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Predictors of disparities in retention in care among African Americans living with HIV

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Abstract

Limited health literacy may contribute to racial disparities in retention in HIV care. The purpose of this study was to evaluate the effects of health literacy and patient and social-level factors on retention in care among African Americans living with HIV. This study included 699 participants recruited from outpatient HIV clinics and retention in care was defined as visit adherence. Multivariable logistic regression models were used to assess predictors of visit adherence among persons with 100% visit adherence compared to less than 100% visit adherence. Controlling for demographic factors, the odds of 100% visit adherence was greater among non-African Americans compared to African Americans. In models that included health literacy, race was no longer significant and health literacy was a significant predictor of 100% visit adherence. Among participants with less than 100% visit adherence, health literacy was not a significant predictor of visit adherence; however, age, marital status, and patient attitudes towards the health care provider were significant predictors. Findings suggest that health literacy may mediate the relationship between race and visit adherence. Future studies should further examine these relationships and develop interventions that target modifiable factors, with a goal of improving health equity and minimizing disparities.

Keywords

health literacy; retention in care; visit adherence; disparities in HIV

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Disclosure Statement

The authors declare that they have no conflicts of interest to report.

Data Availability Statement

The data that support the findings from this study are available on request from the corresponding author (AA). The data are not publicly available due to information that could compromise the privacy of research participants.

Introduction

Although African Americans comprise only 12% of the United States population (Centers for Disease Control and Prevention, 2018a), they are disproportionately affected by HIV compared to other racial and ethnic groups. In 2016, African Americans accounted for 42% of the nearly 1.1 million persons living with HIV (PLWH) and 44% of all new HIV diagnoses (Disease Control and Prevention, 2018a; Centers for Disease Control and Prevention, 2016). Additionally, while the incidence of HIV-associated deaths is declining among all racial and ethnic groups, deaths among African Americans remains higher than among White and Hispanic/Latino persons (Siddiqi, Hu, & Hall, 2015; Centers for Disease Control and Prevention, 2016).

Retention in care, referring to regular attendance at scheduled HIV appointments, is one of the most significant predictors of HIV treatment failure (Rastegar, Fingerhood, & Jasinski, 2003) and may contribute to poor health outcomes among this population. Approximately 46% of African Americans are retained in care, which is 5% less than among White PLWH (Centers for Disease Control and Prevention, 2017). Poor retention in care is associated with elevated viral load (Crawford, 2014; Giordano, et al., 2007; Mugavero, Amico, et al., 2012), lower CD4 count (Berg et al., 2005), and increased likelihood of developing AIDS-defining illnesses (Crawford, 2014; Giordano, et al., 2007; Park et al., 2007) and dying from HIV (Giordano et al., 2007; Mugavero et al., 2014). Retention in care is critical for effective management of HIV associated symptoms and prolonged life. Understanding factors that contribute to disparities in retention in care may assist in improving outcomes among African Americans.

Emerging evidence suggests that health literacy—the ability to access, process, and use health information to make informed health decisions (Institute of Medicine of the National Academies, 2004)—may contribute to poor retention in care and suboptimal health outcomes among African Americans living with HIV (Mallinson et al., 2005). Average health literacy is 20% lower among African American adults compared to White adults (U.S. Department of Education, 2006) and low health literacy is associated with poor retention in care (Jones, Cook, Rodriguez, & Waldrop-Valverde, 2013; Rebeiro et al., 2018), lower overall knowledge of HIV (Kalichman et al., 2000), and lower odds of adhering to antiretroviral therapies (ART; Kalichman, Ramachandran, & Catz, 1999; Miller et al., 2003; Waldrop-Valverde, D., et al., 2010). It is possible that among African Americans, disparities in health literacy may contribute to disparities in retention in care.

There are several patient and social-level factors associated with health literacy, including socioeconomic status, cognitive function, and the patient-provider relationship. Socioeconomic status influences where people look for and interpret health information (Institute of Medicine of the National Academies, 2004), while cognitive function is positively correlated with health literacy among PLWH (Vance, Rubin, Valcour, Waldrop-Valverde, & Maki, 2016; Waldrop-Valverde, D., Jones, Gould, Kumar, & Ownby, 2010; Waldrop-Valverde, D., Jones, Weiss, Kumar, & Metsch, 2008). Health literacy and retention in care are also associated with the patient-provider relationship. Poor health literacy may be a barrier to effective patient-provider communication (Katz, Jacobson, Veledar, & Kripalani,

2007; Kripalani et al., 2010; Williams, Davis, Parker, & Weiss, 2002), which may in turn contribute to ART non-adherence (Baker et al., 1996; Kalichman, et al., 1999) and poor HIV health outcomes (Kalichman and Rompa, 2000). Quality patient-provider relationships may positively influence retention in care (Flickinger, Saha, Moore, & Beach, 2013) and ART medication adherence (Beach, et al., 2006; Roberts, 2002), particularly if providers effectively communicate and build relationships with the patient (Beach, et al., 2006; Flickinger, Saha, Moore, & Beach, 2013).

