Proposed title: HIV-related stigma and uptake of HIV self-testing in Malawi and Zambia.

Authors: Melissa Neuman, Rebecca Nzawa, Katherine Fielding, Karin Hatzold, Bernadette Hensen, Pitchaya Indravudh, Cheryl Johnson, Moses Kumwenda, Paul Mee, Chama Mulubwa, Lucheka Sigande, Miriam Taegtmeyer, Helen Ayles, Elizabeth L. Corbett

Keywords: Stigma, HIV testing, HIV self-testing, Malawi, Zambia

Abstract (502 (including headers) /500)

Background

Individuals’ perceptions of HIV stigma may act as a barrier to accessing HIV testing, prevention, and care, both because of fears of abuse following an HIV diagnosis and because health care workers (HCW) may seem indiscreet or disrespectful. We investigated associations between perceived stigma and use of standard HIV testing services (HTS) and HIV self-testing (HIVST) among HIV-negative community members in rural Malawi and rural and urban Zambia during 2016-2017.

Methods

In a secondary analysis of data collected in two cluster-randomized trials, adults (age ≥16) were interviewed following 12 months of community-based HIVST distribution. A 10-item scale validated for the PopART study in Zambia and South Africa was used to measure stigma as perceived by HIV-negative respondents in the community. We analysed the full scale (“any stigma”) and two subscales of perceived verbal/physical abuse of persons living with HIV (PLHIV) (“perceived abuse”) (3 items) and perceived gossip/disclosure of HIV status by health care workers (“HCW stigma”) (2 items). Internal reliability was evaluated using Cronbach’s alpha, and items were summed to obtain a final score. Associations between sociodemographic characteristics and each stigma score were estimated using Poisson models. HIV testing history was measured using self-report, and compared respondents testing using HIVST, using standard HIV testing services (HTS), and those not testing in the past 12 months. Associations between stigma and HTS and/or HIVST uptake were estimated using multinomial logistic regression in country-stratified models. All models were adjusted for clustered design, respondent age, sex, and education.

Results

Responses from 641 Malawian (40.4% men) and 528 Zambian (42.3% men) participants showed acceptable internal consistency of the “any stigma” score (alpha=0.70 in Malawi, 0.78 in Zambia). In Malawi and Zambia, 26.8% (172/641) and 39.2% (202/515) of respondents had not tested in the past 12 months. Self-testing was more common in Malawi (37.9%, 243/641) than Zambia (11.2%, 58/515). All measures of stigma were higher among Zambian versus Malawian participants (“any stigma”: adjusted risk ratio [aRR] 1.24, 95%CI: 1.31, 1.35; “perceived abuse”: aRR 1.15, 95%CI 1.02, 1.30; “HCW stigma”: 1.49; 95%CI: 1.28, 1.74), but did not differ by age, sex, or education. The “perceived abuse” score was negatively associated with using HTS in Zambia (aRR 0.68, 95%CI 0.50, 0.93), but not with using HIVST (aRR 0.94, 95%CI 0.66,1.36). In Malawi, uptake of both HTS and HIVST was
positively associated with higher “any stigma” score (HIVST aRR 1.12, 95% CI 1.04, 1.20; HTS aRR 1.07, 95% CI 1.01, 1.13). No other independent associations between stigma scores and uptake of either HIVST or HTS were identified.

Discussion

In Zambia higher “perceived abuse” score was associated with reduced HTS use, but not with HIVST use, suggesting that HIVST in this context may appeal to persons who are afraid of being stigmatised by utilizing standard services. Findings from Malawi are counterintuitive but may suggest that stigma is not an important barrier to testing here when services are available. These disparate results highlight the importance of regional and national context in understanding the role of stigma in shaping individual behaviour.

