Development of Parallel Scales to Measure HIV-Related Stigma

Maretha J. Visser, Trace Kershaw, Jennifer D. Makin and

Brian W. C. Forsyth

1. Department of Psychology, University of Pretoria, Brooklyn, Pretoria, 0002, South   Africa
2. School of Public Health, Yale University, New Haven, CT, USA
3. Department of Obstetrics and Gynaecology, University of Pretoria/Medical Research Unit for Maternal and Infant Health Care Strategies, Kalafong Hospital, Pretoria, South Africa
4. Department of Pediatrics, Yale University School of Medicine, New Haven, CT, USA

Maretha J. Visser (Corresponding author)
Email: maretha.visser@up.ac.za

Trace Kershaw
Email: Trace.Kershaw@yale.edu

Jennifer D. Makin
Email: jmakin@medic.up.ac.za

Brian W. C. Forsyth
Email: brian.forsyth@yale.edu

Abstract

HIV-related stigma is a multidimensional concept which has pervasive effects on the lives of HIV-infected people as well as serious consequences for the management of HIV/AIDS. In this research three parallel stigma scales were developed to assess personal views of stigma, stigma attributed to others, and internalised stigma experienced by HIV-infected individuals. The stigma scales were administered in two samples: a community sample of 1,077 respondents and 317 HIV-infected pregnant women recruited at clinics from the same community in Tshwane (South Africa). A two-factor structure referring to moral judgment and interpersonal distancing was confirmed across scales and sample groups. The internal consistency of the scales was acceptable and evidence of validity is reported. Parallel scales to assess and compare different perspectives of stigma provide opportunities for research aimed at understanding stigma, assessing the consequences or evaluating possible interventions aimed at reducing stigma.

Keywords: HIV-related stigma - Stigma scales - Quantitative measurement - African context

Introduction

Since HIV/AIDS first appeared in the 1980s, it has been associated with fear, stigmatisation, and discrimination (Parker and Aggleton _2003_). There is now extensive literature reporting on the substantial and pervasive effects of HIV/AIDS-related stigma on the lives of people living with HIV and the ways in which stigma may be contributing to further expansion of the AIDS epidemic (Aggleton and Parker _2002_; Bond et al. _2002_; Campbell et al. _2005_; Collymore

2002; Medley et al. *2004*; M. D. Mokhoka 2000, unpublished dissertation; Skinner and Mfecane *2004*; Tanzania Stigma-Indicators Field Test Group *2005*). The literature is replete with examples of HIV-infected individuals experiencing discrimination, rejection, abandonment, emotional, or physical abuse or loss of economic support, and it has been reported that in some African communities, people appear to be more fearful of the social consequences of AIDS than of the disease itself (Lie and Biswalo *1994*). Daniel and Parker (cited in Aggleton *2000*) describe stigmatisation as a kind of 'social death' in which individuals no longer feel part of society and cannot access the services and support they need. Stigma and the secrecy that accompanies HIV/AIDS may also affect decisions about HIV testing and accessing treatment and are therefore important obstacles to reducing further spread of the infection within communities (Aggleton *2000*; Bond et al. *2002*; Brown et al. *2001*; Malcolm et al. *1998*; Parker et al. *2002*).

Stigma can be described as a social construction of deviation from an ideal or expectation, contributing to a powerful discrediting social label that reduces the way individuals see themselves and are viewed by others (Parker and Aggleton *2003*). The attribute is not inherently deviant, but the deviance derives from culturally embedded meanings in the context of a particular historic period and cultural context. Deacon et al. (*2005*) integrated various definitions to describe stigma as a social process that results in differentiating those with the disease in negative social terms and projecting the risk of contracting the disease onto others.

Something that is often ignored in the literature, however, is that this complex phenomenon is perceived and experienced differently because of the different perspectives of the infected (a subjective experience) and the non-infected (an outsider perspective). In the present research, we compare these perspectives of stigma to gain an understanding of the complex nature of stigma. We use the term *personal stigma* to refer to the personal beliefs and feelings that individuals hold toward someone with HIV and *attributed stigma* to the attitudes that individuals attribute to others within a group or community. This is a generalised perception of how people in a community feel and respond toward those with HIV/AIDS (Green *1995*). *Internalised stigma* refers to the stigma felt by someone living with HIV as a response to stigma in the community. Stigmatised persons often accept some of the negative social judgements that label them and disqualify them from equal participation. They therefore regularly discredit themselves and accept that they deserve to be treated unequally and expect to be stigmatised further. This can be psychologically damaging for the infected person, since high levels of internalised stigma may be associated with lower levels of self-esteem and depression (Berger et al. *2001*; Goffman *1963*; Santana and Donay *2000*). Internalised, or self-stigma, can also manifest as self-hatred, self-isolation, shame and fear of further stigmatisation resulting in avoidance of situations that may lead to discrimination (Alonzo and Reynolds *1995*; Emlet *2006*; Goffman *1963*).

