

**Individual and community-level risk factors for HIV stigma in 21 Zambian and South African communities: analysis of data from the HPTN071 (PopART) study**

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## **Abstract**

### **Objectives**

Describe the prevalence and determinants of HIV stigma in 21 communities in Zambia and South Africa.

### **Design**

Analysis of baseline data from the HPTN071 (PopART) cluster-randomised trial. HIV stigma data came from a random sample of 3859 people living with HIV. Community-level exposures reflecting HIV fears and judgements and perceptions of HIV stigma came from a random sample of community members not living with HIV (n=5088), and from health workers (n=851).

### **Methods**

We calculated the prevalence of internalised stigma, and stigma experienced in the community or in a healthcare setting in the past year. We conducted risk-factor analyses using logistic regression, adjusting for clustering.

### **Results**

Internalised stigma (868/3859, prevalence 22.5%) was not associated with sociodemographic characteristics but was less common among those with a longer period since diagnosis (p=0.043). Stigma experienced in the community (853/3859, 22.1%) was more common among women (p=0.016), older (p=0.011) and unmarried (p=0.009) individuals, those who had disclosed to others (p<0.001), and those with more lifetime sexual partners (p<0.001). Stigma experienced in a healthcare setting (280/3859, 7.3%) was more common among women (p=0.019) and those reporting more lifetime sexual partners (p=0.001) and higher wealth (p=0.003). Experienced stigma was more common in clusters where community members perceived higher levels of stigma, but was not associated with the beliefs of community members or health workers.

### **Conclusions**

HIV stigma remains unacceptably high in South Africa and Zambia and may act as barrier to HIV prevention and treatment. Further research is needed to understand its determinants.

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Keywords: HIV; AIDS; stigma; Epidemiology; Implementation science; Africa

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## **Author contributions**

JH conceived the analysis and led the writing of the paper. SK undertook the analysis and assisted with the delivery of the study in the field. HM and PL contributed to the analysis. KS undertook literature review. HM, NM, and TM, led delivery of the study in the field. AS and RV oversaw data management and quality assurance. DD, HA and RJ designed and led the cluster-randomised trial and population cohort study within which the study is nested. EP-M oversaw the laboratory testing. GH and VB were responsible for the in-country management including data collection and with AS designed the questions on stigma included in this analysis and are co-investigators on the study protocol. All authors contributed to writing the paper and have agreed the final draft for submission.

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## **Introduction**

HIV stigma is present when HIV infection is linked to negative stereotypes that mark a person living with HIV as different from rest of the population; a separation of “them” from “us”. This separation then leads to status loss, which can result in negative outcomes for people living with HIV (PLHIV)[1]. Stigma experienced by PLHIV can include being gossiped about, insulted or physically assaulted in communities and healthcare settings[2]. Internalized stigma occurs when PLHIV apply the same negative feelings to themselves and can have mental health consequences[3-6]. HIV stigma infringes human rights and can inhibit access to HIV testing and care[7, 8].

Few studies have compared data both from those whose beliefs and behaviours are thought to drive the stigmatization process and also from those who experience it. The community-level factors that give rise to stigma are under-studied[9, 10]. Stigma theories suggest that the beliefs and behaviours of community members and health workers are drivers of stigma[11, 12], but there are few quantitative data to support this.

We analysed baseline data from a large cohort study of HIV stigma nested within the HPTN071 (PopART) trial[13, 14]. The outcomes of interest were experienced and internalised stigma reported by PLHIV. We first explored individual-level risk factors. We then investigated the hypothesis that stigma reported by PLHIV was more common in communities with higher levels of fear and judgement towards PLHIV. Finally, we investigated whether stigma reported by PLHIV was more common in communities with more perceived stigma reported by community members and health workers.

## **Methods**

21 urban communities (9 in South Africa, 12 in Zambia) were purposively selected to take part in the HPTN071 (PopART) cluster-randomised trial. The trial tests the impact of a combination HIV prevention package, including universal door-to-door HIV testing and offer of ART regardless of CD4 count, on HIV incidence. Using a “parallel” approach[15, 16], we combined outcome and exposure data from three separate populations who were interviewed in two data collection activities (see Appendix S1 and below for further details).

### *Stigma outcome measurement*

Outcome data came from individuals recruited to the HPTN071 (PopART) Population Cohort who both self-reported living with HIV and were laboratory-confirmed as HIV-positive. We refer to this group as PLHIV. HIV status was determined by testing blood samples drawn from consenting survey participants. Blood samples were analysed in-country using a single 4th generation assay (Architect HIV Ag/Ab Combo Assay, Abbott Diagnostics, Delkenheim Germany). Further testing was performed at the HPTN Laboratory Center (Baltimore, MD, USA). Samples that had reactive results in-country were tested with a second 4th generation assay (GS HIV Combo Assay, Bio-Rad Laboratories, Redmond, Wa). Samples with discrepant/discordant test results were tested with additional assays to determine HIV status. The cohort was enrolled between November 2013 and March 2015. In each community, household listing generated a sample frame[17]. The target sample size was 2500 individuals per community, of whom 15% were expected to be living with HIV. In randomly sampled households, one adult resident aged 18 to 44 years was selected at random. Participants completed an interviewer-administered questionnaire with data captured on an electronic device. Participants were asked if they had previously had an HIV-test, and if comfortable to do so, to share the result of their last test[13]. Participants were also offered voluntary counselling and testing using rapid HIV test-kits. Individuals testing positive were referred to a government health facility.

