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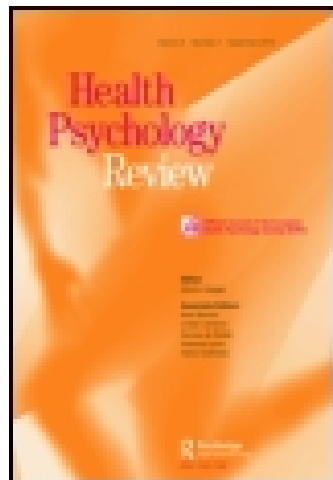


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Predictors of internalised HIV-related stigma: a systematic review of studies in Sub-Saharan Africa

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SYSTEMATIC REVIEW OF PREDICTORS OF INTERNALISED HIV STIGMA IN SUB-SAHARAN AFRICA

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PREDICTORS 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 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 590 potentially relevant titles were identified. Seventeen peer-reviewed articles and one draft book chapter were included. Studies investigated socio-demographic, HIV-related, intra-personal and inter-personal correlates of internalised stigma. Eleven articles used cross-sectional data, six articles used prospective cohort data and one used both prospective cohort and cross-sectional data to assess correlates of internalised stigma. Poor HIV-related health weakly predicted increases in internalized HIV stigma in three longitudinal studies. Lower depression scores and improvements in overall mental health predicted reductions in internalized HIV stigma in two longitudinal studies, with moderate and weak effects respectively. No other consistent predictors were found.

Conclusion: Studies utilizing analysis of change and accounting for confounding factors are necessary to guide policy and programming but are scarce. 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 (Link, Cullen, Struening, Shrout, & Bruce, 1989; Link, 1987).. Internalised stigma is characterised by feelings of shame, guilt, worthlessness and difficulties around HIV status disclosure (Lee, Kochman, & Sikkema, 2002; Tsai et al., 2012).

Following labelling theory (Link et al., 1989; Scheff, 1966), people typically develop perceptions about public attitudes towards HIV prior to their own HIV diagnosis or ART initiation. Labels such as an HIV diagnosis or ART initiation may therefore result in ‘internalized expectations of rejection’ (Link, 1987). Internalized stigma can have detrimental public health consequences through two social psychological mechanisms (Link et al., 1989). First, HIV-positive individuals may devalue themselves because ‘they now belong to a category that they believe most people view negatively’ (Link, 1987). Second, by fuelling fear of rejection from others, internalized stigma may lead to harmful responses such as secrecy, withdrawal and isolation. In line with this, longitudinal evidence from Uganda suggests that internalised stigma predicts non-disclosure of HIV status (Tsai, Bangsberg, Kegeles, et al., 2013). Non-disclosure has in turn been linked to increased HIV risk behaviours (Simbayi et al., 2007a). Systematic review-level evidence also suggests that internalized HIV stigma hinders adherence to antiretroviral treatment (ART) (Katz et al., 2013), which is essential for preventing virological failure (Gross et al., 2006), delaying mortality (Lima et al., 2009) and reducing HIV transmission (Loutfy et al., 2013).

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

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only two interventions targeting internalised HIV stigma in Sub-Saharan Africa (Stangl et al., 2013). Both interventions aimed to improve coping through empowerment and knowledge building. Uys et al. (2009) used a multiple-case study approach to evaluate 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. These programs did not follow an implementation manual. Rather, they were each designed, implemented and evaluated by teams who had undergone a 2-day 'project initiation workshop'.

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; Gilmore & Somerville, 1994; 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 (Fraser, Richman, Galinsky, & Day, 2009). 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, the hypothesized exposure variables in this study did not meet the temporal requirement of predictor variables. Moreover, we should also be

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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, Hispanics and African Americans (CDC, 2013; Katiria Perez & Cruess, 2014). 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. We hope that this review of observational studies will advance theory and inform intervention development in Sub-Saharan Africa. Preliminary literature searches detected few studies that used prospective cohort data and would meet the temporal requirements of predictor variables. Therefore this review also included cross-sectional studies that specified internalised HIV stigma as the dependent variable. It is important to note that such studies were not methodologically equipped to determine predictors but rather correlates of internalised stigma. They were included so as to advance theory and hypothesize predictors to be assessed in future longitudinal research. Cross-sectional studies considering internalized HIV stigma as an independent variable were excluded from this review due to lack of theory to hypothesize that these correlates might be predictors of internalized stigma. More 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, Tetzlaff, & 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.

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The PROSPERO register of systematic reviews was also searched. Final searches were conducted April 1st 2014. 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.

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. To score highest among observational studies, models have to assess within-individual change in internalised stigma and control for relevant confounding variables.

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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

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The search process identified 590 potentially relevant articles and reports. Of these, 262 titles were generated through the database search and 328 titles were generated through harvesting references and communicating with authors. After removing duplicates, 495 abstracts were retained for further review (Figure 1). Next, 38 titles were selected for full-text review. Finally, a total of 18 studies, including 17 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 18 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; Makoe et al., 2009; Simbayi et al., 2007b).