Theoretically these perspectives on stigma are interrelated. Various processes are involved in the development of stigmatising attitudes within a community. The personal stigma of members of a community is most often manifested by discriminatory statements or actions towards people with HIV. An individual's attitudes, however, can be modified by the extent to which stigmatising attitudes are attributed to others within the community. If stigmatising attitudes are considered pervasive within a community then theoretically this allows the individual more latitude to condone such behaviour. For people living with HIV, direct or indirect experiences or even their anticipation of stigmatisation can contribute, amongst other factors, to their sense of being stigmatised. The way stigmatised people respond to stigma by either conforming to it (self-stigmatisation) or resisting it, can affect the impact of stigma in a community, irrespective of the actual level of enacted stigma or discrimination (Deacon et al. *2005*). High levels of internalised stigma reduce the incentives to challenge stigmatisation which has negative consequences for both the individual and public health programmes.

To understand the complexity of stigma in a specific community it is first necessary to be able to measure the beliefs and attitudes that relate to stigma within a community, both among community members as well as those who are HIV-infected. Scales measuring the different perspectives on stigma will allow comparisons between the personal attitudes of people within

a community (personal stigma) and the level of stigmatisation that is attributed to them (attributed stigma). It is not known how the HIV-infected individual's feeling of being stigmatised (internalised stigma) compares to the attitudes that surround them in their communities (personal stigma) and to what extent they attribute stigmatising attitudes to others in their community (attributed stigma). The ability to measure and compare these different perspectives of stigma could provide important opportunities for conducting research aimed at understanding stigma, assessing its consequences, or evaluating possible interventions to reduce stigma. For example, having parallel scales would allow examination of the extent to which such changes as the introduction of routine HIV-testing in a community might affect stigma and to what extent the different perspectives on stigma are modified. Parallel scales might also be useful in assessing the relative effectiveness of interventions aimed at decreasing stigma either at the individual level for those who are HIV-infected or at the community level.

Existing instruments, however, do not allow for a direct comparison of all three perspectives on stigma. Researchers have tended to either examine the internalised stigma experienced by HIV-infected individuals (Berger et al. _2001_; Emlet _2006_; Wright et al. _2007_) or have reported on stigmatising attitudes held by people within communities (Boer and Emons _2004_; Brown _2004_; Herek et al. _2002_; Kalichman et al. _2005_; Letamo _2003_; Pulerwitz et al. _2004_). There have been some attempts to compare and contrast different perceptions of stigma. The instruments developed by Westbrook and Bauman (_1996_), on which the scales in this study are based, examined both internalised and attributed stigma. Clark et al. (_2003_) compared attributed stigma among HIV-infected and non-infected women. The research of the Tanzania Stigma-Indicators Field Test Group (_2005_) explores personal stigma of community members and internalised stigma of HIV-infected individuals. To our knowledge there have been no attempts to compare all three different perceptions of stigma within one community.

The purpose of this research was therefore twofold: first, to develop three equivalent stigma scales that could assess the different perspectives of HIV-related stigma—personal attitudes held by individuals; stigma attributed to others and the internalised stigma felt by those living with HIV—and second, to compare the level of stigma experienced by HIV-infected persons with levels of stigma existing in their community.

Stigma is time- and context-specific, and therefore an instrument designed to assess stigma needs to address the specific nature of people's reaction to HIV in the local context (Herek et al. _2002_; Malcolm et al. _1998_). As in the research of Brown (_2004_) and Kalichman et al. (_2005_) this research was conducted in South Africa and the measure was developed for the African context. Prior research conducted in Tanzania, Ethiopia and Zambia identified two essential core elements of HIV-related stigma in Africa: first, the continued fear of casual transmission based on a lack of in-depth knowledge about HIV which results in people keeping a social distance from those with HIV and second, a moral dimension that creates stigma through judgement, shame and blame (Nyblade and MacQuarrie _2006_; Nyblade et al. _2003_; Ogden and Nyblade _2005_; Tanzania Stigma-Indicators Field Test Group _2005_). Stigma in an African context is built on a series of shared beliefs that HIV is associated with immoral behaviour, religious punishment and lack of adherence to cultural norms, resulting in blame for contracting the disease (Aggleton and Chase _2001_; Deacon et al. _2005_; Niehaus _2006_; Nyblade et al. _2003_). In constructing parallel stigma scales to compare different perspectives of stigma, we intended to include both of these core elements of stigma as they applied to the local context.

Methods

The research was conducted in three phases: (1) construction of the scales through adaptation of earlier scales, addition of items appropriate for the local context, and formulation of items in three parallel scales (personal stigma of community members, stigma attributed to others and internalised stigma of those who are HIV-infected); (2) administration of the scales in two samples: a community sample and a sample of HIV-infected women from the same

community and (3) performance of analyses to finalise the scales and demonstrate their psychometric properties and compare the results obtained with the different scales.

Construction of the Scales

The two equivalent stigma scales of Westbrook and Bauman (_1996_) measuring internalised and attributed stigma were adapted for the African context. Two focus group discussions were held, one with 15 women who take care of young people with HIV and one with 12 health care workers. Through a thematic analysis (Miles and Huberman _1994_) we gained understanding of the perceptions of HIV within the community in order to adapt the stigma scales to be culturally appropriate. Eleven of the 24 original items were included, two new items were identified from the focus group discussions (e.g. using public transport and drinking from a communal tap) and four items were adapted for the local context, by using less complex language and context-appropriate concepts. The scales consisted of 17 parallel items, framed as positive and negative statements.

