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Effects of an intervention on internalized HIV-related stigma for individuals newly entering HIV care

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Abstract

Objective: Considering the association between internalized HIV-related stigma and treatment adherence, an intervention addressing HIV treatment adherence may have the added benefit of reducing internalized stigma. The “integrating ENGagement and Adherence Goals upon Entry” (iENGAGE) intervention was developed to facilitate adjustment to living with HIV among individuals newly engaged in HIV care. We evaluated the effects of this intervention on internalized stigma and examined whether the effect is moderated by depressive symptoms and coping styles.

Design: The iENGAGE intervention was tailored individually to improve information, motivation, and behavioral skills to promote treatment adherence and viral suppression. 371 participants initiating HIV care at four sites in the United States were randomly assigned to either the intervention receiving four face-to-face sessions or standard of care control arm.

Methods: Baseline and 48-week follow-up assessments were conducted, which included validated measures of internalized HIV-related stigma, depressive symptoms, and coping mechanisms (behavioral disengagement and self-blame) as secondary outcomes. A repeated measures ANOVA evaluated the effect of the intervention on change in internalized HIV stigma. Furthermore, the moderating effects of depressive symptoms and coping mechanisms on the decrease in internalized stigma were examined.

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Results: The decrease in internalized stigma from baseline to 48-weeks was significantly larger in the intervention arm compared to the control arm. This effect was significantly moderated by baseline levels of depressive symptoms and self-blame.

Conclusion: The multifaceted iENGAGE intervention is effective in reducing internalized stigma for new-to-HIV care individuals, especially with higher depressive symptoms or when using higher levels of self-blame coping.

Keywords

Stigma; New-to-care; Depression; Coping; HIV; Intervention

Introduction

HIV-related stigma is a complex social process in which people living with HIV (PLWH) experience prejudice, devaluation, discrimination, rejection, and other negative attitudes due to the fact that they are living with HIV [1–4]. Multiple dimensions of HIV-related stigma have been identified, including anticipated, experienced, perceived community, and internalized stigma [2, 4–7]. Internalized HIV-related stigma refers to accepting and adopting negative evaluations held in society about PLWH and applying these evaluations to oneself [2, 8–11]. A significant body of research suggests that internalized HIV-related stigma is associated with poor engagement in HIV treatment and care, sub-optimal medication adherence, missed clinic visits, and lower access to medical care [12–15]. In addition to these adverse health behaviors and outcomes, internalized HIV-related stigma has been linked with affective, cognitive, and mental health outcomes, such as depression [5, 8, 16–21], anxiety [22, 23], hopelessness [22], low medication adherence self-efficacy [24], dysfunctional coping styles (i.e. self-blame, avoidance, denial) [5, 25], and low quality of life [22, 26–29].

Theoretical and empirical work suggests that internalized HIV stigma has a stronger association with HIV treatment behaviors and outcomes compared to other dimensions of HIV-related stigma (i.e., anticipated, perceived community, and enacted) [3, 8]. Furthermore, associations between other dimensions of stigma and outcomes may work through the pathway of increased internalized stigma [5, 6, 10, 30, 31]. Given the importance of sustained and consistent treatment adherence to achieve viral suppression and to prevent onward transmission of HIV [32, 33], interventions aiming to reduce internalized HIV-related stigma are needed.

Many stigma interventions have focused on perceived or enacted stigma as the outcome [34–37]. While some of these interventions resulted in reductions in HIV-related stigma [34, 38–42], some interventions did not seem to decrease HIV-related stigma [35, 43]. Several interventions have been developed that specifically target the internalized HIV-related stigma that PLWH feel [44–46]. For instance, a study with women living with HIV suggested that intensive cognitive behavioral therapy addressing themes such as feelings of powerlessness, guilt, anger, and reactions from others decreases the level of internalized HIV-related stigma [47]. However, a recent review found inconsistent evidence, on average, on the effects of interventions on internalized stigma [48]. This is perhaps not surprising as

interventions vary considerably in their content, format, and targets. This review highlighted that psycho-educational interventions focusing on building skills and social support networks, managing negative feelings, developing strategies for coping with stigma, and education on medical aspects of HIV are more effective in reducing internalized HIV stigma compared to other approaches. A second review of interventions reported reductions in internalized HIV stigma across studies, and suggested that interventions including both structural (e.g. social empowerment, ART roll-out) and individual (e.g. mental health, stigma education) level components are more effective compared to only individual-level interventions [35]. Moreover, among individual-level interventions, only cognitive behavioral therapy was found to have an effect on internalized stigma—other strategies did not seem to be effective in reducing internalized stigma.

