MEASURING THE DEGREE OF HIV-RELATED STIGMA AND DISCRIMINATION IN HEALTH FACILITIES AND PROVIDERS

WORKING REPORT

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September 2010

The views expressed in this publication do not necessarily reflect the views of the U.S. Agency for International Development or the U.S. Government.
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This work and the resulting report would not have been possible without the contributions of numerous individuals and members of the study communities.

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Abbreviations

AIDS acquired immune deficiency syndrome
ARV antiretroviral
ART antiretroviral treatment
DHS Demographic and Health Surveys
ICRW International Center for Research on Women
IPPF International Planned Parenthood Foundation
IWG Interagency Working Group
HIV human immunodeficiency virus
HS high school
M&E monitoring and evaluation
MAC Makeup Art Cosmetics
MSM men who have sex with men
NGO nongovernmental organization
PEPFAR President’s Emergency Plan for AIDS Relief
PLHIV people living with HIV
SW sex worker
UNAIDS Joint United Nations Programme on HIV/AIDS
USAID United States Agency for International Development
WHO World Health Organization
INTRODUCTION

HIV-related stigma and discrimination are major barriers to effective and sustainable prevention, care, treatment, and support efforts. Although progress has been made in developing programs to reduce stigma and discrimination, lack of standardized indicators for measuring their effectiveness has inhibited application and scale-up of proven strategies.

This working report presents the findings from an internet-based survey designed to validate the items in the Health Facility and Provider Stigma Measurement Tool. The goal was to assess the validity of items designed to measure the key drivers of stigma.

This report may be especially useful to stigma researchers, healthcare workers, healthcare administrators, and evaluators.

Early Efforts to Design a Stigma Index

Key expert working groups have met, with the objective to ultimately arrive at a core set of global, program, and community-level indicators. In 2006, the U.S. Agency for International Development (USAID) Interagency Working Group (IWG) on Stigma and Discrimination Indicators designed specific tools to measure stigma and discrimination among communities, facilities/providers, and people living with HIV (PLHIV). In 2008, the MAC AIDS Fund and International Center for Research on Women (ICRW) convened an expert working group to build consensus around key areas to address, identify gaps, and agree on a testing strategy. In 2009, a technical working group convened to begin consolidating existing measures and measurement tools and develop guidance for monitoring and evaluating stigma-reduction efforts at the program and national levels.

Among the measurement tools was a methodology for an index measuring HIV-related stigma and discrimination. The USAID-funded POLICY II Project developed the tool and implemented it in four countries (Bollinger, 2006). The results showed that few studies were reporting on the set of consistent indicators required to construct the index. The foundation of this work included extensive consultation with both the USAID IWG on Stigma and Discrimination Indicators and a similar effort spearheaded by the Joint United Nations Program on HIV/AIDS (UNAIDS) and International Planned Parenthood Foundation (IPPF). A draft index was agreed on by each set of organizations, comprising three main sections: community level, facility/provider level, and PLHIV. The follow-on to the POLICY Project, the USAID | Health Policy Initiative, Task Order 1, has taken the lead on developing the facility/provider stigma measurement tool.

The Health Policy Initiative supported three field studies: one in Kenya (Kamau et al., 2007), one in Ukraine (Health Policy Initiative, 2007), and an Internet-based study in collaboration with ICRW designed to further test the indicators and questions regarding HIV-related stigma and discrimination at the facility/provider level. This report presents findings from the Internet-based study. (See Annex A for the working Health Facility and Provider Stigma Measurement questionnaire.)

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1 This annex includes the revised questionnaire based on the analysis. As such, the included questionnaire does not contain the full set of questions asked in the pilot survey. Individual questions that did not perform well or were included as additional checks for other questions are not presented in this questionnaire. As a result, some items included in the tables in this report have been renumbered in the questionnaire in the annex.
Small sample sizes hampered all three surveys. At a facility level, the research team found that it was important to have a large enough sample so that individuals could not be identified. The Internet-based survey eliminated concern about individual providers’ privacy, but the provider network was not robust enough to generate sufficient numbers to draw final conclusions. For this reason, future research should confirm the health facility/provider level stigma measurement tool with additional field testing. Additional limitations included modifications in item phrasing from previously tested items, the use of an Internet-based questionnaire that favored countries with easy Internet access, and the presentation of the questionnaire only in English.

As described below, the Internet-based survey evaluated several new areas. First, this was the first assessment of “provider experienced” stigma questions. The project found these questions reliable, but because of the low numbers of respondents, they will require further testing. Second, the research team altered the phrasing of the fear of HIV transmission questions slightly from previously tested items, asking if a provider “feels safe” performing a particular duty rather than “had fear.” The team made this modification after sampling a small number of providers who were more likely to respond candidly. These items also will require further testing to compare the reliability of assessing fear of HIV infection to positively versus negatively phrased items.

The Internet-based survey found that questions that assessed HIV stigma and discrimination in the healthcare setting, including items assessing healthcare providers’ fear of HIV transmission and attitudes of shame and blame associated with immoral and improper behavior of PLHIV, are consistent with previous field tests. Additionally, measuring HIV stigma and discrimination experienced by healthcare workers who care for PLHIV is important, as their experience may negatively affect the quality of care they provide.

