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Psychometric Evaluation of a Cross-Culturally Adapted Felt Stigma Questionnaire Among People Living with HIV in Kenya

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Abstract

Psychometric properties of an 18-item HIV felt stigma questionnaire were evaluated utilizing data collected from a diverse ethnic and socioeconomic group of 370 people living with HIV/AIDS and receiving HIV/AIDS-related health services at an HIV clinic in Kenya. Factor analyses revealed a four factor solution (public attitudes, ostracize, discrimination, personal life disrupted) based on the Scree plot with explained variance of 44% that had Eigen values greater than 1.00. The retained felt stigma items revealed a Cronbach's alpha coefficient of 0.828, while the four factors had coefficient alphas ranging from 0.675 to 0.799. The adapted retained questionnaire was deemed a practical guide for measuring felt stigma in a Kenyan cultural context to necessitate provision of the most effective HIV-related mental health services to individuals living with HIV in Kenya.

Introduction

STIGMA, A DISCREDITING PHENOMENON that is socially constructed,^{1,2} is associated with rejection, shame, or blame, and often directed towards an issue frowned upon (e.g., HIV/AIDS) in the social norms of a given community.³⁻⁶ To that end, HIV-related stigma is deemed an impediment to the effectiveness of HIV prevention strategies in relation to HIV testing, education, disclosure of seropositivity, condom use, and treatment.⁷⁻¹⁵

There are different types of stigma documented in the literature: internalized stigma, anticipated stigma, enacted stigma, experienced stigma, felt stigma, symbolic stigma, instrumental stigma, among others.^{2,16-22} Given these different types of stigma, general stigma is deemed a complex and multi-dimensional construct^{4,20,22} that needs to be addressed and measured with nuance. Particularly, research suggests (1) distinguishing across different types of stigma to effectively comprehend and isolate types of stigma that could potentially influence targeted HIV prevention outcomes^{4,20,23} and (2) utilizing subscales (e.g., depression or anxiety) to ascertain whether the interrelationship across related constructs sup-

ports construct validity.^{4,5,22} In the current study, felt stigma is examined among people living with HIV/AIDS. Due to the influence of past experiences of shame, felt stigma may appear in HIV-positive individuals who are fearful of other people's reactions, afraid of infecting others, unaware of other seropositives within their networks and are newly diagnosed.^{24,25}

Roberts and Miller²⁶ suggest that people living with HIV/AIDS (PLWHA) are likely to internalize stigma, which can adversely impact their emotional well-being and overall quality of life. This is possible if there is a shortage of social support and networks, which reportedly serve as a buffer against HIV-related stigma and provide an avenue for HIV-positive individuals to stay engaged in HIV related health care.^{6,9,27-32} Hence, screening for emotional issues such as depression or anxiety, likely to be exacerbated by HIV-related stigma, could be a regular aspect of HIV-related mental health care maintenance.³³

The extent to which HIV individuals become stigmatized varies between different contexts (e.g., in one context PLWHA may be terminated from employment or in another context family members may ostracize the individual after disclosing HIV seropositivity).⁶ The challenge faced by researchers, therefore, is finding out reasons behind stigmatization in

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different contexts at different periods of time.³⁴ For example, Yebei et al.³⁵ examined felt stigma changes over time in Kenya and extent to which it differs across socio-demographic contexts. Findings revealed that felt stigma differed significantly between gender (male vs. females) and whether HIV-positive individuals resided in the urban or rural regions. Authors concluded that variability within social structures vis-à-vis rural versus urban contexts is likely to influence the extent to which either gender internalizes negative perceptions concerning their serostatus.

