

RUNNING HEAD: Validation of a brief stigma-by-association scale

Validation of a brief stigma-by-association scale for use with HIV/AIDS-affected youth in
South Africa

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Abstract

This study validated a brief stigma-by-association scale for use with South African youth (adapted from the HIV Stigma-by-Association Scale for Adolescents; Mason, Berger, Ferrans, Sultzman, & Fendrich, 2010). Participants were 723 youth (364 male, 359 female) from poor urban communities around Cape Town. Youths completed the brief stigma-by-association scale and measures of bullying victimisation and peer-problems, as well as inventories measuring symptoms of depression and anxiety. Exploratory analyses revealed that the scale consists of two subscales: 1) experience of stigma-by-association, and 2) consequences of stigma-by-association. This two factor structure was obtained in the full sample and both the HIV/AIDS-affected and unaffected subgroups. The full stigma-by-association scale showed excellent reliability ($\alpha = .89-.90$) and reliabilities for both subscales were also good ($\alpha = .78-.87$). As predicted, children living in HIV/AIDS-affected households obtained significantly higher stigma-by-association scores than children in non-affected households [$F(1, 693) = 46.53, p < .001$, partial $\eta^2 = .06$] and hypothesized correlations between stigma-by-association, bullying, peer problems, depression, and anxiety symptoms were observed. It is concluded that the brief stigma-by-association scale is a reliable and valid instrument for use with South African youth; however further confirmatory research regarding the structure of the scale is required.

Keywords: stigma-by-association, HIV/AIDS, South Africa, validation, youth

By 2010 approximately 1.9 million South African children had lost one or both parents to the AIDS-epidemic (UNAIDS, 2010), with many more children living with HIV/AIDS-sick parents or caregivers. These children are not necessarily infected with HIV/AIDS (although they may be) but are *affected* by their caregiver's HIV-status. HIV/AIDS is one of the most stigmatised diseases in history (Parker & Aggleton, 2003). Stigma refers to an attribute that is deeply discrediting, and marks the person not only as different but as bad, dangerous, or weak (Goffman, 1963). In the developed world people with HIV report being rejected, excluded, and shunned in social contexts, as well as experiencing feelings of anger, anxiety, hopelessness, depression, and lowered self-esteem (Antle, Wells, Goldie, DeMatteo, & King, 2001; Ingram & Hutchinson, 1999; Leary & Schreindorfer, 1998; Sandelowski, Lambe, & Barroso, 2004). Similar findings have been reported in sub-Saharan Africa (Campbell, Foulis, Maimane, & Sibiya, 2005; Campbell, Skovdal, Mupambireyi, & Gregson, 2010; Greef et al., 2010; Maughan Brown, 2010), and South Africa in particular has high levels of HIV/AIDS-related stigma and discrimination (Skinner & Mfecane, 2004).

Importantly, stigma also impacts on family and friends of the stigmatised person (Goffman, 1963). This stigma-by-association (Mason, et al., 2010) has been linked to increased stress and limited social interactions for family members (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Green, 2003). Research in America suggests that children and adolescents may feel stigma as acutely as their HIV+ parents. Specifically, children of parents who are HIV+ report worries they will be considered HIV+ if others learn about their parents status (Brackis-Cott, Mellins, & Block, 2003; Murphy, Roberts, & Hoffman, 2002). In South Africa there is qualitative evidence that children who are AIDS-orphaned or living with an HIV/AIDS-sick caregiver experience bullying, discrimination, gossip, taunting, and verbal abuse referencing the surviving HIV+ parents or caregivers (Cluver & Gardner, 2007). Additionally, recent research suggests that HIV/AIDS-related stigma-by-association mediates relationships between AIDS-orphanhood and poor psychological outcomes (Cluver, Gardner, & Operario, 2008),

suggesting stigma-by-association is an important mechanism explaining psychological distress in HIV/AIDS-affected children.