PLHIV were asked about their experiences of stigma. Item wording was informed by previous harmonisation work on measures of HIV stigma[18]. PLHIV responded to three items on internalised stigma (see Table 1 for item and response wording). Responses were summarised into a binary variable describing whether participants agreed to feeling any of three manifestations of internalised stigma. Five items captured experienced stigma in a community setting, and three captured stigma experienced in healthcare settings. Pre-coded response categories identified the frequency of experiences during the last year. These items were collapsed to create two binary variables capturing experience of stigma, in the community or in a healthcare setting, during the last year. 3,859 PLHIV had complete data on all eleven stigma items and on all sociodemographic variables (Figure S1a).

### *Exposure measurement*

Individual-level exposure data came from the same interviews with PLHIV as the outcome data. Exposures considered included sex, age, education, marital status, HIV treatment (i.e.

ever started ART), HIV-status disclosure, sexual behaviour and household wealth (AppendixS1).

We also measured community-level characteristics reflecting the level of HIV fear and judgement and the perceptions of stigma reported by community-members and healthworkers. The HIV fear and judgement items captured participants' attitudes towards PLHIV. The perceptions of stigma questions reflected whether participants perceived that stigma was occurring rather than reflecting their attitudes. Data were collected from a random 20% sample of the Population Cohort described above. We included data from participants who did not have a confirmed HIV-positive blood test or self-report being HIV-positive (5088 individuals, range 161 to 441 per community). We refer to this group as CM. We asked CM about their fears and judgement toward PLHIV (3 items), levels of perceived stigma in communities (5 items), and levels of perceived stigma in healthcare settings (2 items). Each question was asked on a 4-point Likert scale scored as follows (strongly disagree 0, disagree 1, agree 2, strongly agree 3) (Figure S1b). Three scores were calculated for each individual as the mean of the item responses. Each score could theoretically range from 0 to 3, with 0 representing all items being responded to as "Strongly Disagree" and 3 representing all "Strongly Agree" [19]. Cluster summary variables were calculated as the mean of the individual responses, with higher scores representing communities with a greater presence of stigmatising attitudes or a higher level of perceived stigma. Thus, for any community, a score of "1" would mean that the average response to all items across all individuals was to "Disagree" with the statements.

Data on the beliefs and perceptions of health workers came from the baseline survey for a separate cohort study conducted as part of the trial [15]. We recruited consenting health-facility staff and community health workers delivering HIV-related services. We also collected data from new trial intervention staff (known as "CHIPS" [13]) but excluded these from this analysis since these individuals had only just begun to work in the communities at the time of data collection. We included data only from health workers who did not self-report being HIV-positive. We refer to this group as HW. Again, three scores were developed reflecting HIV fear and judgement (4 items), perceptions of the stigmatising behaviours of their co-workers (4 items) and perceptions of stigma in the community (5 items). Scoring at individual and community-level was as above. Some 851 health workers contributed data to this analysis (range 13 to 77 per community) (Figure S1c)

## Statistical analysis

We summarised PLHIV characteristics in each country and describe variation in stigma prevalence by cluster (range). There was one cluster with a low sample size ( $n=5$  PLHIV) leading to outlier values. Where relevant we present the outlier value separately, and the cluster range excluding this value. We calculated Cronbach's alpha to assess inter-item agreement.

In risk factor analysis we assessed whether both individual-level and cluster-level characteristics were associated with each of the three PLHIV stigma outcomes (internalised, experienced in the community, experienced in a healthcare setting). We used logistic regression and report the odds ratios and 95% confidence intervals and Wald-test values for each risk factor for each of the three outcomes in turn. Regression analyses were carried out excluding categories where a response was "Don't know" (Ever started ART) or missing (time since first positive HIV test, first time had sex, number of sexual partners, and condom use). We examined the impact of missing data on these four risk factors on the three stigma outcomes and found that PLHIV with missing data were less likely to report HIV stigma. We adjusted the standard errors using the *vce (cluster)* command in Stata v14 to reflect the study design, and adjusted all analyses for sex and age. In Appendix S2 we report on a sensitivity analysis restricted to 2342 PLHIV who, at the time of recruitment to the study, had not yet had a visit from the trial intervention team. We were concerned that this visit may influence stigma reporting. In summary, the prevalence of stigma was largely unchanged and while there were changes in point estimates and significance values for individual variables there were no systematic differences of interpretation.

For individual-level risk factor analysis we included sociodemographic and sexual behaviour characteristics that have been associated with stigma in previous analyses [20, 21]. For cluster-level risk factor analysis we hypothesised that PLHIV-reported levels of internalised stigma and stigma experienced in the community would be correlated with the level of HIV fear and judgement reported by CM, and with perceived levels of community stigma reported by CM and HW. We hypothesised that stigma reported by PLHIV in healthcare settings would be correlated with the level of HIV fear and judgement reported by HW, with perceived levels of stigma in healthcare settings reported by CM, and with perceptions of stigma among co-workers reported by HW. To aid interpretation, we produced cluster-level scatter plots of the associations between the prevalence of each type of stigma and the cluster-level exposures.



Each cluster was represented by a circle proportional in size to the number of PLHIV included in the analysis. We added fit lines from unadjusted, cluster-level linear regressions of the associations weighted by the size of the PLHIV population in each cluster.

### *Ethics*

The HPTN 071 (PopART) trial (Division of AIDS [DAIDS] #11865 and Clinical Trials registration number NCT01900977) and the stigma ancillary study (DAIDS # HPTN 071a) received institutional review board (IRB) approval from the London School of Hygiene and Tropical Medicine LSHTM, the Health Research Ethics Committee, Stellenbosch University, and the Biomedical Research Ethics Committee at the University of Zambia. Written informed consent was sought and obtained from all participants for all aspects of the research.