Relevant to the current study, to ensure valid and reliable measurement of felt stigma within a Kenyan context, it is critical to adapt a measurement tool cross-culturally to reflect the cultural context. Culture is a mixture of shared beliefs, way of thinking, behaviors, and values associated with group identity and membership.^{36–38} Additionally, culture is the foundation for defining and understanding health in order to develop and implement health strategies relevant to a particular cultural context.^{39–41}

Cross-cultural adaptation not only addresses language (linguistic translation) but cultural adaptation needs in order to prepare a questionnaire for use in another setting, so as to enhance elicitation of candid responses and maintain content validity.^{42,43}

The goal of cross-cultural adaptation is to produce equivalence between the source and target population, given that a myriad of questionnaires are adapted from one country for use in another.⁴⁴ This is critical because a lack of equivalence in questionnaires between source and target limits the comparability of responses across different target groups that can impact the questionnaires validity and reliability.⁴² Cross-cultural adaptation is also necessary even when the language between cultures remains the same because their lifestyles and cultural experiences may differ. A major draw-back in cross-cultural adaptation, however, is a shortage of bilingual translators and the complexity of the adaptation process.^{43–46}

In this article, we present the results of psychometric analyses of a cross-culturally adapted HIV felt stigma questionnaire administered to people living with HIV in an urban city in Kenya. The questionnaire is made up of 18 items that examine underlying feelings of fear of stigmatization by PLWHA. The 18-item questionnaire was adapted from a validated 11-item questionnaire²⁹ developed in the USA. The 11-item questionnaire was an adaptation of a validated stigma questionnaire⁴⁷ and included items informed by HIV stigma literature.^{48–50}

Seven items deemed culturally appropriate were added to the 11-item questionnaire in the current study. These seven items, informed by literature,^{3,51–53} examined the relationship between the cultural context and felt stigma with regard to perceived beliefs and attitudes of family, friends, religious organizations, and healthcare systems towards the PLWHA.

Methods

The study protocols were approved by the Institutional Review Boards at Indiana University-Bloomington and by the Ethics and Scientific Review Committee of the African Medical Research Foundation (AMREF) in Nairobi, Kenya.

Translation and back-translation

The questionnaire was translated from English to the Kenyan national language Swahili, with the assistance of two

native Swahili-speaking bilingual translators. Swahili is a national language and widely spoken by the majority of the population in urban towns in Kenya. The questionnaire then underwent back translation to ensure similarity in language and meaning for both versions. Items were checked for similarities in meaning with the English version and those with similar meanings were retained.

Cross-cultural adaptation

To ensure that the questionnaire was conceptually equivalent and culturally relevant to the targeted sample, a group of four experts (two HIV researchers and two graduate students) who are natives of Kenya, knowledgeable of the Kenyan culture, bilingual and fluent in both English and Swahili, were chosen to review the conceptual, idiomatic, and semantic equivalence⁴³ of the English and Swahili questionnaire. The experts provided the questionnaire's face validity. Changes to some items were proposed and after those changes were made, the questionnaire was reviewed again and deemed culturally appropriate for the target population.

Data collection

Data was collected from 370 participants to examine potential underlying HIV felt stigma and the relationship to HIV prevention strategies such as condom use, medication adherence, and disclosure of serostatus, utilizing a researcher administered survey. Participants were recruited from an HIV voluntary testing and counseling clinic in a resource-limited area in an urban city in Kenya in the year 2011. Targeted participants were HIV positive from diverse ethnic and socioeconomic background and receiving HIV/AIDS-related health services at the HIV clinic.

Willing and eligible participants completed surveys after signing an informed consent form. The survey was anonymous; participants were assigned alphanumeric unique identifiers in order to compare responses on the English and translated Swahili questionnaire without using their real names.

Measures

Demographic and HIV-related characteristics. Items included age, gender, employment status, tribal affiliation, highest education level, and length of time since initial diagnosis.

HIV felt stigma questionnaire. Item responses were on a five-point scale ranging from 1 = "never" to 5 = "always," to assess underlying felt stigma symptoms over a 30-day period. This questionnaire has been utilized in the USA²⁹ and western Kenya^{28,54,55} among individuals attending HIV clinics.