Thus, although a variety of interventions are being evaluated and some identified as beneficial [35, 36], the effects of such interventions on internalized HIV-related stigma have yet to be conclusively demonstrated and the evidence on how these interventions work to reduce stigma are not well developed [36, 49]. There is an urgent need for interventions with multidimensional components (e.g. psychosocial support, health education, structural factors, economic empowerment) to address internalized HIV-related stigma. This need is particularly pressing for those who are newly initiating HIV medical care and treatment [50].

Many new-to-care patients have limited experience navigating the health care system and may not be prepared for a long-term commitment to taking prescribed medications [51–53]. The first year for individuals new to care is a critical and vulnerable time for adjusting to a life-changing diagnosis and associated negative physical and psychological health implications [54]. Specifically, PLWH are expected to attend clinic visits and start life-long ART, which are essential to achieving viral load (VL) suppression and optimal health outcomes [51, 54, 55]. Research suggests that newly diagnosed PLWH often delay seeking HIV care and initiating ART and subsequently miss clinic visits, which in turn lead to delayed VL suppression, greater cumulative VL burden, and increased mortality and morbidity [18, 54, 56–59]. In addition, immediately after HIV diagnosis, the level of HIV-related stigma, especially internalized stigma experienced by PLWH, is often high [60–62], potentially resulting in sub-optimal care engagement and ART adherence behaviors. As such, the period when PLWH initiate care is critical and understanding and addressing adjustment to living with HIV and internalized HIV-related stigma early with new-to-care PLWH is crucial in terms of improving treatment outcomes.

The “integrating ENGagement and Adherence Goals upon Entry” (iENGAGE) intervention was developed to facilitate adjustment to living with HIV and thereby to improve engagement in and adherence to HIV treatment and care through different mechanisms among individuals initiating HIV care [50]. The goals of the intervention include helping patients to adjust to living with HIV, to deal with ensuing negative emotions, to normalize the experience of living with HIV, to set goals, and to acquire problem-solving skills, potentially leading to reduced internalized HIV-related stigma and self-depreciating emotions. The intervention also aims to help to actively identify and combat self-identified barriers to treatment adherence, including retention in care and ART adherence [63, 64]. Thus, for patients for whom stigma is identified as a barrier, the intervention has an explicit

focus on stigma. In this article, we examine the effects of the iENGAGE intervention on internalized HIV stigma.

Moreover, there is a lack of understanding of mental health and psychosocial factors that may moderate the effects of psycho-social interventions on internalized HIV-related stigma. Many PLWH who experience HIV-related stigma also report depressive symptoms and develop maladaptive coping skills [5, 25, 31, 65, 66], and interventions usually target all of these factors [48]. Thus, it is important to better understand how these factors interact with a stigma-reducing intervention in order to determine which sub-populations are more vulnerable and should be prioritized. Within this context, one study suggested significant moderation effects of depressive symptoms on the effects of an anti-stigma intervention (including education, contact with PLWH, counseling, and improving coping skills) on HIV-related stigma among African American women living with HIV [67].

The present analyses have two primary aims: (1) to evaluate the effects of the iENGAGE intervention on internalized HIV-related stigma by comparing changes in stigma in the two arms of the randomized controlled trial (RCT) at the conclusion of the 48-week intervention in a sample of PLWH who were newly entering HIV care and (2) to examine whether the effect of the intervention on change in internalized HIV-related stigma is moderated by depressive symptoms and coping styles (i.e., behavioral disengagement and self-blame; two coping styles found important in coping with HIV in previous research [5, 31, 66], and may theoretically affect the degree to which the intervention is effective).

Methods

Trial Design

The iENGAGE randomized controlled trial allocated eligible, new to care PLWH to the intervention arm or standard of care control arm (1:1) using permuted block randomization without any modifications to enrollment or study procedures following commencement of the trial.

Participants

Participants were 18 years and older with documented HIV infection, initiating HIV care at one of the four participating academically affiliated HIV clinical sites: the University of Alabama at Birmingham (UAB), the University of North Carolina at Chapel Hill (UNC), Johns Hopkins University (JHU) and the University of Washington at Seattle (UW). Those who were English speaking, not planning to move in next 12 months, and able and willing to provide informed consent were enrolled in the study within 14 days of their initial HIV primary care appointment [50].