Few studies have examined the relationship between health literacy and retention in care and even fewer have examined these relationships within the context of health disparities. Existing HIV health disparities among African Americans and emerging evidence linking health literacy to retention in care indicates a need to further understand the role of health literacy on retention in care, particularly among health disparate populations. Therefore, the purpose of this study was to evaluate the effects of health literacy and patient and social-level factors on retention in care among African Americans compared to non-African Americans living with HIV.

Methods

This study is ancillary to a non-experimental longitudinal study (Waldrop-Valverde, Murden, Guo, Holstad, & Ownby, 2018). The parent study recruited 699 participants from four outpatient HIV-clinics in urban metro-Atlanta, Georgia between June 2012 and December 2015 and collected data at baseline and six-months. Inclusion criteria for the parent study was a minimum of one scheduled HIV medical appointment and a current prescription for ART within the last nine months. This ancillary study used the following baseline measures from the parent study: demographics, health literacy, cognitive function, patient-provider interactions, and HIV viral load. This study collected retention in care and participant insurance data from the Electronic Medical Records (EMR). Emory University's Institutional Review Board approved the parent and ancillary studies.

Measures

Demographic Information.—Participants reported race, sex, marital status, sexual orientation, education, age, and time since HIV diagnosis. For this ancillary study, we abstracted insurance data from the participant's EMR for an HIV visit closest to the participant's baseline interview date. Consistent with prior HIV research (Rebeiro, et al., 2018), we utilized insurance as a proxy for socioeconomic status (SES; Chen, Moss, Pipkin, & McFarland, 2009; Jain, Schwarcz, Katz, Gulati, & McFarland, 2006) and categorized participant insurance/SES as "not low SES" if using private or commercial insurance or if self-pay; "low SES" if receiving Ryan White services [income eligibility for Ryan White is less than or equal to 400% of the federal poverty level (Georgia Department of Public Health, 2017)]; "very low SES" if receiving Medicare or Medicaid services [income eligibility requirement for Medicaid in Georgia is less than or equal to 133% of the federal poverty level (Georgia Department of Community Health, 2018)].

Health Literacy.—The Short-Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) assesses health literacy with two

prose passages and four numeracy items. The S-TOFHLA score is the cumulative percent correct for both the reading comprehension and the numeracy portions. S-TOFHLA correlates well with other measures of health literacy (Baker, et al., 1999).

Cognitive Function.—The Hopkins Verbal Learning Test Revised (HVLT-R) (Brandt and Benedict, 2001) and the Color Trails Test (CTT) 1 and 2 (D'Elia, Satz, Uchiyama, & White, 1994) assessed cogntive function. This ancillary study averaged the baseline T-scores (standardized scores with a mean of 50 and standard deviation of 10) for HVLT-R, CTT 1, and CCT 2 to create a continuous measure of cognitive functioning for analysis.

Patient-Provider Interactions.—Attitudes Towards the HIV Health Care Provider Scale (ATHCP) (Bodenlos, et al., 2004) assessed patient-provider interactions. ATHCP is a 19-item scale that assesses the provider's professionalism and emotional support toward the patient. Item scores are on a 6-point Likert scale (1 = strongly disagree to 6 = strongly agree; range = 19-114) with higher total scores indicating a more positive attitude toward the HIV health care provider. Past research indicates that ATHCP has acceptable internal consistency (α = 0.69) and the Cronbach's alpha for participants in this study was 0.92.

Viral Load.—The parent study obtained viral load at baseline from HIV-1 RNA assays of participant blood samples. If unable to collect a blood sample, viral load data corresponding closest to the participant's baseline interview date was extracted from the EMR. This study dichotomized viral load as virologically suppressed (HIV-1 RNA values less than 2.3 $\log_{10}$ or 200 copies/mL) or non-suppressed (Centers for Disease Control and Prevention, 2018b).

Retention in Care.—Retention in care was operationalized as visit adherence, calculated as the proportion of kept HIV appointments out of all scheduled HIV appointments (Mugavero, Westfall, et al., 2012) over a 24-month, post-baseline period. From the EMR, this study extracted outpatient appointments with an HIV primary care provider who has prescribing authority, including physicians and advanced care providers. We did not include specialty HIV care visits, nursing visits, and laboratory visits. We utilized visits with a completed status to represent kept HIV appointments and completed, missed, and no-show visits to calculate the total number of scheduled HIV appointments. Among all study participants, visit adherence was skewed; however, data was parametrically distributed among participants with less than 100% visit adherence. Based on this finding, we dichotomized visit adherence as 100% visit adherence and less than 100% visit adherence.

