

Assessing HIV/AIDS Stigma and Discrimination in Developing Countries

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Abstract HIV/AIDS-related stigma and discrimination are barriers to HIV prevention effectiveness, voluntary counseling and testing uptake, and accessing care in many international settings. Most published stigma scales are not comprehensive and have been primarily tested in developed countries. We sought to draw on existing literature to develop a scale with strong psychometric properties that could easily be used in developing countries. From 82 compiled questions, we tested a 50-item scale which yielded 3 dimensions with 22 items in pilot testing in rural northern Thailand ($n = 200$) and urban and peri-urban Zimbabwe ($n = 221$). The three factors (shame, blame and social isolation; perceived discrimination; equity) had high internal consistency reliability and good divergent validity in both research settings. Systematic and significant differences in stigmatizing attitudes were found across countries, with few differences by age or sex noted within sites. This short, comprehensive and standardized measure can be easily incorporated into questionnaires in international research settings.

Keywords HIV/AIDS-related stigma · Discrimination · Scale development

Introduction

In his seminal work, Goffman (1963) defined stigma as “an attribute that is deeply discrediting” which leads an individual to occupy a tarnished and discredited identity and place in society. Stigma has been associated with diseases that are incurable and severe, and with routes of disease transmission that are associated with individual behaviors, particularly behaviors that may not conform to social norms (Crandall and Moriarty 1995). Stigma can have significant deleterious effects on health and disease transmission by delay in seeking care, in failing to disclose one’s condition due to fear of isolation or rejection, and by fear of following medical advice.

Stigma is particularly relevant to prevention and treatment in the global HIV/AIDS pandemic. Stigma surrounding HIV and AIDS has been shown to act as barrier to HIV prevention, treatment, and care, including voluntary counseling and testing (VCT) (Fortenberry et al. 2002; Kalichman and Simbayi 2004; Kalichman et al. 2005; Lieber et al. 2006). Since HIV/AIDS-related stigma acts at both the societal and at the individual level, there is an urgent need in many contexts to address stigma to promote adequate, accessible and acceptable HIV/AIDS programs and services. HIV/AIDS-related stigma has been shown to be inversely related to knowledge of HIV transmission, access to antiretroviral treatment (Castro and Farmer 2005) and disclosure of HIV status (Maman et al. 2003).

Given the adverse effects of stigma, several interventions to reduce stigma have been evaluated (Bellingham

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and Gillies 1993; Brown et al. 2003; Horizons 2002; Newman et al. 1993). However, these efforts have shown inconsistent results, which may be due in part to a focus on the individual-level, which emphasizes improving HIV/AIDS related knowledge rather than addressing the root causes of stigmatizing attitudes. Implementation of stigma reduction programs has primarily addressed school-based youth and developed country populations (Brown et al. 2003). These results may not be generalizable to populations in developing countries or in contexts with differing levels of stigma. Stigma reduction programs should be evaluated in terms of their ability to reduce stigmatizing attitudes and discriminatory actions and by subsequent uptake and utilization of HIV prevention services and treatment.

Defining and assessing stigma presents a challenge. The majority of published studies have relied on measures of stigma that are not comprehensive (Bellingham and Gillies 1993; Lentine et al. 2000; Newman et al. 1993), while those that have been comprehensive are often so extensive that they are impractical to use in the conduct of field studies (USAID 2005). Additionally, early work in the US focused on assessing stigma as perceived from the perspective of HIV-infected individuals (Berger et al. 2001; Siegel and Krauss 1991). This perspective, while indeed important, fails to address the views of the larger population that hold stigmatized and discriminatory attitudes towards those infected with HIV. Measures are needed that focus on the prejudicial attitudes of community members regarding HIV/AIDS, as these may hinder community members from seeking VCT, and may act as a barrier to disclosure of serostatus and access to treatment among HIV-infected individuals.