The intervention

Study Arm (Intervention vs. Control)—The iENGAGE intervention arm participants received four face-to-face sessions (0–2, 2–12, 12–24, and 24–48 weeks after randomization) at the HIV clinic by a study counselor. Additionally, participants received interim enhanced personal contact calls, visit reminder calls, and missed visit calls during

the study period. The iENGAGE intervention was tailored individually to improve participant information, motivation, and behavioral skills (IMB), using an assessment tool mapped to content domains to inform delivery of structured intervention content, by trained counselors, grounded in principles of motivational interviewing. The details of this theory-based intervention can be found elsewhere [50]. The first face-to-face intervention session focused on introducing the participant to the iENGAGE intervention, providing basic education on HIV and HIV care, including importance of attending all medical appointments, and an opportunity to process HIV diagnosis and develop trust and rapport with the iENGAGE counsellor. All intervention participants completed an iENGAGE screener and developed a goal of retaining in care. The follow-up sessions focused on maintaining a positive approach and participating in skills building modules with the counsellors. Another goal was to identify and combat barriers to treatment adherence individually for each participant, including HIV-related stigma (For 21.5% of the participants stigma was identified as a barrier to treatment adherence). Each session included a review of goals from the prior session and adjustment to living with HIV. In addition, counsellors addressed questions raised by participants. At the final intervention session, methods for maintaining intervention gains in the future were discussed. The control arm participants received standard of care at each participating clinic site [68]. Standard of care included various strategies to support ART adherence and retention in care (e.g., use of illustrative materials to deliver information and encouraging participants to store spare doses in particular places). A self-administered standard of care measure was completed by 75 health care providers across the four study sites to determine engagement in care and ART adherence resources available contemporaneously to the iENGAGE trial. On balance, few resources were utilized to systematically monitor care engagement and adherence and provide this information to providers, whereas nearly all providers reported counseling PLWH on ART adherence and the associated favorable health outcomes [50, 68].

The iENGAGE interventionists at each site were provided training on the intervention developed by behavioral scientists on the study team. This training also included a background in providing case management and counseling services. The training consisted of 2-day in-person workshops at UAB and UW, subsequent conference calls every week during the initial year, and then twice monthly, and then monthly calls. Furthermore, a periodic review of recorded interviews was implemented and feedback was provided by the study trainer. During the second year, an in-person booster training workshop was also conducted with feedback. Additionally, for new counselors who joined the study team later, phone trainings were provided. All counselors had a college education –associates or bachelor’s degree.

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Measures

Baseline and 48-week final assessments as secondary outcomes were conducted using a computer administered self-interview (CASI).

Internalized HIV stigma: Internalized HIV stigma was assessed with the revised HIV Stigma Scale [69] using a 4-point Likert-like scale (seven items) (e.g. "*Having HIV/AIDS makes me feel that I'm a bad person.*"). The higher the composite scores, the higher the internalized stigma.

Depressive symptoms: Depressive symptoms were assessed with the Patient Health Questionnaire depression scale-PHQ-8 [70]. PHQ-8 includes eight items and uses a 4-point Likert-like scale ('not at all'= 0 to 'nearly every day'= 3) and scores range from 0–24.

Coping styles—behavioral disengagement and self-blame: Coping styles—behavioral disengagement and self-blame—*w*ere assessed with items from the Brief COPE Scale [71] with a total of four items using a 4-point Likert scale. A mean score was calculated for each coping style.

Sample Size and Power

Overall, 941 participants were screened, of which 372 participants were enrolled across 4 sites. A sample size of 371 was used for analysis, as one participant was deemed not new-to-care after being randomized to the intervention arm and was withdrawn. The study was originally powered at 80% to detect an absolute difference of 15% between arms for the primary outcome, viral suppression at 48 weeks [72]. As for the secondary outcome (effect of the intervention on changes in stigma), the sample size of 400 (200 per arm) was calculated to detect an effect size of Cohen's d=0.3 or larger with 80% power in terms of the scores from baseline to 48 weeks between the intervention and control arms [50, 72]. We used a 2-sided 2-sample independent sample t-test and an alpha of .05. Final survey data and 48-week viral load values were available for 314 participants (85% of iENGAGE sample), including 155 intervention (84%) and 159 control (85%) participants, indicating robust study retention.

Assignment Method and Blinding (Masking)

A permuted block randomization method (1:1 ratio) with random block sizes of 2, 4, or 6 was used for assignment to the intervention or the control arm. Randomization was stratified by site. iENGAGE research staff and patients were blinded to treatment arm assignment until after the baseline assessment was completed. After completion of baseline survey, study personnel and patients were unmasked to study arm assignment to conduct intervention sessions with intervention arm participants. This process resulted in 185 participants in the intervention arm and 186 participants in the control arm (see Figure 1).

