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# Trajectories of HIV-Related Internalized Stigma and Disclosure Concerns Among ART Initiators and Non-initiators in South Africa

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## Trajectories of HIV-Related Internalized Stigma and Disclosure Concerns Among ART Initiators and Noninitiators in South Africa

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1 **Trajectories of HIV-related internalized stigma and disclosure concerns among ART**  
2 **initiators and non-initiators in South Africa**

3 Revision submitted October 25, 2018

4

5 **Abstract**

6 **Background:** HIV-related stigma among people living with HIV (PLHIV) is associated with  
7 worse health outcomes. We used longitudinal data from a multi-site cohort in South Africa  
8 to assess changes over time in stigma after HIV diagnosis and determine whether  
9 antiretroviral therapy (ART) initiation is associated with stigma reduction.

10 **Methods:** We administered the Internalized AIDS-Related Stigma Scale (IARSS, a six-item  
11 dichotomous scale questionnaire) at baseline, three months, and six months to newly  
12 diagnosed ART-eligible participants between 2014-2015. A confirmatory factor analysis  
13 indicated that the IARSS contained a four-item internalized stigma factor ( $\alpha=0.80$ ) and a  
14 two-item disclosure concerns factor ( $\alpha=0.75$ ). We fitted multiple logistic regression models  
15 specifying internalized stigma/disclosure concerns at six months as the outcome and ART  
16 initiation as the predictor of interest.

17 **Results:** Of the 500 participants (187 men and 313 women) enrolled, 308 (62%) initiated  
18 ART. Internalized stigma declined among people entering care (mean score, 1.0 to 0.7,  
19  $p<0.01$ ); however, disclosure concerns remained unchanged (percentage endorsing either  
20 disclosure concern item, 78% to 77%,  $p=0.23$ ). These findings were similar between ART  
21 initiators and non-initiators. We estimated a statistically significant positive association

1 between ART initiation and disclosure concerns at six months (OR=1.88; 95% CI, 1.20-  
2 2.94) but not between ART initiation and internalized stigma at six months (OR=1.15; 95%  
3 CI, 0.75-1.78).

4 **Conclusions:** Among ART-eligible South African PLHIV entering into HIV care, internalized  
5 stigma modestly declined over time but disclosure concerns persisted. PLHIV who initiated  
6 ART were more likely to have persistent disclosure concerns over time as compared with  
7 those who did not start ART.

8 **Key words:** Stigma, internalized stigma, anticipated stigma, disclosure, South Africa

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## 1 Introduction

2 HIV-related stigma has been recognized as a critical barrier to the success of HIV  
3 prevention and treatment efforts worldwide (Grossman & Stangl, 2013; UNAIDS, 2012).  
4 People living with HIV (PLHIV) may encounter multiple dimensions of HIV-related stigma,  
5 including internalized, enacted, and anticipated stigma (Earnshaw, Smith, Chaudoir, Amico,  
6 & Copenhaver, 2013). *Internalized stigma* results when PLHIV accept prevailing negative  
7 stereotypes and prejudice toward PLHIV as valid and apply these beliefs and feelings to  
8 themselves (Earnshaw et al., 2013; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989).  
9 *Enacted stigma* involves experiences of negative treatment, including discrimination,  
10 stereotyping, and prejudice, at the hands of others in the past or the present (Earnshaw et  
11 al., 2013; Scambler & Hopkins, 1986). In addition to experiencing enactments of stigma,  
12 PLHIV may also expect negative treatment from others in the future, a phenomenon known  
13 as *anticipated stigma* (Link, Cullen, Frank, & Wozniak, 1987).