There are few existing instruments that have been developed to measure stigma at the population level, specifically to evaluate the effect of programs to reduce stigma in developing countries. Existing measurement tools have often been developed for a single cultural context (Kalichman and Simbayi 2004). While measures of stigma at the community level might be limited to the local context to maximize relevance, this limits the usefulness of the measure when making cross-cultural comparisons (Weiss et al. 2006). Some researchers have suggested that the underlying contexts of stigma are similar enough across societies, both developed and developing, that a reliable and valid scale should prove useful in multiple contexts (Van Brakel 2006). Thus, there remains a need for standardized stigma measures that are applicable across cultures for comparability that can be assessed by analyzing their psychometric properties.

Many existing measures of stigma are not grounded in a theoretical framework and are developed without the use of appropriate statistical methods to determine the underlying

factor structure. We present results from psychometric analyses that outline a three-factor structure of stigma that maps onto a theoretical framework presented in a recent paper by Link and Phelan (2006). They described five interrelated components that act together to produce stigma. These components included: (1) labeling socially relevant differences, (2) linking the labeled individuals to undesirable characteristics, (3) separation from those who have been labeled, (4) experience of loss or discrimination as a result of stigma, and (5) the exercise of power (Link and Phelan 2006). This framework informed the interpretation of the factor structure observed in this study.

We report on an evaluation of the reliability and validity of a derived measure of HIV/AIDS-related stigma that was tested in multiple cultures and in countries that are at different epidemic stages (alternatively, this could be considered as differences in the duration of time that the general public has been aware of HIV/AIDS). We describe the development of a relatively brief (22-item) stigma scale with three underlying dimensions in two distinct cultural contexts, rural northern Thailand and urban and peri-urban Zimbabwe. We include results from psychometric analysis including reliability and validity of this scale, which features measures of three underlying constructs of stigma. This measure was tested among community members in both countries and assesses the attitudes of community members regarding HIV/AIDS, as well as their perceptions of how individuals with HIV/AIDS are treated in their communities and attributions of how they might experience HIV/AIDS stigma.

The derived measure is now being used in a multi-site community-randomized controlled intervention trial designed to test the efficacy of a community-level structural intervention, with the secondary aim of determining whether mobile community-based VCT, community mobilization and post-test support services are effective in reducing HIV/AIDS-related stigma at the community level (Project Accept). We are assessing baseline stigma levels and will also document subsequent differences in HIV/AIDS-related stigma in communities receiving 3 years of enhanced mobile VCT compared to communities receiving standard clinic-based VCT.

Methods

Measures

We conducted a literature review to identify brief quantitative measures of attitudes of HIV-related stigma and discrimination that had previously been used in international research settings among adult populations. Six measures of HIV/AIDS-related stigma and discrimination

were identified (Boer and Emons 2004; Herek et al. 2002; Kalichman and Simbayi 2003; Letamo 2003; Population Council 2004; UNAIDS/Measure 2001). These measures were all used in single, separate cultural contexts. The surveys included several aspects of stigma, such as: negative attitudes and blame towards people living with HIV/AIDS (PLHA) due to their diagnosis and their perceived HIV/AIDS risk behavior; perceived risk of HIV infection due to casual contact with PLHA; social distancing from PLHA and groups at higher risk of HIV/AIDS; and endorsement of restrictive policies for PLHA (Boer and Emons 2004; Herek et al. 2002; Kalichman and Simbayi 2003). However, none of these studies analyzed scale items using standard psychometric methods. We compiled items from these six measures identified in the literature and added questions regarding discrimination or enacted stigma toward PLHA and/or their families. In our study, these items were arranged by concept and members of the Project Accept, four-country (South Africa, Tanzania, Thailand, and Zimbabwe) study team provided feedback on the content, structure and meaning of the 82 compiled items. Their input was used to improve questions, remove duplicates and provide an assessment of the face validity of the items; after this process, 50 items comprising the six concepts remained. These questions were revised to read as uniform statements with responses in the form of a 4-point Likert scale ranging from strongly agree (coded as 4) to strongly disagree (coded as 1). Endorsement of stigmatizing views yielded a higher score on the 4-point scale. If the respondent refused to provide an answer for any question, the interviewers coded the response as a refusal. During pilot interviews conducted before launching the field trial, study staff discussed problems with the questions after administering the interviews. Feedback and suggestions for each question were provided and used to judge the utility of each item as well as minor revisions in wording. In addition to the HIV/AIDS-related stigma items, we inquired about basic demographic information and in Thailand, participants were asked whether they personally knew someone who had HIV/AIDS.