## **Results**

### *Sociodemographic and behavioural characteristics of PLHIV*

Outcome data were available from 3859 PLHIV (ranging from 60 to 411 PLHIV by study community, with one outlier community, which only had 5 PLHIV). Most participants were women (86.0% Zambia, 90.9% South Africa; Table 1a). Most had attended secondary school, with more doing so in South Africa than Zambia (80.6% vs 45.8%). More Zambian participants were married (61.7%) than in South Africa (30.8%). Approximately 70% of PLHIV reported that they had ever started antiretroviral therapy in both countries. Less than 10% of individuals reported that they had not disclosed their HIV status to anyone. Among those who had, disclosure was most commonly to a family member or a marital or sexual partner. Some 37.6% of PLHIV in South Africa, and 41.9% in Zambia, had been diagnosed 1-5 years previously. Characteristics of sexual behaviour most commonly reported were age at first sex 16-18 years, 2-5 lifetime sexual partners and condom use at last sex.

### *Prevalence of stigma reported by PLHIV*

22.5% of PLHIV (868/3859) agreed or strongly agreed with one of the three items reflecting internalised stigma (cluster range 1.9%-35.4%, outlier cluster 80.0%, Table 2). Agree responses were more common than strongly agree. Inter-item agreement was high (Cronbach's alpha 0.82). Internalised stigma was more common in Zambian than South African clusters (25.9% vs 18.2%,  $p < 0.001$ ). 22.1% of PLHIV (853/3859) reported at least one of the five items reflecting

stigma experienced in the community (cluster range 6.4%-36.8%, outlier cluster 80.0%). Across items, 6.0-9.2% of individuals reported the experiences had not happened because their status was unknown. Most events were experienced once or a few times rather than often. Inter-item agreement was again high (alpha 0.92). Reported experiences of stigma in the community were more common among Zambian than South African clusters (24.7% vs 18.8%,  $p < 0.001$ ). 7.3% of PLHIV (280/3859) reported at least one of the three items reflecting healthcare setting experiences of stigma in healthcare settings (1.0% -21.8%, outlier cluster 60.0%), and more commonly in South African than Zambian communities (8.7% vs 6.1%,  $p < 0.001$ ). Inter-item agreement was again high (alpha 0.90). Overall, the prevalence of reporting any type of stigma was 35.5% (1371/3859).

### *Community-level characteristics*

The cluster-score reflecting fear and judgement towards PLHIV reported by CM was 0.9 in South Africa and 0.8 in Zambia (Table 1b), with substantial variation between clusters (range 0.4-1.2). Note that a score of 0.9 represents that across all communities the average participant response was closer to “Disagree” (1) than to “Strongly Disagree” (0). On average, CM also “disagreed” with statements regarding the perception that stigma was present in communities (1.2 South Africa, 1.3 Zambia) and healthcare settings (1.1 South Africa, 0.9 Zambia), again with large inter-cluster variation. Health workers on average disagreed with statements reflecting HIV fear and judgement (mean 0.8 in both South Africa and Zambia), and there was less variation across clusters (range 0.6-1.1). Health workers reflected a somewhat higher score with regard to statements about the perception of stigma in communities (mean 1.5 South Africa, 1.4 Zambia), but disagreed on average with statements about their co-workers stigmatising PLHIV (0.8 South Africa, 1.0 Zambia), with moderate variation across clusters. For all scores, consistency among items was moderate to high (Cronbach’s alpha 0.66 – 0.84, Table 1b).

### *Risk factor analysis*

Internalised stigma was not significantly associated with sociodemographic or behavioural characteristics, except that it was reported less often by those who had been diagnosed for longer (aOR 0.75 95% CI 0.59-0.96, and aOR 0.73 95% CI 0.56-0.96, comparing 1-5 years and 5+ years since diagnosis with 0-12 months, respectively). There was some evidence of more internalised stigma reported by those of higher wealth ( $p = 0.065$ ). Internalised stigma was more commonly reported by those reporting stigma experienced in both community and

healthcare settings (aOR 4.32 95% CI 3.47-5.37 and 4.37 95% CI 2.71-7.06, respectively) (Table 3). Internalised stigma was not significantly associated with living in a community with a higher score for HIV fear and judgement held by CM (adjusted odds ratio for a unit increase in the score, aOR<sub>score</sub> 1.11 95% CI 0.36-3.44). However, internalised stigma was significantly associated with the average level of perceived stigma reported by CM (aOR<sub>score</sub> 3.36 95% CI 1.86-6.10). There was little evidence of an association between internalised stigma and the HW's perceptions of the level of stigma in the community (aOR<sub>score</sub> 0.16 95% CI 0.01-2.34) (Table 4). These findings were mirrored in the cluster-level scatter plots (Figure 1).

Stigma experienced in the community was more frequently reported by women than men (aOR 1.22 95% CI 1.04-1.43), older individuals (aOR 1.58 95% CI 1.15-2.17 comparing 35-44 with ≤24 year olds) and those who were currently unmarried (aOR 0.77 95% CI 0.63-0.94 comparing married with unmarried). This form of stigma was more commonly reported by those who had disclosed their HIV status (aOR 1.99 95% CI 1.51-2.63), and had been diagnosed longer ago (aOR 2.04 95% CI 1.59-2.63 comparing 5+ years with 0-12 months since diagnosis), as well as those reporting more lifetime sexual partners (e.g., aOR 3.91 95% CI 1.80-8.49 comparing >20 partners with 1 partner in lifetime). Stigma was more commonly experienced in the community among individuals who had also experienced stigma in a healthcare setting (aOR 26.28 95% CI 13.22-52.26) (Table 3). The proportion of PLHIV experiencing stigma in the community was not associated with living in a community with a higher score for fear and judgement in CM's attitudes (aOR<sub>score</sub> 0.89 95% CI 0.31-2.58), but was associated with the level of perceived stigma in the community reported by CM (aOR<sub>score</sub> 3.27 95% CI 1.31-8.19). There was little evidence of an association between community-experienced stigma and HW's perceptions of stigma in communities (aOR<sub>score</sub> 0.34 95% CI 0.07-1.71) (Table 4).