The Patient Health Questionnaire-9 (PHQ-9). Depression was measured, given the documented association with a diagnosis of HIV infection⁵⁶ and to help minimize the complexity of the stigma construct.^{4,57} PHQ-9 is made up of nine items that examine depression symptoms over 2 weeks and summed up on a range of severity between 0–27.^{58,59} Items are on a four-point Likert scale that range from "0-not at all to 3-nearly every day." Higher scores indicate higher levels of depression. PHQ-9 has previously been used among PLWHA in the United States,^{58–61} Kenya^{55,62} and Nigeria⁶³ to examine psychosocial health status.

Data analysis

Data was analyzed utilizing PASW (Predictive Analytics Software) Statistics version 19.0.⁶⁴

Descriptive analyses

Percentages, mean, standard deviation were calculated to describe demographic variables, HIV-related characteristics and HIV felt stigma.

Exploratory factor analyses. A principal factor analysis was conducted to assess the questionnaire's factor structure using a principal factor extraction with Varimax rotation. Number of factors retained was determined by examining Eigenvalues⁶⁵ for each individual factor and the Scree plot.⁶⁶ Items that loaded onto factors needed to have loadings greater than 0.50.

Reliability. Analyses of internal consistency were conducted on the retained items from the felt stigma questionnaire and emerging factors using Cronbach's coefficient alpha.⁶⁷

Construct validity. Bivariate correlations were conducted to determine if there was a relationship between the retained HIV felt stigma questionnaire score, its factors, and depression (a theoretically related variable).

Results

Participant description

The sample comprised 370 participants with a mean age of 37.06 (standard deviation [SD]=8.61) years; 60.4% were female and 39.1% were male. The mean length of time for living with HIV for females was 4.10 (SD=3.76) years, while for males was 3.47 (SD=2.83) years. With regard to socioeconomic status, 48.1% ($n=178$) reported their highest level of education as standard 4–8, the equivalent of the highest elementary American school level, and only 29.7% ($n=110$) were employed, with the majority (19.7%, $n=73$) earning an income of 2000–4000 Kenya Shillings, the equivalent of \$20–\$50 a month. Most of the participants (27.6%, $n=102$) hailed from the *Luhya* ethnic group that hails from western Kenya.

The majority of the participants presented with low levels of felt stigma (males: 41.4%, $n=111$; females: 58.6%, $n=157$) and depression (males: 58.8%, $n=183$; females: 41.2%, $n=128$, $p<0.05$). To determine the levels of stigma and depression, felt stigma and depression scores were recoded into categorical binary response variables (to enable comparison between low and high levels). With regard to felt stigma, sum scores were collapsed, then recoded to reflect two binary categories (1,2): low stigma levels included sum scores lowest through 39=1, while high stigma levels included sum scores of 40 through highest=2. With regard to depression, PHQ-9 sum scores of 0–27 distributed across severity categories, minimal=1, mild=2, moderate=3, moderately severe=4, and severe=5, were collapsed and recoded into two binary categories (1 through 3=0 deemed mild depression and 4 through 5=1 deemed severe depression).

Exploratory factor analyses

Before conducting a principal factor analyses to examine the factor structure of the felt stigma questionnaire, it was

deemed necessary to examine sampling adequacy⁶⁶ via the Kaiser-Meyer-Olkin (KMO). KMO revealed a value of 0.846 with a statistically significant Bartlett's sphericity at 0.000 ($\chi^2=1436.9$, $df=153$, $p=0.000$). The sample was deemed adequate for factor analyses. Results from a principal factor analysis with Varimax rotation revealed a four-factor solution based on the Scree plot. The number of factors retained was determined by examining Eigenvalues.

Four factors, comprising 10 of the 18 items, were extracted, resulting in explained variance of 45% that had Eigen values greater than 1.00. Items that loaded onto the factors had a cut-off point of 0.50 and did not cross-load across the factors (Table 1). Factor one (public attitudes) emerged the strongest, explained the greatest percentage of variance (31.01%), and had three factors load onto it with item-factor correlations ranging from 0.628–0.547. Factor two (ostracize) had a percentage of variance of 6.63% with three item factor loadings ranging from 0.784–0.604. Factor three (discriminate) had a percentage of variance of 4.56% with two item factor loadings ranging from 0.842–0.734. Factor four (personal life disrupted) had two item factor loadings on it ranging from 0.612–0.516 with a percentage variance of 2.88% (Table 1).