Participants

The 50-item questionnaire was field-tested in Zimbabwe and Thailand in 2004 using a common protocol. Interviewer training was conducted at each site to prepare the field team for piloting the stigma measure as well as to evaluate the demographic questions. In Zimbabwe, the questionnaire was translated into Shona and back-translated by an independent language expert. The survey was administered in two settings in Zimbabwe, Chitungwiza (an urban location) and Epworth (a peri-urban location), to

a convenience sample of 244 community residents. In Thailand, the questionnaire was translated into central Thai and reviewed for accuracy by independent reviewers. The questionnaires were administered in two villages in the Chiang Dao district of Chiang Mai Province to a convenience sample of 209 community residents representing six ethnic minority groups and the Thai lowland population.

Data Analysis

All stigma questions that were framed positively were reverse-coded to maintain a consistent interpretation of the final score. Exploratory factor analysis using principal components analysis was conducted, and then evaluated with a varimax rotation using all 50 stigma questions from both sites. The above procedures were then repeated, restricted to the items that were retained from the exploratory analysis. The factor analysis was also performed within each site independently in order to confirm the factor structure. We performed reliability testing using Cronbach's alpha for internal consistency on the resulting factors, as well as item-total correlations and Cronbach's alpha with each item removed for each factor. After the exploratory factor analysis, the mean for each factor was calculated by adding the scores for each construct and dividing by the number of items included in the construct. Differences in mean component scores by research site, gender and age were examined using *t*-tests. Age was dichotomized at the median age (27 years) and comparisons were made both within and between the two countries. In Thailand we also examined the mean scores by whether or not the respondent knew someone who had HIV/AIDS. We used SPSS version 12.0 and Stata version 8.0 to analyze the data.

Twenty-six individuals were missing one item on the first subscale, 13 on the second subscale and 12 on the third. The sample item mean within each site was imputed for respondents missing no more than one item per component subscale. Thirty-two participants were excluded from subsequent analysis because they had more than one item missing on at least one subscale. A total of 421 ($n = 221$ in Zimbabwe and $n = 200$ in Thailand) remaining participants were included in the factor analysis and further psychometric testing.

Results

Demographics

Nearly 60% of the sample of 421 individuals was female (Table 1) with a median age of 27 years among females

Table 1 Gender and age of participants by research site (Zimbabwe and Thailand)

	Zimbabwe (<i>n</i> = 221)		Thailand (<i>n</i> = 200)		All (<i>n</i> = 421)	
	Female	Male	Female	Male	Female	Male
Gender <i>n</i> (%)	138 (62.4)	83 (37.6)	107 (53.5)	93 (46.5)	245 (58.2)	176 (41.8)
Median age in years (IQR)	30 (22.8–38)	27.5 (23–33)	26 (22–30)	25 (21.5–28)	27 (22–32)	26 (22–30)

and 26 years among males. The sample from Zimbabwe had a higher percentage of female respondents (62% compared to 54% in Thailand) who were slightly older than the Thailand sample (median age of 30 years among the females in Zimbabwe compared to 26 years among females in Thailand. The males from both countries were similar in age. In Thailand, 65% of the sample reported knowing someone with HIV/AIDS.

Factor Analysis

A three-factor solution (Table 2) which included factors with eigenvalues greater than 1.0 explained 47% of the total variance using 22 items. The communalities of the items for each subscale were above 0.40 in general with a few exceptions (Table 2). The three-factor solution fit the theoretical conceptualization of stigmatization described

Table 2 Factor loadings, communalities, and eigenvalues from principal components factor analysis with varimax rotation among 421 individuals in Zimbabwe and Thailand