Works cited
Table 1. Measure overview

<table>
<thead>
<tr>
<th>Measure</th>
<th>Malawi (N=641)</th>
<th>Zambia (N=528)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Health care worker behaviours</strong></td>
<td>100 15.7</td>
<td>206</td>
</tr>
<tr>
<td>Health workers sometimes talk badly about people living with or thought to be living with HIV</td>
<td>73 11.5</td>
<td>168</td>
</tr>
<tr>
<td><strong>Physical or verbal abuse</strong></td>
<td></td>
<td>224</td>
</tr>
<tr>
<td>People sometimes talk badly about people living with or thought to be living with HIV</td>
<td>124 19.5</td>
<td>228</td>
</tr>
<tr>
<td>People living with or thought to be living with HIV are verbally insulted, harassed, and/or threatened</td>
<td>53 8.3</td>
<td>169</td>
</tr>
<tr>
<td>People sometimes disclose that other people are HIV positive without their permission</td>
<td>220 34.6</td>
<td>298</td>
</tr>
<tr>
<td>People are hesitant to take an HIV test due to fear of other people's reaction if the test result is positive for HIV</td>
<td>118 18.6</td>
<td>290</td>
</tr>
<tr>
<td>People living with or thought to be living with HIV lose respect or standing</td>
<td>41 6.4</td>
<td>107</td>
</tr>
<tr>
<td>I would be ashamed if someone in my family had HIV</td>
<td>10 1.6</td>
<td>107</td>
</tr>
<tr>
<td>I would not like to sit close to someone living with HIV, for example on public transport, at church, or in a waiting room</td>
<td>171 27</td>
<td>286</td>
</tr>
<tr>
<td>People sometimes disclose that other people are HIV positive without their permission</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 2. Population overview

<table>
<thead>
<tr>
<th></th>
<th>Malawi</th>
<th>Zambia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self-tested</td>
<td>Used HTS</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td><strong>Mean (SD)</strong></td>
<td><strong>Mean (SD)</strong></td>
</tr>
<tr>
<td>Any stigma (0-10 items)</td>
<td>5.1 (2.5)</td>
<td>4.8 (2.3)</td>
</tr>
<tr>
<td>HCW (0-2 items)</td>
<td>1.1 (0.9)</td>
<td>1.2 (0.8)</td>
</tr>
<tr>
<td>Abuse (0-3 items)</td>
<td>1.3 (1.1)</td>
<td>1.1 (0.9)</td>
</tr>
<tr>
<td><strong>Male sex</strong></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Age in years (grouped)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-19</td>
<td>19 (7.8)</td>
<td>20 (8.8)</td>
</tr>
<tr>
<td>20-24</td>
<td>62 (25.5)</td>
<td>53 (23.5)</td>
</tr>
<tr>
<td>25-29</td>
<td>37 (15.2)</td>
<td>42 (18.6)</td>
</tr>
<tr>
<td>30-39</td>
<td>68 (28)</td>
<td>61 (27)</td>
</tr>
<tr>
<td>40-49</td>
<td>31 (12.8)</td>
<td>27 (11.9)</td>
</tr>
<tr>
<td>50-59</td>
<td>16 (6.6)</td>
<td>7 (3.1)</td>
</tr>
<tr>
<td>60+</td>
<td>10 (4.1)</td>
<td>16 (7.1)</td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal schooling</td>
<td>27 (11.1)</td>
<td>24 (10.6)</td>
</tr>
<tr>
<td>Primary incomplete or complete</td>
<td>176 (72.4)</td>
<td>172 (76.1)</td>
</tr>
<tr>
<td>Secondary incomplete</td>
<td>30 (12.3)</td>
<td>24 (10.6)</td>
</tr>
<tr>
<td>Secondary complete or higher</td>
<td>10 (4.1)</td>
<td>6 (2.7)</td>
</tr>
</tbody>
</table>

* p-values assessing differences in mean stigma measures by country: any stigma, p<0.001; HCW stigma, p=0.005; Abuse, p<0.001
* p-values for joint Wald tests of significance of continuous measure in country-level multinomial logit models.