The Health Facility and Provider Stigma Measurement Tool

HIV stigma and discrimination is defined as severe social disapproval that has harmful effects on people living with HIV and their families. Stigma comes in many forms, including gossip and verbal abuse, judgments and morally driven assumptions about how PLHIV acquired the infection, violence and physical abuse, and loss of jobs and livelihood. In the healthcare setting, HIV stigma and discrimination lead to PLHIV barriers in access to prevention, care, and treatment services. Research has shown that the following three main causes of HIV stigma prevail in healthcare settings: (1) health providers’ insufficient awareness of what stigma looks like and its consequences, (2) fear around HIV transmission in the workplace, and (3) attitudes that associate HIV with immoral behaviors (Tanzania Stigma Indicators Field-test Group, 2005). Over time, and through intervention activities targeting each of these three drivers, HIV stigma and discrimination can effectively be reduced.

Nyblade et al. (2009) recommend that health facility programs aimed at reducing the causes and consequences of HIV stigma and discrimination need to focus interventions on individual, environmental, and policy levels. At the individual level, they advocate for increasing awareness of the forms of stigma, reducing fears and misconceptions associated with HIV transmission, and confronting the associations of immoral behavior with HIV-positive individuals. Recommendations at the environmental level focus on providers’ needs for supplies, support, and information at the facility that enable them to perform their duties aptly while practicing universal precautions and
prevention of HIV transmission. At the policy level, guidelines that provide information on how to care for HIV-positive patients are necessary, and the policies need to be enforced and implemented consistently to reduce discriminatory behavior in the healthcare setting.

To assess the effectiveness of stigma-reduction interventions in the healthcare setting, it is crucial to have valid and reliable measures. The purpose of this validation exercise was to refine and test stigma measures at the individual level.

METHODS

Factor Analyses

The methods used in this analysis were drawn from previous work conducted in Tanzania (Cohen, 1988). The project conducted exploratory factor analysis to explore dimensionality of stigma constructs and determine which question items should be grouped together. For example, it is possible to find variations in three or four observed variables that mainly reflect the variations in a single unobserved variable or in a reduced number of unobserved variables. The team used the principal factor method and considered for inclusion those question items that loaded 0.40 or higher. They rotated the factor loadings, assuming correlation between factors, to ease interpretation. Once items were grouped together to form factors, reliability of the scales was assessed by calculating Chronbach's alpha, which measures the degree of interrelatedness among a set of items. The researchers selected or removed items based on obtained alpha coefficients.

The team then named scales based on the items that loaded together and standardized scales to have a mean of 50 and a standard deviation of 10. Each point on the scale represents one-tenth of a standard deviation. Point differences of three to five on the scale are considered significant based on standard guidelines for interpreting psychosocial indices (Cohen, 1988). Scores range from 0 to 100, with higher scores representing more stigmatizing responses.

Sample

The team sent an online health provider questionnaire to a broad network of healthcare workers in April 2010, asking them to complete it and forward the request to colleagues in their professional networks. The request asked providers to complete the questionnaire within two weeks. Ultimately, the questionnaire was left “live” for five weeks. Prior to their completing the questionnaire, the project obtained informed consent from all participants. A total of 82 providers responded to the survey.

Table 1 presents characteristics of respondents who completed the electronic survey. A slightly greater percentage of females (62%) completed the electronic survey. The mean age of respondents was 48.4 years old, and the majority were married or cohabiting with a partner (67%). About 64 percent of respondents held a Master’s degree or are doctors. The majority of respondents were Christian (56%), and more than half were North American (53%).
<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62.0 (49)</td>
</tr>
<tr>
<td>Male</td>
<td>38.0 (30)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>48.4</td>
</tr>
<tr>
<td>Range</td>
<td>28–68</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>67.1 (55)</td>
</tr>
<tr>
<td>Never married/single/widowed</td>
<td>17.7 (15)</td>
</tr>
<tr>
<td>Divorced</td>
<td>15.2 (12)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Masters</td>
<td>40.0 (32)</td>
</tr>
<tr>
<td>Doctors</td>
<td>23.8 (19)</td>
</tr>
<tr>
<td>Bachelors</td>
<td>18.8 (15)</td>
</tr>
<tr>
<td>HS/diploma/certification/other</td>
<td>17.5 (14)</td>
</tr>
<tr>
<td><strong>Region</strong></td>
<td></td>
</tr>
<tr>
<td>North America</td>
<td>53.2 (42)</td>
</tr>
<tr>
<td>Asia</td>
<td>24.1 (19)</td>
</tr>
<tr>
<td>Africa</td>
<td>11.4 (9)</td>
</tr>
<tr>
<td>Europe</td>
<td>10.1 (8)</td>
</tr>
<tr>
<td>Middle East</td>
<td>1.3 (1)</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>55.7 (44)</td>
</tr>
<tr>
<td>Hindu</td>
<td>15.2 (12)</td>
</tr>
<tr>
<td>Other</td>
<td>29.1 (23)</td>
</tr>
<tr>
<td><strong>Primary Role with HIV-positive Patients</strong></td>
<td></td>
</tr>
<tr>
<td>Administrator/supervisor</td>
<td>13.4 (11)</td>
</tr>
<tr>
<td>Clinician/care provider</td>
<td>50.0 (41)</td>
</tr>
<tr>
<td>Counselor</td>
<td>3.7 (3)</td>
</tr>
<tr>
<td>Health educator</td>
<td>14.6 (12)</td>
</tr>
<tr>
<td>Peer/treatment advocate</td>
<td>6.1 (5)</td>
</tr>
<tr>
<td>No answer</td>
<td>12.2 (10)</td>
</tr>
</tbody>
</table>
RESULTS