Questionnaire item	1	2	3	<i>h</i> ²
1. People living with HIV/AIDS should be ashamed	.716	-.032	.048	.516
2. People with AIDS should be isolated from other people	.756	-.082	.066	.583
3. People who have HIV/AIDS are cursed	.646	.145	.033	.440
4. A person with HIV/AIDS should be allowed to work with other people (+)	.647	-.031	.207	.463
5. People living with HIV/AIDS deserve to be punished	.568	.043	.300	.414
6. Families of people living with HIV/AIDS should be ashamed	.727	-.033	.166	.516
7. It is reasonable for an employer to fire people who have HIV/AIDS	.607	-.017	.267	.440
8. People with HIV/AIDS are disgusting	.616	.136	.337	.511
9. People who have HIV/AIDS deserve compassion (+)	.485	-.098	.386	.393
10. People with HIV should be allowed to participate fully in the social events in this community (+)	.450	.017	.419	.378
11. People living with HIV/AIDS face neglect from their family	-.192	.705	-.093	.542
12. People living with HIV/AIDS face physical abuse	.081	.604	.033	.372
13. People want to be friends with someone who has HIV/AIDS (+)	.089	.678	-.020	.468
14. People living with HIV/AIDS face ejection from their homes by their families	.011	.630	-.056	.401
15. Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS	.020	.712	-.070	.513
16. People who are suspected of having HIV/AIDS lose respect in the community	.031	.611	-.027	.375
17. People who have HIV/AIDS face verbal abuse	-.017	.655	-.281	.508
18. People living with HIV/AIDS face rejection from their peers	-.048	.662	.026	.442
19. People who have HIV/AIDS should be treated the same as everyone else (+)	.177	-.107	.730	.576
20. People with HIV/AIDS do not deserve any support	.160	-.029	.713	.535
21. People with HIV/AIDS should not have the same freedoms as other people	.271	-.058	.644	.491
22. People living with HIV/AIDS should be treated similarly by health care professionals as people with other illnesses (+)	.288	-.273	.461	.576
Eigenvalues	5.48	3.60	1.21	
Percent of variance explained	24.9	16.4	5.5	
Cronbach's alpha	0.86	0.82	0.71	

by Link and Phelan (2006) and met Thurstone's criteria for a simple factor structure (Thurstone 1947). When the analysis was restricted to each site independently, the factor structure remained very stable in Zimbabwe, with slightly less stability observed in Thailand (data not shown).

First Component: Shame, Blame, and Social Isolation

The first factor consisted of 10 items (Table 2) all with loadings above 0.40, ranging from 0.45 to 0.73. This factor collectively represents the first three components of stigma proposed by Link and Phelan (2006), with items related to labeling, devaluing and isolation of PLHA, but also encompasses items on the shame of persons living with HIV/AIDS, blame for the responsibility for HIV infection on the HIV-positive individual, and positive and negative feelings about PLHA. Finally, the factor incorporates attitudes regarding the isolation of individuals with HIV/AIDS and their families within a larger context, for example, within the community and by employers. The factor had high internal consistency (Cronbach's $\alpha = 0.86$).

Second Component: Perceived Discrimination

The second factor consisted of eight items (Table 2) with high factor loadings, which ranged from 0.60 to 0.71. This factor addresses the manifestations of stigma and the discrimination that community members perceive PLHA face in their communities; this factor corresponds to Link and Phelan's (2006) fourth component, which has also been described elsewhere (Nyblade 2006). Respondents were asked to report on the types of discrimination that they perceive PLHA are forced to deal with in their communities. This factor also had high internal consistency (Cronbach's $\alpha = 0.82$).

Third Component: Equity

The third factor consisted of five items (Table 2) with factor loadings ranging from 0.46 to 0.73 which focuses on the endorsement of views that PLHA should be considered equal members of society as those who are HIV/AIDS-free. The questions focused on the respondent's attitudes regarding restrictive policies, freedoms and whether or not PLHA should receive equal and fair treatment in society. This factor is related to Link and Phelan's (2006) fifth component, which is concerned with the ability of the stigmatized to exercise power in social situations. This component is distinct from the second factor in that it

reflects the respondent's endorsement of restrictions to PLHA that they believe should occur at the community level, while the second component measures *perceptions* of discriminatory actions that PLHA *experience* in their community. The third component also had acceptable internal consistency (Cronbach's $\alpha = 0.71$), although this factor was somewhat less stable than the first two factors. Further research is needed to validate the three-factor structure described above, particularly in the Thai setting.

