PREDICTORS AND CORRELATES OF INTERNALISED HIV-RELATED STIGMA: A SYSTEMATIC REVIEW OF STUDIES IN SUB-SAHARAN AFRICA

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Abstract

Objective: This systematic review aims to synthesize evidence on predictors of internalised HIV stigma amongst people living with HIV (PLHIV) in Sub-Saharan Africa.

Method: PRISMA guidelines were used. Studies were identified through electronic databases, grey literature, reference harvesting and contacts with key researchers. Quality of findings was assessed through an adapted version of the Cambridge Quality Checklists.

Results: A total of 589 potentially relevant titles were identified. Sixteen peer-reviewed articles and one draft book chapter were included. Prevalence of internalised stigma amongst PLHIV ranged between 26.9% and 66%. Studies investigated socio-demographic, HIV-related, intra-personal and inter-personal correlates of internalised stigma. Eleven articles used cross-sectional data, five articles used prospective cohort data and one used both prospective cohort and cross-sectional data to assess correlates of internalised stigma. Consistent links were found between internalised HIV stigma and poor HIV-related health outcomes, poor mental health and less social support.

Conclusion: Comprehensive treatment and care for people living with HIV may help reduce internalised stigma. Studies utilizing analysis of change and accounting for confounding factors are necessary to inform policy and programming. High-risk populations, other stigma markers that might layer upon internalised stigma, and structural drivers of internalised stigma need to be examined.

Keywords: stigma; HIV/AIDS; systematic review; self-perception; self-image; shame
Background

Three decades into the fight against HIV, stigma remains a major ‘roadblock’ to HIV prevention and treatment (UNAIDS, 2007). In 2011, UN member states committed to eliminating HIV/AIDS-related stigma by 2015 (UNAIDS, 2011). Existing intervention studies heavily focus on reducing enacted stigma (Stangl, Lloyd, Brady, Holland, & Baral, 2013), which refers to negative public attitudes or discrimination towards people living with HIV (Horwitz et al., 2013). Less is known about how to reduce internalised HIV-related stigma, which occurs when an HIV-positive person endorses negative attitudes associated with HIV and accepts them as applicable to his or her self (Earnshaw, Smith, Chau doir, Amico, & Copenhaver, 2013). Internalised stigma is characterised by feelings of shame, guilt, worthlessness and difficulties around HIV status disclosure (Lee, Kochman, & Sikkema, 2002; Tsai et al., 2012).

Reducing internalised HIV stigma may mitigate a range of associated damaging outcomes for people living with HIV (PLHIV). Internalised stigma hinders adherence to antiretroviral treatment (ART) (Katz et al., 2013; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Susan et al., 2012), which is essential for preventing virological failure (Gross et al., 2006) and delaying mortality among PLHIV (Lima et al., 2009). Over time, internalised stigma has been associated with reductions in health-related quality of life (Peltzer, 2012). Victims of internalised stigma also suffer from increased mental health challenges, including depression, anxiety, low self-esteem, hopelessness and poor mental health-related quality of life (Kalichman et al. 2009; Lee, Kochman, and Sikkema 2002; Li et al. 2009; Simbayi et al. 2007b; Tsai et al. 2012; Visser et al. 2008). Cross-sectional evidence suggests that the relationship between internalised stigma and poor antiretroviral adherence may be mediated by poor mental health (Sayles et al., 2009). Internalised stigma may also lead to non-disclosure of HIV status (Tsai, Bangsberg, Kegeles, et al., 2013), which has been linked to HIV transmission risk behaviours (Simbayi et al., 2007a). Therefore, reducing internalised stigma may improve important health outcomes for PLHIV.

Sub-Saharan Africa is home to 70% of the world’s PLHIV but no well-established programmes to reduce internalised HIV stigma have been identified the region. A recent systematic review found only two interventions targeting internalised HIV stigma in Sub-Saharan Africa (Stangl et al., 2013).
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Both interventions aimed to improve coping through empowerment and knowledge building. Uys et al. (2009) used a multiple-case study approach to evaluate non-standardized programmes designed by small groups of 7-10 nurses and 7-10 HIV-positive patients in five healthcare facilities in Lesotho, Malawi, South Africa, Swaziland, and Tanzania. Taken together, the programmes resulted in a significant reduction in negative self-perception among the patients ($M_1=.82; M_2=.36, p<.001$).

Tshabalala and Visser (2011) evaluated a structured cognitive-behavioural therapy intervention in a small mixed methods randomized control trial with HIV-positive women in South Africa (10 HIV-positive women in the intervention group and 10 HIV-positive women in the waitlist control group). The intervention resulted in significantly greater reductions in internalised stigma in the intervention group compared to the control group. These studies are a step in the right direction and suggest it is feasible to reduce internalised HIV stigma by acting on individual-level factors that contribute to it. However, findings should be replicated by large randomized trials before firm inferences are made.

Moreover, there is no evidence of community or macro-level interventions to reduce internalised stigma in Sub-Saharan Africa, but a growing body of work suggests that HIV stigma and its internalization are entrenched in wider structural inequalities (Campbell & Deacon, 2007; Parker & Aggleton, 2003; Tsai, Bangsberg, & Weiser, 2013).

In order to design and test future interventions, we must first understand the full range of predictors of internalised HIV stigma in Sub-Saharan Africa (Blum & Ireland, 2004). To our knowledge, no systematic review on predictors of internalised HIV stigma in sub-Saharan Africa has been conducted to date, despite the region’s disproportionate HIV burden. Logie and Gadalla (2009) conducted a systematic review and meta-analysis of health and demographic correlates of both enacted and internalised HIV-stigma in North America, and found one study assessing correlates of internalised stigma in the US (Lee et al., 2002). However we should be extremely cautious about the transferability of North American studies, where HIV disproportionately affects otherwise stigmatized minorities such as men who have sex with men, people who inject drugs and African Americans (CDC, 2013). In contrast, in sub-Saharan Africa, HIV is prevalent in the general population.

Therefore, the aim of this systematic review is to synthesize existing evidence on predictors of internalised HIV stigma among PLHIV in Sub-Saharan Africa. This review assesses observational
studies of predictors of internalised HIV stigma and is intended to complement the recent systematic review of interventions to reduce HIV stigma (Stangl et al., 2013). We hope the results of this review will advance theory and inform intervention development in Sub-Saharan Africa. Detailed information about the scope of the review can be found in supplementary file 2.