Fear Domain

Table 2 presents the results of the factor analysis conducted on a series of variables designed to measure fear of HIV transmission during various types of contact and medical procedures with PLHIV. Three factors emerged from this analysis, including (1) feelings of safety when working with PLHIV, (2) comfort around PLHIV, and (3) fear of work-related HIV exposure.

Table 2: Factor Loadings for Fear-driven Stigma, Comfort around PLHIV, Work-related HIV Exposure

<table>
<thead>
<tr>
<th>Item No</th>
<th>Indicator</th>
<th>*Factor 1 Feelings of Safety</th>
<th>*Factor 2 Comfort Around PLHIV</th>
<th>*Factor 3 Work-related HIV Exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td>q45</td>
<td>I am comfortable sharing a bathroom with HIV-positive colleagues</td>
<td></td>
<td>0.5519</td>
<td></td>
</tr>
<tr>
<td>q49</td>
<td>I avoid touching the clothing/belongings of patients known or suspected to have HIV</td>
<td></td>
<td>0.7402</td>
<td></td>
</tr>
<tr>
<td>q66</td>
<td>I am willing to provide care to patients with HIV and AIDS</td>
<td></td>
<td>0.5687</td>
<td></td>
</tr>
<tr>
<td>q83</td>
<td>I feel safe assisting or being assisted by a colleague who is HIV positive</td>
<td></td>
<td>0.4443</td>
<td></td>
</tr>
<tr>
<td>q85</td>
<td>If I had a choice, I would work with HIV and AIDS patients</td>
<td></td>
<td>0.6454</td>
<td></td>
</tr>
<tr>
<td>q119</td>
<td>I feel safe assisting in the delivery of an HIV-positive woman</td>
<td>0.8978</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q120</td>
<td>I feel safe dressing the wounds of HIV-positive patients</td>
<td>0.8630</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q121</td>
<td>I feel safe touching the sweat of a patient with HIV or AIDS</td>
<td>0.8967</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q122</td>
<td>I feel safe conducting surgery or suturing an HIV-positive patient</td>
<td>0.7311</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q123</td>
<td>I feel safe touching the saliva of a patient with HIV or AIDS</td>
<td>0.5098</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q124</td>
<td>I feel safe putting an IV drip in someone who is HIV positive</td>
<td>0.8463</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q125</td>
<td>I feel safe drawing blood from a patient with HIV or AIDS</td>
<td>0.9363</td>
<td></td>
<td></td>
</tr>
<tr>
<td>q127</td>
<td>I take special precautions when I provide medical care to HIV and AIDS patients</td>
<td></td>
<td>0.5328</td>
<td></td>
</tr>
<tr>
<td>q55</td>
<td>The most frequent mode of contracting HIV among healthcare workers is through work-related exposure</td>
<td></td>
<td>0.4410</td>
<td></td>
</tr>
<tr>
<td>q61</td>
<td>Most HIV-positive healthcare workers are infected at work</td>
<td></td>
<td>0.7606</td>
<td></td>
</tr>
<tr>
<td>q118</td>
<td>Before examining a patient with HIV, I put on a protective mask</td>
<td></td>
<td>0.9367</td>
<td></td>
</tr>
</tbody>
</table>

*Rotated Factor Loadings

2 Items in the exploratory factor analysis include: q45, q49, q55, q60, q61, q83, q85, q87, q92, q118–q124.
Table 3 presents the reliability assessment and Chronbach’s alpha scores of the items that loaded onto each factor. A total of eight items loaded onto Factor 1. Question q127 was removed from the scale, as it reduced the overall value alpha. The alpha score indicates that 92 percent of the scale’s total variance is attributable to the true score of the latent construct being measured, which is “feelings of safety.” Five items loaded on the second factor, and 63 percent of the scale is explained by the latent construct “comfort around PLHIV.” The final factor consists of three items, with 58 percent of the scale’s variance being explained by the latent variable “work-related HIV exposure.” It is recommended that all three factors be retained.

Table 3. Reliability Results of Fear-driven Stigma Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>N (items)</th>
<th>Coefficient α</th>
<th>Removed item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7</td>
<td>0.9193</td>
<td>n127</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>0.6265</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>0.5790</td>
<td>-</td>
</tr>
</tbody>
</table>

Value-driven Stigma

Table 4 presents the factor loadings of items aimed at measuring attitudes associated with shame and blame toward people living with HIV. Three factors emerged from this analysis: (1) attitudes about blame, (2) shame associated with PLHIV, and (3) attitudes related to providing separate spaces for caring for PLHIV.