Ten 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 (Makoe et al., 2009) did not specify the age range of the sample.

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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

Six articles reported on prospective cohort data (Cuca et al., 2012; Makoe et al., 2009; Peltzer, 2012; Tsai, Bangsberg, Bwana, et al., 2013; Wagner, Ghosh-Dastidar, Garnett, Kityo, & Mugenyi, 2013) and one reported on 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 ($n \geq 400$). 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 fourteen did not report a method for selection. None of the studies reported total or random sampling of facilities.

Within facilities, five studies used total or random sampling of participants (Cuca et al., 2012; Pearson et al., 2009; Takada et al., 2014; Tsai, Bangsberg, Bwana, 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 seven 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; Takada et al., 2014; Tsai et al., 2012; Tsai, Bangsberg, Bwana, et al., 2013). Five articles (Cuca et al., 2012; Holzemer et al., 2007; Makoe 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

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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 underwent some assessment of construct validity (i.e. correlations with theoretically linked constructs). One article additionally reported assessing face validity of the internalized stigma measurement through expert review (Kingori et al., 2013). One article tested measurement invariance (both configural and metric) (Holzemer et al., 2007). One article reported use of non-parametric equality-of-medians tests (Tsai et al., 2012). Thirteen articles reported high measurement reliability for internalised stigma, with alphas at or above .70 and one article reported reliability below .70 (Neuman & Obermeyer, 2013). However, given that the latter measurement consisted of only two items, Cronbach's alpha <.70 might be a result of the measure's brevity. 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 $\geq 70\%$ (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%. Ten articles did not report response or retention rates.

Causality scores

Only two articles assessed within-individual change in internalised stigma over time whilst taking into consideration potential confounding variables (Takada et al., 2014; Tsai, Bangsberg, Bwana, 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 without taking confounders into consideration (Peltzer, 2012). Two articles took potential confounds into account 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

Reports of any indicators 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., 2007b; Sorsdahl et al., 2011; Takada et al., 2014; Visser & Sipsma, 2013), gender (Nattabi et al., 2011; Neuman & Obermeyer, 2013; Simbayi et al., 2007b; Sorsdahl et al., 2011; Takada et al., 2014), 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; Takada et al., 2014; Visser & Sipsma, 2013), employment status (Sorsdahl et al., 2011), marital status (Takada et al., 2014) 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), another one found younger age to be associated with higher odds of experiencing internalised stigma (Sorsdahl et al., 2011) and another found no significant association (Takada et al., 2014). Two studies found a positive association between female gender and internalised stigma (Nattabi et al., 2011; Sorsdahl et al., 2011). Another study detected more internalised stigma among men than women (Simbayi et al., 2007b). One study found no relationship between gender and internalised stigma (Takada et al., 2014). Sorsdahl and colleagues (2011) found higher educational attainment to predict higher odds of

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internalised stigma, whereas Visser and Sipsma (2013) found higher educational attainment to predict lower levels of internalised stigma. Takada and colleagues (2014) found no relationship between educational attainment and 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; Takada et al., 2014; Tsai et al., 2012; Tsai, Bangsberg, Bwana, 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. Makoe 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 two prospective cohort studies (Takada et al., 2014, $\beta = -0.018$; Wagner et al., 2013, $\beta = -0.008$). 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; Takada et al., 2014; 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

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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) and with lower levels of internalised stigma in one cross-sectional analysis (Pearson et al., 2009). One prospective cohort study found a weak relationship between poor mental health and internalized stigma with an adjusted incidence rate ratio of $.79$ (Tsai, Bangsberg, Bwana, et al., 2013). Another prospective cohort study found a moderate relationship ($\beta=0.49$, $p<.001$) between clinical depression and increases in internalized stigma over time (Takada et al., 2014). 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; Takada et al., 2014; 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. All cross-sectional 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); $r=-0.12$ in Pearson et al. (2009); $r=-.29$ in Simbayi et al. (2007a); $r=-.11$ in Visser & Sipsma, (2013). However, the only prospective cohort study assessing whether social support predicts changes in internalised stigma over time found no significant relationship between emotional and tangible social support and internalized stigma (Takada et al., 2014). 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 ($r=.17-.42$).