**Methods**

**Search strategy**

This paper adheres to PRISMA guidelines for systematic reviews (Moher, Liberati, Tetziaff, & Altman, 2009). The full protocol for this systematic review is accessible online (web link provided in separate document to protect blind peer review). Studies were identified through electronic searches of bibliographic databases and grey literature web-sites, examining citations of retrieved studies, and contacting researchers. Our search was restricted to reports after 1983, the year of the first AIDS diagnoses in Africa (Ras, Simson, Anderson, Prozesky, & Hamersma, 1983). Larger databases (PsycARTICLES, Embase, Global Health, Ovid MEDLINE, and PsycINFO) were searched utilizing sensitive search terms including subject heading (MeSH) and free-text search terms for sub-Saharan Africa, people living with HIV and internalised HIV-related stigma or shame (see Supplementary file 4). Smaller databases (CINAHL and WHO Afro Library) used a simpler, more inclusive search string. The PROSPERO register of systematic reviews was also searched. References listed in the included studies as well as in other reviews on HIV/AIDS stigma (Mbonu, van den Borne, & De Vries, 2009; Sengupta, Banks, Jonas, Miles, & Smith, 2011; Stangl et al., 2013; Tsai, Bangsberg, & Weiser, 2013) were also reviewed for eligibility. Email requests for unpublished and ongoing investigations were sent in November-December 2013 to key researchers working on HIV stigma.

**Screening**

Following guidelines in the Cochrane Collaboration Handbook (Deeks, Higgins, & Altman, 2008), search results were merged and de-duplicated. The initial screening involved the lead author’s (MP) examination of titles and abstracts to remove irrelevant reports. Full-text documents were retrieved and examined in detail for compliance with eligibility criteria (Supplementary file 3). Where needed, authors were contacted by email to retrieve reports, clarify study eligibility and request additional information.
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Data abstraction and quality assessment

Data were extracted using a pre-designed piloted form (see supplementary file 6 and protocol) by one reviewer (MP). This was checked independently by a second reviewer (YS) and discrepancies were resolved by discussion. Articles reporting analyses from the same dataset were checked to ensure there was no data duplication. Where data were duplicated, estimates from the largest sample were used. Quality of findings in included studies was assessed using an adapted version of the Cambridge Quality Checklists (CQC) (Murray, Farrington, & Eisner, 2009), developed for drawing conclusions about causes from observational studies (see supplementary file 7). The causal predictor score is the most important indicator as it assesses the extent to which the risk factor is causally related to the outcome. The causal score is determined based on two key features: 1) the extent to which within-individual changes in internalised stigma are associated with within-individual changes in the predictor (analysis of change); and 2) whether the study design and/or statistical analysis account for alternative explanations of the findings. Models assessing whether variation in the predictor is related to within-individual change in internalised stigma and controlling for relevant confounding variables score highest among observational studies.

For the purposes of this systematic review, we adapted CQC to capture reporting quality, in addition to methodological rigor. Studies not reporting reliability of the internalised HIV stigma measure used were ranked lower than those reporting reliability below 0.70. Response rates were scored for cross-sectional designs. Given that the prospective cohort studies reported only retention rates (without response rates at baseline), only retention rates were assessed for longitudinal designs. Studies focusing on people living with HIV in sub-Saharan Africa tend to recruit through healthcare facilities. We therefore adapted CQC sampling scores to assess the method used for the selection of facilities, in addition to the sampling of participants within facilities.

As the included studies assessed more than one internalised stigma predictor, CQC was applied to each association between a correlate and internalised stigma. This allowed for differentiation between the types of analyses used for investigated predictors of internalised stigma. For example, Visser & Sipsma (2013) report a simple correlation between enacted stigma and internalised stigma, whereas other predictors of internalised stigma in the study were assessed in a multivariate model that
received a higher causality score for accounting for confounders.

Any measures of between group differences (e.g. odds ratio, risk ratio, difference in means) or associations between constructs (e.g. r, Beta, B) were extracted. If these were unavailable, where possible Cohen’s d was calculated to illustrate size of effect.

Risk of bias across studies

We sought to minimize risk of publication bias by actively searching for grey literature and ongoing studies. However, the absence of registration procedures for observational studies limits the ability to assess reporting bias. Specifically, the lack of study protocols does not allow differentiation between hypothesis-driven from post-hoc data analyses (Loder, Groves, & MacAuley, 2010).

Data synthesis

A meta-analysis was not conducted due to the diversity of primary studies (Furlan, Pennick, Bombardier, & van Tulder, 2009). Furthermore, cross-sectional data used in the majority of included studies limit causal inferences (Garg, Hackam, & Tonelli, 2008). Meta-analyses can test consistency of a relationship but not causality, so providing a single effect size could be misleading (Weed, 2010).

Results

The search process identified 589 potentially relevant articles and reports. Of these, 262 titles were generated through the database search and 327 titles were generated through harvesting references and communicating with authors. After removing duplicates, 494 abstracts were retained for further review (Figure 1). Next, 37 titles were selected for full-text review. Finally, a total of 17 studies, including 16 peer-reviewed articles and one draft book chapter (Visser and Sipsma 2013) were included in this systematic review.

Study characteristics

Table 1 summarizes the characteristics, quality assessment, findings and effect sizes (where reported) of included studies in chronological order. Represented in the 17 titles are 13 unique samples with 9,088 PLHIV in South Africa, Lesotho, Malawi, Tanzania, Swaziland, Mozambique, Uganda, Kenya and Burkina Faso. There was a general consensus between studies about the definition of internalised HIV stigma: negative self-perception due to HIV status and the resultant feelings of shame, difficulties around disclosure and self-exclusion.
All studies recruited participants through healthcare facilities, and four additionally recruited via support groups, community organizations, social service providers and gay venues (Holzemer et al., 2007; Kalichman et al., 2009; Makoae et al., 2009; Simbayi et al., 2007b).

