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HIV-RELATED STIGMA AND PSYCHOLOGICAL DISTRESS IN A COHORT OF PATIENTS RECEIVING ANTIRETROVIRAL THERAPY IN NIGERIA

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Abstract

Psychological distress is increasingly recognized as a barrier to engagement in HIV care, resulting in poor HIV outcomes. HIV-related stigma is a potential driver of distress in people living with HIV (PLWH). We conducted a prospective cohort study in 288 PLWH who newly initiated ART in a Nigeria. We assessed overall stigma (range 40-160) and four stigma subtypes (personalized, disclosure, negative self-image, and public stigma) at enrollment, and assessed psychological distress at enrollment, 6, and 12-months after ART initiation. We used logistic regression to assess

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the relationship between stigma and 12-month psychological distress. Overall stigma was high (102.34 ± 5.65) and was higher in both unmarried patients ($p < 0.01$) and those who had not disclosed their HIV status to anyone at enrollment ($p < 0.01$). Higher overall stigma (OR: 1.05, 95% CI 1.00 – 1.09) and personalized stigma (OR: 1.08, 95% CI 1.00 – 1.16) were associated with higher odds of psychological distress at 12-months.

Conclusions: Overall stigma levels were high in a cohort of PLWH initiating care in Nigeria. Higher stigma was associated with psychological distress. These data support the need for integration of measures to reduce stigma and psychological distress in the care of PLWH.

Keywords

HIV; stigma; psychological distress

Introduction

Nigeria is the most populated country in Africa, with over 200 million inhabitants (World Bank, 2021). With an estimated 1.8 million people living with HIV (PLWH) in 2018, Nigeria has the fourth largest HIV epidemic worldwide (UNAIDS, 2019). Despite the implementation of universal test and treat strategies leading to an increase in access to antiretroviral therapy (ART), in 2018, only 53% of PLWH in Nigeria were on treatment and 42% were virally suppressed - outcomes well below Joint United Nations Programme on HIV/AIDS (UNAIDS) 95-95-95 targets (UNAIDS, 2014, 2019).

Untreated mental illness in PLWH has increasingly been recognized as a barrier to engagement in HIV care, often resulting in poorer ART adherence and viral suppression (Adewuya et al., 2010). Consequently, attaining UNAIDS 95-95-95 targets may not be possible without routinely identifying and addressing mental health needs among PLWH. Psychological distress, an important manifestation of mental illness, is more prevalent in PLWH than in the general population (Mthembu et al., 2017). Understanding the drivers of psychological distress among PLWH is critical to developing effective mental health interventions to improve both psychological and clinical outcomes.

Across different settings, many factors, such as gender, marital status, and literacy level, have been associated with psychological distress among PLWH (Basha et al., 2019; Monteiro et al., 2017). However, the relationship between HIV-related stigma and psychological distress has not been well explored in sub-Saharan Africa. HIV-related stigma has continued to be a major concern in communities globally, and population-based surveys in Nigeria between 2014 and 2019 showed that almost 60% of people admitted to having discriminatory attitudes towards PLWH (Herek et al., 2002; UNAIDS, 2021). In its 2021 report on HIV-related stigma, UNAIDS suggested that failure to make any progress on HIV-related stigma would undermine efforts to reach HIV care continuum targets (UNAIDS, 2021). Nonetheless, recent passing of the Anti-Homosexuality Bill by the Ugandan parliament in March 2023, goes beyond banning same-sex relations (as 30 other African country have doe) to making it a crime to identify as lesbian, gay, bisexual, trans or queer (LGBTQ+),(AP News, 2023). Such legislation is indicative of just how much stigma against certain populations continues to be a major challenge towards

addressing HIV on the African continent. With high levels of ongoing stigmatizing beliefs in the general community in one of the largest populations of PLWH worldwide, Nigeria represents an important environment for studying the relationship between perceived stigma and psychological distress.

The objective of this study was to describe the patterns of HIV-related stigma in a cohort of patients newly initiated on ART in Nigeria and to assess the relationship between HIV-related stigma and psychological distress in their first year on ART.

Methods

Study setting

The study was set at the Nigerian Institute for Medical Research (NIMR) in Lagos, Nigeria, a President's Emergency Plan for AIDS Relief (PEPFAR)-supported HIV clinic that began providing care in 2002 and currently provides comprehensive HIV care to over 7,000 patients.