Reliability

Cronbach's alpha for the retained felt stigma questionnaire revealed a high internal consistency ($\alpha=0.828$), while the four factors produced alpha coefficients of 0.675–0.799 (Table 2). PHQ-9 Questionnaire also revealed a satisfactory level of internal consistency with an alpha of 0.702.

Construct validity

Pearson correlations were conducted to examine the relationship between the retained HIV felt stigma questionnaire, its factors, and theoretically related depression. Findings revealed a low to moderate significant relationship between depression, HIV felt stigma, and three felt stigma factors. There was a moderate, significant, and positive correlation between depression and overall retained felt stigma tool ($r=0.366$, $n=365$, $p<0.000$). Presence of depression was associated with heightened feelings of stigmatization. Particular to felt stigma factors, depression and factor one—public attitudes—had a moderate, significant, and positive correlation ($r=0.345$, $n=365$, $p<0.000$). Presence of depression was associated with heightened felt stigma related to other people's attitudes towards PLWHA HIV status. There was a low but significantly positive correlation between depression and factor two—ostracize ($r=0.279$, $n=343$, $p<0.000$). Depressive feelings were likely associated with heightened felt stigma related to ostracizing. With regard to depression and factor four—personal life disrupted—there was a moderate, significant, and positive correlation ($r=0.312$, $n=365$, $p<0.000$). Depression was associated with increased feelings of stigmatization related to PLWHA's disruption of their personal life in the workplace and at home.

Discussion

Through cross-cultural adaptation of existing HIV felt stigma questionnaires, HIV prevention interventions in Kenya and similar contexts can have access to culturally sensitive, valid and reliable measurement tools that

TABLE 1. FACTOR STRUCTURE AND LOADINGS OF THE HIV FELT STIGMA QUESTIONNAIRE

Item number on the questionnaire		Factor 1	Factor 2	Factor 3	Factor 4
		Public attitudes	Ostracize	Discriminate	Personal life disrupted
3.	Feared that I would lose my friends if they learned about my having HIV ^a	0.628	0.401	0.003	0.181
8.	Was embarrassed about having HIV ^a	0.589	0.281	0.133	0.203
17.	Felt like people who are important in my life were disappointed by me because of my HIV status ^b	0.547	0.262	0.288	0.115
12.	Felt like disclosing my HIV status would prevent my having a family ^b	0.485	0.100	0.163	0.359
18.	Felt like I could not take my medication as prescribed because I worried about people knowing my HIV status ^b	0.448	-0.038	0.136	0.233
13.	Felt like disclosing my HIV status would interfere with my relationship with my children ^b	0.433	0.228	0.122	0.207
7.	Avoided a situation because I was worried about people knowing I have HIV ^a	0.411	0.114	0.196	0.402
9.	Felt that keeping my HIV status a secret was important ^c	-0.399	-0.054	0.121	0.045
16.	Felt like people were blaming me for acquiring HIV ^b	0.376	0.367	0.315	0.241
4.	Felt like people that I know were treating me differently because of my HIV status ^a	0.138	0.784	0.119	0.240
2.	Felt that people were avoiding me because of my HIV status ^a	0.202	0.653	0.164	0.125
5.	Felt like people looked down on me because I have HIV ^a	0.187	0.604	0.394	0.231
1.	Felt that having HIV was a punishment for things I had done in the past ^a	0.252	0.260	-0.023	0.132
14.	Felt like people were avoiding eating my food because of my HIV status ^b	0.045	0.204	0.842	0.081
15.	Felt like people were avoiding touching me because of my HIV status ^b	0.082	0.110	0.734	0.235
11.	Felt like my working environment has been adversely impacted because of my HIV status ^a	0.060	0.322	0.108	0.612
10.	Felt like my home life has been disrupted because of my HIV status ^a	0.221	0.374	0.113	0.516
6.	Avoided dating because most people don't want a relationship with someone with HIV ^a	0.244	0.117	0.268	0.454

^aOriginal Items from USA questionnaire.