Stigma experienced in a healthcare setting was more commonly reported by women than men (aOR 1.64 95% CI 1.08-2.48), and among those reporting more lifetime sexual partners (e.g., aOR 2.24 95% CI 0.91-5.49 comparing >20 partners with those with 1 partner) (Table 3). Odds ratios for the associations between community level characteristics and stigma experienced in a health setting had wide confidence intervals (Table 4). Despite this, there was evidence of an association such that CM perceptions that stigma was present in healthcare settings was associated with PLHIV reports of this (aOR<sub>score</sub> 14.93 95% CI 3.95-56.43).

## Discussion

In this large study in 21 urban communities across two countries, 35.5% of PLHIV reported some type of stigma. Most PLHIV participants were women, reflecting both higher response rates and a higher prevalence of HIV among women. Individuals reporting one form of stigma were more likely to report the other types. Experienced stigma in the community and internalised stigma were more common in Zambian communities, while experienced stigma in healthcare settings was more common in South African communities. There were few individual predictors of internalised stigma, but experienced stigma was associated with sociodemographic and behavioural characteristics. At cluster level, community members' (but not health workers) perceptions of stigma varied substantially across communities and were associated with PLHIV experiences. However, surprisingly, CM's reported attitudes of fear and judgement toward PLHIV were not associated with PLHIV's reported experiences of stigma.

We have undertaken the largest ever study on experiences of stigma from a random sample of PLHIV, adopting best-practice measures of core manifestations of HIV stigma [7, 22, 23]. While some PLHIV did not participate in the study or did not disclose their status, response rates were high [24, 25]. We have brought data from PLHIV together with independently collected data on the beliefs and perceptions of HIV stigma held by community members and health workers. These fears, judgements and perceptions are thought to act as drivers of stigma in communities [26]. This "parallel" approach to data collection has been discussed in the literature [11, 15, 16] but not operationalised. Aside from the strengths of our work, there are also limitations. Stigma is a sensitive subject and may have been under reported. Social desirability bias might have affected the validity of responses to beliefs and perception questions [22, 23]. Since the communities involved in the study were purposively selected it is unclear how generalizable our findings are to other settings in sub-Saharan Africa. Wide confidence intervals for some associations reflect few events for some outcomes, limited inter-cluster variation for some exposure variables and the small number of clusters [27]. Finally, results for risk factors with missing data should be interpreted with caution noting that PLHIV with missing data were less likely to report HIV stigma.

Reported experience of stigma among PLHIV in our study was lower than in studies employing the PLHIV Stigma index in South Africa [26] and the Gambia [28]. In 2009 51.8% of PLHIV reported having experienced verbal abuse due to their HIV status in Zambia

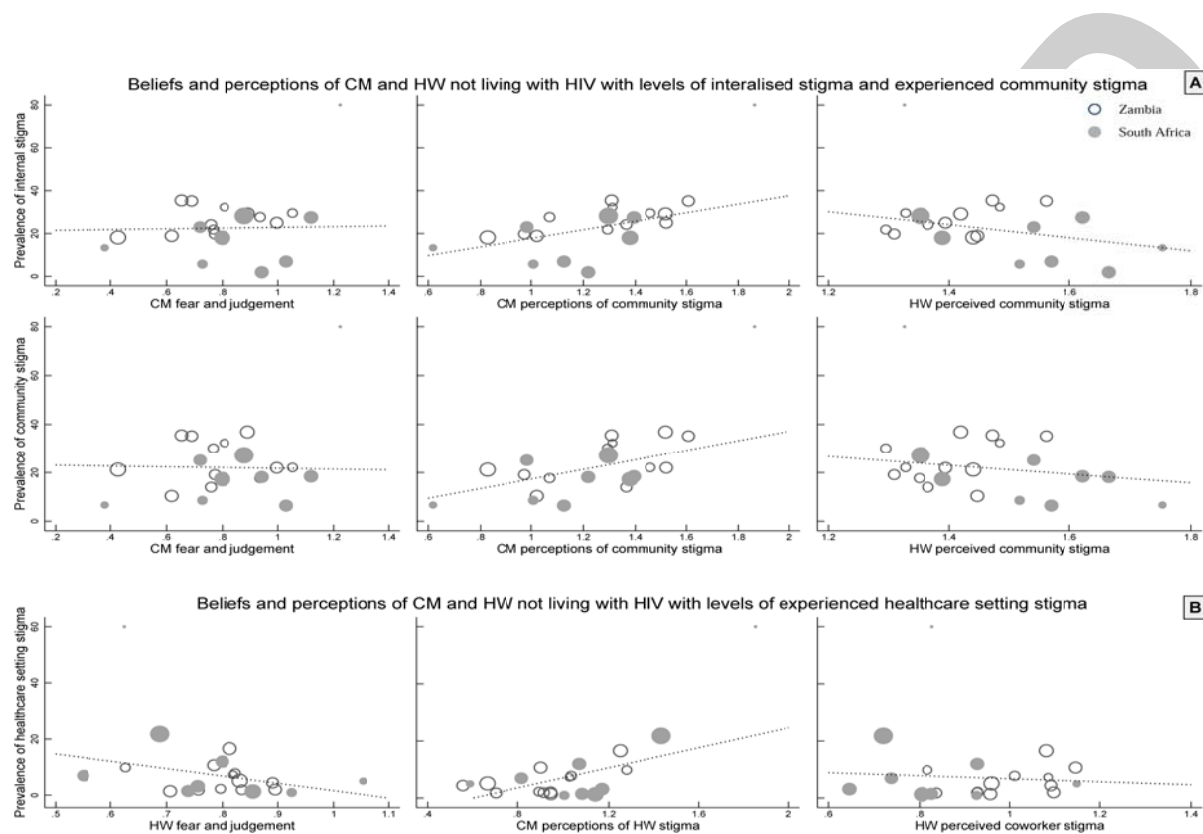
compared to 8.3% in our study [25]. In another study, 16.1% of PLHIV reported physical abuse due to their HIV status compared to 4.6% in our population [26]. Previous studies were conducted on smaller, convenience or snowball samples. Individuals recruited this way may not be representative of all PLHIV. Participants may be more likely to discuss stigma in the PLHIV Stigma Index studies since these are partly used to encourage reflection on life experiences living with HIV [29, 30]. Some forms of stigma may be decreasing over time and as ART access expands, and this would be consistent with our findings [31]. Stigma manifestations may also be shifting with more nuanced forms of stigma replacing overt acts of stigma and discrimination [32].