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 included 7 papers on predictors and 11 papers on correlates of internalised HIV stigma. These papers represented 13 unique samples and a total of 9,088 PLHIV across nine Sub-Saharan African countries. Of the factors that were analysed longitudinally:

- 1. ART use did not significantly influence internalized HIV stigma in the only study that examined this predictor prospectively.**
- 2. Improved physical health (measured as improved physical functioning and fewer HIV-related symptoms) weakly predicted reductions in internalized HIV stigma in three longitudinal studies.** One of these studies tested a lagged mediation model in which fewer HIV-related symptoms and improved physical health mediated the relationship between time on ART and reduced internalised stigma.
- 3. Lower depression scores and improvements in overall mental health predicted reductions in internalized HIV stigma in two longitudinal studies, with moderate and weak effects respectively.** One of these studies tested a lagged mediation model, which suggested that the decrease of internalised stigma over time on ART was mediated via improved mental health (in addition to improved physical health as summarized above).
- 4. Time on ART produced inconsistent findings.** Internalized HIV stigma decreased over time in two studies, increased over time in another two studies, initially decreased but then returned to baseline levels in one study and produced non-significant effects in one study.
- 5. The interaction of time and ART use produced inconsistent findings.** One study found that internalized stigma decreased more over time for those on ART, compared to those not on ART.

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Another study found the opposite trend: internalized stigma decreased more for those not on ART, compared to those on ART.

Implications for research

As is common in a nascent field, the majority of included studies were cross-sectional, with two thirds of included studies scoring below 50% on the Cambridge Quality Checklists. Longitudinal evidence is now needed to establish causality. 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. More prospective longitudinal studies with analyses controlling for planned confounds are needed to resolve these discrepancies.

Some of the noted discrepancies in findings might be a reflection of the differing ways in which internalized stigma was measured. Given that stigma manifestations are culturally and socially embedded, it would be difficult to use a single measurement across sub-Saharan Africa. Future studies would benefit from using tools with strong psychometric properties. However, a recent systematic review on psychometric properties of internalized stigma measurements confirmed that such tools are scarce (Stevenson, Wu, Voorend, & Brakel, 2012). More reliable stigma measurement tools relevant to the African contexts are 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,

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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 (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 potentially differing pathways to internalised stigma among perinatally versus postnatally-infected child and adolescent populations.

No studies assessed how poverty relates to internalised HIV stigma. Two included papers discussed the potential role of poverty in limiting longitudinal reductions in internalised stigma (Peltzer, 2012; Tsai, Bangsberg, Bwana, et al., 2013). Having found increases in internalised stigma after initial declines over time on treatment, Tsai et al. (2013) argue that asset depletion might cause a floor effect in stigma reduction. Similarly, Peltzer (2012) 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

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exist between lack of access to healthcare and stigma. Future studies should therefore examine potential causal relationships 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.

Limitations

The search did not include any language restrictions, but due to resource constraints, we were only able to include records written in English. However, our search did not detect any relevant non-English papers. 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.

Given that this review focused on *predictors* of internalised stigma, only studies that assessed internalised stigma as a dependent variable were included. This resulted in the omission of a considerable amount of cross-sectional work on correlates of internalized stigma. However, such studies were excluded because they hypothesized internalized stigma to be a cause (rather than effect) of the correlates under scrutiny. Findings from such studies by definition lack the needed theoretical underpinning to generate hypotheses about predictors of internalized stigma.

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 no firm implications for practice. With only a year remaining before the 2015 target for eliminating HIV stigma, internalized stigma continues to be a problem. More foundational, longitudinal research is urgently needed to inform understanding of the causal paths and design interventions. 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

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stigma markers that might layer upon internalised stigma, and drivers of internalised stigma at multiple levels. Based on findings from this review, improving the physical health and psychological wellbeing of PLHIV might contribute to slight reductions in internalised HIV stigma. However, it is essential that further research establishes additional effective interventions.

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.