Statistical Analyses

First, we examined differences between the intervention and the control arms in terms of race, gender, insurance status, site, and age using chi squared and t-tests. Then, a repeated

measures ANOVA was used to evaluate the effects of time (baseline vs. follow-up; a within-subject variable) and study arm (control vs. intervention; a between-subject variable) on internalized HIV stigma. Next, we calculated a score for the amount of *decrease* in internalized HIV stigma for each participant by subtracting follow-up stigma from baseline stigma and examined whether depressive symptoms and coping styles (behavioral disengagement, self-blame) moderate the effect of the intervention on decrease in internalized HIV stigma. For this, we conducted a series of moderation analyses using the PROCESS macro for SPSS [73]. In moderation analyses, we used baseline scores of depression and coping styles. In case of significant interaction effects, simple slopes were examined at one standard deviation above and below (±1 SD) the mean of each moderator variable. For all moderation analyses, unstandardized coefficients were reported.

Results

As anticipated due to randomization, the intervention and control arms were similar in terms of race, gender, insurance status, site, and age, with no statistically significant differences (see Table 1). Repeated measures ANOVA revealed a significant main effect of time, $F(1, 298) = 10.10$, $p = .002$, $\eta^2_p = 0.03$, indicating that internalized HIV stigma at follow-up ($M = 2.17$, $SD = 0.73$) was significantly lower than internalized HIV stigma at baseline ($M = 2.30$, $SD = 0.75$, $p = .002$). No significant main effect was found for study arm on average, $F(1, 298) = 0.18$, $p = .674$, $\eta^2_p = .00$.

Importantly, the interaction between time and study arm was significant, $F(1, 298) = 5.06$, $p = .025$, $\eta^2_p = 0.02$. Post-hoc comparisons indicated that in the intervention arm, internalized HIV stigma at follow-up ($M = 2.11$, $SD = 0.68$) was significantly lower than at baseline ($M = 2.32$, $SD = 0.75$, $p = .000$), whereas in the control arm, no significant difference between baseline and follow-up scores of internalized HIV stigma were detected ($M = 2.27$, $SD = 0.75$; $M = 2.23$, $SD = 0.77$, $p = .514$, respectively) (Figure 2).

Next, we tested whether depressive symptoms moderate the effect of the intervention on the observed decrease in internalized HIV stigma. The main effect of study arm on decrease in internalized HIV stigma was significant ($B = 0.17$, $SE = 0.08$, $t = 2.25$, $p = .025$). However, the main effect of depression on decrease in internalized HIV stigma was not significant ($B = 0.01$, $SE = 0.01$, $t = 1.44$, $p = .149$). Importantly, the effect of study arm on decrease in internalized HIV stigma was significantly moderated by depressive symptoms (interaction effect; $B = 0.03$, $SE = 0.01$, $t = 2.05$, $p = .040$). As shown in Figure 3, the effect of study arm on decrease in internalized HIV stigma was significant at one standard deviation above the mean for depression (high level; $B = 0.33$, $SE = 0.11$, $t = 2.89$, $p = .004$), but not at one standard deviation below the mean for depression (low level; $B = 0.01$, $SE = 0.10$, $t = 0.14$, $p = .887$).

Then we tested whether self-blame and behavioral disengagement as coping styles also moderate the effect of the intervention on decrease in internalized HIV stigma in two separate moderation analyses. For the moderation of behavioral disengagement, the main effect of study arm on decrease in internalized HIV stigma was not significant ($B = 0.15$, $SE = 0.08$, $t = 1.84$, $p = .067$). The main effect of behavioral disengagement on decrease in

internalized HIV stigma was significant ($B = 0.07$, $SE = 0.03$, $t = 2.35$, $p = 019$). However, the effect of study arm on decrease in internalized HIV stigma was not significantly moderated by behavioral disengagement (interaction effect; $B = 0.09$, $SE = 0.06$, $t = 1.52$, $p = .128$). As for the moderation of self-blame, the main effect of study arm on decrease in internalized HIV stigma was significant ($B = 0.15$, $SE = 0.07$, $t = 2.10$, $p = .036$). The main effect of self-blame on decrease in internalized HIV stigma was also significant ($B = 0.06$, $SE = 0.02$, $t = 3.79$, $p = .000$). Importantly, the effect of study arm on decrease in internalized HIV stigma was significantly moderated by self-blame (interaction effect; $B = 0.08$, $SE = 0.03$, $t = 2.30$, $p = .022$). As shown in Figure 4, the effect of study arm on decrease in internalized HIV stigma was significant at one standard deviation above the mean for self-blame (high level; $B = 0.33$, $SE = 0.10$, $t = 3.18$, $p = .001$), but not at one standard deviation below the mean for self-blame (low level; $B = -0.02$, $SE = 0.11$, $t = -0.19$, $p = .845$).