Reliability and Validity

Item-to-total correlations and alpha coefficients with each item deleted (data not shown) showed good reliability for the first two subscales (>0.70), but somewhat lower reliability for the third subscale (alphas ranged between 0.50 and 0.70 with item deletions). Item to total correlations by site and within the whole sample showed correlations ranging from 0.30–0.60. Again the third subscale had lower reliability as compared to the first and second subscales. Finally, the factors display good divergent validity, given that only one item loaded strongly on two factors (Table 2). We retained this item despite its dual loadings based on our a priori hypothesis.

Mean Scores

The trends in mean subscale scores (Table 3) across the two research sites shows that respondents in Thailand personally endorsed more stigmatizing views, with higher and therefore more stigmatizing attitudes for both the first and third subscales. However, in Zimbabwe, while having significantly lower scores on the first and third subscales, respondents were more likely to endorse statements about discriminatory practices in their communities, showing a higher level of perceived discrimination in the community towards those living with HIV/AIDS in Zimbabwe. Systematic and significant differences were observed between sites when mean subscale scores were examined overall and within sex and age groups (data not shown). However, there were no significant differences by sex or age for any of the three subscales within the individual countries. Only the equity subscale scores were significantly different by age in Thailand, with older participants reporting somewhat more stigma ($t = -2.16$, $df = 198$, $P < .01$) than younger participants. Finally in Thailand, individuals who reported knowing someone who had HIV/AIDS reported significantly less stigmatizing attitudes on the first ($t = -3.16$, $df = 197$, $P < .01$) and second ($t = -2.50$,

Table 3 Stigma score means (standard deviations) by subscale and site (Zimbabwe and Thailand)

Questionnaire item	Zimbabwe (<i>n</i> = 221)	Thailand (<i>n</i> = 200)
Subscale 1: Shame/Blame/Social isolation		
1. People living with HIV/AIDS should be ashamed	2.17 (0.93)	2.66 (0.70)
2. People with AIDS should be isolated from other people	1.80 (0.88)	2.46 (0.77)
3. People who have HIV/AIDS are cursed	1.94 (0.87)	2.10 (0.70)
4. People living with HIV/AIDS deserve to be punished	1.62 (0.70)	2.06 (0.69)
5. A person with HIV/AIDS should be allowed to work with other people (+)	1.76 (0.75)	2.29 (0.70)
6. Families of people living with HIV/AIDS should be ashamed	1.93 (0.85)	2.69 (0.75)
7. It is reasonable for an employer to fire people who have HIV/AIDS	1.76 (0.80)	2.31 (0.64)
8. People with HIV/AIDS are disgusting	2.05 (0.91)	2.44 (0.72)
9. People who have HIV/AIDS deserve compassion (+)	1.66 (0.77)	2.13 (0.68)
10. People with HIV should be allowed to participate fully in the social events in this community (+)	1.80 (0.76)	2.09 (0.62)
Subscale total	1.85 (0.52)	2.32 (0.44) ^a
Subscale 2: Perceived discrimination		
11. People living with HIV/AIDS face neglect from their family	3.24 (0.72)	2.23 (0.68)
12. People living with HIV/AIDS face physical abuse	2.69 (0.92)	2.13 (0.65)
13. People want to be friends with someone who has HIV/AIDS (+)	2.95 (0.85)	2.38 (0.76)
14. People living with HIV/AIDS face ejection from their homes by their families	2.82 (0.90)	2.34 (0.71)
15. Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS	3.21 (0.79)	2.51 (0.75)
16. People who have HIV/AIDS face verbal abuse	3.26 (0.78)	2.45 (0.70)
17. People living with HIV/AIDS face rejection from their peers	3.01 (0.79)	2.49 (0.64)
18. People who are suspected of having HIV/AIDS lose respect in the community	3.00 (0.77)	2.53 (0.62)
Subscale total	3.01 (0.48)	2.38 (0.41) ^b
Subscale 3: Equity		
19. People with HIV should be allowed to participate fully in the social events in this community (+)	1.80 (0.76)	2.09 (0.62)
20. People living with HIV/AIDS should be treated similarly by health care professionals as people with other illnesses (+)	1.47 (0.59)	1.92 (0.66)
21. People who have HIV/AIDS should be treated the same as everyone else (+)	1.67 (0.79)	2.01 (0.60)
22. People with HIV/AIDS do not deserve any support	1.61 (0.82)	2.00 (0.65)
23. People with HIV/AIDS should not have the same freedoms as other people	1.58 (0.72)	2.07 (0.62)
Subscale total	1.62 (0.49)	2.02 (0.39) ^c