By changing the sentence structure and wording of each item an additional parallel scale was developed to assess an individual's level of stigmatising attitudes, here referred to as personal stigma. This resulted in three parallel scales with almost identical statements to assess three different perspectives of HIV-related stigma. The wording of the original items in all three scales is provided in Table _1_.

Table 1 Items used in three parallel stigma scales

Personal stigma for community members	Attributed stigma (perception how most people feel)	Internalised stigma of HIV positive women
1. I think getting HIV is a punishment for bad behaviour	Most people think that getting HIV is a punishment for bad behaviour	Getting HIV is a punishment for bad behaviour
2. If I was in public or private transport, I would not like to sit next to someone with HIV	Most people would not sit next to someone with HIV in public or private transport	If I was in public or private transport and someone knew I had HIV they would not sit next to me
3. Having HIV is just a matter of bad luck	Most people think that having HIV is just a matter of bad luck	I think my getting HIV was just a matter of bad luck
4. I think less of someone because they have HIV	Most people think less of someone because they have HIV	I think less of myself because I have HIV
5. I would not like someone with HIV to be living next door	Most people would not like someone with HIV to be living next door	My neighbours would not like me living next door if they knew I had HIV
6. I would not like to be friends with someone with HIV	Most people would reject the friendship of someone with HIV	I would understand if people rejected my friendship because I am HIV+
7. It is safe for a person with HIV to look after somebody else's children (reverse)	Most people feel that it is safe for a person with HIV to look after somebody else's children	I feel it is completely safe for me to handle other people's children (reverse)
8. People with HIV can teach us a lot about life (reverse)	Most people think that people with HIV can teach us a lot about life (reverse)	I have a lot to teach people about life through having HIV (reverse)
9. I would not date a person if I know that he/she has HIV	Most people would not date a person if they know that he/she has HIV	Because of my HIV people would not date me
10. I feel afraid to be around people with HIV	Most people are afraid to be around people with HIV	People are right to be afraid of me because I have HIV

11. People with HIV/AIDS have only themselves to blame	Most people feel that if you have HIV it is your own fault	I feel that it is my fault that I got HIV
12. People with HIV deserve as much respect as anyone else (reverse)	Most people feel that people with HIV deserve as much respect as anyone else (reverse)	Although I have HIV I am a person who deserves as much respect as anyone else
13. I would not employ someone with HIV	Most employers would not hire someone with HIV to work for them	Most employers would not employ me because I am HIV+
14. I would not drink from a tap if a person with HIV had just drunk from it	Most people would not drink from a tap if a person with HIV had just drunk from it	If I drank from a tap and people knew I had HIV they would not drink from the same tap
15. If you have HIV you must have done something wrong to deserve it	Most people believe that if you have HIV you must have done something wrong to deserve it	I must have done something wrong to deserve getting HIV
16. People with HIV should be ashamed of themselves	Most people believe that someone with HIV should be ashamed of themselves	I feel ashamed that I have HIV
17. I feel uncomfortable around people with HIV	Most people feel uncomfortable around people with HIV	When people know I have HIV I feel uncomfortable around them

Initially the scales completed by HIV-infected individuals (internalised and attributed) had four-point responses for each item (strongly agree, agree, disagree and strongly disagree) but an examination of responses suggested that respondents tended to use only two responses (either agree or disagree), thus only two responses were provided in the scales included in the community survey and all analyses for both samples were conducted using only two responses. All questionnaires were developed in English and translated into Sepedi, Setswana and Isizulu, the most common African languages spoken in the area.

Administration of the Scales in Two Samples

The scales were administered in two different samples, a large community sample and a smaller sample of HIV-infected women. The personal and attributed stigma scales were included in the interviews administered to the community sample and the internalised and attributed scales were included in the interviews conducted with the HIV-infected women. In both samples the scale assessing the individual's perception of stigma was presented before the attributed stigma scale.

Participants in Community Sample

This sample included 1,077 participants in two urban townships in Tshwane (also known as Pretoria): Atteridgeville and Mamelodi. These two townships are part of a historically disadvantaged area and are home to a mainly black, low to middle socio-economic class urban population, representative of a large portion of the urban population in South Africa. A proportional sample was obtained using a stratification technique to approximate the age and gender distribution of the population in each community based on 2001 census data. Participants were recruited from key areas in the community such as a clinic, shopping centres, community centres, taxi waiting areas and the areas around street vendors, purposely selected because they represent public access sites. A systematic sampling method was used (Struwig and Stead 2001) in which interviewers approached every third passer-by and requested an interview. Consenting adults aged older than 18 years were eligible to participate in the survey.

Participants in HIV-Infected Sample

A sample of 317 HIV-infected women, enrolled in the Serithi project which is a prospective longitudinal study of women diagnosed as HIV positive in pregnancy, completed the stigma scales. These women were recruited from four antenatal clinics in Tshwane, two in each of the two communities described above. Trained HIV counsellors, employed by the clinics, referred recently diagnosed HIV positive women to the research project. The data used for the present study were obtained in the baseline interviews, which for the majority of women (74%) were conducted within 4 weeks of receiving the result of the HIV test. Interviews were conducted in the subject's preferred language, either Sepedi, Setswana or Isizulu. Characteristics of each of the samples are shown in Table 2.