14

15 Among PLHIV, internalized stigma has been associated with worse mental health  
16 (Simbayi et al., 2007; Tsai et al., 2012), decreased adherence to antiretroviral therapy  
17 (ART) (Boyer et al., 2011; Katz et al., 2013), and reduced likelihood of serostatus disclosure  
18 (Norman, Chopra, & Kadiyala, 2007; Tsai, Bangsberg, Kegeles, et al., 2013c). Although there  
19 may be a bidirectional or cyclical relationship between internalized stigma and ART  
20 initiation (Earnshaw et al., 2018), the nature of this relationship is unclear. While  
21 internalized stigma has been associated with reduced likelihood of ART initiation (Logie et  
22 al., 2018), longitudinal studies conducted in low- and middle-income countries (LMICs)

1 have yielded conflicting results about the extent to which taking ART is associated with  
2 changes over time in internalized stigma among PLHIV (Makoae et al., 2009; Tsai,  
3 Bangsberg, Bwana, et al., 2013b). It has been theorized that engagement in HIV care and  
4 ART initiation may attenuate stigma among PLHIV through ART-related counseling and  
5 improvements in physical health that reduce the extent to which PLHIV internalize  
6 stigmatizing beliefs (Castro & Farmer, 2005; Tsai, Bangsberg, Bwana, et al., 2013b) and  
7 restore or maintain their economic viability and social connectedness (Campbell et al.,  
8 2011; Venkataramani et al., 2014). Most of the evidence in support of this hypothesis  
9 comes from qualitative studies, including from Haiti (Castro & Farmer, 2005) and multiple  
10 countries in sub-Saharan Africa (Campbell et al., 2011; Tsai, Bangsberg, & Weiser, 2013a;  
11 Zuch & Lurie, 2012). Moreover, extensive pre-ART counseling has historically been the  
12 norm in LMICs, with countries such as South Africa often requiring up to six visits prior to  
13 ART initiation (Maughan-Brown et al., 2018). These ART preparation activities, aimed at  
14 improving long-term adherence (Myer, Zulliger, & Pienaar, 2012), could also plausibly  
15 counter internalized stigma among PLHIV. Conversely, others have suggested that ART may  
16 worsen internalized stigma because of the widespread belief that one only takes ART when  
17 one is very sick (Makoae et al., 2009; Roura et al., 2009). For PLHIV who harbor this belief,  
18 initiating ART may be perceived as an acknowledgement of poor health and potentially  
19 one's own mortality (Katz et al., 2015).

20

21 Similarly, the impact of ART initiation on anticipated stigma among PLHIV remains  
22 unclear. The consistent behaviors required for successful ART initiation may make it more

1 difficult for PLHIV to hide their serostatus, thus increasing their perceived risk of being  
2 subjected to stigma (Makoae et al., 2009). Conversely, PLHIV may be motivated to start  
3 ART to stay healthy and thus avoid involuntary serostatus disclosure resulting from visibly  
4 apparent HIV-related wasting and opportunistic infections (van Loggerenberg et al., 2015).

5  
6 Whether the effect of ART initiation on these dimensions of stigma differs between  
7 men and women is also largely unknown. Previous studies have suggested differences in  
8 levels of stigma experienced by men and women in sub-Saharan Africa (Chan, Tsai, &  
9 Siedner, 2015; Mugoya & Ernst, 2014) and in South Africa particularly (Sorsdahl, Mall,  
10 Stein, & Joska, 2011). In a cross-country analysis of 18 countries in sub-Saharan Africa,  
11 women in the general population were more likely to hold stigmatizing attitudes compared  
12 to men (Chan et al., 2015). This finding suggests that women may be more likely than men  
13 to internalize stigma after HIV diagnosis, in light of recent studies indicating that prejudice  
14 before HIV/sexually transmitted infection (STI) diagnosis (Eaton et al., 2018) and  
15 perceived community stigma (Turan et al., 2017) are associated with internalized stigma  
16 after HIV/STI diagnosis. Women living with HIV may also be more likely to hold disclosure  
17 concerns, given the particularly dangerous consequences of disclosure faced by women,  
18 including violence, shaming, and abandonment at the hands of partners and family  
19 members (Evangeli & Wroe, 2017; Maman, Groves, McNaughton Reyes, & Moodley, 2016;  
20 Medley, Garcia-Moreno, McGill, & Maman, 2004; Monteiro, Villela, Soares, Pinho, & Fraga,  
21 2018). Accordingly, women may be more likely to anticipate stigma, as disclosure concerns



1 reflect the expectation of rejection or discrimination were one's serostatus revealed to  
2 others (Gilbert & Walker, 2010; Olley, Ogunde, Oso, & Ishola, 2016).