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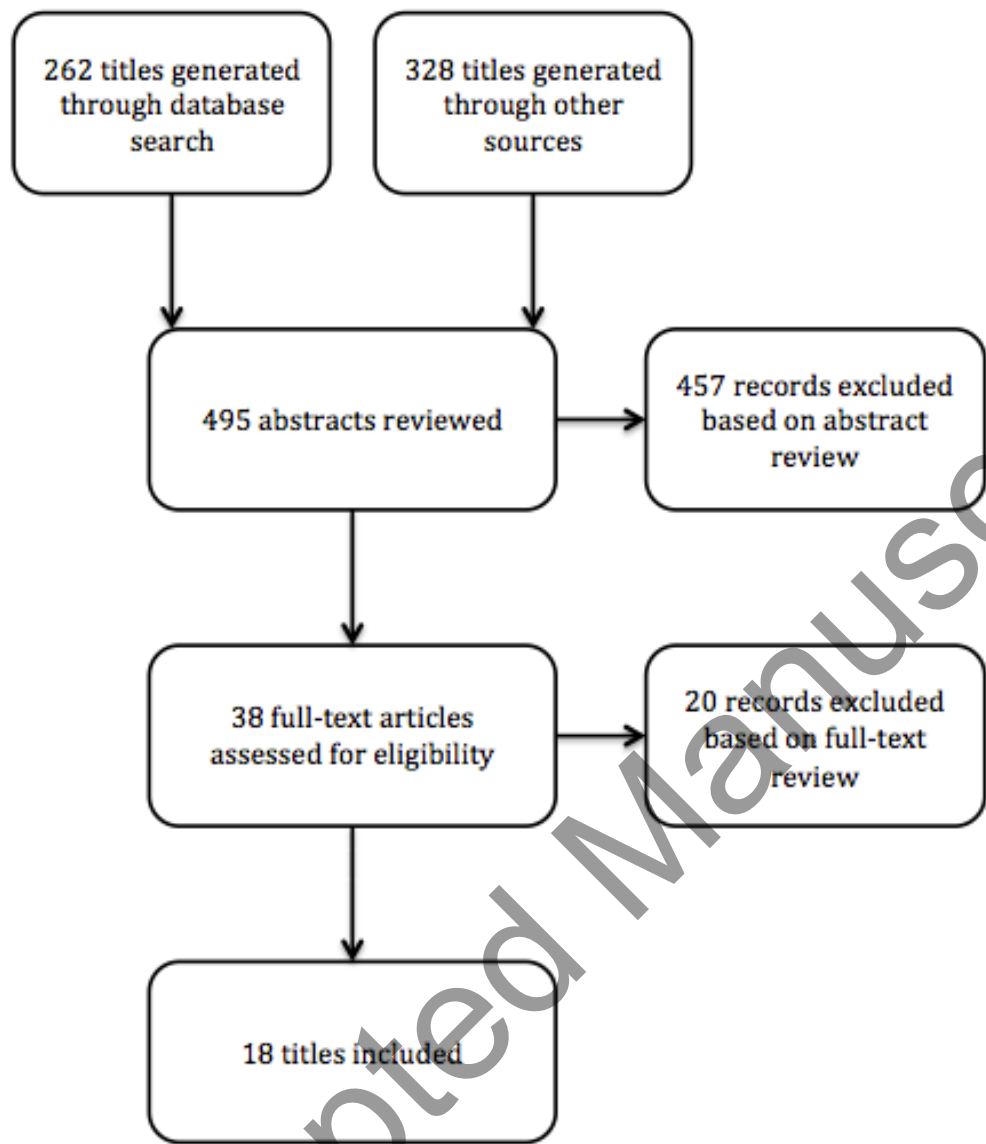
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Figure 1 PRISMA flow diagram



SYSTEMATIC REVIEW OF PREDICTORS OF INTERNALISED HIV STIGMA IN SUB-SAHARAN AFRICA

Table 1 Summary of included studies

First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC score ¹	Predictors/correlates of internalised stigma
Simbayi, 2007	South Africa	N	Adults	1063	60.5	CS	39% 39% 39% 39% 39% 39% 39% 39% 39% 39%	Male gender ($d=.26, p<.01$) Age (NS) Race (NS) Discrimination/enacted stigma ($r=.31, p<.001$) Low social support ($r=-.29, p<.01$) Alcohol use ($r=.1, p<.01$) Drug use ($r=.16, p<.01$) Fewer years HIV+ ($r=-.09, p<.01$) HIV symptoms (NS) ART use (NS)
Holzemer, 2007	Lesotho, Malawi, South Africa, Swaziland, Tanzania	P	Adults	1477	74.1	CS	35% 35% 35% 35% 35% 35%	HIV symptoms ($r=.09, p<.05$) Life satisfaction ($r=-.23, p<.05$) Overall functioning ($r=-.23, p<.05$) Enacted stigma: social isolation ($r=.42, p<.05$) Enacted stigma: fear of contagion ($r=.24, p<.05$) Enacted stigma: workplace stigma ($r=.17, p<.05$) Enacted stigma: healthcare neglect ($r=.23, p<.05$)
Visser, 2008	South Africa	P	Women	317	100	CS	<i>To avoid data duplication, estimates from Visser 2013 were extracted as it reported findings from a larger sample size</i>	
Cloete, 2008	South Africa	Y	MSM and MSW	422	0	CS	43%	MSM versus MSW (NS)
Kalichman, 2009	South Africa sample	P	Adults	1068	61	CS	44% 44% 44% 44%	Depression ($r=.27, p<.01$) Social support ($r=-.32, p<.01$) HIV symptoms (NS) Enacted stigma (discrimination) ($d=.43, p<.01$)
Kalichman, 2009	Swaziland sample			1087	67		44% 44% 44% 44%	Depression ($r=.31, p<.01$) Social support ($r=-.08, p<.05$) HIV symptoms ($r=.18, p<.01$) Enacted stigma (discrimination) (NS)