Table 2 Socio-demographic characteristics of the two study populations

		Community sample (N = 1,077)	HIV+ women sample (N = 317
Gender	Male (%)	54	-
	Female (%)	46	100
Age	18–25 years (%)	31	14
	26–50 years (%)	55	54
	>51 years (%)	46	0
			Range 16–42 years
			Mean age
		Community sample (N = 1,077)	HIV+ women sample (N = 317)
Marital status			26.5 years
	Married (%)	27	21
	Single with partner (%)	50	68
	Single without partner (%)	23	11
Highest level of education	No schooling (%)	3	2
	Primary school (%)	10	9
	Secondary school (%)	63	75
	Tertiary (%)	24	14
Employment	Employed (%)	33	24
	Unemployed (%)	67	76
Knows someone who is HIV+	Acquaintance (%)	60	26
	Know someone, any category (%)	73	36
Were HIV-tested (%)		40	100

Other Measures Included to Examine Validity of the Scales

HIV-Knowledge Scale

It has consistently been found that a lack of HIV-related knowledge and high levels of misconceptions correlate with fear of casual transmission and high levels of HIV-related stigma (Herek et al. *2002*; Ogden and Nyblade *2005*; Sihlangu *2000*). A knowledge scale with 14 items relating to the transmission and presentation of HIV, adapted from the WHO Research Package (WHO *1990*), was used in this research. Both the community and HIV-infected sample completed the questionnaire. All correct answers were counted into a scale score ranging from 0 to 14. The reliability coefficient of the scale was 0.66 for the community sample and 0.64 for the sample of HIV-infected women, which can be considered as satisfactory for a scale assessing various aspects of HIV knowledge.

Knowing Someone with HIV

Previous research has shown that people who know someone with HIV tend to be less stigmatising (Herek and Capitanio *1997*). Respondents in the community sample were asked whether they knew someone in their family or a close friend with HIV.

The following scales were completed by HIV positive women and were used to assess the validity of the internalised stigma scale.

Self-Esteem

The self-esteem of HIV positive women was assessed using the Rosenberg Self-Esteem scale (*1965*) which measures the extent to which one values and feels content with oneself on a four-point scale (10 items, $\alpha = 0.75$).

Depression

The Centre for Epidemiologic Studies Depression scale (Radloff *1977*) consists of 20 items designed to measure depressive symptoms experienced during the previous week. For the purposes of this study, the somatic items which could have been related to symptoms attributable to pregnancy or HIV status were removed (15 items, $\alpha = 0.88$).

Social Support

The Multidimensional Social Support Inventory of Bauman and Weiss (*1995*) was adapted to assess the individual's perceived practical, emotional and affirmational support integrated into a positive support scale (9 items, $\alpha = 0.87$).

Data Analyses

The analyses to finalise the scales and demonstrate their psychometric properties were conducted in the following order.

Item-total correlations were conducted to identify "poor" items. For these analyses we first examined the items included in the personal and attributed stigma scales completed by the community sample. Items with low correlations with the total score (using $r < 0.3$) were iteratively removed from the scale. After each iteration, item-totals were recalculated and this process was continued until all items had a total correlation greater than 0.3. The item-total correlations were then repeated for the two scales completed by the sample of HIV positive women to assess whether similar results were obtained in this second sample.

A factor analysis was conducted on a "derivation sample" to identify different factors present in the scales. The community sample was randomly divided into two samples—a derivation sample and a confirmatory sample—in order to be able to develop and test the factor

structure of the stigma scales using similar samples. A 70/30 per cent split was used in order to maximise the number of individuals in the derivation sample. A random number generator was used to divide the sample into the two groups applying the 70/30 per cent split within each of the sampling criteria (e.g. age and gender) to ensure equal distribution of the primary sampling characteristics. The final sample size of the derivation sample was 768 and the confirmatory sample was 309. There were no systematic differences between the derivation and confirmatory sample on any key demographic variable or on the total personal or attributed stigma scores.

Exploratory factor analysis for the personal scale was conducted on the derivation sample using principal components analysis with oblimin rotation to account for possible correlation among factors. Scree plots were used to identify a factor solution. Items that had a factor loading of >0.40 and did not load on multiple factors were considered part of a factor. Items that did not have a factor loading of 0.4 or greater or items that had a factor loading of >0.4 on multiple factors were not included on any factor.

Internal consistency analyses were conducted on all scales and subscales across all samples to determine reliability of the chosen items across all scales.

Confirmatory factor analyses were then conducted with the remaining scales in each sample. These include the attributed stigma scale in the community derivation sample (this demonstrates that the attributed stigma scale has the same factor structure as the personal stigma scale within the derivation sample), the personal and attributed stigma scales in the community confirmatory sample (this demonstrates that the factor structure cross-validates across an independent sample of the same population), and the internalised and attributed stigma scales in the pregnant HIV positive sample (this demonstrates that the factor structure cross-validates across an independent sample of a different population). For each sample three things were assessed: the overall fit of the factor solution obtained from the exploratory analysis; a comparison of fit of a one-factor solution with the solution obtained from the exploratory factor analysis and the factor loadings.