Nine articles assessed predictors of internalised stigma as a primary objective (Table 1). Five articles were psychometric assessments of measurements and analysed correlates of internalised stigma as part of construct validity checks (Holzemer et al., 2007; Kalichman et al., 2009; Kingori et al., 2013; Tsai et al., 2012; Visser et al., 2008). Three articles aimed to assess predictors of another outcome and assessed correlates of internalised stigma as part of exploratory analyses to inform more complex modelling of other outcomes (Neuman & Obermeyer, 2013; Pearson et al., 2009; Simbayi et al., 2007b).

Most studies included only adults. One study (Nattabi, Li, Thompson, Orach, & Earnest, 2011) included adolescents (15-49 age range), however the analysis did not differentiate between adolescents and adults. No studies included children below the age of 15. One study (Makoae et al., 2009) did not specify the age range of the sample.

In terms of key high-risk populations, three articles focused on women attending antenatal care clinics (Cuca, Onono, Bukusi, & Turan, 2012; Visser et al., 2008; Visser & Sipsma, 2013). Cloete and colleagues (2008) included men who have sex with men and compared them to men who have sex with women. Perinatally infected youth were not studied.

**Quality assessment**

**Study design**

Five articles used prospective cohort data (Cuca et al., 2012; Makoae et al., 2009; Peltzer, 2012; Tsai, Bangsberg, Bwana, et al., 2013; Wagner, Ghosh-Dastidar, Garnett, Kityo, & Mugyenyi, 2013) and one used both prospective cohort data and cross-sectional data (Pearson et al., 2009). Cross-sectional data were used to assess correlates of internalised stigma in the remaining 11 articles.

Most studies used large samples (n≥400). All studies recruited from healthcare facilities. Two articles reported purposively sampling the main HIV/AIDS clinics where patients from other health facilities are referred (Nattabi et al., 2011) and clinics with representative HIV testing services and healthcare provision (Neuman & Obermeyer, 2013). One study reported convenience sampling of
facilities (Sorsdahl, Mall, Stein, & Joska, 2011) and thirteen did not report a method for selection. None of the studies reported total or random sampling of facilities.

Within facilities, four studies used total or random sampling of participants (Cuca et al., 2012; Pearson et al., 2009; Tsai, Bangsberg, Kegeles, et al., 2013; Wagner et al., 2013); one used purposive sampling (Cloete et al., 2008); and five used convenience sampling (Kalichman et al., 2009; Neuman & Obermeyer, 2013; Sorsdahl et al., 2011; Visser et al., 2008; Visser & Sipsma, 2013). The remaining six articles did not report methods used to sample participants within facilities.

Internalised HIV Stigma Measurement Validity and Reliability

The most common measurement used in six included articles was the Internalized AIDS-related Stigma Scale (IA-RSS), developed by Kalichman and colleagues (2009) (Cloete et al., 2008; Kalichman et al., 2009; Peltzer, 2012; Simbayi et al., 2007b; Tsai et al., 2012; Tsai, Bangsberg, Bwana, et al., 2013). Five articles (Cuca et al., 2012; Holzemer et al., 2007; Makoae et al., 2009; Nattabi et al., 2011; Sorsdahl et al., 2011) reported use of the negative self-perception subscale of the HIV/AIDS Stigma Instrument-PLWA (HASI-P). Two reports used the Serithi Internalised Stigma Scale developed by Visser and colleagues (Visser et al., 2008; Visser & Sipsma, 2013). Kingori and colleagues (2013) used the HIV Felt Stigma Questionnaire, and Pearson and colleagues (2009) used the Berger HIV Stigma Scale. Neuman & Obermeyer (2013) developed two items asking about feelings of worthlessness and guilt to assess internalised stigma.

Thirteen articles used internalised stigma measures that had been validated within the same population or adapted versions of measures validated in other populations. Two articles validated author-developed measures (Holzemer et al., 2007; Visser et al., 2008). One article used a non-validated internalised stigma measurement (Neuman & Obermeyer, 2013), and another (Simbayi et al., 2007b) used a measurement that had not been validated at the time of publication but was validated afterwards (Kalichman et al., 2009). Twelve articles reported high internalised stigma measurement reliability, with alphas at or above .70 and one article reported reliability below .70 (Neuman & Obermeyer, 2013). The remaining articles did not report internalised stigma measurement reliability in the study sample.

Response and retention rates
Five articles reported a response or retention rate ≥70% (Nattabi et al., 2011; Pearson et al., 2009; Simbayi et al., 2007b; Tsai, Bangsberg, Bwana, et al., 2013; Wagner et al., 2013). Three studies (Cuca et al., 2012; Makoae et al., 2009; Peltzer, 2012) reported response or retention rates below 70%. Nine articles did not report response or retention rates.

*Causality scores*

Only one article assessed within-individual change in internalised stigma over time whilst taking into consideration potential confounding variables (Tsai, Bangsberg, Kegeles, et al., 2013). Another article conducted within-group change in internalised stigma over time while adequately controlling for confounders (Wagner et al., 2013). One article explored within group changes in internalised stigma over time but without taking confounders into consideration (Peltzer, 2012). Two articles took potential confounds into account but without analysis of change (Cloete et al., 2008; Visser & Sipsma, 2013). The remaining articles did not control for confounders or did not explicitly state the choice of confounders when predicting internalised stigma.

*Internalised stigma prevalence, observed predictors and correlates*

Prevalence of internalised stigma ranged between 26.9% and 66% (Cloete et al., 2008; Cuca et al., 2012; Kingori et al., 2013; Neuman & Obermeyer, 2013; Sorsdahl et al., 2011; Visser & Sipsma, 2013). We identified four categories of internalized stigma predictors and correlates: (1) socio-demographic, (2) HIV- and treatment-related, (3) intra-personal and (4) inter-personal factors. Each category and its correlates are described below. We report effect sizes where consistent directionality was observed between an investigated correlate and internalised stigma. We have summarized the directionality of findings for each correlate of internalised stigma in supplementary file 8.