SYSTEMATIC REVIEW OF PREDICTORS OF INTERNALISED HIV STIGMA IN SUB-SAHARAN AFRICA

First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC score ¹	Predictors/correlates of internalised stigma
Makoae, 2009	Lesotho, Malawi, South Africa, Swaziland and Tanzania	Y	Adults	1454	54.2 non ART takers; 45.7 ART takers	PCS	61% 61%	Time – internalised stigma significantly decreased over time for everyone, both on ARVs and not ($d=49, p<.001$) Time by ARV use- those taking ARV's showed significantly less reduction in internalised stigma ($d=.18, p<.05$)
Pearson, 2009	Mozambique	N	Adults initiating ART	277	56.3	PCS	74% 57% 57% 57% 57% 57% 57%	Time: internalised stigma significantly increased over time from ART initiation ($t=4.49, p<.001$) Lower depression ($r=-0.13, p<.05$) Lower perceived social support ($r=-0.12, p<.05$) Fewer people disclosed to ($r=-0.24, p<.001$) Disclosure to family member - compared to others ($t=3.41, p<.001$) Disclosure to friend- compared to others ($t=4.21, p<.001$) Disclosure to coworker- compared to others ($t=3.01, p<.01$) Disclosure to spouse or partner (<i>NS</i>)
Nattabi, 2011	Uganda	Y	People aged 15-49	497	50	CS	48% 48% 48% 48% 48% 48% 48%	Age group (30 used as cutoff for dichotomous variable) (<i>NS</i>) Female gender ($r=.09, p<.05$) HIV status of partner (<i>NS</i>) Months on HAART (<i>NS</i>) Months since HIV diagnosis (<i>NS</i>) Months attending HIV clinic (<i>NS</i>) Desire more children (<i>NS</i>) HAART use (<i>NS</i>)
Sorsdahl, 2011	South Africa	Y	Adults	400	78.5	CS	48% 48% 48% 48% 48% 48%	Younger age ($OR=.95, p<.001$) Female gender ($OR=.59, p<.05$) Xhosa language (<i>NS</i>) Years of education ($OR=1.26, p<.01$) Employment (<i>NS</i>) Shorter time of knowing HIV status ($OR=.87, p<.001$) Lack of disclosure ($OR=3.11, p<.05$)
Peltzer, 2012	South Africa	Y	Adults	499	70.5	CS	61%	Time on ART ($d=0.29, p<.01$)
Tsai, 2012	Uganda	P	Adults	456	69.5	CS	39% 39% 39% 39%	Depression symptom severity ($r=.28, p<.05$) Mental health related quality of life ($r=-.38, p<.05$) HIV symptom burden ($r=.38, p<.05$) Physical health related quality of life ($r=-.24, p<.05$)

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First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC score ¹	Predictors/correlates of internalised stigma
Wagner, 2012	Uganda	Y	Adults	602	68	PCS	83% 83% 83% 83%	ART use (<i>NS</i>) Time on ART (<i>NS</i>) Time by ART use ($\beta = -.30, p < .001$) Change in physical health functioning ($\beta = -.008, p < .001$)
Cuca, 2012	Kenya	Y	Pregnant women	147	100	CS	52% 52% 52% 52% 52%	Age (25 cutoff used) (<i>NS</i>) Woman's major contribution to support household is housework (<i>NS</i>) Family knows HIV+ status (<i>NS</i>) Perceives community stigma (<i>NS</i>) Post partum depression ($OR = 4.6, 95\% CI: 1.7, 12.9, p < .01$)
Neuman, 2013	Burkina Faso, Kenya, Malawi, Uganda	N	Adults	536	67.4	CS	39% 39% 39% 39%	Female gender (<i>NS</i>) Age (categorized into three age groups) (<i>NS</i>) Educational attainment (<i>NS</i>) Urban location (<i>NS</i>)
Kingori, 2013	Kenya	P	Adults	370	60.4	CS	35%	Depression ($r = .345, p < .000$)
Tsai, 2013	Uganda	Y	Adults	262	66	PCS	83%	Time on ART ($d = .70, p < .05$), mediated by reduced HIV-related symptoms, improved physical and mental health, and lower depression scores
Visser, 2013	South Africa	Y	Pregnant women	609	100	CS	43% 57% 57% 57% 57% 57% 57% 57%	Attributed stigma (perceive other people in community to be highly stigmatizing) ($r = .334, p < .01$) Older age ($\beta = .123, p < .01$) Lower educational attainment ($\beta = -.115, p < .01$) Victim of sexual violence (<i>NS</i>) Disclosed HIV status ($\beta = -.085, p < .05$) HIV knowledge (<i>NS</i>) Low self-esteem ($\beta = -.197, p < .01$) Depression ($\beta = .179, p < .01$) Low social support ($\beta = -.114, p < .01$)
Takada, 2014	Uganda	Y	Adults	422	71%	PCS	87%	Age (<i>NS</i>) Gender (<i>NS</i>) Marital status (<i>NS</i>) Education (<i>NS</i>) Household asset wealth (<i>NS</i>) Emotional support (<i>NS</i>) Tangible support (<i>NS</i>) Poor HIV-related physical health ($\beta = -0.018, p < .001$) Depression ($\beta = 0.49, p < .001$)