Study design

We conducted a prospective cohort study of patients who enrolled in the NIMR HIV clinic between November 2013 and May 2014, who: 1) were ART eligible (baseline CD4 count of 500 cells/uL or less), 2) completed required counseling for ART initiation, 3) were at least 18 years of age, 4) initiated ART within 90 days of study enrollment, 5) were fluent in English (the official language of Nigeria) or one of the three major Nigerian dialects (Igbo, Yoruba, or Hausa). Participants were recruited from the clinic waiting room during clinic hours by study staff. Consented patients were followed for one year and seen at baseline, 6, and 12 months after enrollment for data collection.

Data collection

Demographic information (sex, age, marital status, level of education, employment status, food security, and poverty status), was collected using baseline questionnaires at study entry. Poverty status was assessed using the United States Agency for International Development (USAID) Poverty Assessment Tool (USAID, 2012). Food security was assessed using the USAID Household Food Insecurity Access Scale for measurement of food access (USAID, 2007). Disclosure of HIV status was assessed at enrollment, at 6, and at 12 months by asking patients "Have you disclosed your HIV diagnosis to any friends or family members?" Participants were considered to have either disclosed early (at baseline) or late/never (by the 6 or 12 -month follow-up or not at all).

HIV-related stigma was measured at baseline using the HIV-Stigma Scale (HSS) (Berger et al., 2001). The HSS is a 40-item scale that measures an individual's perception of societal attitudes towards PLWH as well as their personal thoughts and feelings of what it means to live with HIV. The scale provides scores for overall stigma, and four subtypes of HIV-related stigma: personalized disclosure, negative self-image, and public stigma. Individual questions are scored on a scale of 1 to 4, and the range for overall stigma scores is 40 to 160. This scale has been validated in resource-limited settings similar to the current study setting

(Ajong et al., 2018; Feyissa et al., 2012; Oke et al., 2019). Though there are no validated cut-off definitions, higher scores are associated with higher perceived stigma.

Outcome assessment

We measured psychological distress using the World Health Organization Self-Reporting Questionnaire-20 (SRQ-20) at baseline, 6, and 12 months. The SRQ-20 has been validated for use in low- and middle- income countries (Netsereab et al., 2018; van der Westhuizen et al., 2016). Scores range from 0 to 20 with higher scores correlating with clinically significant distress. Based on the application of this scale in similar settings, we defined clinically significant psychological distress as a score of ≥ 5 (Mba et al., 2008). The primary outcome of interest for this analysis was psychological distress at 12 months.

Statistical analysis

We summarized the baseline characteristics of patients including age, sex, marital status, education, employment, disclosure status, poverty, and food insecurity status. We described patterns of perceived overall stigma as well as different subtypes of stigma for the entire cohort, and by baseline characteristics using 2-tailed t-tests. For missing data on the HSS, we assessed for missingness completely at random (using Little's MCAR), and replaced the missing values with the mean of the remaining answered questions.

The association between stigma and psychological distress was assessed using logistic regression. Stigma was modeled as a continuous variable while psychological distress was dichotomized (a score of ≥ 5 signified clinically significant psychological distress). We modelled overall stigma and the four stigma subtypes separately as the subtypes contain shared questions with each other and with the overall stigma measure.

We built univariate and multivariable logistic regression models to determine the predictors of psychological distress. Multivariable models included factors identified *a priori* that might be associated with psychological distress or be potential confounders in the relationship between stigma and psychological distress (age, gender, marital status, educational level, employment status, disclosure of status, poverty status, food insecurity status, and stigma). Variables included in the model were assessed for collinearity using the variance inflation factor.

Statistical analysis was done using STATA version 16 (StataCorp, 2019).

IRB approval—We obtained IRB approval from Partners HealthCare (Protocol no. P002460 Boston, MA, USA), the Nigerian Institute for Medical Research (Protocol no. 14/28 Lagos, Nigeria) and Vanderbilt University Medical Center (Protocol no. 161779 Nashville, TN, USA).