*Socio-demographic factors*

Socio-demographic factors assessed were age (Cuca et al., 2012; Nattabi et al., 2011; Neuman & Obermeyer, 2013; Simbayi et al., 2007a; Sorsdahl, Mall, Stein, & Joska, 2011; Visser & Sipsma, 2013), gender (Nattabi et al., 2011; Neuman & Obermeyer, 2013; Simbayi et al., 2007a; Sorsdahl et al., 2011), urban household location (Neuman & Obermeyer, 2013), race (Simbayi et al., 2007b), Xhosa
language (Sorsdahl et al., 2011), educational attainment (Neuman & Obermeyer, 2013; Sorsdahl et al., 2011; Visser & Sipsma, 2013), employment status (Sorsdahl et al., 2011) and whether a woman’s main contribution to the household was housework (Cuca et al., 2012). Findings on the relationships between internalised stigma and age, gender and educational attainment produced inconsistent directionality. One study found older age to be associated with higher levels of internalised stigma (Visser & Sipsma, 2013) whereas another one found younger age to be associated with higher odds of experiencing internalised stigma (Sorsdahl et al., 2011). Two studies found a positive association between female gender and internalised stigma (Nattabi et al., 2011; Sorsdahl et al., 2011) whilst another study detected more internalised stigma among men than women (Simbayi et al., 2007b). Sorsdahl and colleagues (2011) found higher educational attainment to predict higher odds of internalised stigma, whereas Visser and Sipsma (2013) found higher educational attainment to predict lower levels of internalised stigma. No other socio-demographic factors were significant internalised stigma correlates. Overall, no consistent relationships between socio-demographic factors and internalised stigma were observed.

**HIV- and treatment-related factors**

The following variables were assessed as potential HIV- and treatment-related correlates of internalised stigma: time since diagnosis (Cloete et al., 2008; Makoae et al., 2009; Nattabi et al., 2011; Sorsdahl et al., 2011), HIV symptomatology and physical health (Holzemer et al., 2007; Kalichman et al., 2009; Simbayi et al., 2007b; Tsai et al., 2012; Wagner et al., 2013), ART use (Nattabi et al., 2011; Simbayi et al., 2007b; Wagner et al., 2013), time on ART (Nattabi et al., 2011; Pearson et al., 2009; Tsai, Bangsberg, Bwana, et al., 2013; Wagner et al., 2013), interaction of time by ART (Makoae et al., 2009), time attending healthcare facility (Nattabi et al., 2011; Simbayi et al., 2007b) and HIV-related knowledge and misconceptions (Visser et al., 2008; Visser & Sipsma, 2013). Time since diagnosis was associated with less internalised stigma in two cross-sectional studies (Simbayi et al., 2007b; Sorsdahl et al., 2011) with small effect sizes ($r=-.09$, $p<.01$ and $OR=.87$, 95% CI .80-.95, respectively).

Longitudinally, Visser & Sipsma (2013) also detected a significant decrease in internalised stigma since diagnosis over a 3-year time period. This decline became non-significant when accounting for changes in HIV knowledge and knowing someone with HIV, suggesting potential mediation effects but
mediation analysis was not conducted. Makoae et al. (2009) also found that internalised stigma decreased over time for both patients taking and not taking ART.

When compared to no ART use, ART use was not associated with internalised stigma in two cross-sectional (Nattabi et al., 2011; Simbayi et al., 2007b) and one prospective cohort study (Wagner et al., 2013). Time on ART produced inconsistent effects on internalised stigma. Longer time on ART resulted in an increase in internalised stigma in one study (Pearson et al., 2009), a U trend in another study (Peltzer, 2012) and an overall decline in a third study (Tsai, Bangsberg, Bwana, et al., 2013). Peltzer and colleagues found that internalised stigma decreased at 6 and 12 months post ART initiation but then increased to baseline levels at 20-month follow-up. Tsai et al. (2013) found that the relationship between reduction in internalised stigma and time on ART was mediated by a reduction in HIV symptoms, improved physical and mental health, and lower depression scores. However, similarly to Peltzer (2012), they found a slight upward trend in internalised stigma towards the end of the 40-month follow-up.

The interaction between time and ART use on internalised stigma also rendered inconsistent findings. Makoae and colleagues (2009) found that respondents not taking ART experienced a greater decrease in internalised stigma than those taking ART. Conversely, Wagner and colleagues (2013) found that reduction in internalised stigma over time was significantly greater in the ART group compared to the non-ART group. With physical health functioning included in the latter model, the adjusted beta weight for time by ART decreased (from $\beta = -.30$ to $\beta = -.21$), suggesting that the reductions in internalised stigma among ART users might be mediated by improved health. However the paper did not include mediation analysis.

Despite inconsistent findings on how internalised stigma changes over time on ART, indicators of poor HIV-related health and treatment outcomes were consistently associated with more internalised stigma. Specifically, HIV symptom burden weakly correlated ($r = .09-.38$) with more internalised stigma in three cross-sectional studies (Holzemer et al., 2007; Kalichman et al., 2009; Tsai et al., 2012). Poor physical health was also weakly associated with more internalised stigma in one cross-sectional (Tsai et al., 2012; $r = .24$) and one prospective cohort study (Wagner et al., 2013; $\beta = -.008$). Holzemer and
colleagues (2007) found that higher HIV-related life satisfaction and overall functioning were weakly associated with lower levels of internalised stigma ($r=-.23$ and $r=-.23$).

_Intra-personal factors_

At the intra-personal level, depression (Cuca et al., 2012; Kalichman et al., 2009; Kingori et al., 2013; Pearson et al., 2009; Tsai et al., 2012; Visser et al., 2008; Visser & Sipsma, 2013), mental health-related quality of life (Tsai et al., 2012), self-esteem (Visser et al., 2008; Visser & Sipsma, 2013), alcohol and drug use (Simbayi et al., 2007b) and the desire to have children (Nattabi et al., 2011) were assessed. Higher mental health-related quality of life was moderately associated with lower levels of internalised stigma ($r=-.38$) in one cross-sectional study (Tsai et al., 2012). Higher levels of depression were moderately associated with more internalised stigma in six cross-sectional studies ($OR=4.6$ in Cuca et al., 2012; $r=.27$ and $.31$ in Kalichman et al., 2009; $r=.35$ in Kingori et al., 2013; $r=.28$ in Tsai et al., 2012; $\beta=.179$ in Visser & Sipsma, 2013) but with lower levels of internalised stigma in one cross-sectional analysis (Pearson et al., 2009). Higher self-esteem was associated with lower levels of internalised stigma among HIV-positive women ($\beta=-.197$ in Visser & Sipsma, 2013). One study found alcohol and drug use to be weakly correlated with higher levels of internalised stigma cross-sectionally ($r=1$ and $r=.16$ respectively in Simbayi et al., 2007a).