^bNew added items.

adequately measure felt stigma among PLWHA. The current study is unique, given that it is the first study to conduct cross-cultural adaptation of an HIV felt stigma questionnaire in an urban population of PLWHA in Kenya. While cross-cultural adaptation is critical for validity and cultural relevance, Zometa et al.⁵² suggests that "methods must limit the effect of culture and language on the measurement properties of the questionnaire" given the complex nature of the adaptation process.^{45,46}

The current study sought to assess the psychometric properties of a cross-culturally adapted HIV felt stigma questionnaire among people living with HIV in an urban city in Kenya. Study findings suggest that retained questionnaire items are valid and reliable to measure HIV felt stigma in that context. To use these retained items in different contexts, even with a similar target group, it is necessary to adapt them to enhance relevance.

Participants reported low levels of HIV felt stigma that could be attributed to their being recruited from an HIV clinic where they had access to social support groups that may have

minimized any adverse negative impact of felt stigma. There is documented evidence highlighting that social support (friends, family, involvement in community activities, etc) may help to minimize social isolation tendencies that are likely to exacerbate the fear of being stigmatized.^{9,27} However, in this study we cannot ascertain that the social support groups caused low levels of stigma.

Construct validity findings revealed a statistically significant relationship between the overall felt stigma construct, three of its emerging factors, and the theoretically related depression construct. However, the relationship was low to moderate, which may be linked to participants' reported low levels of depression that could potentially have influenced the low levels of HIV felt stigma given that depression is likely to enhance PLWHA's perception of HIV stigma.^{4,56,57} Future research could examine this relationship in a longitudinal study to determine if there would be any variability from the current findings.

Factor analyses revealed four factors containing seven items from the original HIV felt stigma questionnaire¹⁹ and three items from those added to enhance relevance of the

TABLE 2. INTERNAL CONSISTENCY FOR PHQ-9, HIV FELT STIGMA QUESTIONNAIRE WITH RETAINED ITEMS AND EMERGING FACTORS

	Number of items	Coefficient alpha
English questionnaire	10	0.828
Retained items		
Factors		
Public attitudes	3	0.722
Ostracize	3	0.770
Discrimination	2	0.799
Personal life disrupted	2	0.675
PHQ-9 questionnaire	9	0.702

questionnaire to the cultural context in Kenya.^{3,6,38,51,69} The three new items demonstrated moderate to strong item factor loadings (0.547–0.842). This indicates that these new items were strongly related to the stigma construct and reliable in measuring felt stigma in this context.

Of the four factors that emerged, factor three (3) and factor four (4) (see Table 1) only had two items that loaded onto these two factors, respectively. From a statistical perspective, a factor needs a minimum of three items to load onto it in order to retain it. However, in this study, factors three and four were retained because conceptually the items that loaded are critical to understanding stigmatizing and discriminating beliefs and behaviors within an African context. In essence, items from these two factors (fear of touch, fear of eating food prepared by an HIV infected individual, and disruption of work and home environment) revolve around social networks and group perspectives that are critical in determining the identity of an individual and sense of belonging within a cultural context, given that stigma is a socially constructed phenomenon and HIV/AIDS is a socially frowned upon issue.^{1–6,38,39,70}