RESULTS

Cohort description

The cohort consisted of 288 individuals, no individuals declined to participate in the study. The mean age of individuals in the cohort was 40.04 (SD \pm 9.21); participants were

predominantly female (62%, n=179). Fifty-one percent (n=146) of patients were married, 82% (n=238) attained secondary education or higher, and 47% (n=146) were formally employed. Ten percent (n=30) of the patients lived on less than 1.25 USD/day, while 9% (n=25) reported food insecurity.

Eighty-three percent (n=239) of patients had disclosed their HIV status at the time they enrolled in the clinic. Twelve percent of patients disclosed their HIV status after the first encounter (n=34) and 5% (n=15) had not disclosed by the end of the follow-up period. CD4 count at baseline was less than 200cells/mL³ for 39% (n=112) of patients. Prevalence of psychological distress increased from 2% at baseline, to 13% at 6 months, and 37% at 12 months [Table 1].

Description of overall stigma and stigma subtypes

For overall stigma scores, <1% of responses were missing (n=43 missing items); these were found to be missing completely at random (Little's MCAR p=0.92). Overall stigma scores patients ranged from 80 to 126 with a mean stigma score of 102.34 (SD±5.65, range 80 – 126). The mean score for personalized stigma was 40.55 (range 36 – 58), for disclosure was 29.47 (range 20 – 36), negative self-image was 32.42 (range 26 – 39), and public stigma was 51.88 (range 40 – 62) [Table 2].

Patients who were unmarried (vs. married, 103.25 vs 101.39, p<0.01), who had not disclosed their HIV status at enrollment (vs. those who had disclosed, 109.83 vs 100.80, p<0.01) and who had a baseline CD4 count of ≥200 cells/uL (vs. those with baseline CD4 counts <200 cells/uL, 102.90 vs 101.33, p=0.02) all had higher mean overall stigma scores. Patients who had not disclosed at baseline also had higher mean stigma scores for all the four stigma subtypes: personalized (45.78 vs 39.48, p<0.01), disclosure (31.04 vs 29.18, p<0.01), negative self-image (34.35 vs 32.02, p < 0.01), and public stigma (54.96 vs 51.25, p < 0.01). Additionally, patients with CD4 counts ≥ 200 cells/uL had higher mean scores for personalized (40.83 vs 40.07, p = 0.04), disclosure (29.72 vs 29.06, p < 0.01), and public stigma (52.16 vs 51.46, p = 0.02).

Mean scores for overall stigma and all four stigma subtypes did not differ significantly by sex, education status, employment category, poverty status, or food security [Table 3].

Relationship between stigma and psychological distress 12 months after ART initiation

In univariate analysis, overall, personalized, and negative self-image stigma were found to be associated with psychological distress [Table 4]. A one-point increase in overall, personalized, and negative self-image stigma at baseline was associated with 5%, 8% and 3% increase in odds of clinically significant distress after 12 months on ART, respectively (OR 1.05, 95% CI 1.00 – 1.09; OR 1.08, 95% CI 1.00 – 1.16; OR 1.13 95% CI 1.00 – 1.27). Neither disclosure nor public stigma were significantly associated with psychological distress at 12 months [Table 4]

Given these findings, we built three multivariable models including all patient characteristics and each with one stigma measure (either overall, personalized, and negative self-image stigma). In adjusted analysis, none of these stigma measures were significantly associated

with 12-month psychological distress (overall aOR 1.00 (95% CI 0.94 – 1.07), personalized aOR 1.01 (95% CI 0.90 – 1.14), negative self-image aOR 1.01 (95% CI 0.86 – 1.17)).

Other predictors of psychological distress 12 months after ART initiation

In univariate logistic regression analysis, female sex (OR 2.57, 95% CI 1.52 – 4.34) and late/never disclosure (OR 2.60, 95% CI 1.39 – 4.86) were associated with increased odds of clinically significant psychological distress. Being married (OR 0.32, 95% CI 0.19 – 0.53) was found to be protective against psychological distress [Table 5].

In multivariable analysis, whether the model included overall, personalized, and negative self-image stigma, the odds of female sex (aOR 2.33, 95% CI 1.26 – 4.23) and older age (aOR 1.04, 95% CI 1.00 – 1.07) were associated with increased risk of 12-month psychological distress, while being married (aOR 0.32, 95% CI 0.18 – 0.58) was associated with a decreased risk of 12-month psychological distress (aOR for overall stigma listed for brevity). Disclosure status was a significant predictor of psychological distress in univariate analysis and remained significant in multivariable analysis including negative self-image stigma (aOR 2.44, 95% CI 1.10 – 5.40), but not overall or personalized stigma [Table 5].