_Inter-personal factors_

At the inter-personal level, social support (Kalichman et al., 2009; Pearson et al., 2009; Simbayi et al., 2007b; Visser & Sipsma, 2013), perceived stigma (Cuca et al., 2012; Visser & Sipsma, 2013), enacted stigma (Simbayi et al., 2007b), different types of HIV status disclosure (Cuca et al., 2012; Pearson et al., 2009; Sorsdahl et al., 2011; Visser & Sipsma, 2013), HIV status of partner (Nattabi et al., 2011), homosexual versus heterosexual preferences among men (Cloete et al., 2008) and history of sexual abuse among women (Visser & Sipsma, 2013) were assessed. Consistently, all studies assessing social support found that it was weakly associated with lower levels of internalised stigma: $r=-.32$ and $r=-.08$ in Kalichman et al. (2009); $r=-.012$ in Pearson et al. (2009); $r=-.29$ in Simbayi et al. (2007a); $r=-.11$ in Visser & Sipsma, (2013). Perceived stigma (Visser & Sipsma, 2013) and different forms of enacted stigma (Holzemer et al., 2007; Kalichman et al., 2009; Simbayi et al., 2007b) were weakly to moderately associated with higher levels of internalised stigma in bivariate cross-sectional analyses
Various aspects of serostatus disclosure were assessed. Respondents who had not disclosed their HIV status to others reported higher odds of internalised stigma in one cross-sectional study ($OR=3.11$ in Sorsdahl et al., 2011) and lower levels of internalised stigma in another ($\beta=-0.085$ in Visser and Sipsma 2013). Having disclosed one’s HIV status to fewer people was weakly associated with higher levels of internalised stigma ($r=-0.24$) cross-sectionally (Pearson et al., 2009). Pearson and colleagues (2009) also found that having disclosed to family, friends, or co-workers was associated with lower levels of internalised stigma when compared to having disclosed to other people.

**Discussion**

This review found 17 studies assessing correlates and predictors of internalised HIV stigma, representing 13 unique samples and a total of 9,088 PLHIV across nine Sub-Saharan African countries. We classified the assessed correlates and predictors of internalised stigma into four broad categories: (1) socio-demographic, (2) HIV- and treatment-related, (3) intra-personal and (4) inter-personal factors. Consistent links were found between internalised HIV stigma and poor HIV-related health outcomes, poor mental health and less social support. We additionally identified that up to two thirds of PLHIV in sub-Saharan Africa may be suffering from internalised stigma.

**Implications for research**

Studies identified by this review provide valuable indications of the correlates of internalised stigma among PLHIV in sub-Saharan Africa, and longitudinal evidence is now needed to establish causality. As is common in a nascent field, the majority of included studies were cross-sectional, resulting in suboptimal causality scores. Two thirds of included studies scored below 50% on the Cambridge Quality Checklists. However it is important to note that many of the studies received low causality scores because they did not aim to assess predictors of internalised stigma. Rather, they were designed to validate measurements of internalised stigma or to predict outcomes other than internalised stigma. Such studies utilized simple bivariate correlations with internalised stigma scores, which was sufficient for psychometric assessments and informing more complex multivariate models but not for generating robust estimates of predictors of internalised stigma. We found only one study that assessed change in internalised stigma over time at the individual level and another that assessed within-group
change in internalised stigma, whilst adequately controlling for potential confounds. Both of these studies concentrated on factors related to antiretroviral treatment. Future studies would make valuable contributions by considering predictors of internalised stigma across multiple domains, using analysis of change and accounting for alternative explanations of findings.

Future research is also needed to help resolve inconsistent directionality of findings. The present review highlights inconsistent findings on the relationship between internalised stigma and socio-demographic variables, as well as on how internalised stigma changes over time on ART. The shortage of prospective cohort studies limits our ability to resolve these discrepancies. Therefore longitudinal analysis controlling for planned confounds is urgently needed.

There were some notable gaps in the literature. In terms of high-risk populations, internalised stigma was studied only among women attending antenatal clinics and men who have sex with men. Studies assessing factors contributing to compounded stigma among populations living with HIV in sub-Saharan Africa are also needed as no known interventions tackle compounded stigma (Stangl et al., 2013). Evidence from the US suggests that high-risk behaviours linked to HIV such as same-sex intercourse and bartering sex contribute to the layering of HIV stigma (Swendeman, Rotheram-borus, Comulada, & Ramos, 2008). The only included study to assess the role of HIV risk behaviour examined the association between homosexual orientation and internalised stigma (Cloete et al., 2008). An HIV risk highly pertinent to the African context is transactional sex (Jewkes & Dunkle, 2012) and research examining links between transactional sex and internalised stigma is needed.

Internalised stigma was not assessed among children, nor among adolescents living with HIV, despite high HIV incidence and prevalence in this age group in sub-Saharan Africa (UNAIDS, 2013). This high-risk group faces unique challenges (Li et al. 2010). Adolescence is characterized by social and biological transitions, often compromising youth’s self-worth and general self-esteem (Wigfield, Eccles, Iver, Reuman, & Midgley, 1991). Self-perception of adolescents living with HIV is likely to be further threatened by difficulties associated with transition from paediatric to adult HIV care, HIV status disclosure to peers (Wiener & Battles, 2006), the shame associated with young people’s sexuality (Campbell, Nair, & Maimane, 2007), parental AIDS illness and death (Battles & Wiener, 2002; Cluver, Orkin, Boyes, Gardner, & Nikelo, 2012), and the resultant poverty, stigma and bullying victimization
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(Cluver & Orkin, 2009). Longitudinal evidence also suggests that adolescents who have lost a parent due to AIDS are at heightened risk of psychological distress due to stigma-by-association (Boyes & Cluver, 2013). Therefore it is essential to investigate internalised stigma in this high-risk age group, particularly as African epidemics witness the first generation of perinatally infected children entering adolescence due to the late rollout of ART in the region (Ferrand, Corbett, Wood, Hargrove, & Chiratidzo, 2012). Given that HIV transmission in sub-Saharan Africa is driven by heterosexual intercourse and mother-to-child transmission (UNAIDS, 2010), research is needed to assess the differing levels of internalised stigma among perinatally versus postnatally-infected child and adolescent populations to inform targeted intervention design.