Table 4. Factor Loadings for Value-driven Stigma

<table>
<thead>
<tr>
<th>Item Number</th>
<th>Indicator</th>
<th>Rotated Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Factor 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Attitudes about Blame</td>
</tr>
<tr>
<td>q48</td>
<td>Promiscuous men should be blamed for spreading HIV in our community</td>
<td>0.8078</td>
</tr>
<tr>
<td>q52</td>
<td>Female sex workers should be blamed for spreading HIV in our community</td>
<td>0.7526</td>
</tr>
<tr>
<td>q76</td>
<td>Injecting drug users should be blamed for spreading HIV in our community</td>
<td>0.5684</td>
</tr>
<tr>
<td>q65</td>
<td>I would feel ashamed if I was infected with HIV</td>
<td>0.6961</td>
</tr>
<tr>
<td>q70</td>
<td>I would feel ashamed if someone in my family was infected with HIV</td>
<td>0.6395</td>
</tr>
<tr>
<td>q59</td>
<td>People living with HIV should feel ashamed</td>
<td>0.3542</td>
</tr>
</tbody>
</table>

---

3 Items included in the exploratory factor analysis include the following: q44, q47, q48, q52, q54, q56–q59, q63, q65, q68, q70, q72, q73, q76, q79, q80, q84–q86, q89, q91, q93, q94, q96.

4 This is the only exception to our factor loading rule of >0.4 and was left in the factor because this item has previously shown to work well when assessing attitudes associated with shame among healthcare providers.
Table 5 presents the reliability test results for the factors formed from factor analysis of value-driven items. Three items make up the first factor, and 86 percent of the scale’s variation can be explained by the latent construct “attitudes about blame.” Factor two consists of four items; 71 percent of the variation can be explained by the latent construct “shame of PLHIV.” Two items formed the third factor, with 62 percent of the scale’s variation explained by the latent construct “attitudes about isolated care for PLHIV.” While the two items on the third factor demonstrated adequate reliability, it is unclear whether affirmative responses to them represent stigmatizing responses. For example, respondents may have agreed with these statements due to a belief that specialized care for PLHIV is preferable. Given this, the research team recommends retaining only Factors 1 and 2. Alternatively, the questions could be modified to more specifically capture a stigmatizing response.5

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>q73</td>
<td>HIV-positive physicians and nurses should not practice medicine</td>
<td>0.5184</td>
</tr>
<tr>
<td>q56</td>
<td>HIV-positive patients should not be cared for in the same facility as non-HIV-positive patients</td>
<td>0.7869</td>
</tr>
<tr>
<td>q94</td>
<td>HIV-positive patients should be treated in separate healthcare facilities</td>
<td>0.4634</td>
</tr>
</tbody>
</table>

Table 5. Reliability Results of Value-driven Stigma

<table>
<thead>
<tr>
<th>Factor</th>
<th>N (items)</th>
<th>Coefficient α</th>
<th>Removed item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>0.8551</td>
<td>-</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>0.7104</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>0.6246</td>
<td>-</td>
</tr>
</tbody>
</table>

Experienced Stigma

Table 6 presents the factor loadings of items that measured respondents’ experiences of HIV-related stigma or perception of stigma as a result of their work with PLHIV.6 Only one factor formed from these items.

<table>
<thead>
<tr>
<th>Item Number</th>
<th>Indicator</th>
<th>Rotated Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td>q97</td>
<td>I have been neglected by family and friends because I care for HIV-positive patients</td>
<td>0.9418</td>
</tr>
<tr>
<td>q98</td>
<td>I have stopped socializing with some people because of their reaction to me as a healthcare worker for people living with HIV</td>
<td>0.9589</td>
</tr>
<tr>
<td>q99</td>
<td>I have lost friends because I told them I provide care to people living with HIV</td>
<td>0.9686</td>
</tr>
</tbody>
</table>

5 The following question was included in the 2005 Tanzania field testing of stigma measures among healthcare providers: “People who are infected with HIV should not be treated in the same place as other patients in order to protect other patients from infection.”

6 Items in the exploratory factor analysis include: q97–q117.
Table 7 presents the results from the reliability testing of the experienced stigma factor. The Cronbach’s alpha was quite high—0.99 when all 13 items were included in the scale. This means that 99 percent of the variance in the scale is attributed to the latent variable of “experienced stigma.” Given the large number of items, however, items that loaded lowest on the factor were removed iteratively until a final factor of six items was obtained (see Annex A). The recommendation is to use the six item factors to measure experienced stigma. However, it should be noted that only five respondents reported experiencing the types of stigma included in the scale, which may have influenced the results of the factor analysis. Therefore, this report team recommends further testing of these items in a larger and more diverse sample before making a final decision about which items to include in the scale.