Combined risk factors for psychological distress

Seventy-seven percent of females who were unmarried, had not disclosed their HIV status to anyone at enrollment, and had high perceived overall stigma (mean cohort score of 102.34), developed clinically significant psychological distress at 12 months. The lowest prevalence of psychological distress (0%) was among married males who had late or never disclosure and reported lower overall stigma.

Discussion

We assessed multiple types of stigma in a cohort of nearly 300 PLWH initiating ART in Nigeria. Our study enabled us to gain important insight into perceived HIV-related stigma and psychological distress among PLWH in Nigeria. Individuals in the cohort reported high levels of stigma upon enrollment in care, and while only 2% reported clinically significant distress at enrollment; this increased to nearly 40% after 12 months on ART. Unmarried females who had not disclosed their HIV status to anyone and reported high levels of overall stigma, were most vulnerable to psychological distress.

Assessing psychological distress over a one-year period allowed us to notice a quite remarkable increase in its prevalence over the first 12 months on ART. Our findings are consistent with data from Mozambique where there was an increase in depressive symptomatology one year after ART initiation (Pearson et al., 2009). Our 12-month prevalence of distress was higher than in other cross-sectional analyses from Nigeria and Ethiopia (Basha et al., 2019; Olagunju et al., 2012). The increasing prevalence of distress over time in our cohort underscores the need for ongoing mental health assessments in PLWH during the period after establishing care and when they are at great risk for morbidity and mortality, and also challenges the notion that psychological well-being will improve after establishing care and starting ART (Ingle et al., 2014; Remien et al., 2019).

In addition to high prevalence of psychological distress, we observed higher levels of overall stigma in our study compared to PLWH in similar settings in sub-Saharan Africa. For example, mean overall stigma was higher in our cohort 102.34 (\pm 5.65) than the mean scores among PLWH in other parts of Nigeria (95.74) and Cameroon (88.30) (Ajong et al., 2018; Oke et al., 2019). However, these differences may be a consequence of higher levels of perceived stigma experienced by individuals with a more recent HIV diagnosis (Ajong et al., 2018). Amongst our patients, higher overall stigma was found in unmarried patients, patients who had not disclosed their HIV status, and patients with higher CD4 counts. The higher overall stigma in unmarried PLWH could be attributed to the absence of a close companion or partner to provide social support which has a protective effect against HIV stigma (Rao et al., 2012; Takada et al., 2014).

Not only was stigma common in our cohort, but we also found a significant association between overall stigma and both disclosure practices and psychological distress. The relationship between stigma and psychological distress may have been driven by particular stigma subtypes - primarily personalized stigma and a negative self-image. These are the forms of stigma that specifically relate to an individual's personal experiences with- and fears of rejection related to HIV (personalized), and inwardly directed negative thoughts and feelings about one's HIV status (negative self-image). In our cohort, stigma was assessed within 3 months of establishing care in clinic. It is plausible that this period may have been particularly fraught for people struggling to come to terms with their diagnosis and prevent unwanted disclosure. This finding adds to the limited literature on the subject and is consistent with data from similar studies from sub-Saharan Africa (Basha et al., 2019; Deribew et al., 2010; Gupta et al., 2010; Pappin et al., 2012; Parcesepe et al., 2018). Interestingly, these baseline stigma scores were strongly associated with disclosure behaviors over the follow-up year.

Our analysis revealed several independent predictors of clinically significant distress at 12 months. Females had two-fold increased odds of distress compared to males. This is similar to findings both in the region and more broadly and may reflect more generalized differences in the prevalence of affective disorders (Albert, 2015; Basha et al., 2019; Ofovwe & Ofovwe, 2013). In addition to female sex, increasing age was also a predictor of psychological distress. Each 10-year increase in age was associated with a 35% increase in the odds of being distressed. As people get older, they are more likely to develop age-related comorbid non-communicable diseases. A possible explanation for the higher likelihood of distress in older patients could be the higher frequency of comorbidities in older patients (Allavena et al., 2018; Wing, 2016). Being married appeared to be protective against psychological distress. Married individuals had 70% reduced odds of significant psychological distress compared to their unmarried peers, highlighting the critical role of social support for psychological outcomes among PLWH (Ofovwe & Ofovwe, 2013; Olagunju et al., 2012).