Until recently no measures of HIV/AIDS-related stigma-by-association relevant to adolescents were available – research relied on qualitative interviews (Cree, Kay, Tisdall, & Wallace, 2004; Murphy, et al., 2002) and short scales for which validation information is scarce. Validated scales are useful, as they allow comparisons both within and across samples that have used the same instrument. To address the need for a validated measure of HIV/AIDS-related stigma-by-association Mason and colleagues (Mason, et al., 2010) developed the HIV Stigma-by-Association Scale for Adolescents. This scale was adapted from the HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001) and contains 24 items responded to on a four-point scale ranging from strongly disagree to strongly agree. The scale demonstrated good reliability in a sample of African American adolescents with HIV+ mothers ($\alpha = .87$); however, its performance in a developing world context has not been documented. Additionally, in large studies incorporating multiple outcomes (Cluver, Gardner, & Operario, 2007) brevity of measures is essential, and is particularly important when working with children and youth. Furthermore, in the context of low rates of HIV testing (only 8% of South Africans know their HIV status; Peltzer, Matseke, Mzolo, & Majaja, 2009), it is important to develop a measure that is not *specifically* linked to HIV/AIDS, but is sensitive to HIV/AIDS-related stigma-by-association. The aim of this study was to validate a brief stigma-by-association scale, adapted from the Mason et al (2010) HIV Stigma-by-Association Scale for Adolescents, for use with South African youth.

Method

Study population and procedures

In 2005, 1025 children and adolescents were interviewed in a study examining psychological distress in children from poor communities of Cape Town (Cluver, et al., 2007).

Participants were recruited from nine schools, 18 non-government organisations, and from door-to-door sampling. The study area covered deprived peri-urban settlements in Cape Town, characterised by high population density, unemployment, property crime, rape, and violent crime (South African Police Services, 2009). Inclusion criteria were age (youth were 10-19 in 2005); however, in order to exclude acute bereavement reactions youth orphaned in the previous six months were not interviewed. Four years later, 723 youth were followed-up (71% retention rate). The stigma-by-association scale was included in the longitudinal follow-up and psychometric analyses were conducted on data obtained from this sample of 723 youth in 2009.

Ethical approval was obtained from the Universities of Oxford and Cape Town. All measures were translated into Xhosa by two Masters level researchers and independently back-translated by a Xhosa-speaking research psychologist. Informed consent was obtained from both children and their caregivers. In the context of low literacy rates (Mulis, Martin, Kennedy, & Foy, 2007) questionnaires were administered verbally by interviewers – all local Xhosa speaking community health or social workers trained in working with children from deprived communities and the administration of standardised questionnaires. Confidentiality was maintained unless children were at risk of harm or requested assistance. Participation took approximately 40-60 minutes and no incentives for participation were provided.

Measures

The brief stigma-by-association scale was adapted from the HIV Stigma-by-Association Scale for Adolescents (Mason, et al., 2010). In order to ensure that items reflected local understanding of stigma, qualitative interviews with 60 children orphaned by HIV/AIDS, 42 caregivers of HIV/AIDS-orphaned children, and 20 care professionals were conducted (Cluver & Gardner, 2007). Being gossiped about or teased because someone in the family was sick or unwell were identified as being particularly relevant to youth in South Africa and items measuring this were

included in the brief scale. Two South African academics were also consulted (Deacon, 2006; Maughan Brown, 2006) and consistent with information from qualitative interviews they recommended including items related to being gossiped about, teased, and treated badly due to parental/caregiver HIV/AIDS. Additionally, based on the qualitative interviews and information obtained from local researchers, seven items from the Mason et al (2010) scale were identified as being most relevant to the South African context. This resulted in a final 10-item scale (Appendix 1), which was administered in the current study. Due to low literacy rates (Mulis, et al., 2007), and on the advice of local academics and youth interviewed in the qualitative study (Cluver & Gardner, 2007), the response scale was reduced to a three-point scale (*0: Not at all; 1: Sometimes; 2: All the time*). In the context of low levels of HIV-testing, and in order to leave the scale open for use across a range of stigmatising illnesses/conditions, children were instructed to respond to the items with regard to parent/caregiver sickness in general (see Appendix 1).