(+) Questions with positively framed statements were reverse coded

^a $t = 10.11$, $df = 419$, $P < .01$; ^b $t = -14.34$, $df = 419$, $P < .01$; ^c $t = 9.02$, $df = 419$, $P < .01$

$df = 194$, $P < .01$) subscales, and less stigmatizing, but not significantly lower scores, on the third subscale ($t = -1.53$, $df = 198$, $P > .05$) (data not shown).

Discussion

This paper presents the development of a comprehensive, standardized stigma measure that is applicable across cultures. The psychometric properties of the scale are presented, comparing the results from Thailand and Zimbabwe. This scale measured three factors of HIV/AIDS-related stigma: shame, blame, and social isolation;

perceived discrimination; and equity. In addition, the scale was easy to administer, is short, and is appropriate for use in international research settings. Furthermore, the scale was shown to be reliable across both research sites and for different population segments and the subscales measured three related although distinct domains of stigmatized attitudes held about PLHA.

The reliability of this scale in both Zimbabwe and Thailand shows its utility in the context of two distinct stages of the HIV epidemic. The Thai epidemic is more recent and concentrated, while the epidemic in Zimbabwe is older and generalized. Important country-specific differences in HIV prevalence, access to antiretroviral

treatment and intensity of prevention campaigns may help to explain the differences in stigma and discrimination observed in the current study.

The endorsement of stigmatizing attitudes is consistent within the cultural context and may reflect the complex dynamic of HIV/AIDS-related stigma. The first and third subscales focus on personal beliefs that the respondent holds in relation to PLHA as well as their beliefs regarding the origins of stigmatizing attitudes and discrimination practices within their communities. In Thailand, community respondents are exposed to PLHA less frequently, as today HIV is concentrated in stigmatized groups, including female sex workers (who are frequently illegal immigrants), injection drug users and men who have sex with men. Perhaps because of the marginalization of groups at risk for HIV in Thailand, the general community has more negative attitudes and corresponding higher scores on the first and third subscales, than what is observed in Zimbabwe, where in the context of a generalized epidemic, the likelihood of being personally affected by the HIV/AIDS is more common. In fact, in Thailand those who personally knew someone with HIV/AIDS had less stigmatizing attitudes than those who did not know someone, providing some evidence that personal experience with PLHA decreases stigmatizing attitudes.

The second subscale relates to respondent perceptions about the manifestations of stigmatizing attitudes existing within their community. Specifically, the questions in the second subscale ask the participant to react to statements that reflect the amount of discriminatory practices that occur in their community. In this context, the perceptions in Zimbabwe that PLHA experience greater community-level discrimination than what was reported in Thailand may accurately reflect the more common experience of a high prevalence situation where resources are lacking. The lower perceived discrimination of PLHA in Thailand compared to Zimbabwe could potentially be explained by the more aggressive response in Thailand at the national level in terms of prevention, the existence of VCT in all districts and expanded access to antiretroviral treatment. In Thailand access to antiretroviral treatment is provided universally through a government program, while in Zimbabwe access to treatment and resources in general remain limited to date. Previous research has demonstrated the inverse relationship between access to therapies and HIV/AIDS-related stigma (Castro and Farmer 2005). Access to antiretroviral treatment potentially reduces HIV/AIDS-related stigma in that it makes HIV a treatable, chronic condition, and it improves the health and physical appearance of infected individuals, thereby removing visual cues that trigger fears of death and contagion that may underlie stigma (Furber et al. 2003; WHO 2003).