For example, relevant to food prepared by an HIV person, an HIV stigma study conducted in South Africa by Airhihnenbuwa et al.³ found that “food, for example, represents a form of nurturance that is a cornerstone in the bonding that is established in the family...Beyond the physical ingestion, food becomes an important way to contextualize relations and connectedness in a culture in ways that could inform sustainable intervention.”³ Basically, sharing of food is a cultural practice that is key in enhancing a sense of belonging, connectedness, and identity within an African context vis-à-vis Kenya. Therefore, when an HIV-infected person is concerned about those within his/her group setting avoiding eating food prepared by him/her, such discriminating behavior produces feelings of shame because group connectedness is deemed severed. Thus, the resulting outcome may be avoidance, alienation (e.g., refusing to interact or touch HIV infected individual), lack of trustworthiness, and disruption of home/work life, which may potentially impact the success of HIV prevention strategies such as condom use, medication adherence, or disclosure of serostatus.^{3,38,39,70}

Overall, the emerging four dimensions may provide pertinent information for HIV interventions and clinics regarding the multidimensionality of stigma, and the need to focus on each different dimension at a time to adequately address HIV felt stigma among PLWHA.

Reliability analyses of the felt stigma questionnaire and its factors revealed high coefficient alphas, indicating a high in-

ternal consistency. High reliability scores are consistent with other studies assessing psychometric assessment of HIV stigma questionnaires.^{4,5,51,53} Future studies could examine if there would be changes across time in the same community.

In summary, compared to other HIV stigma questionnaires,^{4,47,71} this study's retained HIV felt stigma questionnaire is unique. First, it addresses different dimensions of stigma, whereas other questionnaires examine HIV stigma in general albeit its multidimensionality that could potentially be measuring different aspects of stigma.^{4,20,21,23} Examining HIV stigma in general may present challenges in determining which dimensions could be influencing the targeted behavior(s). Second, the retained questionnaire has items that focus on the relationship between PLWHA and his/her cultural context in influencing feelings of stigma that could impact uptake of HIV prevention behaviors. Such items are necessary, given that research suggests the importance of comprehending cultural contexts where stigmatizing behavior such as blame, ostracizing, or fear is exhibited against PLWHA.^{3,51}

While the intention of the researcher is not to generalize the findings to all individuals living with HIV, the findings can speak to the importance of having a cross-culturally adapted measurement tool that can enhance: (1) equivalence of questionnaires between the source and target so as to compare responses across groups in different contexts and maintain validity and reliability; (2) the likelihood of eliciting candid HIV felt stigma responses from respondents within a particular cultural context; and (3) HIV health care system based on candid responses from PLWHA in order to provide access to efficient HIV care in resource-limited settings in Kenya.

Relevant to the HIV health care system, it is also critical to examine HIV stigma among health care providers. In a fragmented health care system such as those found in developing countries like Kenya, health care workers may be overworked, lack critical training in stigma and mental health issues, are underpaid, are looked down upon for caring for HIV infected individuals.³ Hence, PLWHA may encounter stigmatizing beliefs and behaviors within a health care setting. To that end, within such settings, it is imperative to train health care workers on the importance of enhancing compassionate care, helpful behaviors, increased use of condom use, and confidentiality and sensitivity of PLWHA serostatus.^{72,73} Addressing such challenges can enhance adequate measurement of felt stigma within a clinic setting given that stigma may have an impact on HIV treatment strategies.

Limitations

The study is not without limitations. First, findings are only relevant to PLWHA attending an HIV clinic and have potentially participated in a social support group. Second, there is likelihood of self-selection bias whereby only participants who agreed to participate in the study were recruited. Third, this questionnaire only measured HIV *felt stigma* and may not be suitable to measure general stigma given the complexity and multidimensionality of the stigma construct. Finally, since the questionnaire was researcher administered, given the variability in educational levels whereby majority of the participants revealed their highest level of education as standard 4–8 (the equivalent of the highest elementary American school level), the psychometric properties of the questionnaire could have been impacted.

The findings of the current study support documented evidence that considers stigma in general as a socially constructed phenomenon capable of negatively impacting shared values, beliefs, or norms. Therefore, HIV interventions and clinics can focus on developing and promoting HIV education via social marketing, targeting the public to desensitize them, and minimize HIV felt stigma on PLWHA.

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Author Disclosure Statement

No competing financial interests exist.

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