No studies assessed how poverty relates to internalised stigma. Both Peltzer and Tsai et al. discuss the potential role of poverty in limiting longitudinal reductions in internalised stigma. Having found increases in internalised stigma after initial declines over time on treatment, Tsai et al. argue that asset depletion might cause a floor effect in stigma reduction. Similarly, Peltzer suggests that persistent treatment-related costs and loss of the disability grants due to improved clinical outcomes might compromise health-related quality of life in South Africa. In the context of sub-Saharan Africa, poverty might exclude HIV-positive people from local ‘solidarity networks’ by undermining their ability to maintain economic contributions to community life (Tsai, Bangsberg, & Weiser, 2013). Poverty might also perpetuate stigmatization by undermining adherence to treatment, for instance due to food shortage (Kalichman & Grebler, 2010), thereby resulting in worsened health outcomes and symptom visibility. A similar mechanism might exist between lack of access to healthcare and stigma. Future studies should therefore examine the relationship between material and service deprivation and HIV stigmas.

Associations between internalised stigma and perceived and enacted stigma were only assessed in three papers through bivariate correlations. These relationships should be further examined through robust analyses to inform theory.

**Implications for practice**

This review identified only a limited number of studies on predictors of internalised stigma, and much of the evidence was cross-sectional which precludes the determination of casual risk factors. However, we did find consistent evidence on the relationship between internalised stigma and poor
HIV-related health, poor mental health, and low social support. All of these findings are also supported by evidence from the United States (Lee et al., 2002). With this reasonable level of evidence, we have identified four recommendations for practice that may contribute to achieving the 2015 target to eliminate HIV/AIDS stigma (UNAIDS, 2011).

1. **Addressing factors, other than ART, that contribute to the physical and mental health of people living with HIV may help reduce internalised stigma.** Our findings suggest that ART access, although necessary, is not sufficient to reduce internalised HIV stigma. Sub-Saharan Africa has achieved remarkable progress in ART coverage in the past decade. However, there is a clear need to translate ART use into optimal physical and psychological outcomes. We found that higher HIV symptom burden and poorer physical health were consistently associated with more internalised stigma, suggesting that manifestations of health problems contribute to HIV-related shame. This seems to be irrespective of ART access because ART use alone was not associated with reductions in internalised stigma when compared to non-use. One of the most rigorous studies included in this review found that the reductions in internalised stigma over time on ART were driven by improvements in HIV symptom burden, physical health, cognitive functioning and depression (Tsai, Bangsberg, Bwana, et al., 2013). In light of these findings, enhancing other factors that contribute to the physical health and psychological wellbeing of people living with HIV might also help reduce internalised stigma. These factors include ART adherence (Gross et al., 2006), prevention of co-infections (Lawn, 2004) and food security (Anema, Vogenthaler, Frongillo, Kadiyala, & Weiser, 2009).

2. **There is an important need for psychological support for PLHIV.** Several included studies point to associations between poor mental health and higher levels of internalised stigma. Specifically, higher levels of depression were related to more internalised stigma in five out of six studies exploring this association. Similarly, alcohol and drug use, poor mental health-related quality of life and low self-esteem were associated with more internalised stigma. However, the link between other mental health indicators and internalised stigma must be interpreted with caution due to the strong likelihood of bidirectionality. Moreover, given that both internalised stigma and mental health indicators were measured via self-report, there is risk of method overlap bias. Nevertheless, these
observations suggest that internalised stigma occurs within a syndemic of a number of psychological challenges, highlighting the need for psychological support for PLHIV.

3. **In addition to clinic-based interventions, family- and community-level interventions might be suitable for tackling internalised stigma through enhanced social support.** To our knowledge, interventions targeting internalised HIV stigma in sub-Saharan Africa were investigated only within healthcare facilities (Tshabalala & Visser, 2011; Uys et al., 2009). However we found a consistent association between perceived social support and lower internalised stigma, which suggests that enhancing the broader social support systems of PLHIV might contribute to the reduction of internalised stigma.

4. **Internalised HIV stigma is salient and warrants more programmatic attention.** Prevalence of internalised stigma in included studies was high: 26.9% - 66%. By contrast, only two interventions targeting internalised stigma have been evaluated in Sub-Saharan Africa. Interventions should aim to address correlates of internalised stigma identified by this review and in future studies, and be evaluated ideally through randomized control trials.

*Limitations*

Due to resource constraints, we were only able to search records written in English. The review focused on observational studies, and future randomized trials will be valuable in increasing capacity for causality inference (Smith & Ebrahim, 2002). However, the current shortage of randomized trials to reduce internalised stigma in sub-Saharan Africa (Stangl et al., 2013) rendered a review of observational studies necessary. Furthermore, a meta-analysis was not conducted as diversity between studies and cross-sectional findings limit inferences about causality and strength of effect.

*Conclusions*

Research on predictors of internalised HIV stigma in sub-Saharan Africa is in its early stages. Therefore this review generated a wide range of implications for research, with more tentative implications for practice. With only a year remaining before the 2015 target for eliminating HIV stigma, the extent of the problem remains large: included studies suggest that up to two thirds of PLHIV in sub-Saharan Africa are experiencing internalised stigma. More foundational research to inform interventions is urgently needed. In particular future studies can contribute to this field by utilizing
analyses of change and accounting for planned, literature-informed confounds. It is necessary to carry out studies on high-risk populations, different modes of HIV transmission, other stigma markers that might layer upon internalised stigma, and drivers of internalised stigma at multiple levels. Improving the physical health, psychological wellbeing and social support systems of PLHIV might contribute to the reduction of internalised HIV stigma. However such efforts must be coupled with rigorous process and outcome evaluations.

**Authors’ contributions:**

MP conceptualized the study, led the systematic review process, developed and implemented the search strategy, led the title, abstract, full-text review and data extraction process, conducted the quality assessment and drafted the first version of this article. YS contributed to the development of the search strategy, data extraction, quality assessment, write-up and interpretation of findings. LC contributed to the conceptualization of the study and write-up. MB contributed to the write-up and interpretation of findings.

