.962, 1.135) p=0.299		(0.827, 1.62) p=0.394
Age 35-44 years		1.04 (0.938, 1.153)		1.035 (0.944, 1.135)		0.801 (0.53, 1.212)
Age 45 years and higher		p=0.455 1.073		p=0.461 1.067		p=0.294 1.11
Primary education complete		(0.923, 1.248) p=0.359 1.185		(0.972, 1.171) p=0.173 1.075		(0.732, 1.683) p=0.625 0.965
Secondary and higher education		(0.998, 1.407) p=0.052 0.988		(0.955, 1.21) p=0.233 1.061		(0.593, 1.571) p=0.887 0.991
		(0.912, 1.07) p=0.766 0.972		(0.943, 1.195) p=0.327 1.012		(0.748, 1.314) p=0.95 0.856
		(0.889, 1.062) p=0.527		(0.864, 1.185) p=0.884		(0.581, 1.26) p=0.43

	Disclosed status		Referred for medication		Joined support group	
	Discrimination measures only	Individual-level covariates	Discrimination measures only	Individual-level covariates	Discrimination measures only	Individual-level covariates
	Adj. PR	Adj. PR	Adj. PR	Adj. PR	Adj. PR	Adj. PR
Urban location		1.035 (0.924, 1.159)		0.984 (0.928, 1.043)		0.589 (0.382, 0.909)
Kenya		p=0.552 0.831 (0.735, 0.94)		p=0.588 1.319 (1, 1.741)		p=0.017 0.217 (0.078, 0.605)
Malawi		p=0.003 1.055 (0.919, 1.211)		p=0.05 1.27 (0.969, 1.665)		p=0.004 0.654 (0.355, 1.203)
Uganda		p=0.449 0.891 (0.747, 1.062)		p=0.084 1.392 (1.067, 1.817)		p=0.172 0.28 (0.122, 0.643)
Constant	0.8 (0.736, 0.869)	p=0.197 0.712 (0.522, 0.971)	0.833 (0.792, 0.876)	p=0.015 0.592 (0.462, 0.76)	0.206 (0.133, 0.32)	p=0.003 0.566 (0.219, 1.463)
N	p=0 536	p=0.032 536	p=0 536	p=0 536	p=0 536	p=0.24 536

* Reference: male, no primary education, urban resident, in Burkina Faso. Adjusted for clustered study design using GEE

Table 6
Mutually adjusted associations between discrimination and disclosure of status on medication referral and support group membership*

	Referred for medication		Join support group	
	Disclosure measure only	Discrimination and individual-level covariates	Disclosure measure only	Discrimination and individual-level covariates
	Adj. PR	Adj. PR	Adj. PR	Adj. PR
Disclose status	0.985 (0.845, 1.149) p=0.849	1.018 (0.902, 1.15) p=0.769	2.86 (1.604, 5.1) p=0	1.715 (1.001, 2.939) p=0.05
Interpersonal measure		1.031 (0.961, 1.106) p=0.397		1.805 (1.389, 2.346) p=0
Internalized measure		1.091 (1.033, 1.153) p=0.002		0.862 (0.672, 1.106) p=0.244
Health care measure		1.084 (1.033, 1.139) p=0.001		1.041 (0.737, 1.472) p=0.819
Female		1.042 (0.967, 1.124) p=0.281		1.107 (0.789, 1.553) p=0.555
Age 25-34 years		1.035 (0.943, 1.136) p=0.471		0.813 (0.541, 1.223) p=0.321
Age 35-44 years		1.066 (0.971, 1.17) p=0.179		1.139 (0.752, 1.723) p=0.539
Age 45 years and higher		1.072 (0.954, 1.205) p=0.244		0.958 (0.585, 1.568) p=0.864
Primary education complete		1.061 (0.943, 1.195) p=0.326		0.991 (0.744, 1.32) p=0.95
Secondary and higher education		1.012 (0.864, 1.185) p=0.882		0.847 (0.573, 1.252) p=0.406
Urban location		0.983 (0.923, 1.046) p=0.58		0.582 (0.374, 0.905) p=0.016
Kenya		1.061 (0.943, 1.195)		0.991 (0.744, 1.32)

	Referred for medication		Join support group	
	Disclosure measure only	Discrimination and individual-level covariates	Disclosure measure only	Discrimination and individual-level covariates
	Adj. PR	Adj. PR	Adj. PR	Adj. PR
Malawi		p=0.326 1.012 (0.864, 1.185)		p=0.95 0.847 (0.573, 1.252)
Uganda		p=0.882 0.983 (0.923, 1.046)		p=0.406 0.582 (0.374, 0.905)
Constant	0.87 (0.756, 1.002)	0.585 (0.447, 0.766)	0.111 (0.052, 0.236)	0.36 (0.127, 1.017)
N	p=0.054 536	p=0 536	p=0 536	p=0.054 536

* Reference: male, never disclosed, no primary education, urban resident, in Burkina Faso. Adjusted for clustered study design using GEE