Some findings were as hypothesised. Experienced stigma was more common among those reporting more risk behaviour. Those who had been diagnosed for longer and who had disclosed to others reported more experienced stigma, perhaps reflecting their greater visibility. They also reported less internalised stigma, perhaps reflecting having had a longer period to “accept” their status[34-36]. Other findings were unexpected. While community members’ perceptions of levels of stigma were correlated with the reported experiences of PLHIV, neither their beliefs, nor the beliefs or perceptions of health workers were. This may reflect misreporting of either stigma experiences, or of beliefs, due to social desirability bias[22, 23]. However, our study used electronic data collection devices and sought to encourage honest reporting. Stigma reported by PLHIV might also have occurred outside the study communities or healthcare settings from which belief data were collected. Nevertheless, our results suggest caution in situations where reported fears and judgements are interpreted as a proxy for the experiences of PLHIV. It also underscores the role of internalised stigma in contributing to stigma experiences.

Stigma remains an important phenomenon in these study communities. Our results will inform ongoing work addressing the core hypotheses for our nested study: that the HPTN 071 (PopART) intervention may reduce levels of stigma in study communities, that stigma may undermine the effectiveness of efforts to scale up testing and treatment, or that the forms of HIV stigma may change over the period of the trial[15].

## Tables and Figures

**Figure 1:** Cluster-level scatter plots showing the association between the beliefs and perceptions of community members and health workers not living with HIV and levels of (A) internalised stigma and experienced community stigma, and (B) experienced healthcare setting stigma reported by PLHIV in 21 communities in South Africa and Zambia



Footnote: Each circle represents one cluster. Size of the circles are proportional to the number of PLHIV respondents in each cluster. Dotted lines reflect linear regression slopes from cluster-level analyses of the associations and weighted by the size of the PLHIV community in each cluster.

CM fear and judgement: Average level of HIV fear and judgement reported by community members

CM perceptions of community stigma: Average level of perceived stigma in the community reported by community members

HW perceived community stigma: Average level of perceived stigma in the community reported by health workers

HW fear and judgement: Average level of fear and judgement reported by health workers

HW perceived co-worker stigma: Average level of perceived co-workers stigmatising behaviour reported by health workers

CM perceptions of HW stigma: Average level of perceived stigma in healthcare settings reported by community members

CM: Community member; HW: Health worker

Table 1a: Sociodemographic and behavioural characteristics of 3859 people living with HIV who responded to survey items measuring internalized and experienced stigma

		South Africa	Zambia
Individual Characteristics		n/1704 (%)	n/2155 (%)
Sex	Male	155 (9.1%)	301 (14.0%)
	Female	1549 (90.9%)	1854 (86.0%)
Age	<=24	166 (9.7%)	257 (11.9%)
	25-34	827 (48.5%)	950 (44.1%)
	35-44	711 (41.7%)	948 (44.0%)
Education	Did not complete secondary	292 (17.1%)	1052 (48.8%)
	Completed secondary	1374 (80.6%)	986 (45.8%)
	Further	38 (2.2%)	117 (5.4%)
Marital Status	Not Married	1180 (69.2%)	825 (38.3%)
	Married	524 (30.8%)	1330 (61.7%)
Ever started ART	Yes	1185 (69.5%)	1505 (69.8%)
	No	172 (10.1%)	168 (7.8%)
	Don't know	347 (20.4%)	482 (22.4%)
Disclosed to <sup>1</sup>	No-one	118 (6.9%)	182 (8.4%)
	<i>Husband/wife/sexual partner</i>	644 (37.8%)	1062 (49.3%)
	<i>Family member</i>	1313 (77.1%)	1530 (71.0%)
	<i>Friend/neighbour/colleague</i>	301 (17.7%)	221 (10.3%)
	<i>Religious leader/worker</i>	26 (1.5%)	64 (3.0%)
	<i>Health care worker</i>	83 (4.9%)	106 (4.9%)
	<i>Other</i>	11 (0.6%)	25 (1.2%)
How old were you the first time you had sex	11-15	230 (13.5%)	402 (18.7%)
	16-18	891 (52.3%)	963 (44.7%)
	19-24	406 (23.8%)	558 (25.9%)