For the overall fit, the Root Means Square of Approximation (RMSEA) was used. The RMSEA is a highly recommended fit index (Loehlin *1987*; Jaccard and Wan *1998*) that tests goodness of fit (i.e. high scores indicate a worse fit). Values range from 0 to 1 with values of 0 indicating perfect fit, values less than 0.08 indicating good fit, values of 0.08 to 0.1 suggesting acceptable fit and 0.1 or greater indicating unacceptable fit (Browne and Cudeck *1993*). Differences between the one- and two-factor models were explored using a Chi-square difference test, which assesses the differences in goodness-of-fit between two nested models. A significant difference indicates that the model with additional parameters (e.g., two-factor model) has a better fit than the alternative model (e.g. one-factor model). The confirmatory factor analysis was conducted using structural equation modelling with unweighted least squares to account for the dichotomous nature of the indicator variables.

Validity was assessed by conducting correlations of the subscales to theoretically related variables (e.g. HIV knowledge, self-esteem, depression, social support) and by comparing known groups that should theoretically differ with regard to stigma (e.g. those who did and did not know someone with HIV). All analyses were conducted using M-Plus[®] and SPSS Version 14.0[®].

Finally, the results of the stigma scores for the community and HIV positive samples were compared to illustrate similarities and differences in perceptions of HIV-related stigma. We specifically examined the differences between the internalised stigma felt by HIV positive women, the level of stigma they attribute to others, and the personal stigma expressed by members of their community using *t*-tests.

Results
Development of Stigma Scales

Item Analysis

An item-analysis of the stigma scales was done to determine which items to include in the scales. This was first done for both scales ("personal" and "attributed") for the entire community sample (N = 1,077) and then was repeated for the two scales ("internalised" and "attributed") completed by the sample of HIV positive women (N = 317). Item 3 was removed prior to empirical analyses because participants and research staff reported numerous problems in the interpretation and understanding of the item. Three of the items (items 7, 8 and 12) had item-total correlations less than 0.30 in each of the two scales completed by both samples. A fourth item (item 9) had an item-total correlation less than 0.30 in the personal stigma scale in the community sample (r = 0.22) and also in the attributed stigma scale (r = 0.26) in the HIV positive sample. Thus, it was decided to eliminate all four of these items from the final instrument. An additional two items had item-total correlations less than 0.30 in the scales completed by the HIV positive women, despite satisfactory item-total correlations in the scales completed by the larger community sample. These included item 17 (feel uncomfortable when people know status) in the internalised stigma scale (r = 0.25) and item 2 (public transport) (r = 0.20) in the attributed stigma scale. Because we wished to maintain parallel scales with an adequate number of items, and these two items had satisfactory item-total correlations in three of the four administered scales, it was decided to retain these items in the scales.

Factor Analysis

Exploratory factor analysis was conducted on the 12 remaining items from the personal stigma scale for the 768 respondents defined as part of the derivation sample. Scree plots and magnitude and distance of eigenvalues suggested a two-factor solution. The structure matrix was used to interpret factors (factor loadings are presented in Table 3). The factors were identified as "Blame and Judgement" and "Interpersonal Distancing". Items 1, 10, 11, 15, 16 and 17 loaded on the Blame and Judgement factor and items 2, 4, 5, 6, 13 and 14 loaded on the Interpersonal Distancing factor. All items loaded greater than 0.4 on one of the two factors, and no items double-loaded.

Table 3 Exploratory factor analysis loadings for personal stigma scale for the derivation community sample

Question	Blame and judgement	Interpersonal distancing
16. People with HIV should be ashamed of themselves	0.71	
15. Person with HIV must have done something wrong to deserve it	0.69	
11. People with HIV have themselves to blame	0.61	
17. I feel uncomfortable around people with HIV	0.55	
1. Getting HIV is a punishment for bad behaviour	0.54	
10. I feel afraid to be around people with HIV	0.50	
6. I would not like to be friends with someone with HIV		0.80
5. I would not like someone with HIV to be living next door		0.76

2. I would not like to sit next to someone with HIV in public transport		0.66
14. I would not drink from a tap if a person with HIV had just drunk from it		0.56
4. I think less of someone because they have HIV		0.47
13. I would not employ someone with HIV		0.42

Note: For ease of interpretation, only loadings greater than 0.4 are presented

Internal Consistency

Analyses were then conducted to obtain the internal consistency for all scales and for all samples. The internal consistency for the total scores is acceptable in all samples ranging from 0.70 for internalised stigma to 0.87 for attributed stigma in the community sample (see Table 4). In general, the internal consistency is lower for the HIV positive sample and tends to be similar between the two factors: "Blame and Judgment" and "Interpersonal Distancing".