### Table 3. Predictors of stigma (general, abuse, HCW)

<table>
<thead>
<tr>
<th></th>
<th>Any stigma</th>
<th>HCW</th>
<th>Abuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country only</td>
<td>RR (95% CI)</td>
<td>p-value</td>
<td>RR (95% CI)</td>
</tr>
<tr>
<td>Country + Sociodemographics</td>
<td>RR (95% CI)</td>
<td>p-value</td>
<td>RR (95% CI)</td>
</tr>
</tbody>
</table>

* p-values assessing differences in mean stigma measures by country: any stigma, p<0.001; HCW stigma, p=0.005; Abuse, p<0.001
* p-values for joint Wald tests of significance of continuous measure in country-level multinomial logit models.
<table>
<thead>
<tr>
<th>Country - Zambia</th>
<th>1.23</th>
<th>0.000</th>
<th>1.24</th>
<th>0.000</th>
<th>1.16</th>
<th>0.008</th>
<th>1.15</th>
<th>0.019</th>
<th>1.45</th>
<th>0.000</th>
<th>1.49</th>
<th>0.000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1.13, 1.35)</td>
<td>(1.13, 1.35)</td>
<td>(1.04, 1.29)</td>
<td>(1.02, 1.30)</td>
<td>(1.24, 1.70)</td>
<td>(1.28, 1.74)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male sex</td>
<td></td>
<td>-</td>
<td>1.00</td>
<td>0.985</td>
<td>-</td>
<td>0.98</td>
<td>0.773</td>
<td>-</td>
<td>1.03</td>
<td>0.595</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0.95, 1.06)</td>
<td>-</td>
<td>(0.88, 1.10)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td>(0.93, 1.13)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age in years (grouped)</td>
<td>0.215</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.703</td>
</tr>
<tr>
<td>20-24</td>
<td>-</td>
<td>-</td>
<td>1.03</td>
<td>0.489</td>
<td>-</td>
<td>1.09</td>
<td>0.388</td>
<td>-</td>
<td>0.95</td>
<td>0.537</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-29</td>
<td>-</td>
<td>-</td>
<td>0.99</td>
<td>0.790</td>
<td>-</td>
<td>0.97</td>
<td>0.772</td>
<td>-</td>
<td>0.92</td>
<td>0.400</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>-</td>
<td>-</td>
<td>1.08</td>
<td>0.097</td>
<td>-</td>
<td>1.03</td>
<td>0.748</td>
<td>-</td>
<td>1.05</td>
<td>0.554</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>-</td>
<td>-</td>
<td>1.05</td>
<td>0.396</td>
<td>-</td>
<td>1.06</td>
<td>0.594</td>
<td>-</td>
<td>0.96</td>
<td>0.672</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>-</td>
<td>-</td>
<td>1.09</td>
<td>0.189</td>
<td>-</td>
<td>1.07</td>
<td>0.612</td>
<td>-</td>
<td>1.00</td>
<td>0.992</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60+</td>
<td>-</td>
<td>-</td>
<td>1.11</td>
<td>0.071</td>
<td>-</td>
<td>1.13</td>
<td>0.332</td>
<td>-</td>
<td>1.04</td>
<td>0.728</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational attainment</td>
<td>0.818</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary incomplete or complete</td>
<td>-</td>
<td>-</td>
<td>0.96</td>
<td>0.407</td>
<td>-</td>
<td>0.98</td>
<td>0.813</td>
<td>-</td>
<td>0.89</td>
<td>0.159</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary incomplete</td>
<td>-</td>
<td>-</td>
<td>0.98</td>
<td>0.730</td>
<td>-</td>
<td>1.02</td>
<td>0.840</td>
<td>-</td>
<td>0.82</td>
<td>0.062</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary complete or higher</td>
<td>-</td>
<td>-</td>
<td>0.98</td>
<td>0.743</td>
<td>-</td>
<td>1.00</td>
<td>0.973</td>
<td>-</td>
<td>0.88</td>
<td>0.308</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Bold numbers are results from multivariate Wald tests of all parameters in the construct (age/education).)
Table 4. Stigma models