**Acknowledgements:**

We would like to thank authors of primary studies included in this review for pioneering crucial work on internalised HIV/AIDS stigma in sub-Saharan Africa. We are also grateful for the assistance from researchers who have supplied the additional information and references needed to complete this review, in particular Alexander Tsai, Yvette Cuca, Eme Owoaye, Cynthia Pearson, Maretha Visser, Leickness Simbayi, Seth Kalichman, Michael Evangeli, Nuala McGrath and Cilna de Kock.
SYSTEMATIC REVIEW OF PREDICTORS OF INTERNALISED HIV STIGMA IN SUB-SAHARAN AFRICA

References


Table 1 Summary of included studies

<table>
<thead>
<tr>
<th>First author, year</th>
<th>Location</th>
<th>Primary outcome</th>
<th>Target population</th>
<th>n</th>
<th>% Female</th>
<th>Study design</th>
<th>CQC score</th>
<th>Predictors/correlates of internalised stigma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simbayi, 2007</td>
<td>South Africa</td>
<td>N</td>
<td>Adults</td>
<td>1063</td>
<td>60.5</td>
<td>CS</td>
<td>39%</td>
<td>Male gender ($d=.26$, $p&lt;.01$)</td>
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<td>39%</td>
<td>Age (NS)</td>
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<td>39%</td>
<td>Race (NS)</td>
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<td>39%</td>
<td>Discrimination/enacted stigma ($r=.31$, $p&lt;.001$)</td>
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<td>39%</td>
<td>Low social support ($r=-.29$, $p&lt;.01$)</td>
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<td>39%</td>
<td>Alcohol use ($r=.1$, $p&lt;.01$)</td>
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<td>Drug use ($r=.16$, $p&lt;.01$)</td>
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<td>39%</td>
<td>Fewer years HIV+ ($r=-.09$, $p&lt;.01$)</td>
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<td>39%</td>
<td>ART use (NS)</td>
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<tr>
<td>Holzemer, 2007</td>
<td>LeSotho, Malawi, Swaziland, Tanzania</td>
<td>P</td>
<td>Adults</td>
<td>1477</td>
<td>74.1</td>
<td>CS</td>
<td>35%</td>
<td>HIV symptoms ($r=-.09$, $p&lt;.05$)</td>
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<td>35%</td>
<td>Life satisfaction ($r=-.23$, $p&lt;.05$)</td>
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<td>Overall functioning ($r=-.23$, $p&lt;.05$)</td>
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<td>35%</td>
<td>Enacted stigma: social isolation ($r=-.42$, $p&lt;.05$)</td>
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<td>35%</td>
<td>Enacted stigma: fear of contagion ($r=.24$, $p&lt;.05$)</td>
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<td>35%</td>
<td>Enacted stigma: workplace stigma ($r=.17$, $p&lt;.05$)</td>
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<td></td>
<td>35%</td>
<td>Enacted stigma: healthcare neglect ($r=.23$, $p&lt;.05$)</td>
</tr>
<tr>
<td>Visser, 2008</td>
<td>South Africa</td>
<td>P</td>
<td>Women</td>
<td>317</td>
<td>100</td>
<td>CS</td>
<td>To avoid data duplication, estimates from Visser 2013 were extracted as it reported findings from a larger sample size</td>
<td></td>
</tr>
<tr>
<td>Cloete, 2008</td>
<td>South Africa</td>
<td>Y</td>
<td>MSM and MSW</td>
<td>422</td>
<td>0</td>
<td>CS</td>
<td>43%</td>
<td>MSM versus MSW (NS)</td>
</tr>
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<td>Kalichman, 2009</td>
<td>South Africa sample</td>
<td>P</td>
<td>Adults</td>
<td>1068</td>
<td>61</td>
<td>CS</td>
<td>44%</td>
<td>Depression ($r=.27$, $p&lt;.01$)</td>
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<td>44%</td>
<td>Social support ($r=-.32$, $p&lt;.01$)</td>
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<td>44%</td>
<td>HIV symptoms (NS)</td>
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<td></td>
<td>44%</td>
<td>Enacted stigma (discrimination) ($d=.43$, $p&lt;.01$)</td>
</tr>
<tr>
<td>Kalichman, 2009</td>
<td>Swaziland sample</td>
<td>P</td>
<td>Adults</td>
<td>1087</td>
<td>67</td>
<td>CS</td>
<td>44%</td>
<td>Depression ($r=.31$, $p&lt;.01$)</td>
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<td>44%</td>
<td>Social support ($r=-.08$, $p&lt;.05$)</td>
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<td>44%</td>
<td>HIV symptoms ($r=.18$, $p&lt;.01$)</td>
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<td>44%</td>
<td>Enacted stigma (discrimination) (NS)</td>
</tr>
<tr>
<td>First author, year</td>
<td>Location</td>
<td>Primary outcome</td>
<td>Target population</td>
<td>n</td>
<td>% Female</td>
<td>Study design</td>
<td>CQC score</td>
<td>Predictors/correlates of internalised stigma</td>
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<td>Makoae, 2009</td>
<td>Lesotho, Malawi, South Africa, Swaziland and Tanzania</td>
<td>Adults</td>
<td>1454</td>
<td>54.2 non ART takers; 45.7 ART takers</td>
<td>PCS 61%</td>
<td>Time – internalised stigma significantly decreased over time for everyone, both on ARVs and not ($d=49, p&lt;.001$) Time by ARV use- those taking ARV’s showed significantly less reduction in internalised stigma ($d=.18, p&lt;.05$)</td>
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<td>Pearson, 2009</td>
<td>Mozambique</td>
<td>Adults initiating ART</td>
<td>277</td>
<td>56.3</td>
<td>PCS 74%</td>
<td>Time: internalised stigma significantly increased over time from ART initiation ($r=4.49, p&lt;.001$) Lower depression ($r=-0.13, p&lt;.05$) Lower perceived social support ($r=-0.12, p&lt;.05$) Fewer people disclosed to ($r=-0.24, p&lt;.001$) Disclosure to family member - compared to others ($t=3.41, p&lt;.001$) Disclosure to friend- compared to others ($t=4.21, p&lt;.001$) Disclosure to coworker- compared to others ($r=3.01, p&lt;.01$) Disclosure to spouse or partner (NS)</td>
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<tr>
<td>Nattabi, 2011</td>
<td>Uganda</td>
<td>People aged 15-49</td>
<td>497</td>
<td>50</td>
<td>CS 48%</td>