Discussion

The first year following entry to HIV care is an overwhelming time for many PLWH, posing challenges to early treatment adherence and achieving desired clinical outcomes, including viral suppression. Existing studies of stigma-reduction interventions have mainly focused on PLWH who have been in HIV care for many years. The present study examined the effectiveness of the iENGAGE intervention to reduce internalized HIV-related stigma in a sample of PLWH who were newly initiating HIV care, and results suggest that the iENGAGE intervention is effective in reducing internalized HIV-related stigma. This is an important finding, as internalized HIV-related stigma over time negatively affects retention in HIV care, medication adherence, and viral suppression [15, 65, 74]. In addition to addressing stigma, the iENGAGE intervention includes a variety of modules that facilitate information, motivation, and behavioral skills for adherence to care and ART, focusing on adjustment, problem solving, affect management, and communication. Thus, our findings support the notion that multifaceted and multiphase approaches incorporating psychosocial skill-building can reduce internalized HIV-related stigma. Future research should examine which of these ingredients of the intervention is most important for which sub-populations. Furthermore, research focusing on the effects of linkage to HIV care and ART initiation on internalized HIV-related stigma yielded inconsistent results [75]. Our findings did not support the hypothesis that without a supportive intervention (i.e., in the control group that received standard of care), linkage to HIV care leads to a reduction in internalized HIV stigma. However, if linkage to care is combined with a supportive intervention, internalized HIV stigma does seem to decrease.

This study also advances our knowledge of stigma interventions by examining the moderating effects of depressive symptoms and coping styles in the association between the intervention (control vs. intervention arms) and internalized HIV-related stigma. The results suggest that the intervention has stronger effects for those who have higher levels of depressive symptoms or who use self-blame as coping mechanisms upon HIV medical care initiation. In other words, the higher the level of depressive symptoms and self-blame coping at baseline, the higher the benefit of the iENGAGE intervention in reducing internalized HIV-related stigma over the first year in medical care. This finding is in line with a recent

study suggesting that individuals initiating HIV care with posttraumatic stress disorder or depressive symptoms benefit more from a stigma-reduction intervention, resulting in greater improvement in engagement in care [67]. Thus, it appears that these interventions may have greater benefit for those who have multiple psychosocial challenges. Based on these data, future interventions may specifically focus on individuals with higher levels of depressive symptoms and who use maladaptive coping strategies. Further research should also focus on the role of other potential moderators of the association between intervention and internalized stigma. It is also possible that associations among internalized HIV-related stigma, depression, and coping styles are bidirectional.

This study had several limitations. Participants were all patients at well-resourced HIV clinics affiliated with major academic health centers. Generalizability to other settings, as well as to other geographical locations, remains an open question. Furthermore, the long-term effects of the iENGAGE intervention need to be examined. In addition, the outcome assessment of internalized HIV stigma was based on self-report and may be subject to biases. However, this measure of internalized HIV stigma has been used extensively in previous research, which strongly supports its construct validity [1, 15, 24]. Finally, this study did not include an attention control condition, which might have affected our conclusions [76].

Despite these limitations, the findings from this study have important implications for the field of stigma intervention research and provide crucial information for policy and programs aiming to improve outcomes for PLWH, particularly during the vulnerable time following diagnosis and HIV care entry. Knowledge about the effect of the iENGAGE intervention on internalized stigma and the moderating mechanisms for this effect can be used to tailor and strengthen interventions to reduce internalized stigma and thereby to maximize benefits for early retention in care and health among PLWH who are new to care, particularly those with higher depressive symptoms and those engaging in self-blame coping.

Conflicts of Interest and Sources of Funding:

This work was supported by the National Institutes of Allergy and Infectious Diseases (NIAID) grant numbers 5R01AI103661-05 and 3R01AI103661-03S1; ClinicalTrials.gov NCT01900236. This research was also supported by the University of Alabama at Birmingham (UAB) Center for AIDS Research CFAR, an NIH funded program (P30 AI027767) that was made possible by the following institutes: NIAID, NCI, NICHD, NHLBI, NIDA, NIA, NIDDK, NIGMS, and OAR.