Sociodemographic characteristics included age, gender, ethnicity, household size, whether children lived in informal (shack) housing, and whether children had migrated to Cape Town. Bullying victimisation was measured using the nine item Social and Health Assessment Peer Victimisation Scale (Ruchkin, Schwab-Stone, & Vermeiren, 2004), which has been used previously with vulnerable children in Cape Town (Ward, Martin, Theron, & Distiller, 2007) and has shown good reliability in a South African sample ($\alpha = .82$; Cluver, Bowes, & Gardner, 2010). Peer-problems were measured with the peer-problems subscale of the well-validated Strengths and Difficulties Questionnaire (Goodman, 1997). The peer-problems subscale contains five items that are responded to on a three-point scale (*0: Not true for me; 2: Certainly true for me*). Reliability estimates of the peer-problems subscale range between $\alpha = .39-.46$ (Di Riso et al., 2010). Depression was measured with the short-form of the Children's Depression Inventory (Kovacs, 1992). This 10-item scale has been used previously in South Africa (Cluver, et al., 2007), has good psychometric properties ($\alpha = .71-.94$; Saylor, Finch, & Spirito, 1984), and is highly correlated with the full version of the inventory ($r = .89$; Kovacs, 1992). Anxiety was measured using an abbreviated version of the Revised Children's Manifest Anxiety Scale

(Reynolds & Richmond, 1978). The scale contains 28 anxiety-related items responded to on a yes/no scale, and has been validated for use in South Africa (Boyes & Cluver, in press). The scale shows good internal consistency ($\alpha = .79-.85$) and test-retest reliability ($r = .68$; Gerard & Reynolds, 1999). Due to time constraints only the 14 highest loading items (after factor analysing the 2005 data) were administered in 2009 ($\alpha = .82$).

Death certificates are unreliable sources regarding HIV/AIDS deaths in South Africa and clinical data is rarely available. Cause of parental death was therefore determined using the Verbal Autopsy method (Lopman et al., 2006), based on youth responses. Verbal Autopsy has been validated in studies of adult mortality in South Africa (Kahn, Tollman, Garenne, & Gear, 2000). In the current study, determination of HIV/AIDS-related parental death required a conservative threshold of three or more HIV/AIDS-defining illnesses (e.g. Kaposi's sarcoma or shingles) to be identified by the youth. The UN definition of orphanhood was used – the loss of one or both parents among children up to the age of 18 years (UNAIDS, 2008). For determining caregiver illness, self-reported current HIV-status is also unreliable. High levels of stigma in South Africa result in low HIV-testing (8% in the past year; Peltzer, et al., 2009), and many people are unaware of their HIV-status. Consequently, caregiver HIV/AIDS-sickness was determined using a similar symptom checklist procedure based on youth responses. A conservative threshold of three or more HIV/AIDS-defining symptoms was required in order for the caregiver to be categorised as HIV/AIDS-sick. This information was used to classify youth as HIV/AIDS-affected (HIV/AIDS-orphaned or living with an HIV/AIDS-sick caregiver) or unaffected (neither HIV/AIDS-orphaned nor living with an HIV/AIDS-sick caregiver).

Statistical Analyses

Analyses were conducted using SPSS 19. Frequencies, means, and standard deviations described sociodemographic characteristics of the sample. The structure of the brief stigma-by-association scale was examined through a series of exploratory factor analyses (using oblique

oblimin rotation – as factors were hypothesized to be correlated) on the full sample and the subgroups of HIV/AIDS-affected and unaffected youth. Principal axis factoring was used as variance unique to individual items, as well as error variance, is excluded from analyses (Tabachnick & Fidell, 2001). The number of factors extracted was determined by examining individual eigenvalues for each factor (eigenvalues greater than one indicate a factor should be extracted) and visual inspection of scree plots. Reliability of the scale was evaluated using item-total correlations and internal consistency (Cronbach's α). Discriminant validity of the scale was assessed by comparing stigma-by-association scores reported by HIV/AIDS-affected and unaffected youth. It was hypothesized that HIV/AIDS-affected youth would obtain significantly higher scores than unaffected youth. Convergent validity was evaluated by examining associations between stigma-by-association scores and predicted correlates (bullying, peer-problems, and symptoms of depression and anxiety) in the full sample and the HIV/AIDS-affected and unaffected subgroups. As stigma-by-association, bullying, peer problems, depression, and anxiety are conceptualised to be distinct constructs only moderate positive correlations between these variables were hypothesized.