It is likely that the sample in Zimbabwe is speaking from firsthand knowledge of HIV/AIDS-related stigma while a significant proportion of the respondents in Thailand reported not knowing anyone with HIV/AIDS (35%). In Thailand, the subgroup who knew an individual with HIV/AIDS reported less stigmatizing attitudes and lower perceived discrimination than those who did not know someone, perhaps reflective of personal experience with accessing the support and care that is available for PLHA in Thailand. This may also suggest that in Thailand, the reported attitudes of approximately one-third of the sample are an overestimated projection of what people believe happens to PLHA rather than of firsthand experience. Again, this overestimation may be partially due to the marginalization of individuals who are at greatest risk of HIV in Thai society and the lack of personal experience with the management of HIV/AIDS.

Despite these differences in observed levels of stigma, the scale was found to be reliable in both settings. Additionally, the factor structure was relatively stable when the analysis was conducted in each country separately, providing evidence that the scale is appropriate for cross-cultural evaluations. This scale can be used to describe stigma and discrimination and evaluate stigma reduction programs in multiple cultural contexts as it reliably measures community perceptions of HIV/AIDS-related stigma.

There are several challenges to measuring HIV-related stigma. Stigma is difficult to define and may be manifested in complex ways. There is no clear, established relationship between stigmatizing attitudes and resulting behaviors and discriminatory practices. Further, validating measures of stigma in the field is also difficult.

This study provides some improvements over previous measures of HIV/AIDS-related stigma both in terms of format and content. For example, a likert scale was used instead of dichotomous responses (Kalichman et al. 2005). Additionally, the psychometric scale was developed with factor analysis instead of relying on peer review of scale items (assessing “face validity”). The other innovation was testing this scale in two cultural contexts simultaneously and having both yield similar, reliable results. Finally, the subscales provide measures of stigma from differing perspectives; the first and third subscales estimate the respondent’s personal attitudes regarding HIV/AIDS, while the second subscale measures the respondent’s perceptions regarding the experience of individuals with HIV/AIDS living within his/her community. Use of the three subscales simultaneously allows the researcher to consider stigmatizing attitudes endorsed by the individual separately from the stigma perceived to be experienced by the HIV-positive individuals in their community.

This study had several limitations. The co-layering of stigma (related to social position, sexual orientation, risk

behavior, etc.) is not addressed in our scale (Herek and Capitanio 1999; Parker and Aggleton 2003; Reidpath and Chan 2005). For example in Thailand, ethnic minorities who are HIV-positive may experience dual-stigma due to both their minority and disease status. Although this scale was shown to be statistically reliable, and showed reasonable divergent validity in that most items loaded primarily onto only one factor, construct validity was not further investigated in the current study, but will be addressed by Project Accept. Self-reported measures of stigma are subject to reporting bias since some survey questions are framed around hypothetical scenarios and may provoke socially desirable answers from respondents. The limited scope of the questions administered to this sample in our pilot study prohibited a more in-depth analysis of the concurrent validity of the scale with respect to related constructs.

Further research is needed to validate scales that attempt to measure the dynamic and complex nature of HIV/AIDS-related stigma and discrimination. In addition studies are needed that continue to examine HIV/AIDS-related stigma and discrimination across multiple cultural contexts and to determine whether the factor structure presented here is stable across other diverse research settings in various stages of the HIV epidemic. Data at both the individual and community levels are also needed to further explore the mechanisms that may explain the different level and direction of stigma as measured by the three subscales that was observed in this study in Thailand and Zimbabwe and to further validate the scale in similar samples. Data from the five research sites (Thailand, Zimbabwe, Tanzania, and two sites in South Africa) in the on-going community-based VCT trial (Project Accept) will provide important data speaking to this issue.