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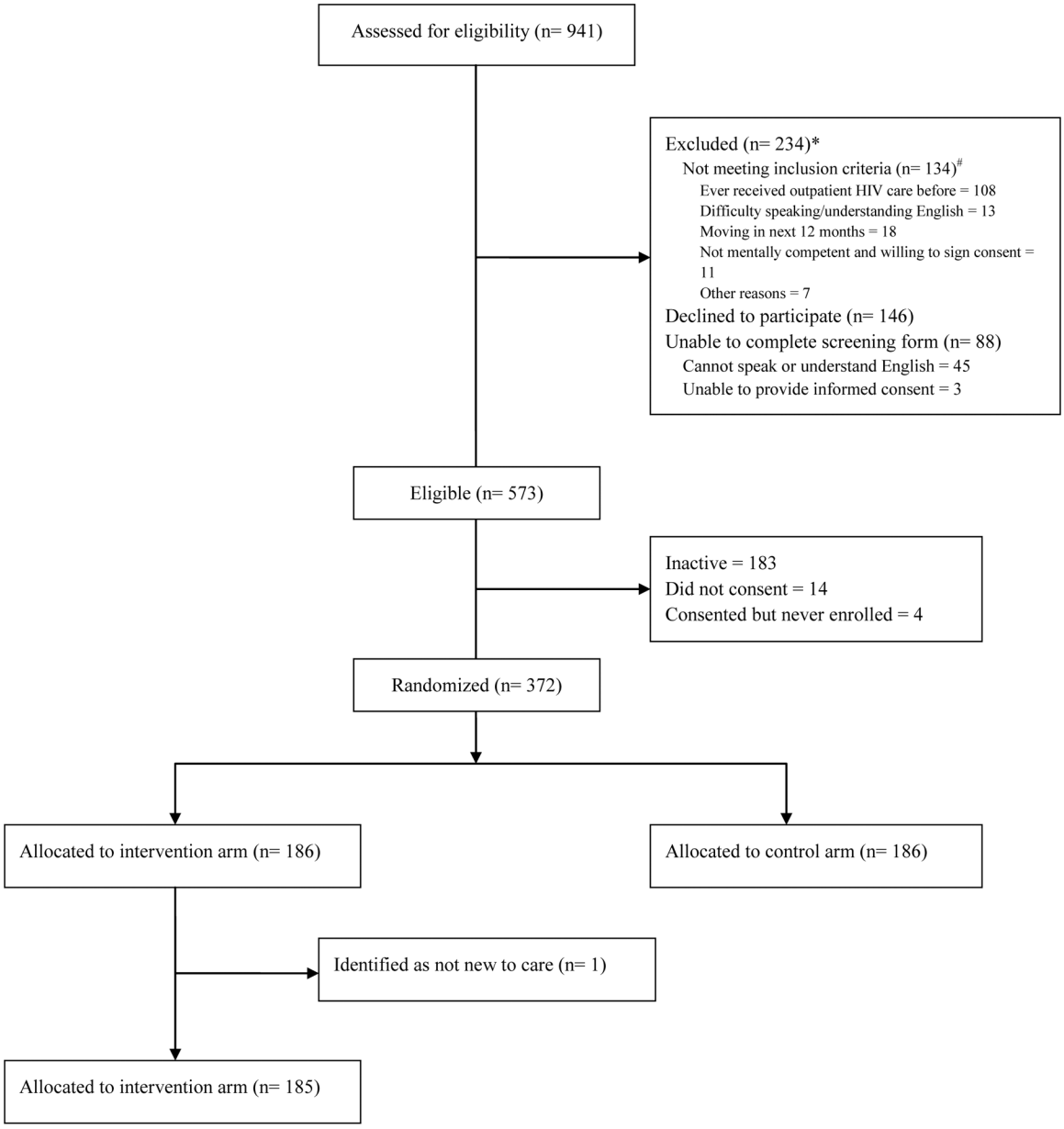

Figure 1. Participant flow diagram.

*93 of the 234 were not new to care participants; # There were 5 questions for participants to meet the inclusion criteria and participants could choose multiple reasons.