Results

Sample characteristics

The sample was 723 youth aged between 11 and 25 ($M = 16.90$, $SD = 2.50$). Verbal Autopsy scores determined orphanhood status and caregiver sickness status, and sociodemographic information as a function of these groupings is summarised in Table 1. Two hundred and ninety-six youths were HIV/AIDS-affected (HIV/AIDS-orphaned or living with an HIV/AIDS-sick caregiver) and 496 youths were HIV/AIDS-unaffected (neither HIV/AIDS-orphaned nor living with an HIV/AIDS-sick caregiver). Youths whose orphanhood ($n = 46$) or caregiver sickness status ($n = 38$) was unclear were excluded from analyses involving the HIV/AIDS-affected and unaffected subgroups. (**Table 1**)

Structure of the brief stigma-by-association scale

Factor analyses (using principal axis factoring) were conducted to examine the structure of the stigma-by-association scale in the full sample and the HIV/AIDS-affected and unaffected subgroups. The Kaiser-Meyer-Olkin statistic revealed that sampling was adequate and Bartlett's test indicated that the correlations between items were sufficiently large for analyses to be conducted in the full sample and both subgroups. Two factors with eigenvalues greater than one emerged in all analyses, suggesting a two-factor solution was appropriate in the full sample and both subgroups. However, in both the full sample and the HIV/AIDS-affected subgroup item 5 (see Appendix 1) cross-loaded onto both factors and was excluded from the analyses. After excluding item 5, the two-factor structure of the scale was identical in all analyses (see Table 2). Factors were labelled 1) *experience of stigma-by-association*, and 2) *consequences of stigma-by-association*, and accounted for 61-69% of overall variance. The two factors were correlated in all analyses ($r = .59$ in the full sample; $r = .59$ in the HIV/AIDS-affected subgroup, and $r = .56$ in the HIV/AIDS-unaffected subgroup).

(Table 2)

Reliability of the brief stigma-by-association scale

Item-total correlations for individual items (with the exception of excluded item 5) were calculated in the full sample and the subgroups of HIV/AIDS-affected and unaffected youth. An item-total correlation of less than .30 indicates an item is a poor indicator of the measured construct (Nunnally & Bernstein, 1994). Item-total correlations ranged between $r = .57$ (Item 6 in the HIV/AIDS-unaffected subgroup) and $r = .74$ (Item 2 in the full sample and the HIV/AIDS-affected subgroup). All item-total correlations comfortably met the .30 criteria. Cronbach's alpha (α) was used to assess the internal consistency of the full scale and both subscales. Nunnally and Bernstein (1994) suggest that α of .70 or above is acceptable and that α

of .80 or above is good. The internal consistency of the complete scale was $\alpha = .89$ in the full sample, $\alpha = .90$ in the subgroup of HIV/AIDS-affected children, and $\alpha = .85$ in the subgroup of HIV/AIDS-unaffected children. Internal consistencies for the two subscales identified in factor analyses ranged between $\alpha = .78$ -.88 and are reported in Table 2.

Validity of the brief stigma-by-association scale

Stigma-by-association scores clearly discriminated between HIV/AIDS-affected and non-affected youth. HIV/AIDS-affected youth ($M = 4.54$, $SD = 5.10$) obtained significantly higher scores than non-affected youth ($M = 2.34$, $SD = 3.41$) [$F(1, 693) = 46.53$, $p < .001$, partial $\eta^2 = .06$]. To examine the convergent validity of the stigma-by-association scale correlations between total scores and predicted correlates of stigma-by-association were examined (in the full sample and the HIV/AIDS-affected and unaffected subgroups). As hypothesized, stigma-by-association was positively correlated with bullying victimisation, peer-problems, depression, and anxiety in the full sample and both subgroups (see Table 3).