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First author, year	Location	Primary outcome	Target population	n	% Female	Study design	CQC score ¹	Predictors/correlates of internalised stigma
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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 ($p > .5$)

¹ 100% would indicate the maximum possible score of 23; decimals were rounded up to the nearest whole percent

This document is a supplement to the manuscript submitted to Health Psychology Review, titled 'Predictors and correlates of internalised HIV-related stigma: A systematic review of studies in Sub-Saharan Africa'. It includes:

- Supplementary file 1: Disclosure statement (p. 1)
- Supplementary file 2: Full scope of the review (p. 2)
- Supplementary file 3: Inclusion and exclusion criteria (p.2)
- Supplementary file 4: Full search strategy (p. 3)
- Supplementary file 5: Screening questions for determining inclusion of primary studies (p. 3)
- Supplementary file 6: Full data extraction form (p. 4-6)
- Supplementary file 7: Adapted Cambridge Quality Checklists used for assessment of primary studies included in the review (p. 7)
- Supplementary file 8: Summaries of directionality of findings for each correlate of internalised stigma (p. 8-11)
- Supplementary file 9: References of primary studies reviewed (p. 12-13)

Supplementary file 1: Disclosure statement

The authors declare that they have no conflict of interest. This systematic review was conducted as part of completion of the corresponding author's DPhil requirements at the Department of Social Policy and Intervention, University of Oxford. Funding for the DPhil was provided by the Joint Green Templeton College – Clarendon Scholarship, University of Oxford. The research leading to these results has received funding from the European Research Council under the European Union's Seventh Framework Programme (FP7/2007-2013) / ERC grant agreement n°313421. The funders were not involved in any parts of the review process or manuscript preparation.

Supplementary file 2: Scope of the review

Table 1 Scope of the review

Outcome	HIV/AIDS related internalised or self-stigma, shame, negative self-image, negative self-perception
Population	People living with HIV of all ages
Geographic location	Sub-Saharan Africa
Study design	Cross-sectional surveys, case-control studies, cohort studies, psychometric studies (scale validity and reliability studies)

Supplementary file 3:

Table 2 Systematic Review Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Study population: <ul style="list-style-type: none"> HIV-positive persons who are aware of their seropositivity 	<ul style="list-style-type: none"> People whose HIV status is unknown or not specified
Sampling: <ul style="list-style-type: none"> Located in sub-Saharan Africa 	<ul style="list-style-type: none"> Sub-Saharan African immigrants living outside of sub-Saharan Africa
Study design: <ul style="list-style-type: none"> Quantitative or mixed methods study design measuring internalised HIV stigma as an outcome, including longitudinal studies, cross-sectional surveys or case-control studies Psychometric studies validating measurements of internalised HIV stigma Prevalence studies that assess internalised HIV stigma and report on demographic comparisons (e.g. gender differences in internalised stigma) 	<ul style="list-style-type: none"> Qualitative studies Intervention studies
Outcome measure <ul style="list-style-type: none"> A measure of internalised HIV stigma 	<ul style="list-style-type: none"> A multidimensional stigma outcome measure without differentiation between enacted stigma and internalised stigma, making it impossible to infer what factors are associated with internalised stigma.

Supplementary file 4: Full search strategy

Table 3 Search string for databases searched in OvidSP (PsychARTICLES, Embase, Global Health, Ovid MEDLINE and PsycINFO)

1	Population	People living with HIV	(HIV or AIDS or PLWHA or PLWH or ((human or acquired) adj1 (immunodeficiency or immune-deficiency or immuno-deficiency))).ab,hw,ti.
2	Outcome	HIV-related internalised stigma	((stigma adj1 (self or internal* or auto)) or (self adj1 (perception or image)) or (shame adj2 HIV) or (shame adj2 AIDS)).mp. or (shame adj2 antiretroviral*).ab,hw,ti,tx. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, ps, rs, an, ui, tc, id, tm]
3	Location	Sub-Saharan Africa	((sahara* adj1 africa) or Angola or Benin or Botswana or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Brazzaville or Democratic Republic of Congo or Cote d'Ivoire or Djibouti or Equatorial Guinea or Eritrea or Ethiopia or Gabon or Gambia or Ghana or Guinea or Guinea-Bissau or Kenya or Lesotho or Liberia or Madagascar or Malawi or Mali or Mauritania or Mauritius or Mozambique or Namibia or Niger or Nigeria or (Reunion adj3 africa) or Rwanda or Sao Tome or Senegal or Seychelles or Sierra Leone or Somalia or South Africa or Sudan or Swaziland or Tanzania or Togo or Uganda or Western Sahara or Zambia or Zimbabwe).ab,cp,hw,ti.
Final search: 1 AND 2 AND 3			

