The HIV stigma landscape in sub-Saharan Africa: baseline findings of a mixed-method, comprehensive evaluation nested in the HPTN 071 (PopART) trial

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BACKGROUND

HIV STIGMA AND HIV PREVENTION AND TREATMENT

HIV stigma may be a critical barrier to the success of HIV prevention and treatment. However, stigma may also change in prevalence and form over time, as might its impact on HIV programmes.

Mixed methods research from multiple perspectives is essential to understand these complex dynamics

AIM

To understand how HIV-related stigma is operating within the setting of HPTN 071 (PopART) trial, a large, longitudinal study in 21 communities in South Africa and Zambia, using mixed-method baseline data.

Figure 1. HIV stigma arises through interactions between different, overlapping population groups.

METHODS

STUDY DESIGN

The HPTN 071 (PopART) trial is a cluster randomised trial of a combination HIV prevention and treatment intervention incorporating a universal testing and treatment approach, underpinned by a cadre of Community HIV-care Providers (CHiPs) delivering HIV testing and referral services door-to-door throughout the community. The trial is being undertaken in 21 communities in Zambia and South Africa. We nested data collection on stigma within several aspects of the study, with a view to understanding stigma from multiple perspectives (Table 1). Here we report only on data collected during the first year of the study ("baseline").

TABLE 1. Data collection modules incorporating data on HIV stigma and nested within the HPTN 071 (PopART) trial

Population	Design of baseline quantitative data collection focused on stigma	Quantitative Sample Size	Qualitative data
Health workers, including those based in health facilities, working in the community and delivering the HPTN 071 (PopART) intervention	We recruited all health workers in all 21 communities to an open cohort study. We asked questions about attitudes, perceptions and experience of HIV and key population stigma. Around 18% of health workers reported that they were living with HIV.	1875	Health facility space: mapping, observation, stakeholder survey. Key informant interviews
Community members who do not report living with HIV	The man trial outcome is measured among a random sample of community members, known as the Population Cohort. We asked questions about attitudes and perceptions of stigma from a random 20% sample of the whole cohort who did not report living with HIV .	5088	In-depth discussions and observations using participatory research and ethnography
Community members living with HIV	Among the Population Cohort, we asked people if they had previously tested for HIV. We asked questions about internalised and experienced stigma from all those who both self-reported having had a positive HIV test and who tested HIV positive at baseline	3859	In-depth discussions and observations using participatory research and ethnography
Nested case control study comparing those accepting and not accepting home based HIV testing	Following the first round of the home-based testing intervention, we recruited random samples of those who accepted and refused home based testing, and compared attitudes and anticipated stigma among these groups	400/400	-
Nested case control study comparing PLHIV who did and did not initiate ART within 6 months of referral.	Following the first round of the home-based testing intervention, among PLHIV (newly diagnosed by CHiPs or self-reported, and not on already on ART) we recruited random samples of those who did and did not initiate ART within 6 months and compared attitudes and anticipated stigma among these groups	400/400	-
Key Populations	We did not collect quantitative data directly from these groups. However, in the health worker study we asked about attitudes, perceptions and observations of stigma toward "women who sell sex", "men who have sex with men", and "young women who get pregnant before marriage"	-	In-depth discussions and observations using participatory research and ethnography

DATA ANALYSIS

We calculated the prevalence of HIV stigma among PLHIV, levels of agreement / disagreement with statements on HIV fear and judgement and perception of stigma reported by community members and health workers, and attitudes towards key populations among health workers. Logistic regression was used to examine the association between stigma and ART adherence among PLHIV, adjusted for country, community, gender, age, wealth, education, nights spent away from home, alcohol consumption and other types of stigma, and to compare cases and controls in two case control studies. Qualitative data were organized, coded and analysed using ATLAS.ti version 7.

RESULTS: THREE DYNAMICS

HIV STIGMA REMAINS PREVALENT BUT WAS LOWER THAN EXPECTED

We found a high prevalence of internalised and experienced stigma reported by PLHIV, though this was lower than in previous studies. Most community members and health workers disagreed or strongly disagreed with statements reflecting HIV fear and judgement. Overall 1371/3859 (35.5%) of people living with HIV reported at least one of 11 types of stigma in the last year. Experienced stigma was more frequently reported in the community (22.1%) than in health settings (7.3%), and internalised stigma was fairly common (22.5%).

TABLE 2. Population Cohort PLHIV: Prevalence of reported HIV stigma among PLHIV

Form of stigma	South Africa (n=1,704)	Zambia (n=2,155)
Internalized stigma	18.2%	25.9%
Experienced stigma in the community	18.8%	24.7%
Experienced stigma in the health setting	8.7%	6.1%
Any stigma in the past 12 months	29.5%	40.3%

STIGMA MAY ACT AS A BARRIER TO SUCCESSFUL TREATMENT FOR SOME, BUT WAS NOT A BARRIER TO HOME BASED TESTING

Health facility structures and client-flow patterns in clinics sometimes identified people's HIV status and made people living with HIV uncomfortable. Stigma was experienced acutely close to time of diagnosis. Among those already living with HIV before the start of the trial and recruited to the population cohort, experienced community stigma was more commonly reported by those reporting poor adherence (adjusted Odds Ratio, 1.52 95% CI:1.12-2.07). In the case control studies linked to the first round of the intervention, feelings of shame were associated with slower linkage to care, although other aspects of stigma were not and there was no association with uptake of home based testing.

> *"they [People Living with HIV] will hesitate to go to the ART clinic and they will look at the direction of the OPD to see if there is no one seeing them. That is when they would go to the ART [clinic] and sometimes when they are at the ART pharmacy area they might feel uncomfortable because they fear that when they see them collecting ARVs, they think their neighbour might tell others that they saw him or her at the ART[clinic] where they collect ARVs"*

Community Health worker, Zambia

STIGMA TOWARD KEY POPULATIONS WAS HIGH

We found a high level of stigma toward members of key populations. For example, health workers rarely reported they would be ashamed if a family member was living with HIV. In contrast, high proportions reported they would be ashamed if a family member were a man having sex with men, a woman selling sex or a young woman falling pregnant before marriage. This was especially the case in Zambia (Table 3). In qualitative research we identified narratives showing examples of stigma and discrimination toward key population groups

TABLE 3. Health worker study: Prevalence of agreement with the statement

"I would be ashamed if someone in my family was …"	South Africa	Zambia
A person living with HIV	5.5%	5.2%
A man who has sex with men	53.1%	88.1%
A women who sells sex	70.2%	81.3%
A young woman who became pregnant before marriage	31.2%	51.9%

Researcher	How's it going?
Participant	A little bit well
Researcher	And you were saying the guys [who beat you up] were claiming that you stole the TV that you were carrying?
Participant	Uhm, actually they were not beating me up for the TV thing, because they know I'm not (pauses) a criminal. They were beating me up of, all because of this gayness.

Male MSM participant, South Africa

CONCLUSIONS

HIV stigma remains a commonly experienced phenomenon for PLHIV. Going forward, it may be particularly important to address any negative effects of HIV stigma on treatment success, and to reduce stigma toward key populations.

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