(Table 3)

Discussion

The current study aimed to validate a brief stigma-by-association scale (adapted from the HIV Stigma-by-Association Scale for Adolescents; Mason, et al., 2010) for use with South African youth. Findings demonstrated both the reliability and validity of the scale in the South African sample. The internal consistency of the full scale was excellent ($\alpha = .89$ -.90) and all item-total correlations comfortably met the .30 criteria. This suggests that the brief scale is a reliable measure of stigma-by-association in the South African context. The internal consistencies obtained using the brief scale in the current study are almost identical to the reliability reported in the original Mason et al. paper ($\alpha = .87$). Regarding the validity of the scale, as hypothesized, HIV/AIDS-affected youth reported significantly higher stigma-by-

association scores than HIV/AIDS-unaffected youth; suggesting that the scale is sensitive to HIV/AIDS-related stigma-by-association. Moreover, predicted correlations between stigma-by-association and bullying, peer-problems, as well as symptoms of depression and anxiety were obtained, and offer evidence for the convergent validity of the scale. Taken together these findings offer sound evidence for the validity of the brief stigma-by-association scale for use with South African youth.

Exploratory analyses of the structure of the questionnaire in the full sample of youth, as well as the HIV/AIDS-affected and unaffected subgroups, revealed that is comprised of two factors: 1) experience of stigma-by-association, and 2) consequences of stigma-by-association. Both these subscales demonstrated good reliability ($\alpha = .84-.88$ and $\alpha = .78-.87$ respectively); however, further work is needed to replicate this two-component structure of the scale using confirmatory techniques. If this two-component structure is replicated, research should explore whether these two aspects of stigma-by-association are similarly or differentially linked to mental health outcomes and other correlates of stigma-by-association.

It is important to note the limitations of the current study. First, to date no measures of depression and peer-problems have been comprehensively psychometrically tested in South African samples and correlations between these variables and stigma-by-association therefore need to be interpreted with caution. Additionally, a recent study reported reliability of the peer-problems subscale to be problematic in a number of samples (Di Riso, et al., 2010), and findings should be interpreted in light of this. Second, due to low levels of literacy questionnaires were verbally administered. Although this minimises missing data and ensures youths understanding of questionnaire items, it may have increased the risk of socially desirable responding. However, substantial attempts were made to ensure that children were completely comfortable during the interviews. Children were assured that the information they provided would remain confidential, and particularly sensitive sections of the questionnaire (e.g. information on HIV/AIDS and sexual behaviour) were separated from the rest of the

questionnaire and stored in a sealed envelope. Additionally, interviewers were all local Xhosa speaking community health or social workers and were trained in both working with children from deprived communities and the administration of questionnaires. Finally, due to constraints of the dataset, the test-retest reliability of the stigma-by-association scale was not able to be assessed in the current sample.

However, bearing these limitations in mind, the findings clearly established the reliability and validity of the brief stigma-by-association scale for use in a South African context. The scale is easy to administer, short, and whilst not specifically linked to HIV/AIDS is sensitive to HIV/AIDS-related stigma-by-association. Given the low HIV-testing rates and knowledge of HIV-status in South Africa (Peltzer, et al., 2009) this is a particularly useful characteristic of the scale. Additionally, because the stigma-by-association scale is not specifically linked to HIV/AIDS it will be possible to use the questionnaire as an empirical tool for studying stigma-by-association across a variety of illnesses and other stigmatising characteristics or conditions. Given the accumulating evidence suggesting that HIV/AIDS-related stigma-by-association is an important mechanism explaining increased psychological distress in HIV/AIDS-affected children in South Africa (Cluver, et al., 2007), and the current focus on HIV/AIDS-related stigma in sub-Saharan Africa in general, we believe that information demonstrating the reliability and validity of this brief stigma-by-association scale will promote further research in this important area.