Table 4 Internal consistency for total and subscales of the different scales in all samples

	Community derivation Sample ($N = 768$)		Community confirmatory sample ($N = 309$)		HIV+ pregnant women sample ($N = 317$)	
	Personal	Attributed to others	Personal	Attributed to others	Internalised	Attributed to others
Total	0.75	0.87	0.73	0.87	0.70	0.77
Blame and judgement	0.69	0.80	0.63	0.77	0.61	0.71
Interpersonal distancing	0.69	0.79	0.67	0.81	0.61	0.65

Confirmatory Factor Analyses

Confirmatory factor analyses were conducted on the attributed stigma scale for the community derivation sample, and the two separate scales for each of the community confirmatory sample ($n = 309$), and the HIV positive sample ($n = 317$). Results showed that the two-factor model fit well, RMSEA = 0.075 and the Chi-square difference test between the one- and two-factor solution was significant (χ^2 difference (1) = 30.15, $P < 0.05$), indicating the two-factor solution had significantly better fit than the one-factor solution. For the community confirmatory sample, the two-factor solution had good fit for both the personal stigma scale (RMSEA = 0.067) and the attributed stigma scale (RMSEA = 0.057). In addition, the two-factor solution had significantly better solution than the one-factor solution for both the personal stigma scale (χ^2 difference (1) = 43.31, $P < 0.05$) and the attributed stigma scale (χ^2 difference (1) = 16.19, $P < 0.05$). Finally, for the HIV positive sample, the model showed adequate fit for both the internalised stigma scale (RMSEA = 0.097) and the attributed stigma scale (RMSEA = 0.098). In addition, the two-factor solution had significantly better solution than the one-factor solution for both the internalised stigma scale (χ^2 difference (1) = 25.77, $P < 0.05$) and the attributed stigma scale (χ^2 difference (1) = 11.97, $P < 0.05$). As can be seen in Table 5, however, the factor loadings obtained for the two factors were substantially lower in both scales used in the HIV positive sample than was true in the community sample.

Table 5 Factor loadings for the confirmatory factor analysis for personal and attributed stigma scales for the community and HIV+ samples

	Community derivation sample	Community confirmatory sample		HIV+ pregnant women sample	
	Stigma attributed to others	Personal stigma	Stigma attributed to others	Personal stigma	Stigma attributed to others
Blame and judgement					
1. Getting HIV is a punishment for bad behaviour	0.64	0.39	0.53	0.45	0.33
10. I feel afraid to be around people with HIV	0.87	0.74	0.86	0.31	0.45
11. People with HIV have only themselves to blame	0.75	0.52	0.81	0.31	0.45
15. If you have HIV you must have done something wrong to deserve it	0.79	0.55	0.73	0.47	0.42
16. People with HIV should be ashamed of themselves	0.76	0.70	0.76	0.49	0.38
17. I feel uncomfortable around people with HIV	0.82	0.79	0.81	0.27	0.43
Interpersonal distancing					
2. If I was in public or private transport I would not like to sit next to someone with HIV	0.72	0.64	0.89	0.46	0.33
4. I think less of someone because they have HIV	0.84	0.68	0.75	0.24	0.34
5. I would not like someone with HIV to be living next door	0.76	0.90	0.74	0.52	0.45
6. I would not like to be friends with someone with HIV	0.82	0.89	0.90	0.30	0.39
13. I would not employ someone with HIV	0.72	0.62	0.67	0.45	0.39
14. I would not drink from a tap if person with HIV had just drunk from it	0.74	0.64	0.75	0.36	0.43

Validation

To provide evidence supporting the validity of the scales, we conducted analyses to determine whether the scales identified those who know someone with HIV infection as being less stigmatising than others who did not know anyone with HIV, something that has been found to be true in other research (Herek and Capitanio *1997*). Results showed that respondents in the community sample who knew someone with HIV/AIDS had significantly lower total personal stigma scores than respondents who did not know anyone with HIV (mean score 2.49 vs 3.11, $t = 4.05$, $P < 0.001$). This difference remained significant for both of the subscales: people who know someone with HIV had lower scores for blame and judgement (1.51 vs 1.92, $t = 4.13$, $P < 0.001$), and also interpersonal distancing (0.98 vs 1.20, $t = 2.60$, $P < 0.05$) than those who did not know anyone with HIV. Conversely, people who knew someone with HIV infection attributed increased levels of stigma to others in their community than those who did not know anyone with HIV infection (7.70, vs 6.90, $t = -3.59$, $P < 0.01$). As before, this difference was evident both in the blame and judgment subscale (4.06 vs 3.65, $t = 3.36$, $P < 0.01$) and interpersonal distancing subscale (3.65 vs 3.25, $t = 3.24$, $P < 0.01$).

Analyses were also conducted to determine whether there was an association between HIV-related knowledge and stigmatising attitudes, and in this instance the analyses were conducted for both the community sample as well as the HIV-infected pregnant women sample. In the community sample, people who were more knowledgeable about HIV had lower levels of personal stigma ($r = -0.40$, $P < 0.001$) but attributed higher levels of stigma to others ($r = 0.15$, $P < .01$). For the HIV positive women, those who were more knowledgeable had lower levels of internalised stigma ($r = -0.12$, $P < 0.05$), but there was no significant relationship between knowledge and the level of stigma they attributed to others.

Finally, we conducted analyses to examine whether there were associations between stigma and other psychological characteristics reported for the HIV-positive sample. Higher levels of internalised stigma were significantly associated with increased levels of depression ($r = 0.20$, $P < 0.001$), decreased self-esteem ($r = -0.16$, $P < 0.01$) and decreased perceived social support ($r = -0.18$, $P < 0.01$). In contrast, the level of stigma women attributed to people in the community had a significant but weaker association with depression ($r = 0.12$, $P < 0.05$) and was not significantly associated with social support ($r = -0.05$) or self-esteem ($r = 0.03$).