**Table 7. Reliability Results of Experienced Stigma**

<table>
<thead>
<tr>
<th>Factor</th>
<th>N (items)</th>
<th>Coefficient α</th>
<th>Removed item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13</td>
<td>0.9884</td>
<td>-</td>
</tr>
<tr>
<td>11</td>
<td>9</td>
<td>0.9889</td>
<td>n103, n114</td>
</tr>
<tr>
<td>9</td>
<td>0.9889</td>
<td>n110, n112</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>0.9894</td>
<td>n109</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>0.9900</td>
<td>n108</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>0.9908</td>
<td>n111</td>
<td></td>
</tr>
</tbody>
</table>

**Construct Validity**

To test the construct validity of the scales developed above, each scale was compared against a set of sociodemographic and construct validity variables to determine the extent to which the scales performed in the expected manner. The research team assessed the relationships observed between
the scales and the variables based on existing conceptual knowledge of the determinants of HIV-related stigma. The results of this analysis are presented in Table 8. All relationships were tested for significance; only a few significant results were obtained. This is likely due to the small number of health providers interviewed. When no significant differences were detected, the direction of the trends in mean scores across groups was examined to assess validity.

Education was the only sociodemographic variable used in the validation. Other variables, such as age, gender, and marital status, were explored, but results were inconclusive due to uncertainty about directionality of HIV-related stigma (e.g., are men or women more likely to stigmatize?). A three-category education variable was used in the validation analysis. Providers with masters or doctoral degrees were significantly less likely to feel unsafe working with PLHIV (p-value<0.10), to have stigmatizing attitudes associated with blame, and to recommend isolated care for PLHIV, compared with providers with bachelors degrees and high school or other diplomas/certifications. Personal attitudes of shame were higher among providers with higher levels of education, suggesting that providers would feel shameful if they were HIV positive.

The assessment used a number of indicators to test knowledge of HIV among healthcare providers. Bivariate analysis revealed high levels of general HIV knowledge among health providers. The team generated two composite indices to assess both basic and more in-depth HIV knowledge.

The basic HIV knowledge index was generated from question 31, which asked respondents which body fluids have high enough concentrations of HIV to transmit the virus. For validation purposes, a dichotomous variable was constructed comparing respondents who correctly identified all body fluids that transmit HIV to those who did not. Across all associations, respondents who incorrectly reported a body fluid also indicated more fear around HIV transmission while caring for PLHIV and held more discriminatory attitudes toward PLHIV, compared with respondents who correctly identified all body fluids that transmit HIV.

The in-depth HIV knowledge index was based on responses to three questions:

(1) q39: Can HIV live outside the human body?

(2) q40: Is the risk of HIV transmission following a needle stick approximately 1 in 300?

(3) q41: Is the risk of HIV transmission following a splash of blood to non-intact skin or mucus membranes approximately 1 in 1,000?

A dichotomous variable was created from the responses to these three questions for validation purposes (see Table 8, in-depth HIV knowledge). Those who provided correct responses to at least two of the questions were considered to have in-depth knowledge. Providers with more in-depth knowledge were less likely to feel unsafe providing care to PLHIV, significantly less likely to feel uncomfortable around PLHIV (p-value<0.10), and less likely to have stigmatizing attitudes around blame and shame (p-value<0.10).

Two additional validation indicators were selected: (1) whether the respondent received stigma training within the past 12 months and (2) the number of PLHIV the respondent has cared for. Respondents who had received stigma training in the past 12 months were significantly more comfortable around PLHIV and appeared to have less fear of HIV transmission and less shame and blame toward PLHIV. Similarly, respondents who had cared for PLHIV had significantly less fear of
HIV infection and were more comfortable around PLHIV. In addition, it appears that healthcare workers who had cared for PLHIV held less stigmatizing attitudes toward them.

The results of the construct validity testing are similar to those from the 2005 field-testing exercise of similar measures in Tanzania (Tanzania Stigma Indicators Field-test Group, 2005). This provides further evidence that scales to assess the key drivers of stigma, fear, shame, and blame among healthcare workers are accurately measuring the constructs intended. However, further validation should be conducted using larger samples of healthcare workers and across multiple country settings.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>Fear of HIV transmission while caring for PLHIV</th>
<th>Hold morally based discriminatory attitudes toward PLHIV</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Feels of safety</td>
<td>Work-related HIV exposure</td>
</tr>
<tr>
<td></td>
<td>Mean Score (Valid Resp)</td>
<td>Mean Score (Valid Resp)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Masters/Doctors</td>
<td>48.4* (23)</td>
<td>48.7 (47)</td>
</tr>
<tr>
<td>Bachelors</td>
<td>49.9* (10)</td>
<td>53.2 (15)</td>
</tr>
<tr>
<td>HS/Diploma/Cert/other</td>
<td>56.5* (6)</td>
<td>51.2 (13)</td>
</tr>
<tr>
<td>In-depth HIV knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–1 correct response</td>
<td>51.4 (21)</td>
<td>50.8 (40)</td>
</tr>
<tr>
<td>2–3 correct responses</td>
<td>48.2 (18)</td>
<td>49.0 (34)</td>
</tr>
<tr>
<td>Knowledge of HIV transmission fluids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any question incorrect</td>
<td>51.5 (23)</td>
<td>51.8** (45)</td>
</tr>
<tr>
<td>All correct</td>
<td>47.9 (16)</td>
<td>47.2** (30)</td>
</tr>
<tr>
<td>Received stigma training in past 12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>52.1 (24)</td>
<td>50.0 (45)</td>
</tr>
<tr>
<td>Any</td>
<td>49.8 (8)</td>
<td>49.7 (16)</td>
</tr>
<tr>
<td>No. of PLHIV care for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>56.2* (9)</td>
<td>49.2 (28)</td>
</tr>
<tr>
<td>Any</td>
<td>49.2* (23)</td>
<td>49.3 (37)</td>
</tr>
</tbody>
</table>

Note: Higher mean score represents more stigmatizing response. For stigma indexes, t-tests of significance were conducted for dichotomous variables; f-tests were conducted for variables with multiple response categories.