<table>
<thead>
<tr>
<th></th>
<th>Malawi</th>
<th></th>
<th>Zambia</th>
<th></th>
<th>Country interaction p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self-tested v. did not test</td>
<td>Used HTS v. did not test</td>
<td>Self-tested v. did not test</td>
<td>Used HTS v. did not test</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RR (95% CI)</td>
<td>p-value</td>
<td>RR (95% CI)</td>
<td>p-value</td>
<td>RR (95% CI)</td>
</tr>
<tr>
<td>Any stigma</td>
<td>1.12</td>
<td>0.003</td>
<td>1.07</td>
<td>0.031</td>
<td>0.87</td>
</tr>
<tr>
<td></td>
<td>(1.04, 1.20)</td>
<td></td>
<td>(1.01, 1.13)</td>
<td></td>
<td>(0.75, 1.02)</td>
</tr>
<tr>
<td>HCW</td>
<td>1.10</td>
<td>0.450</td>
<td>1.13</td>
<td>0.276</td>
<td>0.78</td>
</tr>
<tr>
<td></td>
<td>(0.85, 1.42)</td>
<td></td>
<td>(0.91, 1.41)</td>
<td></td>
<td>(0.58, 1.06)</td>
</tr>
<tr>
<td>Abuse</td>
<td>1.16</td>
<td>0.156</td>
<td>1.00</td>
<td>0.967</td>
<td>0.94</td>
</tr>
<tr>
<td></td>
<td>(0.94, 1.43)</td>
<td></td>
<td>(0.85, 1.18)</td>
<td></td>
<td>(0.66, 1.36)</td>
</tr>
</tbody>
</table>

All estimates additionally adjusted for age (15-19, 20-24, 25-29, 30-39, 40-49, 50-59, 60+), gender, and educational attainment (no formal education, primary incomplete or complete, secondary incomplete, secondary complete or higher).

Country interaction p-value obtained by using two-country pooled dataset - other values from country-stratified analysis.
<table>
<thead>
<tr>
<th></th>
<th>Malawi</th>
<th>Zambia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Crude</td>
<td>Adjusted</td>
</tr>
<tr>
<td></td>
<td>Self-tested v. did not test</td>
<td>Used HTS v. did not test</td>
</tr>
<tr>
<td>10-item stigma measure</td>
<td>1.10 (1.02, 1.19)</td>
<td>0.018 (1.00, 3.91)</td>
</tr>
<tr>
<td></td>
<td>0.88 (0.75, 1.02)</td>
<td>0.080 (0.79, 1.04)</td>
</tr>
<tr>
<td>Male sex</td>
<td>0.90 (0.57, 1.43)</td>
<td>0.649 (0.24, 0.91)</td>
</tr>
<tr>
<td>Age in years (grouped)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-24</td>
<td>2.42 (0.99, 5.89)</td>
<td>0.052 (0.60, 1.48)</td>
</tr>
<tr>
<td>25-29</td>
<td>1.59 (0.85, 3.57)</td>
<td>0.391 (0.60, 6.28)</td>
</tr>
<tr>
<td>30-39</td>
<td>2.19 (0.55, 4.73)</td>
<td>0.105 (0.60, 6.28)</td>
</tr>
<tr>
<td>40-49</td>
<td>0.34 (0.13, 0.90)</td>
<td>0.030 (0.16, 2.27)</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary incomplete or complete</td>
<td>1.65 (0.97, 2.79)</td>
<td>0.065 (1.05, 3.94)</td>
</tr>
<tr>
<td>Secondary incomplete</td>
<td>1.78 (0.67, 4.73)</td>
<td>0.251 (0.98, 4.72)</td>
</tr>
<tr>
<td>Secondary complete or higher</td>
<td>1.78 (0.67, 4.73)</td>
<td>0.251 (0.98, 4.72)</td>
</tr>
</tbody>
</table>

Note that multivariate tests are not included but would be similar to those presented in table 2 (which present crude multivariate tests for significance of age/education).