3  
4 Understanding the association of ART with multiple dimensions of stigma is  
5 important for policymakers, as a finding of persistent stigma among PLHIV in HIV care  
6 would provide an impetus for investment in anti-stigma interventions. To help answer this  
7 question, we used longitudinal data from a sample of PLHIV in South Africa, where a recent  
8 nationwide study revealed high levels of internalized, anticipated, and enacted stigma  
9 among PLHIV (Simbayi et al., 2016). We assessed changes over time in multiple dimensions  
10 of HIV-related stigma among a sample of predominantly Black, newly diagnosed, and ART-  
11 eligible South Africans. We also sought to understand the extent to which ART initiation is  
12 associated with changes in these dimensions of stigma and whether the association  
13 between ART initiation and change in stigma differs by sex.

14

## 15 **Methods**

### 16 *Study design*

17 Data for this analysis were drawn from a study that was conducted at three sites in  
18 two townships in South Africa, the Zazi Testing Center and a Ministry of Health (MOH)  
19 clinic in Soweto and an MOH testing center in Gugulethu (outside of Cape Town). Both  
20 townships are densely populated urban areas with an overall HIV prevalence of  
21 approximately 20%. People undergoing HIV testing and counseling were given their HIV

1 results, and if positive, had blood drawn for a CD4+ count and asked to return in a week for  
2 CD4+ count results. Patients receiving CD4+ count results who were eligible for ART were  
3 referred to trained counselors or social workers to discuss ART initiation.

4

5 We sequentially recruited and enrolled 500 ART-eligible adults ( $\geq 18$  years old)  
6 between July 2014 and July 2015, as they received their CD4+ count results. ART eligibility  
7 was based on South African guidelines, which changed over the duration of the study  
8 ( $CD4+ \leq 350$  cells/mm<sup>3</sup> before Jan 1, 2015, and  $CD4+ \leq 500$  cells/mm<sup>3</sup> after Jan 1, 2015). We  
9 excluded children and pregnant women, as they qualified for intensive adherence support  
10 under South African guidelines. Ethical approval for all study procedures was obtained  
11 from the Human Subjects Committees at Partners Healthcare, the University of  
12 Witwatersrand Ethics Committee, the Gauteng Department of Health, and the University of  
13 Cape Town Ethics Committee. All participants provided written informed consent. Study  
14 data were collected and managed using a secure, web-based, Research Electronic Data  
15 Capture (REDCap) tool hosted at Partners Healthcare (Harris et al., 2009).

16

### 17 *Measures*

18 At baseline, month three, and month six, trained multilingual interviewers  
19 administered to study participants a questionnaire that measured clinical, structural and  
20 psychosocial factors, including the six-item Internalized AIDS-Related Stigma Scale (IARSS)  
21 (Kalichman et al., 2009). The IARSS collects responses on a binary scale (agree/disagree)

1 and scores represent the sum of endorsed items. Four of the six items in the IARSS relate  
2 unequivocally to internalized stigma, including items on feelings of shame and/or self-  
3 hatred, whereas two items relate more closely to disclosure concerns (Figure 1). We  
4 regarded disclosure concerns as a correlate of anticipated stigma. There is recent evidence  
5 for a two-factor structure for the IARSS items, including a four-item internalized stigma  
6 factor and a two-item disclosure concerns factor, among PLHIV in India (Chan et al., 2018).  
7 Therefore, we conducted a confirmatory factor analysis on the IARSS items using a two-  
8 factor structure. The Chi-sq statistic had a p-value of <0.01 with a root mean square error  
9 of approximation of 0.06 and a Bentler's comparative fit index of 0.98, indicating good  
10 model fit with the two-factor structure. At baseline, the estimated scale reliability  
11 coefficient for the internalized stigma and disclosure concerns sub-scales was 0.80 and  
12 0.75, respectively.

13

14 The primary exposure of interest was ART initiation within six months of HIV  
15 testing. This variable was ascertained by matching participants' name and date of birth to  
16 routine laboratory data collected by the National Health Laboratory Service (NHLS), which  
17 provides services to all public-sector facilities in South Africa. ART initiation was imputed  
18 based on a measure of creatinine, which is performed prior to initiation of standard first-  
19 line ART in South Africa. ART workup blood testing as recorded in NHLS has been  
20 previously validated as an accurate measure of ART initiation among PLHIV who are in  
21 care in the South African public sector (Maskew et al., 2017). We also collected baseline

1 socio-demographic variables (age, sex, educational attainment, marital status, and  
2 employment status) and CD4+ cell count.