Represents significance at the *<.10, **<.05, and ***<.01 levels.
LIMITATIONS

There are several limitations of the analysis presented here. First, the analysis consisted of only 82 respondents, and in some instances, due to missing and not applicable data, the team conducted factor analysis on even fewer respondents. (Usually a minimum of 100 respondents is optimal for factor analysis.) It is important, therefore, to recognize that conclusions and interpretations drawn from this analysis need to be confirmed with additional item testing. This analysis also was the first time that the “experienced stigma” questions were tested. While the items in each factor correlated well with high scale reliability, only five respondents reported having actually experienced HIV stigma due to their work with people living with HIV. Further testing of the experienced stigma items and scales is imperative before they are disseminated broadly.

Another limitation of this analysis is the wording and phrasing of the fear of HIV transmission questions. The researchers modified these questions after sampling a small number of providers who were found to respond more candidly. In this survey, the team altered these items slightly from previously tested items, such that questions asked respondents if they felt safe when performing certain duties on HIV-positive patients instead of whether they had fear of HIV transmission when performing these duties. In addition, the fear of HIV transmission questions were worded in a positive manner (e.g., I feel safe dressing the wounds of an HIV-positive patient); previous research has shown that asking about fear of HIV transmission in the negative elicits more candid and potentially honest responses (e.g., Please tell me if you have fear of HIV transmission, have no fear of HIV transmission, or do not know when taking blood samples from a person living with HIV). Therefore, further testing to compare the reliability of positively versus negatively phrased items to assess fear of HIV infection is recommended.

Although using an Internet-based questionnaire eliminated potential privacy issues, the responses clearly favored countries where there was easy Internet access, even though the request was sent to networks of providers in countries in all regions. In the future, teams should undertake further field testing of this Internet-based questionnaire in non-first world settings using e-mail, offline surveys, or cellular phone technology.

Finally, researchers presented the questionnaire only in English. Although the questionnaire reached healthcare workers in all regions, those with limited English skills were reluctant to complete the survey. Future research teams should do field testing of the questionnaire in multiple languages.

RECOMMENDATIONS AND NEXT STEPS

Based on the results of this analysis, the research team recommends that surveys designed to assess HIV stigma and discrimination in the healthcare setting include question items that assess healthcare provider’s fear of HIV transmission and attitudes of shame and blame associated with immoral and improper behavior of people living with HIV. The results of this study are in line with findings from the 2005 Tanzania Field Testing Report in that the items loading strongly onto factors were similar to the results obtained in the 2005 report.

This analysis supported recommendations from the technical working group on stigma to assess HIV stigma and discrimination experienced by healthcare workers who care for people living with HIV. The experienced stigma felt by providers can inhibit their ability to provide high-quality care.
and treatment services to people living with HIV. Therefore, understanding the types of that stigma providers experience is a crucial component of effectively reducing HIV stigma and discrimination in the healthcare setting.

With further testing, the scales developed in the analysis could be used by healthcare workers as a self-assessment, by trainers as a learning tool, and by healthcare administrators to assess the levels of HIV stigma and discrimination among their staff before and after stigma-reduction interventions. Evaluators assessing the effectiveness of interventions aimed at reducing HIV stigma and discrimination in the healthcare setting may also find these scales helpful in their work.

Because Internet-based questionnaires are relatively easy to administer, they have the potential to provide participants with immediate feedback on their “level” of stigma compared with participants in other institutions, regions, countries, or globally. Additionally, it is possible to develop a list of online tools, resources, and training materials based on the participants’ results that could be used for self-directed learning or at the facility level to assist an administrator in implementing the most effective intervention.

As part of the global stigma movement, these indicators should be further developed and harmonized with the proposed Demographic and Health Survey (DHS) questions and key indicators of the PLHIV Stigma Index. Once the indices have been coordinated, they should be further tested to assess language and cultural nuances.

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7 See http://www.stigmaindex.org/.
ANNEX A: HEALTH FACILITY AND PROVIDER QUESTIONNAIRE

Thank you for taking the time to complete the Health Facility and Provider Questionnaire. This questionnaire will help us to measure and detect changing trends in HIV care practice.

Your responses will be anonymous. You may decline to answer any question or cease completing the questionnaire at any time and for any reason. You will not be compensated to complete the questionnaire.

Completing the questionnaire will take approximately 25 minutes.

The information you share will be kept entirely confidential. Only members of the research team will have access to the data. The data you submit online at will be archived to a physical medium and deleted from the server. The data archive will be stored in a locked filing cabinet in the for a period of three years, after which point it will be destroyed.