<td>Age group (30 used as cutoff for dichotomous variable) (NS) Female gender ($r=.09, p&lt;.05$) HIV status of partner (NS) Months on HAART (NS) Months since HIV diagnosis (NS) Months attending HIV clinic (NS) Desire more children (NS) HAART use (NS)</td>
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<tr>
<td>Sorsdahl, 2011</td>
<td>South Africa</td>
<td>Adults</td>
<td>400</td>
<td>78.5</td>
<td>CS 48%</td>
<td>Younger age ($OR=.95, p&lt;.001$) Female gender ($OR=.59, p&lt;.05$) Xhosa language (NS) Years of education ($OR=1.26, p&lt;.01$) Employment (NS) Shorter time of knowing HIV status ($OR=.87, p&lt;.001$) Lack of disclosure ($OR=3.11, p&lt;.05$)</td>
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<tr>
<td>Peltzer, 2012</td>
<td>South Africa</td>
<td>Adults</td>
<td>499</td>
<td>70.5</td>
<td>CS 61%</td>
<td>Time on ART ($d=0.29, p&lt;.01$)</td>
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<tr>
<td>Tsai, 2012</td>
<td>Uganda</td>
<td>Adults</td>
<td>456</td>
<td>69.5</td>
<td>CS 39%</td>
<td>Depression symptom severity ($r=.28, p&lt;.05$) Mental health related quality of life ($r=-.38, p&lt;.05$) HIV symptom burden ($r=-.38, p&lt;.05$) Physical health related quality of life ($r=-.24, p&lt;.05$)</td>
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<tr>
<td>First author, Location</td>
<td>Year</td>
<td>Primary outcome</td>
<td>Target population</td>
<td>n</td>
<td>% Female</td>
<td>Study design</td>
<td>CQC score</td>
<td>Predictors/correlates of internalised stigma</td>
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<td>Wagner, 2012 Uganda</td>
<td></td>
<td>Y Adults</td>
<td>602</td>
<td>68</td>
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<td>PCS</td>
<td>83%</td>
<td>ART use (NS)</td>
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<td>83%</td>
<td>Time on ART (NS)</td>
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<td></td>
<td>83%</td>
<td>Time by ART use ($\beta$=-.30, $p&lt;.001$)</td>
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<td>83%</td>
<td>Change in physical health functioning ($\beta$=-.008, $p&lt;.001$)</td>
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<tr>
<td>Cuca, 2012 Kenya</td>
<td></td>
<td>Y Pregnant women</td>
<td>147</td>
<td>100</td>
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<td>CS</td>
<td>52%</td>
<td>Age (25 cutoff used) (NS)</td>
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<td>52%</td>
<td>Woman's major contribution to support household is housework (NS)</td>
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<td>52%</td>
<td>Family knows HIV+ status (NS)</td>
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<td>52%</td>
<td>Perceives community stigma (NS)</td>
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<td></td>
<td>52%</td>
<td>Post partum depression ($OR=4.6, 95% CI: 1.7, 12.9, $p&lt;.01$)</td>
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<tr>
<td>Neuman, 2013 Burkina Faso, Kenya, Malawi, Uganda</td>
<td></td>
<td>N Adults</td>
<td>536</td>
<td>67.4</td>
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<td>39%</td>
<td>Female gender (NS)</td>
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<td>39%</td>
<td>Age (categorized into three age groups) (NS)</td>
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<td>39%</td>
<td>Educational attainment (NS)</td>
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<td></td>
<td></td>
<td>39%</td>
<td>Urban location (NS)</td>
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<tr>
<td>Kingori, 2013 Kenya</td>
<td></td>
<td>P Adults</td>
<td>370</td>
<td>60.4</td>
<td></td>
<td>CS</td>
<td>35%</td>
<td>Depression ($r=.345, p&lt;.000$)</td>
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<td>Tsai, 2013 Uganda</td>
<td></td>
<td>Y Adults</td>
<td>262</td>
<td>66</td>
<td></td>
<td>PCS</td>
<td>83%</td>
<td>Time on ART ($d=.70, p&lt;.05$), mediated by reduced HIV-related symptoms, improved physical and mental health, and lower depression scores</td>
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<tr>
<td>Visser, 2013 South Africa</td>
<td></td>
<td>Y Pregnant women</td>
<td>609</td>
<td>100</td>
<td></td>
<td>CS</td>
<td>43%</td>
<td>Attributed stigma (perceive other people in community to be highly stigmatizing) ($r=.334, p&lt;.01$)</td>
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<td></td>
<td>57%</td>
<td>Older age ($\beta=.123, p&lt;.01$)</td>
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<td>57%</td>
<td>Lower educational attainment ($\beta=-.115, p&lt;.01$)</td>
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<td>57%</td>
<td>Victim of sexual violence (NS)</td>
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<td></td>
<td>57%</td>
<td>Disclosed HIV status ($\beta=-.085, p&lt;.05$)</td>
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<td>57%</td>
<td>HIV knowledge (NS)</td>
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<td></td>
<td>57%</td>
<td>Low self-esteem ($\beta=-.197, p&lt;.01$)</td>
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<td>57%</td>
<td>Depression ($\beta=.179, p&lt;.01$)</td>
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<td>57%</td>
<td>Low social support ($\beta=-.114, p&lt;.01$)</td>
</tr>
</tbody>
</table>

Notes:
- In the 'Primary outcome' column, 'Y' indicates that internalised stigma was a primary outcome of interest, 'N' indicates that an outcome other than internalised stigma was primary and 'P' indicates that the study was a psychometric assessment of an internalised stigma measurement.
- CS indicates a cross-sectional study design; PCS indicates a prospective cohort study design.
- In the 'Predictors of internalised stigma column, 'NS' indicates non significant association ($p>.5$).
- 100% would indicate the maximum possible score of 23; decimals were rounded up to the nearest whole percent.
SYSTEMATIC REVIEW OF PREDICTORS OF INTERNALISED HIV STIGMA IN SUB-SAHARAN AFRICA

Figure 1 PRISMA flow diagram