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References

- Bellingham, K., & Gillies, P. (1993). Evaluation of an AIDS education programme for young adults. *Journal of Epidemiology and Community Health, 47*, 134–138.
- Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health, 24*, 518–529.
- Boer, H., & Emons, P. A. (2004). Accurate and inaccurate HIV transmission beliefs, stigmatizing and HIV protection motivation in northern Thailand. *AIDS Care, 16*, 167–176.
- Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention, 15*, 49–69.
- Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health, 95*, 53–59.
- Crandall, C. S., & Moriarty, D. (1995). Physical illness stigma and social rejection. *British Journal of Social Psychology, 34*, 67–83.
- Fortenberry, J. D., McFarlane, M., Bleakley, A., Bull, S., Fishbein, M., Grimley, D. M., Malotte, C. K., & Stoner, B. P. (2002). Relationships of stigma and shame to gonorrhea and HIV screening. *American Journal of Public Health, 92*, 378–381.
- Furber, A. S., Hodgson, I. J., Desclaux, A., & Mukasa, D. S. (2003). Barriers to better care for people with AIDS in developing countries. *British Medical Journal, 329*, 1281–1283.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.
- Herek, G. M., & Capitanio, J. P. (1999). AIDS stigma and sexual prejudice. *American Behavioral Scientist, 42*, 1130–1147.
- Herek, G. M., Capitanio, J. P., & Widaman, K. F. (2002). HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *American Journal of Public Health, 92*, 371–377.
- Horizons. (2002). *Addressing HIV/AIDS stigma and discrimination in a workplace program: Emerging findings*. Washington: Population Council.
- Kalichman, S. C., & Simbayi, L. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS Care, 16*, 572–580.
- Kalichman, S. C., & Simbayi, L. C. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections, 79*, 442–447.
- Kalichman, S. C., Simbayi, L. C., Jooste, S., Toefy, Y., Cain, D., Cherry, C., & Kagee, A. (2005). Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS and Behavior, 9*, 135–143.
- Lentine, D., Hersey, J., Iannacchione, V., Laird, G., McClamroch, K., & Thalji, L. (2000). HIV-related knowledge and stigma - United States, 2000. *Morbidity and Mortality Weekly Report (MMWR), 49*, 1062–1064.
- Letamo, G. (2003). Prevalence of, and factors associated with, HIV/AIDS-related stigma and discriminatory attitudes in Botswana. *Journal of Health, Population and Nutrition, 21*, 347–357.
- Lieber, E., Li, L., Wu, Z., Rotheram-Borus, M. J., & Guan, J. (2006). HIV/STD stigmatization fears as health-seeking barriers in China. *AIDS and Behavior, 10*, 463–471.
- Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *Lancet, 367*, 528–529.
- Maman, S., Mbwambo, J. K., Hogan, N. M., Weiss, E., Kilonzo, G. P., & Sweat, M. D. (2003). High rates and positive outcomes of HIV-serostatus disclosure to sexual partners: reasons for cautious optimism from a voluntary counseling and testing clinic in Dar es Salaam, Tanzania. *AIDS and Behavior, 7*, 373–382.
- Newman, C., DuRant, R. H., Ashworth, C. S., & Gaillard, G. (1993). An evaluation of a school-based AIDS/HIV education program for young adolescents. *AIDS Education and Prevention, 5*, 327–339.
- Nyblade, L. C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health and Medicine, 11*, 335–345.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine, 57*, 13–24.
- Population Council. (n.d.) AIDSQuest: The HIV/AIDS Survey Library, *Topic L: Stigma and Discrimination*. Retrieved January 30, 2004, from <http://www.popcouncil.org/horizons/AIDSquest/topics/stigma.html>.
- Reidpath, D. D., & Chan, K. Y. (2005). A method for the quantitative analysis of the layering of stigma. *AIDS Care, 17*, 425–32.

- Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior*, 32, 17–32.
- Thurstone, L. L. (1947) *Multiple-factor analysis*. Chicago: University of Chicago Press.
- UNAIDS/Measure Evaluation Indicator Field Test Group. (2001). The hidden truth: Trying to measure HIV-related stigma. *Measure Evaluation Bulletin*, 2, 13–15.
- USAID. (2005). Working report measuring HIV stigma: Results of a field test in Tanzania. Retrieved June 4, 2007, from <http://www.synergyaids.com/resources.asp?id=5976>.
- Van Brakel, W. H. (2006). Measuring health-related stigma—a literature review. *Psychology, Health and Medicine*, 11, 307–334.
- Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, Health and Medicine*, 11, 277–287.
- World Health Organization (WHO). (2003). Treating 3 million by 2005: Making it happen: The WHO strategy. Retrieved June 5, 2007, from <http://www.who.int/3by5/publications/documents/en/3by5StrategyMakingItHappen.pdf>.