	<i>25+</i>	12 (0.7%)	38 (1.8%)
	<i>Skipped/missing</i>	165 (9.7%)	194 (9.0%)
How long has it been since your first positive HIV test?	<i>0-11 months</i>	255 (15.0%)	495 (23.0%)
	<i>1-5 years</i>	641 (37.6%)	902 (41.9%)
	<i>More than 5 years</i>	369 (21.7%)	385 (17.9%)
	<i>Skipped/missing</i>	439 (25.8%)	373 (17.3%)
How many sexual partners have you had in your lifetime?	<i>1</i>	224 (13.1%)	415 (19.3%)
	<i>2-5</i>	874 (51.3%)	1282 (59.5%)
	<i>6-10</i>	242 (14.2%)	168 (7.8%)
	<i>11-15</i>	29 (1.7%)	23 (1.1%)
	<i>16-20</i>	17 (1.0%)	11 (0.5%)
	<i>More than 20</i>	12 (0.7%)	28 (1.3%)
	<i>Skipped/missing</i>	306 (18.0%)	228 (10.6%)
The last time you had sex, did you use a condom	<i>No</i>	274 (16.1%)	727 (33.7%)
	<i>Yes</i>	1039 (61.0%)	818 (38.0%)
	<i>Skipped/missing</i>	391 (22.9%)	610 (28.3%)
Wealth Tertile	<i>Lowest</i>	772 (45.3%)	775 (36.0%)
	<i>Middle</i>	614 (36.0%)	969 (45.0%)
	<i>Highest</i>	318 (18.7%)	411 (19.1%)
Visit from community HIV care providers (CHiPs)	<i>No</i>	1237 (72.6%)	1105 (51.3%)
	<i>Yes</i>	369 (21.7%)	996 (46.2%)
	<i>Missing</i>	98 (5.8%)	54 (2.5%)

<sup>†</sup>: Multiple responses could be given and totals don't add up to 100. Responses were aggregated as a binary variable for subsequent analysis to reflect whether individuals reported that they had disclosed their HIV status to no-one or to anyone.



Table 1b: Cluster level characteristics describing the beliefs and perceptions of community members and health workers

Scores	N / Population (Range)	Mean score - South Africa (Cluster Range)	Mean score - Zambia (Cluster Range)	Cronbach's Alpha (items)
		9 clusters	12 clusters	
Average level of fear and judgement reported by CM	5088 (127-382)	0.9 (0.4-1.2)	0.8 (0.4-1.1)	0.74 (3)
Average level of perceived HIV stigma in the community reported by CM	5088 (127-382)	1.2 (0.6-1.9)	1.3 (0.8-1.6)	0.84 (5)
Average level of perceived HIV stigma in healthcare settings reported by CM	5088 (127-382)	1.1 (0.6-1.8)	0.9 (0.6-1.3)	0.76 (2)
Average level of HIV fear and judgement reported by HW	851(13- 77)	0.8 (0.6-1.1)	0.8 (0.6-0.9)	0.67 (5)
Average level of perceived HIV stigma in the community reported by HW	851(13- 77)	1.5 (1.3-1.8)	1.4 (1.3-1.6)	0.66 (5)
Average level of perceived co-workers stigmatising behaviour reported by HW	851(13- 77)	0.8 (0.6-1.1)	1.0 (0.8-1.1)	0.76 (4)

CM: Community members not living with HIV; HW:Health workers not living with HIV.

All scores have a theoretical range from 0 (all answers of all individuals 'Strongly Disagree') to 3 (all answers of all individuals 'Strongly Agree'). A mean score of 1 indicates a person that, on average, responds "Disagree" to items within a score; a mean score of 2 indicates a person that on average responds "Agree".

Table 2: Responses from People Living with HIV to items on internalised and experienced stigma items (n=3859)

Internalised stigma	Strongly Disagree	Disagree	Agree	Strongly Agree	
I have lost respect or standing in the community because of my HIV status	1296 (33.6%)	2093 (54.2%)	316 (8.2%)	154 (4.0%)	
I think less of myself because of my HIV status	1224 (31.7%)	2138 (55.4%)	340 (8.8%)	157 (4.1%)	
I have felt ashamed because of my HIV status	1295 (33.6%)	2046 (53.0%)	364 (9.4%)	154 (4.0%)	
<b>“Current internalised stigma”: Responding Agree or Strongly Agree to any of the above</b>	868/3859 (22.5%); South Africa (18.2%) vs Zambia (25.9%), p<0.001; Cronbach's alpha (0.82); cluster range (1.9%-35.4%); outlier 80.0%				
Frequency of experienced stigma (any setting)	Never	Not disclosed	Once	A few times	Often
People have talked badly about me because of my HIV status	2908 (75.4%)	356 (9.2%)	233 (6.0%)	272 (7.0%)	90 (2.3%)
Someone else disclosed my HIV status without my permission	3119 (80.8%)	258 (6.7%)	277 (7.2%)	163 (4.2%)	42 (1.1%)
I have been verbally insulted, harassed and/or threatened because of my HIV status	3304 (85.6%)	234 (6.1%)	131 (3.4%)	156 (4.0%)	34 (0.9%)
I have been physically assaulted because of my HIV status	3455 (89.5%)	230 (6.0%)	66 (1.7%)	86 (2.2%)	22 (0.6%)
I have felt that people have not wanted to sit next to me, for example on public transport, at church or in a waiting room because of my HIV status	3387 (87.8%)	330 (8.6%)	76 (2.0%)	49 (1.3%)	17 (0.4%)
<b>“Experienced any stigma in past year”: Responding Once, A few times or Often (“ever”) to any of the above</b>	853/3859 (22.1%); South Africa (18.8%) vs Zambia (24.7%), p<0.001; Cronbach's alpha (0.92); cluster range (6.4%-36.8%); outlier 80.0%				