3

#### 4 *Statistical analysis*

5 We used descriptive statistics to characterize the sample and levels of stigma at  
6 baseline, three months, and six months, including McNemar's tests for the binary stigma  
7 outcomes and paired t-tests for the stigma scales. To help understand to what extent  
8 changes over time in stigma were related to non-random attrition of study participants, we  
9 fitted a logistic regression model with attrition by six months as the outcome variable and  
10 baseline disclosure concerns score or internalized stigma score as the primary exposure of  
11 interest, adjusted for sociodemographic characteristics, CD4+ count, and study site (Soweto  
12 vs. Gugulethu). We then fitted logistic regression models to the data with ART initiation as  
13 the primary exposure of interest and disclosure concerns / internalized stigma (=1 if study  
14 participant endorsed either disclosure concerns item or any of the four internalized stigma  
15 items) at six months as the outcome variable, adjusted for sociodemographic  
16 characteristics, CD4+ count, study site, and disclosure concerns / internalized stigma at  
17 baseline. A statistically significant regression coefficient was considered evidence that an  
18 association existed between ART initiation and disclosure concerns/internalized stigma at  
19 six-month follow-up. As a sensitivity analysis, we fitted binomial regression models using  
20 the disclosure concerns score (0-2) or internalized stigma score (0-4) (expressed as R of N,  
21 where R is the participant's score and N is the maximum possible score) as the outcome  
22 variable (adjusted for sociodemographic characteristics, CD4+ count, study site and

1 disclosure concerns / internalized stigma score at baseline). Finally, we fitted all models  
2 with a product term to test for an interaction between sex and ART initiation. All analyses  
3 were performed using Stata software (Version 15.0, StataCorp, College Station, TX, USA).

## 5 **Results**

6 We enrolled 500 participants (200 in Soweto and 300 in Gugulethu) into the study  
7 (Table). A total of 308 (62%) participants initiated ART within six months; nine (2%)  
8 participants died before accessing treatment. We located and verified clinical data for 473  
9 (95%) of the participants in this cohort through NHLS. Three hundred and eighty-three  
10 (81%) participants had complete follow-up survey data through six months. At baseline  
11 (i.e., one week after testing, at the determination of ART eligibility), disclosure concerns  
12 were particularly high, with 78% endorsing at least one disclosure concern item (Figure 1).  
13 Internalized stigma at baseline was also common, with 46% endorsing at least one  
14 internalized stigma item, including 35% who agreed with the statement “I feel guilty that I  
15 am HIV positive.”

16  
17 Internalized stigma declined over six months among participants (mean score, 1.0  
18 to 0.7,  $p<0.01$ ), including ART non-initiators (1.1 to 0.8,  $p<0.01$ ) and ART initiators (1.0 to  
19 0.7,  $p<0.01$ ). There were declines in the percentages agreeing with each of the four  
20 internalized stigma items. Nevertheless, 39% of participants, including 40% of ART non-  
21 initiators and 38% of ART initiators, continued to endorse at least one internalized stigma

1 item after six months (Figures 2 and 3). Disclosure concerns did not significantly decrease  
2 over six months among participants (percentage endorsing either disclosure concern item,  
3 78% to 77%,  $p=0.23$ ), including both ART non-initiators (76% to 71%,  $p=0.07$ ) and ART  
4 initiators (79% to 80%,  $p=0.90$ ). Findings appeared similar between men and women  
5 (results available in Supplementary Digital Content 1). Using a logistic regression model  
6 adjusted for sociodemographic characteristics, CD4+ count, and study site, we did not find  
7 a statistically significant association between baseline disclosure concerns (Odds Ratio  
8 [OR]=0.91, 95% Confidence Interval [CI], 0.71-1.18) or internalized stigma (OR=0.93; 95%  
9 CI, 0.79-1.10) with attrition of study participants by six months.