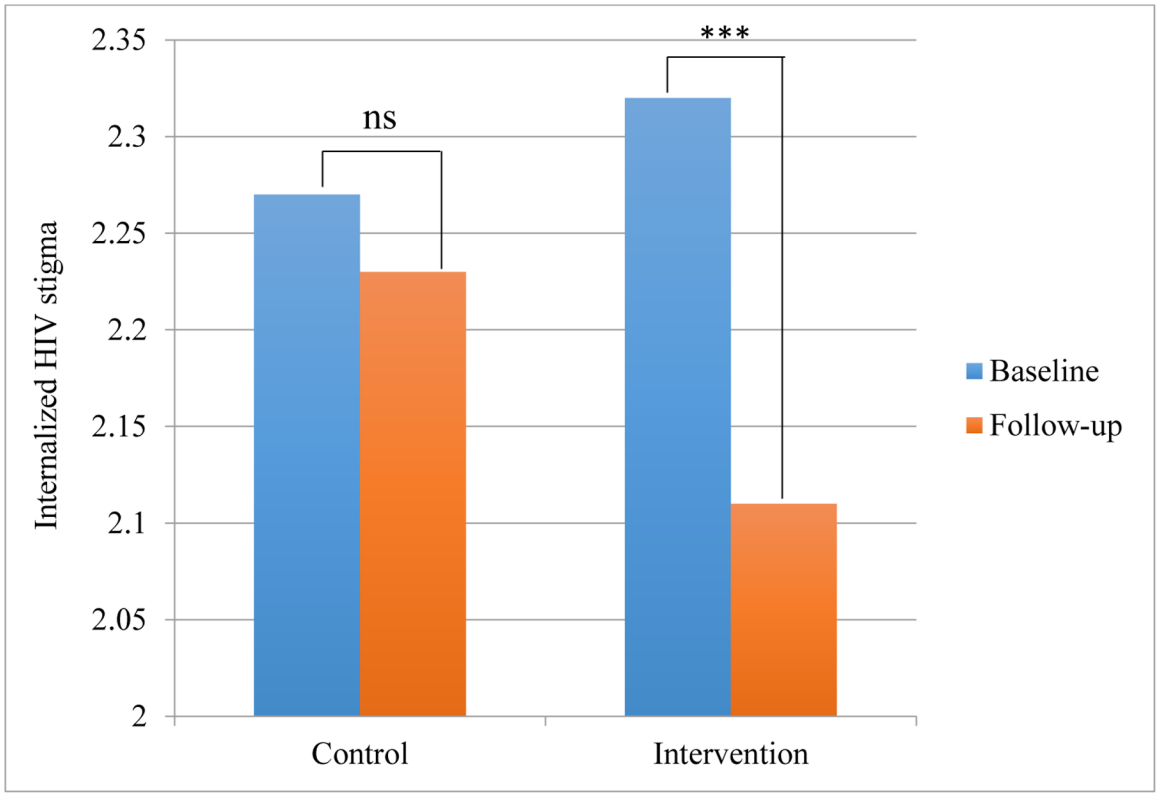

Figure 2.
Effect of study arm on in internalized HIV stigma. ***$p < .001$, ns = not significant.

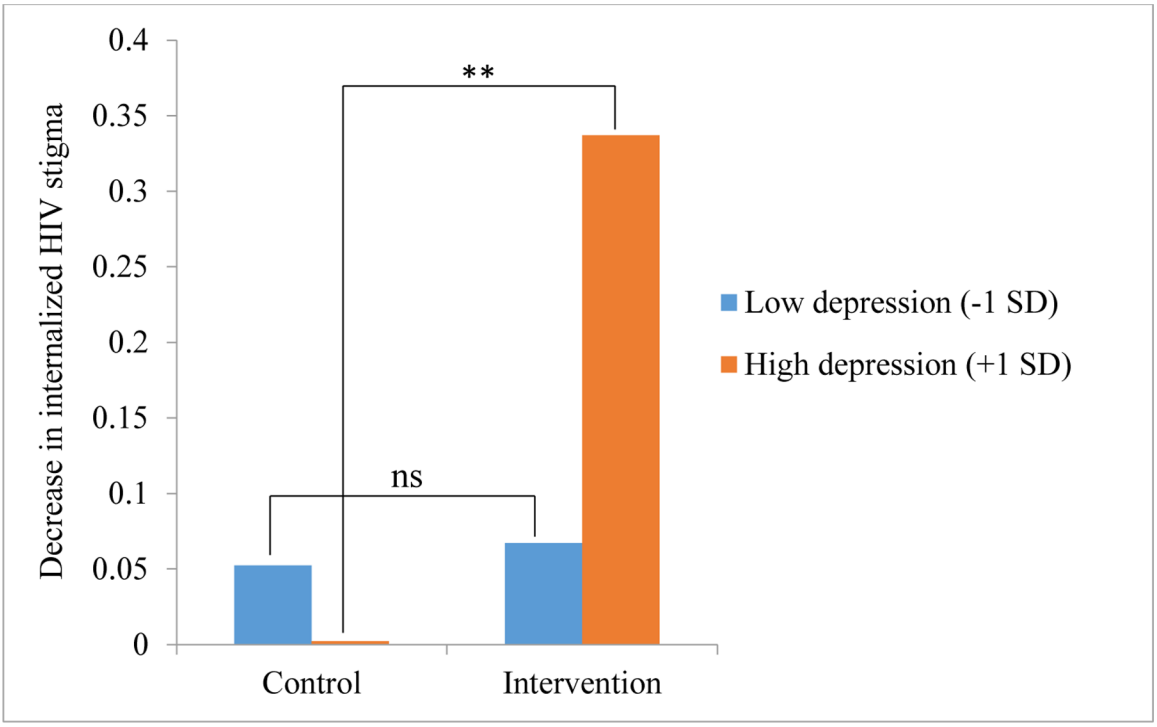

Figure 3.

