HIV stigma and baseline quantitative data collection focused on stigma

We asked all health workers in the 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.

The main 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.

Studies have been carried out in South Africa, Zambia, and other countries. We asked questions about experiences of stigma from all those who did and did not report living with HIV.

The intervention was a combination of HIV prevention and treatment. The trial was conducted in two phases: a home-based testing intervention and a community-based intervention.

The intervention was implemented in South Africa, Zambia, and other countries. We asked questions about experiences of stigma from all those who did and did not report living with HIV.

In the health facility setting, health workers were asked about their experiences of stigma from all those who did and did not report living with HIV. We asked questions about experiences of stigma from all those who did and did not report living with HIV.

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 fear of stigmatisation and discrimination. Of the 1317/3859 (35.5%) people living with HIV reported at least one of 11 types of stigma in the last year. Experience of 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 1 shows the distribution of stigma among community members and health workers. The table includes the number of respondents who reported experiencing stigma in the past 12 months, as well as the number of respondents who did not report experiencing stigma.

<table>
<thead>
<tr>
<th>Form of stigma</th>
<th>South Africa (n=5088)</th>
<th>Zambia (n=525)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internalised stigma</td>
<td>18.8%</td>
<td>25.9%</td>
</tr>
<tr>
<td>Experienced stigma in the community</td>
<td>18.8%</td>
<td>24.7%</td>
</tr>
<tr>
<td>Experienced stigma in the health setting</td>
<td>8.7%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Any stigma in the past 12 months</td>
<td>29.5%</td>
<td>40.3%</td>
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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 Rato, 1.02, CI: 1.2-2.07). 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.

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

We recruited random samples of PLHIV (newly diagnosed or at the ART clinic), community members, health workers and members of key populations such as female sex workers and men who have sex with men (Figure 1). 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.

STIGMA TOWARDS 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 from specific examples of stigma and discrimination toward key population groups.

Table 3 shows the distribution of stigma among key population groups. The table includes the number of respondents who reported experiencing stigma in the past 12 months, as well as the number of respondents who did not report experiencing stigma.

<table>
<thead>
<tr>
<th>Form of stigma</th>
<th>South Africa (n=5088)</th>
<th>Zambia (n=525)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A person living with HIV</td>
<td>5.5%</td>
<td>5.2%</td>
</tr>
<tr>
<td>A man who has sex with men</td>
<td>53.1%</td>
<td>88.1%</td>
</tr>
<tr>
<td>A woman who sells sex</td>
<td>70.2%</td>
<td>81.3%</td>
</tr>
<tr>
<td>A young woman who became pregnant before marriage</td>
<td>31.2%</td>
<td>51.9%</td>
</tr>
</tbody>
</table>

CONCLUSIONS

HIV stigma remains a common 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.

ACKNOWLEDGMENTS

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The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIAID, NIMH, NIDA, PEPFAR, 3ie, the Bill & Melinda Gates Foundation.

Community Health worker, Zambia

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, undertaken by a cadre of Community HIV-care Providers (CHPs) 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 needed 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 (of 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 field 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 main 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. | 9368 | 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 tested a positive HIV test and who tested HIV positive at baseline. | 3859 | In-depth discussions and observations using participatory research and ethnography
Nestled case control study comparing those accepting and not accepting HIV home based testing | Following the first round of the home-based testing intervention, we recruited random samples of those who did and did not accept home-based testing, and compared attitudes and anticipated stigma among these groups | 400/400 | In-depth discussions and observations using participatory research and ethnography
Nestled case control study comparing PLHIV who did and did not initiate ART within 6 months of enrollment | Following the first round of the home-based testing intervention, among PLHIV (mostly diagnosed by CHPs or self-reported, and not on ART already) on ART within 6 months of diagnosis, we asked questions about attitudes and perceptions of stigma from all those who did and did not initiate ART within 6 months of diagnosis and anticipated stigma among these groups. | 400/400 | In-depth discussions and observations using participatory research and ethnography
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’. | | Health facility space: mapping, observation, stakeholder survey, Key informant interviews

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.