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Table 1. Summary of sample characteristics and stigma-by-association scores

	Children orphaned by AIDS (n = 269)	Children orphaned by other causes (n = 228)	Non-orphaned children (n = 180)	<i>p</i> value	AIDS-sick caregiver (n = 103)	Other-sick caregiver (n = 146)	Healthy caregiver (n = 436)	<i>p</i> value
Age (<i>M</i> , <i>SD</i>)	17.2 (2.7)	17.0 (2.6)	16.5 (1.9)	.01	17.0 (2.5)	16.9 (2.3)	16.8 (2.5)	ns
Age Range	11-24	12-25	12-22	-	12-23	12-22	11-25	-
Female	52.8%	45.2%	49.4%	ns	59.2%	44.5%	48.2%	ns
Xhosa ethnicity	99.2%	97.4%	98.2%	ns	100%	99.3%	99.3%	ns
Household size (<i>M</i> , <i>SD</i>)	5.1 (2.3)	5.0 (2.1)	5.3 (2.4)	ns	5.2 (2.0)	5.7 (2.2)	4.9 (2.3)	< .01
Informal dwelling	34.5%	31.1%	30%	ns	41.6%	27.1%	33.5%	.02
Migration (at least once)	45.4%	46.1%	39.3%	ns	43.1%	47.9%	44.8%	ns
Total stigma-by-association (<i>M</i> , <i>SD</i>)	4.86 (5.33)	2.58 (3.56)	2.01 (3.04)	< .01	5.48 (3.91)	3.15 (3.96)	2.73 (3.91)	< .01

Note: *p* value associated with one-way ANOVA or chi-square test

Table 2. Factor loadings of individual items on the experience of stigma-by-association and the consequences of stigma-by-association components (obtained in the full sample, the HIV/AIDS-affected subgroup, and the HIV/AIDS-unaffected subgroup).

	Experience of stigma-by-association			Consequences of stigma-by-association		
	Full sample	AIDS-affected	AIDS-unaffected	Full sample	AIDS-affected	AIDS-unaffected
1: Teased	.91	.92	.81			
2: Treated badly	.88	.92	.71			
3: Gossiped about	.72	.68	.75			
7: Feel different or alone	.69	.69	.64			
4: Worry about rejection	.62	.65	.52			
6: Avoid making new friends	.48	.48	.50			
9: Afraid of me				.92	.94	.81
10: Think I am a bad person				.76	.76	.73
8: Avoid touching me				.75	.75	.62
Eigenvalue	4.87	4.98	4.32	1.18	1.23	1.14
Variance	54.15%	55.36%	47.96%	13.15%	13.68%	12.68%
α	.87	.88	.84	.86	.87	.78

Note: Oblique rotation (oblimin) and component loadings < .30 are suppressed

Table 3. Correlations between total stigma-by-association scores, bullying victimisation, peer problems, depression, and anxiety in the full sample, HIV/AIDS-affected subgroup, and the HIV/AIDS-unaffected subgroup.

	Bullying victimisation	Peer problems	Depression	Anxiety
Stigma-by-association				
(full sample)	.43*	.32*	.43*	.49*
Stigma-by-association				
(HIV/AIDS-affected)	.55*	.34*	.48*	.55*
Stigma-by-association				
(HIV/AIDS-unaffected)	.23*	.25*	.30*	.41*

Note: * $p < .01$

Appendix 1: Brief Stigma-by-Association Scale

Some kids have parents who were ill for some time before they die. Or their parent is unwell at the moment. It is difficult for kids to handle sometimes. Could you say how much these things are true for you?

Because someone in my family is sick or has died...

- 1) I've been teased*
- 2) I've been treated badly*
- 3) People have gossiped behind my back*
- 4) I worry about being rejected⁺
- 5) Parents who know don't want me around their kids⁺
- 6) I avoid making new friends⁺
- 7) I feel different and alone⁺
- 8) If people know, they avoid touching me⁺
- 9) If people know, they are afraid of me⁺
- 10) If people know, they think I am a bad person⁺

Response Scale: 0: *Not at all*, 1: *Sometimes*, 2: *All the time*

Note:

* Items generated through qualitative interviews and consulting local researchers

+ Items adapted from the HIV Stigma-by Association Scale for Adolescents (Mason, et al., 2010)