Interaction of depressive symptoms with study arm on decrease in internalized HIV stigma. ** $p < .01$, ns = not significant. Note that "decrease in internalized HIV stigma" indicates difference between the baseline and follow-up levels in internalized HIV stigma.

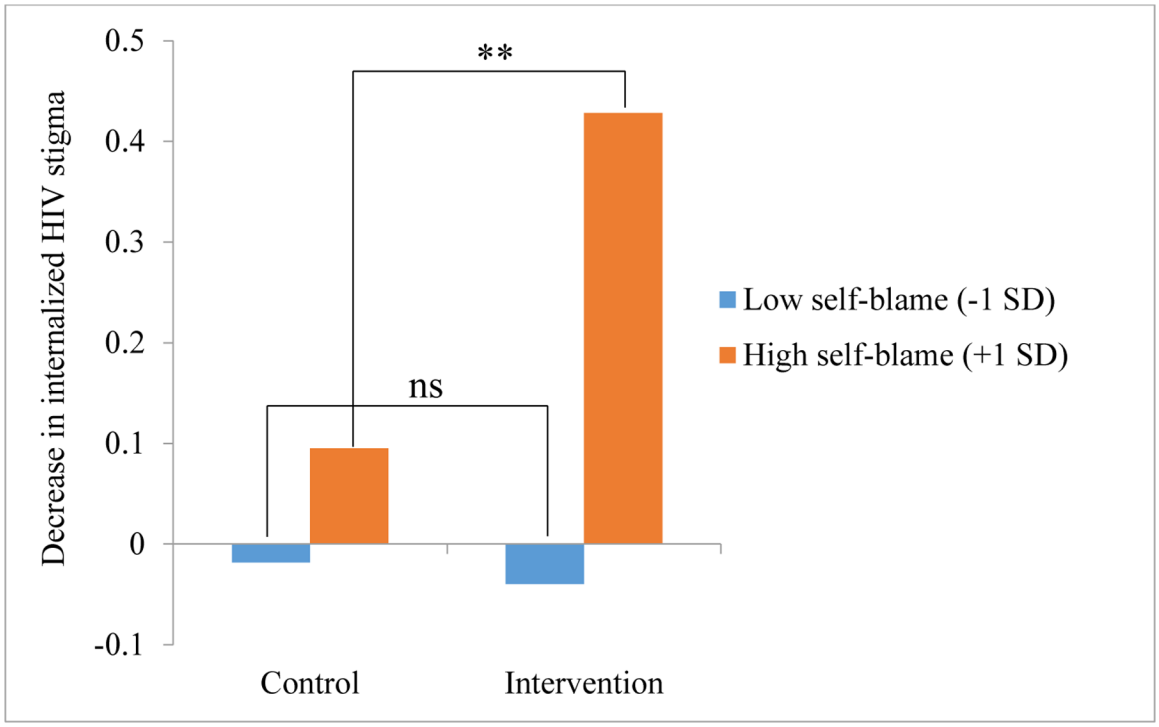

Figure 4.

Interaction of self-blame with study arm on decrease in internalized HIV stigma. ** $p < .01$, ns = not significant. Note that negative values for "decrease in internalized HIV stigma" indicate an "increase" as opposed to a "decrease" in internalized HIV stigma from baseline to follow-up.

Table 1.

Race, gender, insurance status, site, and age by study arm

		Study arm			
	Total (%)	**Control (%)**	**Intervention (%)**	χ^2	***p***
Race				1.61	.447
White	109(29.4)	60(32.3)	49(26.5)		
Black or African American	231(62.3)	112(60.2)	119(64.3)		
Other	31(8.4)	14(7.5)	17(9.2)		
Gender				.69	.708
Male	294(79.2)	148(79.6)	146(78.9)		
Female	71(19.1)	36(19.4)	35(18.9)		
Transgender	6(1.6)	2(1.1)	4(2.2)		
Insurance				1.14	.567
Public	174(47.3)	92(49.7)	82(44.8)		
Private	107(29.1)	53(28.6)	54(29.5)		
None	87(23.6)	40(21.6)	47(25.7)		
Site				.00	1.00
JHU	78(21)	39(21)	39(21.1)		
UAB	153(41.2)	77(41.4)	76(41.1)		
UNC	76(20.5)	38(20.4)	38(20.5)		
UW	64(17.3)	32(17.2)	32(17.3)		
				t	***p***
Age *(Mean)*		36.22	35.20	.83	.409

JHU: Johns Hopkins University, UAB: University of Alabama at Birmingham, UNC: The University of North Carolina at Chapel Hill, UW: University of Washington.