10

11 Using logistic regression models adjusted for sociodemographic variables, baseline  
12 CD4+ count, study site, and baseline disclosure concerns / internalized stigma, we  
13 estimated a statistically significant positive association between ART initiation and  
14 disclosure concerns at six months (OR=1.88; 95% CI, 1.20-2.94) but not between ART  
15 initiation and internalized stigma at six months (OR=1.15; 95% CI, 0.75-1.78). In the  
16 models including a product term testing for an interaction between sex and ART initiation,  
17 the estimated regression coefficient for the product term was not statistically significant  
18 for either the association between ART initiation and disclosure concerns ( $p=0.40$ ) or the  
19 association between ART initiation and internalized stigma ( $p=0.90$ ).

20

21 The sensitivity analysis using binomial regression models for the disclosure  
22 concerns score (0-2) / internalized stigma score (0-4) as the outcome variable yielded

1 similar results. We estimated a statistically significant positive association between ART  
2 initiation and disclosure concerns score at six months (adjusted  $b=0.44$ ; 95% CI, 0.11-0.76)  
3 but not between ART initiation and internalized stigma score at six months (adjusted  $b=$  -  
4 0.05; 95% CI, -0.34 to 0.24). In the models including a product term testing for an  
5 interaction between gender and ART initiation, the estimated regression coefficient for the  
6 product term was again not statistically significant for either the association between ART  
7 initiation and disclosure concerns ( $p=0.50$ ) or the association between ART initiation and  
8 internalized stigma ( $p=0.15$ ). The regression estimates for all models used in this analysis  
9 are available in Supplementary Digital Content 2.

10

## 11 **Discussion**

12 In this analysis of prospective data collected from a multi-site cohort of  
13 predominantly Black South Africans eligible for ART, we found that internalized stigma was  
14 commonly endorsed at the time of ART eligibility determination and declined modestly  
15 over time among both ART non-initiators and initiators. Internalized stigma may naturally  
16 decrease over time as people have time to process, adjust to their diagnosis, and acquire  
17 social support. Further, the education, counseling, and support experienced by PLHIV  
18 accessing HIV care (regardless of ART initiation) may diminish internalized stigma,  
19 however slightly. It is worth noting that while internalized stigma declined among both  
20 ART initiators and non-initiators, it did so only modestly, with 39% of participants  
21 endorsing at least one internalized stigma item at six-month follow-up. This indicates that

1 although engagement in HIV care may be mildly beneficial in countering internalized  
2 stigma, it is unlikely to be a panacea (Treves-Kagan et al., 2016).

3  
4 Previous evidence suggests that ART may reduce internalized stigma over time as  
5 PLHIV experience improvements in HIV symptom burden and physical and psychosocial  
6 well-being (Tsai, Bangsberg, Bwana, et al., 2013b). Furthermore, at the time this study was  
7 conducted, PLHIV in South Africa frequently underwent multiple visits prior to ART  
8 initiation to enhance readiness for treatment (Maughan-Brown et al., 2018), a process that  
9 could also be expected to reduce internalized stigma. Unfortunately, our findings suggest  
10 that ART initiation is not associated with meaningful reductions in internalized stigma  
11 beyond usual HIV care, at least within the first six months after diagnosis. Given the  
12 striking rates of internalized stigma at the time of HIV diagnosis (46% of respondents  
13 endorsing at least one internalized stigma item) and the deleterious effects of internalized  
14 stigma on HIV-related outcomes (Boyer et al., 2011; Katz et al., 2013; Norman et al., 2007;  
15 Tsai, Bangsberg, Kegeles, et al., 2013c), further efforts to attenuate internalized stigma at  
16 the time of HIV diagnosis and during the first six months of care may be warranted. Such  
17 efforts could include initiatives to reduce stigmatizing attitudes in the general population  
18 such as educational campaigns or contact interventions (Chan & Tsai, 2017; Stangl, Lloyd,  
19 Brady, Holland, & Baral, 2013) or initiatives to help PLHIV build skills to cope with a  
20 stigmatizing environment such as support groups and patient empowerment interventions  
21 (Bogart et al., 2018; Roy et al., 2016). Another possible implication of our findings is that  
22 the practice of multiple counseling sessions prior to ART initiation may not necessarily



1 lessen internalized stigma; thus, the current practice of fast-tracked ART initiation is  
2 unlikely to be disadvantageous in this regard.