Table 4 Search string used for smaller databases (WHO Afro Library and CINAHL*)

1	Population	People living with HIV	HIV or AIDS
2	Outcome	HIV-related internalised stigma	stigma OR negative self-perception OR negative self-image OR shame
Final search: 1 AND 2			
*CINAHL search selected Africa under 'Geographic Subset'			

Supplementary file 5: Screening questions

Note: continue to subsequent question only if the answer to the current question is “yes”

1. Does the study sample include HIV positive people?
2. Is the study sample located in sub-Saharan Africa?
3. Does the study measure and report on internalized stigma?
4. Does the study use quantitative methods?
5. Does the study fall within one of the following designs?
 - a. Quantitative study assessing internalized stigma as a dependent variable or through a simple bivariate correlation
 - b. Study validating an internalized stigma scale

Supplementary file 6: Data extraction form

A. Publication information

1. Authors
2. Title
3. Year
4. Reviewer (Date of coding)
5. Internalised HIV-related stigma (IHS) definition:

B. Sample information

6. Location
7. Population of interest
 - HIV-positive children (specify ages and whether sample consists of perinatally infected, postnatally infected, combination of both, or not specified)
 - HIV-positive adolescents (specify ages and whether sample consists of perinatally infected, postnatally infected, combination of both, or not specified)
 - HIV-positive adults (specify ages and mode of infection, or not specified)
 - HIV-positive women accessing antenatal care clinics
 - HIV-positive high risk population (MSM, IDU, SW)
 - Other (specify):
8. Gender breakup
 - Female %
9. Other potential stigma markers assessed?
 - Women
 - Poverty
 - Transactional sex
 - Sex work
 - MSM
 - Other (specify)

C. CQC Assessment¹

10. Facility (clinic) sampling
 - total population or random sampling
 - purposive sampling
 - convenience sampling

¹ CQC assessment to be completed separately for each association between a correlate and IHS

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- not reported
 - 11. Within-facility sampling of individual participants
 - total population or random sampling
 - purposive sampling
 - convenience sampling
 - not reported
 - 12. Response rate
 - response² and retention³ rates $\geq 70\%$ and differential attrition⁴ $\leq 10\%$
 - response rate $< 70\%$ or retention rate $< 70\%$ or differential attrition $> 10\%$
 - not reported
 - 13. Sample size:
 - Sample size ≥ 400
 - Sample size < 400
 - 14. Outcome measure used
 - IHS measure
 - Enacted stigma measures
 - Other outcome measures (specify):
- Measure/Scale name:
- 15. IHS measure validity
 - Use of a validated standardized scale with the same target population *OR* use of an adapted scale that had been validated with another target population
 - Validation of a newly developed instrument
 - Use of a non-validated measurement
 - Not reported
 - 16. IHS measure reliability
 - Reliability coefficient $\geq .7$
 - Reliability coefficient $< .7$
 - Not reported
 - 17. Study design score
 - cross-sectional data
 - retrospective data
 - prospective data (or study of fixed factor)
 - 18. Causal predictor score
 - study without variation in the risk factor, no analysis of change

² Response rate scored for cross-sectional design

³ Retention rate scored for longitudinal design

⁴ Differential attrition scored for case control design

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- study with variation in the risk factor but inadequately balanced, no analysis of change
- study without variation in the risk factor, with analysis of change
- study with variation in the risk factor but inadequately balanced, with analysis of change
- study with variation in the risk factor and adequately balanced, no analysis of change
- study with variation in the risk factor and adequately balanced, with analysis of change

19. CQC total score

D. Results

20. Quantitative results

- Correlates/predictors of IHS (include OR, effect size, correlation coefficient, etc)
- Prevalence of internalized stigma
- Prevalence of other types of stigma, if applicable

21. Notes

Supplementary file 7: Adapted Cambridge Quality Checklists

Table 5 Adapted CQC for quality assessment of primary studies

Quality Assessment*	
Facility sampling	
3	Total population or random sampling
2	Purposive sampling
1	Convenience sampling
0	Not reported
Within-facility sampling of participants	
3	Total population or random sampling
2	Purposive sampling
1	Convenience sampling
0	Not reported
Response rates	
2	Response ⁱ or retention ⁱⁱ rates $\geq 70\%$ or differential attrition ⁱⁱⁱ $\leq 10\%$
1	Response rate $< 70\%$ or retention rate $< 70\%$ or differential attrition $> 10\%$
0	Not reported
Sample size score	
1	Sample size ≥ 400
0	Sample size < 400
Internalised stigma measure validity	
3	Use of a validated standardized scale with the same target population OR use of an adapted scale that had been validated with another target population
2	Validation of a newly developed instrument
1	Use of a non-validated measurement
0	Not reported
Internalised stigma measure reliability	
2	Reliability coefficient $\geq .7$
1	Reliability coefficient $< .7$
0	Not reported
Study design score	
3	Prospective cohort data used in analysis
2	Retrospective cohort data used in analysis
1	Cross-sectional data used in analysis
Causal predictor score	
6	Analysis with variation in the predictor and adequately balanced, with analysis of change
5	Analysis with variation in the predictor and adequately balanced, no analysis of change
4	Analysis with variation in the predictor but inadequately balanced, with analysis of
3	change
2	Analysis without variation in the predictor, with analysis of change
1	Analysis with variation in the predictor but inadequately balanced, no analysis of change
	Analysis without variation in the predictor, no analysis of change