If you have any questions about the questionnaire you may contact:
Health Facility and Provider Questionnaire

**Respondent Profile**

1. This information is used only to help us reduce duplicated entries.
   a. What are the first two initials of your first (given) name? 
   b. What are the first two initials of your mother’s first (given) name?

2. In what year were you born? (YYYY)

3. What is your nationality?

4. What is your gender?
   - ☐ Female  ☐ Male

5. What is your marital status?
   - ☐ Married / Cohabitating  ☐ Divorced  ☐ Widowed  ☐ Never married / Single

6. What is your religion?
   - ☐ Christian  ☐ Hindu  ☐ Jewish  ☐ Muslim  ☐ Traditional  ☐ Other: 

---

15
7. How often do you attend religious activities?
   - More than once a week
   - Once a week
   - 1–3 times a month
   - Rarely
   - Never

8. What is the highest level of school you completed?
   - High school degree
   - Bachelor’s degree
   - Master’s degree
   - Doctor’s degree
   - Diploma
   - Certificate
   - Other: [Enter]

9. In your personal life, do you know anyone living with HIV?
   - Yes
   - No
   - Don’t know

10. What is your professional designation?
    - Medical specialist
    - General practitioner
    - Clinical officer
    - Nurse officer
    - Nurse midwife
    - Nurse assistant
    - Health attendant
    - Other: [Enter]

11. How many years have you been working in your current designation?
    [Enter]

12. In which type of medical facility do you spend the majority of your time? (Select one):
    - Public Hospital/Hospital-based Clinic
    - Private Hospital/Hospital-based Clinic
    - Private practice

13. Is your primary health facility located in an urban (city), peri-urban (suburban), or rural (countryside) area?
    - Urban/City
    - Peri-Urban/Suburban
    - Rural/Countryside

14. In which country is your primary health facility?

15. Do you work in an HIV Specialty Clinic?
16. Which statement best describes the care or services YOU provide to people living with HIV and AIDS?
☐ I don't see HIV or AIDS patients  ☐ Refer HIV-positive patients for all care  ☐ Refer when initiating antiretroviral treatment
☐ Refer when failing antiretroviral treatment  ☐ Provide HIV treatment, and adherence counseling
☐ Provide non-HIV care and treatment to HIV-positive patients  ☐ Provide all care to HIV-positive patients

17. What is your primary functional role in your interactions with HIV patients?
☐ Administrator/Supervisor  ☐ Health Educator  ☐ Clinician/Care Provider  ☐ Counselor
☐ Case Manager  ☐ Peer/Treatment Advocate

18. In the last month, how many HIV-positive patients have you personally cared for?

19. In the last month, how many of your HIV-positive patients have been taking antiretroviral medicine?

20. How many hours a week do you provide direct outpatient care and treatment for HIV-positive patients?

21. How many hours a week do you provide inpatient treatment for HIV-positive patients?

22. In what year did you see your first HIV-positive client/patient?
23. Do you receive continuing education credit for attending trainings?
☐ Yes  ☐ No

a. In the last 12 months, how many hours of continuing education credit have you received?

24. In the last 12 months, how many hours of training did you receive in the following subjects:

1. Stigma
2. Gender
3. HIV treatment
4. Infection control
5. Policy and procedures
6. HIV counseling and testing
7. Preventing mother-to-child transmission
8. Adherence
9. Orphans and vulnerable children care
10. Other (list)

25. In the last 12 months, how many TOTAL hours of HIV training have you received?

26. In the last 12 months, was HIV training provided at your workplace?
27. How would you rate your overall HIV knowledge level?
   - ☐ Extensive
   - ☐ Moderate
   - ☐ Minimum
   - ☐ None

28. What percentage of your HIV-positive patients are:

1. Male

2. Female

3. Transgender
   - Should total 100%

4. Adults (15 and older)

5. Children (Less than 15 years old)
   - Should total 100%

6. Substance user

7. Severely or persistently mentally ill

8. Racial/Ethnic Minority

9. Sex workers

10. Men who have sex with men (MSM)

---

**Facility Profile**

29. My health facility has a policy to protect HIV-positive patients from discrimination.
   - ☐ Yes
   - ☐ No
   - ☐ Don’t know
30. Policies to protect HIV-positive patients are enforced.
   ☐ Yes  ☐ No  ☐ Don’t know

31. Do healthcare workers receive higher wages because they provide care and treatment to HIV-positive patients than healthcare workers that do not care or treat HIV-positive patients?
   ☐ Yes  ☐ No  ☐ Don’t know

32. Are the following policies/guidelines/protocols readily available in your health facility?

<table>
<thead>
<tr>
<th></th>
<th>1. National HIV Policy</th>
<th>☐ Yes  ☐ No  ☐ Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. HIV counseling and testing</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>3. HIV testing procedure</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>4. Confidentiality</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>5. Informed consent</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>6. Post-exposure prophylaxis</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>7. National clinical HIV guidelines</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>8. Treatment of opportunistic infections</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>9. National clinical tuberculosis (TB) guidelines</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>10. Blood safety</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>11. Universal precautions</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
<tr>
<td></td>
<td>12. Anti-discrimination against people living with HIV</td>
<td>☐ Yes  ☐ No  ☐ Don’t know</td>
</tr>
</tbody>
</table>
33. Do staff at your health facility receive training on implementing these policies?