Comparison of Stigma Scores in the Two Samples

The scores obtained on the stigma scales in the two study samples are shown in Table <u>6</u>. People in the community attributed much higher levels of stigma to others than they reported for themselves (mean score 7.32 vs 2.79, $t = -34.35$, $P < 0.001$) and HIV positive women felt that people in the community were even more stigmatising than did community members (9.83 vs 7.32, $t = -11.28$, $P < 0.001$). The level of internalised stigma felt by these HIV positive women was significantly higher than the level of stigma expressed by people in the community (4.64 vs 2.79, $t = -11.19$, $P < 0.001$). There was only a weak correlation between personal and attributed stigma scores in the community sample ($r = 0.09$, $P < 0.05$) although this association was stronger among the HIV positive women ($r = 0.28$, $P < 0.001$), suggesting that women who attributed higher levels of stigma to others tended to feel more stigmatised. Analysis of the scores on the two sub-scales for the two sample groups showed that the scores for blame and judgment were significantly higher than the interpersonal distancing scores for all scales ($P < 0.001$) except for the scale measuring internalised stigma among the HIV positive women in which the scores obtained on the two sub-scales were similar. For each of the scales there was a strong association between the scores obtained on the two subscales ($r > 0.4$, $P < 0.001$ for each of the four scales).

Table 6 Descriptive statistics for the stigma scales of both samples

| | Scale range | Community sample (*N* = 1,077) | | HIV+ pregnant women sample (*N* = 317) | |
		Personal stigma	Stigma attributed to others	Internalised stigma	Stigma attributed to others
Total	0–12	2.79 (SD = 2.5)	7.32 (SD = 3.7)	4.64 (SD = 2.7)	9.83 (SD = 2.4)
Blame and judgement	0–6	1.71 (SD = 1.6)	3.87 (SD = 2.0)	2.25 (SD = 1.6)	5.08 (SD = 1.4)
Interpersonal distancing	0–6	1.09 (SD = 1.4)	3.45 (SD = 2.1)	2.39 (SD = 1.6)	4.75 (SD = 1.4)

Discussion

Stigma continues to have an extremely important role in the AIDS epidemic, not only because of its effects on HIV-infected individuals, but also because of the ways in which stigma might be contributing to the spread of the epidemic. There is, therefore, a need for research to provide a greater understanding of stigma and how best to ameliorate its effects both on HIV-infected individuals and the society as a whole. Presently, however, instruments to measure stigma in African cultures are few (Brown *2004*; Kalichman et al. *2005*; Letamo *2003*; Tanzania Stigma-Indicators Field Test Group *2005*) and there has been little attempt to assess and compare different perceptions of stigma. Such comparisons require instruments that, in effect, measure the same thing, but from different perspectives. In this study, we have built on the work of other investigators and have developed three parallel scales that use the same items in each scale but are worded to capture the meaning appropriate to assess a specific perspective of stigma. The three scales have been labelled "Personal Stigma" which measures the level of stigmatising attitudes held by individuals within a group or community, "Attributed Stigma" which measures the level of stigma that individuals attribute to others in their group or community, and "Internalised Stigma" which assesses the extent to which an HIV-infected individual feels stigmatised because of the disease. Because the items are similar across the three scales this allows for a comparison of different types of stigmatising attitudes both within groups and across different populations.

From analyses of data obtained for the 12-item scale from the community sample two factors were identified. The first factor, labelled "blame and judgement" is based on moral judgement and represents an affective component of stigma. The second factor labelled "interpersonal distancing" relates to the uncertainty and fear regarding transmission of the disease and represents the interpersonal reaction to stigma. The two-factor structure was confirmed by using a split-sample design and by examining its application to the three other parallel scales. Though the same factor structure was found in the scales used in the HIV positive sample, the two factors have slightly different meanings. For HIV positive individuals the "blame and judgement" factor might more appropriately be labelled as "self-stigma" or the degree to which the individual blames or passes judgement on herself. The "interpersonal distancing" factor relates to a woman's level of "expected stigma" or fear of being stigmatised. Expected stigma is a subjective fear of the infected person that people will discriminate against him/her and is not necessarily related to enacted stigma which is an objective description of discriminative interpersonal interaction (Deacon et al. *2005*). While we did not attempt in this research to relate expected and enacted stigma, this is potentially an important area for future research.

Each of the scales showed adequate internal consistency (ranging from 0.70 to 0.87) in all three samples: the derivation and confirmatory community samples and the sample of HIV positive women. The internal consistency and the goodness-of-fit of the two-factor model were lower for the internalised stigma scale completed by the HIV-infected women. The

decision to keep the scales parallel by matching the items may have resulted in some sacrifice of accuracy in the measurement of internalised stigma in HIV-infected individuals.

The validity of the scales is supported by the findings that people who are more knowledgeable about HIV and people who know someone with HIV have lower levels of stigma scores using the scales, findings that have been reported in earlier research. Additionally, the demonstration that for HIV positive individuals there are significant associations between internalised stigma and measurements of self-esteem, depression and social support provides some evidence supporting the validity of the internalised stigma scale.