*Scoring to be completed separately for each analyzed association between a correlate and internalised stigma; ⁱresponse rate scored for cross-sectional study designs; ⁱⁱretention rate scored for longitudinal study designs; ⁱⁱⁱdifferential attrition scored for case control study designs

Supplementary file 8: Directionality of findings between investigated correlates and internalised stigma

Table 6 Findings on socio-demographic correlates of internalised stigma

	Cuca et al. 2012	Neuman and Obermeyer 2013	Nattabi et al. 2011	Simbayi et al. 2007	Sorsdahl et al. 2011	Visser et al. 2013
Age	0	0	0	0	-	+
Female		0	+	-	+	
Urban		0				
Race				0		
Xhosa					0	
Education		0			+	-
Employment status					0	
Housewife/mother	0					

+ indicates a positive association, whereby an increase in the hypothesized factor is associated with higher levels of internalised stigma

- indicates a protective process, whereby an increase in the hypothesize predictor is associated with lower levels of internalised stigma

0 indicates a non-significant association

Table 7 Findings on HIV- and treatment-related correlates of internalised stigma

	Kalichman et al. 2009 (SA)	Kalichman et al. 2009 (Swaziland)	Holzemer et al. 2007*	Nattabi et al. 2011	Simbayi et al. 2007	Tsai et al. 2013	Sorsdahl et al. 2011	Tsai et al. 2012	Wagner et al. 2012	Visser et al. 2013	Makoe et al. 2009	Peltzer 2012	Pearson et al. 2009
Time since diagnosis	0	+	+	0	-		-	+		-			
HIV symptomatology					0								
Physical health				0	0			-	-				
ART use									0				
Time													
Time on ART				0		-			0		-	U	+
Time*ART									§		⌘		
Time attending health facility				0									
HIV-related knowledge										0			
Life satisfaction			-										
Overall functioning			-										

+ indicates a positive association, whereby an increase in the hypothesized factor is associated with higher levels of internalised stigma

- indicates a protective process, whereby an increase in the hypothesized predictor is associated with lower levels of internalised stigma

0 indicates a non-significant association

§ respondents taking ART experienced a greater decrease in internalised stigma than respondents not taking ART

⌘ respondents not taking ART experienced a greater decrease in internalised stigma than those taking ART

U indicates that the initial significant decline in internalised stigma was followed by an increase in internalised stigma to baseline levels

Table 8 Findings on intra-personal correlates of internalised stigma

Intra-personal factors		Kingori et al. 2013	Kalichman et al. 2009 (SA)	Kalichman et al. 2009 (Swaziland)	Cuca et al. 2012	Nattabi et al. 2011	Simbayi et al. 2007	Tsai et al. 2012	Visser et al. 2013	Pearson et al. 2009
Mental health QoL										
Depression		+	+	+	+			+	+	-
Self-esteem										
Alcohol use							+			
Drug use							+			
Wish more children						0				

+ indicates a positive association, whereby an increase in the hypothesized factor is associated with higher levels of internalised stigma

- indicates a protective process, whereby an increase in the hypothesized predictor is associated with lower levels of internalised stigma

0 indicates a non-significant association

Table 9 Findings on inter-personal correlates of internalised stigma

	Kalichman et al. 2009 (SA)	Kalichman et al. 2009 (Swaziland)	Holzemer 2007	Cuca et al. 2012	Nattabi et al. 2011	Simbayi et al. 2007	Sorsdahl et al. 2011	Visser et al. 2013	Cloete et al. 2008	Pearson et al. 2009
Social support	-	-				-		-		-
Perceived stigma				0		+		+		
Enacted stigma										
Healthcare neglect			+							
Social isolation			+							
Fear of contagion			+							
Workplace stigma			+							
Disclosed HIV							-			
# of ppl disclosed to										-
Disclosed to family				0						-
Disclosed to friend										-
Disclosed to co-worker										-
Disclosed to partner										0
Partner HIV+					0					
Sexual abuse victim								0		
MSM (vs MSW)									0	

+ indicates a positive association, whereby an increase in the hypothesized factor is associated with higher levels of internalised stigma

- indicates a protective process, whereby an increase in the hypothesized predictor is associated with lower levels of internalised stigma

0 indicates a non-significant association

Supplementary file 9: References of primary studies included in the review

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