3

4         While internalized stigma declined modestly among PLHIV in the first six months  
5 after HIV diagnosis, we found that disclosure concerns persisted. ART initiation may do  
6 little to counter disclosure concerns; indeed, the consistent behaviors required to  
7 successfully initiate ART may make it more difficult for PLHIV to hide their serostatus. Our  
8 findings of persistent disclosure concerns among PLHIV in care are important for  
9 policymakers, as non-disclosure has been associated with negative outcomes including  
10 poor mental health and reduced quality of life (Chandra, Deepthivarma, Jairam, & Thomas,  
11 2003; Patel et al., 2012), loss to care (Akilimali et al., 2017), virological failure (Izudi, Alioni,  
12 Kerukadho, & Ndungutse, 2016; Ramadhani et al., 2007), and risky sexual behaviors  
13 (Booyesen, Wouters, de Walque, & Over, 2017; Wong et al., 2009).

14

15         Previous studies have demonstrated differences in stigma experiences between men  
16 and women in LMICs; in particular, women living with HIV may face uniquely dangerous  
17 consequences of disclosure, including intimate partner violence and shaming and  
18 abandonment by partners or families (Evangeli & Wroe, 2017; Maman et al., 2016; Medley  
19 et al., 2004; Monteiro et al., 2018). However, the prevalence and trajectories of disclosure  
20 concerns and internalized stigma appeared similar between men and women in our cohort.  
21 Although women appear to be more likely than men in the general population of sub-  
22 Saharan Africa to hold stigmatizing attitudes (Chan et al., 2015), our findings indicate that

1 this may not necessarily translate into women being more likely than men to internalize  
2 stigma after HIV diagnosis. Moreover, we did not find that the association between ART  
3 initiation and change in stigma differs significantly by sex. Our results suggest that  
4 interventions to counter stigma and to promote serostatus disclosure among PLHIV should  
5 target both women and men.

6

7         Our study has several limitations. First, our results may have been biased by the  
8 substantial rate of loss to follow-up, which affected about one-quarter of the enrolled  
9 participants. However, concern for non-random attrition of participants is mitigated by the  
10 lack of a statistically significant association between disclosure concerns or internalized  
11 stigma at baseline and attrition by six months. Moreover, any differential loss to follow-up  
12 would have likely biased our estimates of persisting stigma toward the null (because  
13 persistent stigma may have caused study participants to select out of the study, further  
14 enriching the sample for participants with lower levels of stigma)—buttressing our  
15 conclusion that stigma remains persistently high among PLHIV who access HIV care.  
16 Second, our primary exposure of interest, ART initiation, was obtained through a national  
17 database that relies upon clinician input into a registry. Despite the possibility of  
18 inaccuracies in this process, this method of imputing ART initiation has been previously  
19 validated among PLHIV in care in the public sector of South Africa (Maskew et al., 2017).  
20 Finally, the IARSS disclosure concerns items may not precisely capture the concept of fear  
21 of disclosure that may be deleterious to HIV-related outcomes. PLHIV who “hide [their] HIV  
22 status from others” or find it “difficult to tell people about [their] HIV infection” may have

1 understandably decided against public disclosure, while garnering social support from  
2 select family and friends to whom they have disclosed. However, we feel that the use of the  
3 terms “hide” and “difficult” grants these items a negative connotation that likely reflects  
4 fears of rejection and exclusion that go beyond “normal” privacy concerns.

5

6           In conclusion, among a cohort of ART-eligible, predominantly Black South Africans  
7 recently diagnosed with HIV, internalized stigma modestly declined over time while  
8 disclosure concerns persisted, with ART initiators more likely to have persistent disclosure  
9 concerns over time compared with non-initiators. Policymakers should prioritize  
10 interventions to promote safe disclosure of serostatus among PLHIV, as well as consider  
11 redoubling efforts to counter internalized stigma among PLHIV.

12

13 **Acknowledgements:** This study would not have been possible with the dedication of the  
14 study participants in Soweto and Gugulethu.

15

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