The benefit of using the three parallel stigma scales is demonstrated by the results of this research. It was found that HIV-infected women believe that others in their community are extremely stigmatising, which contrasts with the relatively low level of stigmatising attitudes expressed by people in that same community. The same individuals in the community also attributed high levels of stigma to others, although not as high as that perceived by the HIV-infected women. Because stigma is a multi-dimensional concept perceived differently from different perspectives, it cannot be assumed that one of these measures represents the "real" stigma in this community. Enacted stigma will probably result from a combination of personal and attributed perspectives [in accordance with the theory of planned behaviour (Ajzen _1991_)] as well as various other community variables. It is dangerous to assume that there is a lower level of stigma in the community than people infected with HIV believe, because it is difficult to measure the amount of stigma in the public sphere and stigma may be significantly under-reported (Deacon et al. _2005_). It needs to be recognised that the personal attitudes reported by individuals in the community may be low due to the well-documented tendency for people to perceive themselves as better or less negative than others (Alicke _1985_; Taylor and Brown _1988_) or to project themselves in the most positive light. Also, items that explore social distancing often represent hypothetical situations and responses may not be an accurate reflection of an individual's behaviour in a similar situation where additional social dynamics play a role. It may be easier to be liberal in a hypothetical situation than in reality where one is confronted with the various levels of social stigma (Ajzen _1991_; Eagly and Chaiken _1993_; Nyblade and MacQuarrie _2006_). The level of stigma attributed to others represents how the community reaction to HIV is perceived. This perspective may be influenced by the continuous media reporting of individual examples of violence and discrimination against people with HIV/AIDS (Keeten _1999_; Maman et al. _2001_) and the unhelpful responses of community leaders and governments (Aggleton and Parker _2002_). The high level of attributed stigma surely affects the perceptions of HIV infected individuals which can have a serious impact on the lives of those living with HIV. The perception that others are stigmatising can cause those living with HIV to withdraw from interpersonal contact and avoid disclosing their status so as to reduce opportunities for discrimination (Scambler and Hopkins _1986_). This can again impact on the unchallenged negative perceptions of HIV in the community. The assessment of different perspectives of stigma can therefore contribute to the understanding of different interacting reactions to HIV. The discrepancy found between the perspectives on stigma was previously found in research that compared some combinations of these perspectives (Green _1995_; Nyblade and MacQuarrie _2006_).

Despite attempts to make the items the same across the three scales, change in wording and slight differences in meaning could contribute to some of the differences in scores between scales. The fact that the factor analyses and internal consistency remained fairly similar across the different scales however suggests individual items did not act very differently between scales. In this research some evidence of validity of the scales was found, though more research is needed. In each sample the scale assessing personal perceptions of stigma was presented before the attributed stigma scale. It was not assessed what impact the order of the presentation of the scales had on the levels of stigma obtained. Another limitation of the study is that in developing the internalised stigma scale for HIV-infected individuals the sample included only HIV positive pregnant women who attended antenatal care. Obviously, men and women who are not pregnant could experience stigma very differently. Similarly, the majority of women in the sample had recently been diagnosed with HIV and it is likely that individuals who are infected for longer periods of time might also perceive things differently. Although differences in study populations might affect the level of stigma obtained with the scale, it would unlikely affect the construct of the scale, as is demonstrated by the fact that the

factor structure of the scale remained similar across two entirely different samples in this study. Lastly, it should be noted that a sampling bias may have decreased the actual reporting of stigma among the HIV-infected women, because as is true for all studies of HIV-infected individuals, those who feel most stigmatised by their disease may be least likely to agree to participate in such a study (Tanzania Stigma-Indicators Field Test Group *2005*).

In this research the development of three parallel scales assessing different perspectives on stigma is outlined. The scales show acceptable reliability scores and some evidence of validity for the samples used. Further research in other communities is encouraged to build evidence of the applicability of the scales to assess stigma in the African context.

The use of the three scales in this study and the differences found illustrate that stigma is not one all-encompassing entity, but depends on the perspective of the individual. These results suggest opportunities for addressing both the internalised stigma felt by those living with HIV, as well as possibilities for decreasing stigmatising attitudes within communities. While it is true that HIV-infected individuals suffer adverse societal consequences because of their disease, helping individuals recognise the extent to which stigma has been internalised and addressing this, could help them cope better with their HIV status. More openness about their HIV status may also affect the stigma attributed to HIV in the community. For interventions focused on decreasing stigmatising attitudes within communities, an important first step might be to recognise the difference between the limited extent to which people express stigmatising attitudes and the much higher perceptions of stigma attributed to others within their community. A focus on decreasing perceptions of stigma could have an important effect both for HIV-infected individuals living within the community as well as changing behaviours of those in the community, such as making HIV testing more acceptable.

Since this study was first initiated, there have been a number of efforts internationally to develop measures for HIV-related stigma (e.g. Nyblade and MacQuarrie *2006*; Tanzania Stigma-Indicators Field Test Group *2005*). We hope that the results of this study and its unique focus on developing parallel instruments to measure different perspectives of stigma will contribute significantly to efforts to assess and decrease the pervasive effects of HIV-related stigma.

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