The relationship between disclosure, stigma, and psychological distress in our analysis was important, but complex. In unadjusted analysis, individuals who had disclosed their HIV status at baseline had more than twice the odds of being clinically distressed than patients who had not disclosed at baseline. However, when we accounted for both stigma (either

overall or personalized) and disclosure status, and they were included in the same adjusted analysis, both constructs lost statistical significance. Given that disclosure and stigma were associated with each other, and both were associated with psychological distress, there is likely a confounding relationship between these variables.

Despite its strengths, our study has important limitations. First, our study described individuals who were retained in care in the year after ART initiation, and this may actually underestimate stigma and distress (which may be higher among patients who are lost from care). Second, HIV-related stigma was only assessed at baseline, so we were unable to determine how the relationships between stigma, disclosure, and psychological distress changed early after ART initiation. Nonetheless, our study is one of a few that assessed psychological outcomes, such as distress, in a longitudinal manner among PLWH during a period that is critical for engagement and care outcomes. Finally, we did not identify a sample size required to have 80% power for this secondary analysis of an established cohort, and therefore our significant findings should be interpreted in this context.

This study has important implications for policy regarding the care of PLWH. Given the high levels perceived stigma and prevalence of distress, and the association between them, this study supports the need for ongoing stigma reduction interventions which may contribute to improved psychosocial outcomes for PLWH. To this end, in 2016, the National Agency for AIDS Control (NACA) in Nigeria, published the *National HIV/AIDS Stigma Reduction Strategy* with the goal of eliminating all forms of stigma and discrimination by 2020 (National Agency for the Control of AIDS, 2016). Other researchers have recognized these efforts as relevant, and continued to recommend the strengthening, design, planning, implementation, monitoring, and evaluation of context-specific stigma reduction programs; this includes for sexual and gender minorities who's identities have been stigmatized and criminalized (Odimegwu et al., 2017, AP News, 2023). Our findings support these assertions. In addition to stigma mitigation, our analysis further underscores the need for broadly integrated services for the screening and treatment of psychological distress among PLWH.

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Table 1:

Descriptive characteristics of study population

Study Population and Descriptive Characteristics, N = 288	
Age (years)	
Mean	40.04 (\pm 9.21)
Median	38
Gender	
Female	179 (62%)
Male	110 (38%)
Marital Status	
Married	146 (51%)
Unmarried	142 (49%)
Education	
None/Primary	50 (17%)
Secondary/Tertiary	238 (83%)
Employment	
Formal Employment	136 (47%)
No Formal Employment	137 (49%)
Unknown	15
Disclosure	
Early	239 (83%)
Late/Never	49 (17%)
Poverty Assessment	
< 1.25 USD/day	30 (10%)
1.25USD/day	258(90%)
Food Insecurity	
Secure	263 (91%)
Insecure	25 (9%)
CD4 Count	
<200	112 (39%)
200	166 (58%)
Unknown	10 (3%)

Table 2:

Perception of stigma and stigma subtypes in the study population

Perceived Stigma			
Stigma Type	Cohort Mean	Cohort Range	Scale Range
Overall	102.34	80 - 126	40 - 160
Personalized	40.55	36 - 58	18 - 72
Disclosure	29.47	20 - 36	10 - 40
Negative Self-Image	32.42	26 - 39	13 - 52
Public	51.88	40 - 62	20 - 82

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Table 3:

HIV-related stigma by patient characteristics

	Overall Stigma		Personalized Stigma		Disclosure Stigma		Negative Self Image Stigma		Public Stigma	
Sex										
Female	102.23	0.69	40.31	0.14	29.49	0.84	32.48	0.50	51.77	0.38
Male	102.51		40.94		29.44		32.31		52.06	
Age Category										
18-29 years	102.73	0.66	40.63	0.89	29.16	0.23	33.00	0.13	51.87	0.97
30 years	102.29		40.53		29.51		32.35		51.88	
Marital Status										
Unmarried	103.25	<0.01*	40.90	0.06	29.62	0.20	32.86	<0.01*	52.12	0.11
Married	101.39		40.18		29.31		32.95		51.63	
Education										
None/Primary	101.30	0.10	40.08	0.16	29.18	0.21	32.24	0.46	51.56	0.26
Secondary/Tertiary	102.56		40.65		29.53		32.45		51.95	
Disclosure										
Early	100.80	<0.01*	39.47	<0.01*	29.15	<0.01*	32.02	<0.01*	51.25	<0.01*
Late/Never	109.84		45.78		31.04		34.35		55.96	
Formal Employment										
Yes	102.21	0.80	40.42	0.56	29.44	0.71	32.39	0.99	51.70	0.28
No	102.39		40.65		29.53		32.39		52.04	
Poverty Assessment										
Below \$1.25	101.40	0.15	39.97	0.21	29.47	0.98	31.93	0.05	51.60	0.42
\$1.25	102.45		40.61		29.47		32.47		51.92	
Food Security										
Secure	102.27	0.55	40.53	0.71	29.41	0.14	32.41	0.87	51.88	0.94
Insecure	103.04		40.80		30.12		32.48		51.92	
CD4 Count										
<200	101.33	0.02*	40.07	0.04*	29.06	<0.01*	32.14	0.08	51.46	0.02*
200	102.91		40.83		29.72		32.57		52.16	

Table 4:Association between HIV-related stigma and psychological distress[†]

	Odds Ratio	95% CI
Overall Stigma	1.05	1.00 - 1.09
Personalized Stigma	1.08	1.00 - 1.16
Disclosure Stigma	1.05	0.93 - 1.18
Negative Self-Image	1.13	1.00 - 1.27
Public Stigma	1.06	0.97 - 1.16

[†]Logistic regression. See Methods for details. CI: confidence interval

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Table 5:

Predictors of psychological distress 12 Months after ART Initiation Among PLWH in Nigeria

	Unadjusted Analysis		Adjusted Model with Overall Stigma		Adjusted Model with Personalized Stigma		Adjusted Model with Negative Self Image Stigma	
	cOR	95% CI	aOR	95% CI	aOR	95% CI	aOR	95% CI
Gender								
Male	1		1		1		1	
Female	2.57	1.52 - 4.34	2.33	1.26 - 4.23	2.34	1.27 - 4.33	2.32	1.26 - 4.27
Age	1.010	0.98 - 1.04	1.04	1.00 - 1.07	1.035	1.00 - 1.07	1.04	1.00 - 1.07
Marital Status								
Unmarried	1		1		1		1	
Married	0.14	0.19 - 0.53	0.32	0.18 - 0.58	0.32	0.18 - 0.58	0.32	0.18 - 0.58
Education								
None/Primary	1		1		1		1	
Secondary/Tertiary	1.10	0.58 - 2.07	0.91	0.41 - 1.99	0.91	0.42 - 1.99	0.912	0.42 - 2.00
Employment								
No formal employment	1		1		1		1	
Formal Employment	0.77	0.47 - 1.26	0.79	0.40 - 1.23	0.70	0.40 - 1.23	0.698	0.40 - 1.23
Disclosure								
Early	1		1		1		1	
Late/Never	2.60	1.39 - 4.86	2.41	0.99 - 5.87	2.29	0.82 - 6.38	2.44	1.10 - 5.40
CD4 Count								
<200	1		1		1		1	
200	1.37	0.83 - 2.26	1.27	0.71 - 2.28	1.27	0.71 - 2.27	1.27	0.71 - 2.28
Poverty Assessment								
<\$1.25	1		1		1		1	
\$1.25	1.25	0.56 - 2.77	1.28	0.48 - 3.42	1.28	0.48 - 3.42	1.28	0.48 - 3.42
Food Insecurity								
Secure	1		1		1		1	
Insecure	0.61	0.25 - 1.52	0.38	0.13 - 1.15	0.39	0.13 - 1.15	0.38	0.13 - 1.15
Overall Stigma	1.05	1.00 - 1.09	1.00	0.94 - 1.07				
Personalized Stigma	1.08	1.00 - 1.16			1.01	0.90 - 1.14		
NSI Stigma	1.13	1.00 - 1.27					1.01	0.86 - 1.17

Adjusted models include either overall, personalized, or (Negative Self-Image) NSI stigma.