Frequency of experienced stigma (health setting)	Never	Not disclosed	Once	A few times	Often
I have been denied health services because of my HIV status	3627 (94.0%)	114 (3.0%)	55 (1.4%)	51 (1.3%)	12 (0.3%)
Healthcare workers talked badly about me because of my HIV status	3558 (92.2%)	121 (3.1%)	101 (2.6%)	66 (1.7%)	13 (0.3%)
A health worker disclosed my HIV status without my permission	3593 (93.1%)	103 (2.7%)	90 (2.3%)	64 (1.7%)	9 (0.2%)
<b>“Experienced healthcare setting stigma in last year”: Responding Once, A few times or Often (“ever”) to any of the above</b>	280/3859 (7.3%); South Africa (8.7%) vs Zambia (6.1%), p=0.002; Cronbach's alpha (0.90); cluster range (1.0%-21.8%); outlier 60.0%				
<b>“Any stigma last year”: Yes to current internalised stigma, experienced any or healthcare setting stigma in last year”</b>	1371/3859 (35.5%); cluster range (11.4%-55.8%); outlier 100.0%				

**Table 3:**The association between sociodemographic and behavioural characteristics and three types of stigma among 3859 PLHIV from 21 study communities in Zambia and South Africa.

Variable	Categories	Any internalised stigma			Stigma experienced in the community			Stigma experiences in a healthcare setting		
		n/N (%)	aOR (95% CI) <sup>a</sup>	P <sub>w</sub> <sup>b</sup>	n/N (%)	aOR (95% CI) <sup>a</sup>	P <sub>w</sub> <sup>b</sup>	n/N (%)	aOR (95% CI) <sup>a</sup>	P <sub>w</sub> <sup>b</sup>
Sex	Male	108/456 (23.7%)	1.00	0.136	92/456 (20.2%)	1.00	0.016	23/456 (5.0%)	1.00	0.019
	Female	760/3403 (22.3%)	0.90 (0.78-1.03)		761/3403 (22.4%)	1.22 (1.04-1.43)		257/3403 (7.6%)	1.64 (1.08-2.48)	
Age	<24	111/423 (26.2%)	1.00	0.154	74/423 (17.5%)	1.00	0.011	17/423 (4.0%)	1.00	0.086
	25-34	402/1777 (22.6%)	0.82 (0.64-1.05)		370/1777 (20.8%)	1.25 (0.93-1.68)		130/1777 (7.3%)	1.91 (0.96-3.82)	
	35-44	355/1659 (21.4%)	0.75 (0.56-1.01)		409/1659 (24.7%)	1.58 (1.15-2.17)		133/1659 (8.0%)	2.19 (1.07-4.48)	
Education	Did not complete secondary	334/1344 (24.9%)	1.00	0.277	326/1344 (24.3%)	1.00	0.063	78/1344 (5.8%)	1.00	0.352
	Completed secondary	500/2360 (21.2%)	0.81 (0.62-1.05)		483/2360 (20.5%)	0.82 (0.62-1.07)		191/2360 (8.1%)	1.45 (0.87-2.42)	
	Further	34/155 (21.9%)	0.84 (0.59-1.18)		44/155 (28.4%)	1.28 (0.91-1.80)		11/155 (7.1%)	1.32 (0.69-2.53)	
Marital status	Not married	456/2005 (22.7%)	1.00	0.881	483/2005 (24.1%)	1.00	0.009	160/2005 (8.0%)	1.00	0.349
	Married	412/1854 (22.2%)	0.98 (0.80-1.21)		370/1854 (20.0%)	0.77 (0.63-0.94)		120/1854 (6.5%)	0.77 (0.45-1.32)	
Ever started ART	No	68/340 (20.0%)	1.00	0.631	70/340 (20.6%)	1.00	0.416	27/340 (7.9%)	1.00	0.792
	Yes	590/2690 (21.9%)	1.14 (0.67-1.94)		645/2690 (24.0%)	1.19 (0.78-1.81)		197/2690 (7.3%)	0.89 (0.39-2.05)	
	Don't know	210/829 (25.3%)	-		138/829 (16.6%)	-		56/829 (6.8%)	-	
Disclosed to (ever disclosed HIV status)	No	72/300 (24.0%)	1.00	0.578	38/300 (12.7%)	1.00	<0.001	16/300 (5.3%)	1.00	0.379
	Yes	796/3559 (22.4%)	0.93 (0.71-1.21)		815/3559 (22.9%)	1.99 (1.51-2.63)		264/3559 (7.4%)	1.37 (0.68-2.74)	
How long has it been since your first positive HIV test?	0-11 months	212/750 (28.3%)	1.00	0.043	115/750 (15.3%)	1.00	<0.001	36/750 (4.8%)	1.00	0.097
	1-5 years	351/1543 (22.7%)	0.75 (0.59-0.96)		342/1543 (22.2%)	1.51 (1.20-1.89)		106/1543 (6.9%)	1.36 (0.85-2.18)	
	More than 5 years	167/754 (22.1%)	0.73 (0.56-0.96)		215/754 (28.5%)	2.04 (1.59-2.63)		60/754 (8.0%)	1.53 (1.02-2.30)	
	Skipped/missing	138/812 (17.0%)	-		181/812 (22.3%)	-		78/812 (9.6%)	-	
How old were you the first time you had sex	11-15	157/632 (24.8%)	1.00	0.527	158/632 (25.0%)	1.00	0.361	45/632 (7.1%)	1.00	0.477
	16-18	421/1854 (22.7%)	0.91 (0.69-1.20)		414/1854 (22.3%)	0.83 (0.63-1.09)		139/1854 (7.5%)	1.00 (0.50-1.98)	
	19-24	213/964 (22.1%)	0.88 (0.63-1.24)		215/964 (22.3%)	0.81 (0.62-1.05)		81/964 (8.4%)	1.10 (0.57-2.13)	
	25+	8/50 (16.0%)	0.59 (0.30-1.19)		13/50 (26.0%)	0.99 (0.48-2.03)		1/50 (2.0%)	0.25 (0.03-2.42)	
	Skipped/missing	69/359 (19.2%)	-		53/359 (14.8%)	-		14/359 (3.9%)	-	
How many sexual partners have you had in your lifetime?	1	120/639 (18.8%)	1.00	0.107	108/639 (16.9%)	1.00	0.002	39/639 (6.1%)	1.00	0.001
	2-5	520/2156 (24.1%)	1.38 (0.90-2.13)		518/2156 (24.0%)	1.55 (0.94-2.55)		168/2156 (7.8%)	1.29 (0.57-2.91)	
	6-10	88/410 (21.5%)	1.17 (0.68-2.02)		107/410 (26.1%)	1.76 (0.98-3.18)		32/410 (7.8%)	1.37 (0.40-4.72)	
	11-15	12/52 (23.1%)	1.27 (0.69-2.37)		17/52 (32.7%)	2.46 (1.14-5.28)		7/52 (13.5%)	2.64 (0.86-8.15)	
	16-20	7/28 (25.0%)	1.43 (0.54-3.75)		11/28 (39.3%)	3.24 (1.40-7.53)		5/28 (17.9%)	3.71 (0.61-22.63)	
	More than 20	16/40 (40.0%)	2.73 (1.19-6.26)		17/40 (42.5%)	3.91 (1.80-8.49)		4/40 (10.0%)	2.24 (0.91-5.49)	