<table>
<thead>
<tr>
<th>Policy</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>National HIV Policy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV testing procedure</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Confidentiality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informed consent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-exposure prophylaxis</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>National clinical HIV guidelines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment of opportunistic infections</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National clinical TB guidelines</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood safety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Universal precautions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-discrimination against people living with HIV</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

34. Are the policies followed at your health facility?

<table>
<thead>
<tr>
<th>Policy</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>National HIV Policy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV counseling and testing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV testing procedure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidentiality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informed consent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-exposure prophylaxis</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7. National clinical HIV guidelines   □ Yes □ No □ Don’t know
8. Treatment of opportunistic infections □ Yes □ No □ Don’t know
9. National clinical TB guidelines □ Yes □ No □ Don’t know
10. Blood safety □ Yes □ No □ Don’t know
11. Universal precautions □ Yes □ No □ Don’t know
12. Anti-discrimination against people living with HIV □ Yes □ No □ Don’t know

### HIV Knowledge

35. Which body fluids have a high enough concentration of HIV to transmit the virus?

☐ Breast milk □ Blood □ Saliva □ Semen □ Sweat □ Tears □ Vaginal fluid □ Other body fluids containing blood
☐ Don’t know □ Other

36. Which body fluids do not have a high enough concentration of HIV to transmit the virus?

☐ Breast milk □ Blood □ Saliva □ Semen □ Sweat □ Tears □ Vaginal fluid □ Other body fluids containing blood
☐ Don’t know □ Other

37. Can people reduce their chances of getting HIV by having a monogamous sexual relationship with an HIV-negative partner?

□ Yes □ No □ Don’t know

38. Can people get HIV from mosquito bites?
39. Can people reduce their chances of getting HIV by using a condom every time they have sex?
   ☐ Yes  ☐ No  ☐ Don’t know

40. Can people get HIV from sharing food with a person who has HIV or AIDS?
   ☐ Yes  ☐ No  ☐ Don’t know

41. Is it possible for a healthy-looking person to transmit HIV?
   ☐ Yes  ☐ No  ☐ Don’t know

42. Can HIV live outside the human body?
   ☐ Yes  ☐ No  ☐ Don’t know

43. Is the risk of HIV transmission following a needle stick approximately 1 in 300?
   ☐ Yes  ☐ No  ☐ Don’t know

44. Is the risk of HIV transmission following a splash of blood to non-intact skin or mucus membranes approximately 1 in 1,000?
   ☐ Yes  ☐ No  ☐ Don’t know
Fear Domain

45. I am comfortable sharing a bathroom with HIV-positive colleagues.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

46. I avoid touching the clothing/belongings of patients known or suspected to have HIV.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

47. I am willing to provide care to patients with HIV and AIDS.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

48. I feel safe assisting or being assisted by a colleague who is HIV positive.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

49. If I had a choice, I would work with HIV and AIDS patients.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

50. The most frequent mode of contracting HIV among healthcare workers is through work-related exposure.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

51. Most HIV-positive healthcare workers are infected at work.
   ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

---

8 Questions were grouped under the stigma domains “fear, value-driven, and experienced” to facilitate use by non-researchers. The research team recommends removing the stigma domain labels when administering the questionnaire.
52. Before examining a patient with HIV, I put on a protective mask.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree

### Value-driven Stigma

53. Promiscuous men should be blamed for spreading HIV in our community.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree

54. Female sex workers should be blamed for spreading HIV in our community.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree

55. Injecting drug users should be blamed for the spread of HIV.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree

56. I would feel ashamed if I was HIV positive.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree

57. I would feel ashamed if someone in my family was HIV positive.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree

58. People living with HIV should feel ashamed.
   - [ ] Strongly Agree
   - [ ] Agree
   - [ ] Disagree
   - [ ] Strongly Disagree
59. HIV-positive physicians and nurses should not practice medicine.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree

**Experienced Stigma**

60. I have been neglected by family and friends because I care for HIV-positive patients.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree

61. I have stopped socializing with some people because of their reaction to me as a healthcare worker for people living with HIV.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree

62. I have lost friends because I told them I provide care to people living with HIV.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree

63. I have been denied social exchanges and friendships because people know that I care for people living with HIV.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree

64. I have felt that people are afraid of me because they think they can get HIV from me because I care for people living with HIV.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree

65. Some people avoid touching me because they know I take care of HIV-positive patients.
   □ Strongly Agree  □ Agree  □ Disagree  □ Strongly Disagree
Please answer the following questions as fully as possible.

66. Please list all the ways you know of that HIV can be transmitted

67. How can people protect themselves from getting HIV?

68. Please briefly describe your instrument sterilization procedures.

69. Why should or should not an HIV-positive woman have children?

70. Please list situations in which you would disclose or have disclosed the HIV status of a patient without his/her consent.
REFERENCES