	Skipped/missing	105/534 (19.7%)	-		75/534 (14.0%)			25/534 (4.7%)	-	
The last time you had sex, did you use a condom	No	250/1001 (25.0%)	1.00	0.323	236/1001 (23.6%)	1.00	0.187	66/1001 (6.6%)	1.00	0.604
	Yes	413/1857 (22.2%)	0.86 (0.65-1.15)		394/1857 (21.2%)	0.87 (0.71-1.07)		137/1857 (7.4%)	1.11 (0.74-1.66)	
	Skipped/missing	205/1001 (20.5%)	-		223/1001 (22.3%)			77/1001 (7.7%)	-	
Wealth Tertile	Lowest	318/1547 (20.6%)	1.00	0.065	307/1547 (19.8%)	1.00	0.197	88/1547 (5.7%)	1.00	0.003
	Middle	387/1583 (24.4%)	1.26 (1.03-1.55)		364/1583 (23.0%)	1.19 (0.94-1.51)		116/1583 (7.3%)	1.28 (0.99-1.66)	
	Highest	163/729 (22.4%)	1.12 (0.84-1.51)		182/729 (25.0%)	1.32 (0.96-1.80)		76/729 (10.4%)	1.90 (1.30-2.79)	
Stigma experienced in the community	No	486/3006 (16.2%)	1.00	<0.001	-	-		-	-	
	Yes	382/853 (44.8%)	4.32 (3.47-5.37)		-	-		-	-	
Stigma experienced in a healthcare setting	No	723/3579 (20.2%)	1.00	<0.001	616/3579 (17.2%)	1.00	<0.001	-	-	
	Yes	145/280 (51.8%)	4.37 (2.71-7.06)		237/280 (84.6%)	26.28 (13.22-52.26)		-	-	

aOR: adjusted Odds Ratio ; CI: Confidence Interval ; n: Number of individuals experiencing the three types of stigma within groups; N: Total number of individuals within groups; P<sub>w</sub>: P value of the Wald test.

<sup>a</sup>: The aOR for sex is adjusted for age group; The aOR for age group is adjusted for sex; The aOR for all other predictor variables are adjusted for sex and age group.

<sup>b</sup>: A p value of less than 0.05 indicates that the predictor creates a statistically significant improvement in the fit of the model.

**Table 4: Association between attitudes and perceptions of stigma held by community members and health workers and levels of internalised and experienced stigma reported by people living with HIV adjusted for age, sex and clustering (n=3,859)**

Cluster-level exposure variables	Any internalised stigma	Any experienced stigma	Stigma experience in a healthcare setting
	aOR <sub>score</sub> (95% CI) for unit increase in score	aOR <sub>score</sub> (95% CI) for unit increase in score	aOR <sub>score</sub> (95% CI) for unit increase in score
Average level of HIV fear and judgement reported by CM	1.11 (0.36-3.44)	0.89 (0.31-2.58)	-
Average level of perceived HIV stigma in the community reported by CM	3.36 (1.86-6.10)	3.27 (1.31-8.19)	-
Average level of perceived HIV stigma in healthcare settings reported by CM	-	-	14.93 (3.95-56.43)
Average level of HIV fear and judgement reported by HW	-	-	0.02 (0.01-1.60)
Average level of perceived HIV stigma in the community reported by HW	0.16 (0.01-2.34)	0.34 (0.07-1.71)	-
Average level of perceived co-worker stigmatising behaviour reported by HW	-	-	0.49 (0.01-32.0)

aOR<sub>score</sub>: Adjusted Odds Ratio for age, sex and clustering within communities; CI: Confidence interval; CM: Community members not living with HIV; HW: Health workers not living with HIV.

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