Statistical Analysis

We began by performing multiple imputation for data missing at random for predictor variables (cognitive function [1.24%], ATHCP [0.77%], sex/gender [0.31%], insurance/SES [4.64%], and baseline viral load [0.93%]) and used all study variables to create ten imputed data sets. We then conducted bivariate analyses of predictors of visit adherence (race, sex, marital status, sexual orientation, baseline viral load, health literacy, cognitive function, and patient provider interactions) between participants with 100% and less than 100% visit adherence. Education, insurance, and cognitive function exhibited issues of collinearity with health literacy and were not included in the following regression analyses.

We performed 1) multivariable logistic regression analyses comparing PLWH with 100% visit adherence to PLWH with less than 100% visit adherence and 2) multivariable linear regression analyses for PLWH with less than 100% visit adherence. We performed a sequential, block-wise regression that first included demographic characteristics followed by S-TOFHLA and ATHCP. We used SAS Studio software version 3.71 for descriptive and bivariate statistics and Mplus version 8.2 for multiple imputation and multivariable regression. We used the IMPUTE command for multiple imputation, which utilizes Bayesian estimation models (Muthén and Muthén, 1998-2017; Rubin, 1987; Schafer, 1997), and the DATA TYPE = IMPUTATION command for regression analyses.

Results

The parent study included 699 participants. We included participants with complete percent visit adherence data and excluded participants whose total number of scheduled HIV appointments were greater than three standard deviations above the mean (Leys, et al., 2013; n = 12; mean = 12.75 ± 11.01). Resulting, we included a total of 634 participants in this analysis. Detailed participant characteristics are in Table 1. Participant racial groups included African Americans (60.41%) and non-African Americans. Among non-African Americans, 81.27% identified White/non-Hispanic, 6.37% identified Hispanic/Latino, and 12.35% identified with another race (Asian, Native American/Alaska Native, or biracial). Most participants identified male (69.62%), were single or never married (56.78%), had greater than a high school education (58.52%), and identified as non-heterosexual (60.88%). The majority of participants were virally suppressed (91.56%) and were living with HIV for an average of 15.49 years. Participants ranged in age from 20 to 83 years, with a mean age of 47.97 years. Participants with 100% visit adherence had an average of 8 ± 6 scheduled appointments over the 24-month period (range: 1- 33). Participants with less than 100% visit adherence averaged 14 ± 6 appointments over the 24-month period (range: 1 - 43). Among participants with less than 100% visit adherence, percent visit adherence ranged from 0% to 98% with a mean percent visit adherence of 74%.

We conducted multivariable logistic regression analysis to identify significant predictor variables of visit adherence among PLWH with 100% visit adherence compared to less than 100% visit adherence (Table 2). In model 1, race was the only significant predictor of visit adherence, whereby the odds of 100% visit adherence among non-African Americans was 1.56 times the odds of 100% visit adherence among African Americans (OR = 1.56, 95% CI = [1.10, 2.20], p =.044). In model 2, race was no longer significant and S-TOFHLA was the only significant predictor (OR = 1.02, 95% CI = [1.00, 1.04], p =.024). In model 3, S-TOFHLA remained the only significant predictor, with each unit increase in S-TOFHLA increasing the odds of 100% visit adherence by 2% when controlling for all other model variables (OR = 1.02, 95% CI = [1.00, 1.04], p =.016). Model 3 explained 7% of the variance in visit adherence among PLWH with 100% and less than 100% visit adherence.

To understand factors associated with less than perfect visit adherence, we performed multivariable linear regression analysis (Table 3). In the final model (model 3), age, marital status, and ATHCP were significant predictors of percent visit adherence. For each unit increase in age, percent visit adherence increased by 0.14%, controlling for all other

variables (β = 0.14, 95% CI = [0.04, 0.23], p = .007). Findings also indicated that PLWH who were previously married (β = −0.14, 95% CI = [−0.25, −0.04], p = .008) or currently married/living with a partner (β = −0.12, 95% CI = [−0.22, −0.02], p = .023) had lower percent visit adherence compared to PLWH who were single or never married. Additionally, for each unit increase in a participant's ATHCP score, percent visit adherence decreased by 0.10% (β = −0.10, 95% CI = [−0.20, −0.01], p = .037). Model 3 explained 6% of the variance in percent visit adherence among PLWH with less than 100% visit adherence.

Discussion

This study sought to understand factors that contribute to racial disparities in retention in care and is among the first to examine the effects of health literacy. We utilized a series of regression analyses to assess patient and social level factors on retention in care, operationalized as 100% visit adherence and less than 100% visit adherence. These factors were assessed among African Americans living with HIV compared to non-African Americans living with HIV.

Findings suggest health literacy is an important contributor to the relationship between race and 100% visit adherence. When not accounting for the effects of health literacy, this study found that African Americans were less likely than non-African Americans to have 100% visit adherence. When health literacy was included in the logistic regression model, the effect of race on visit adherence diminished to non-significance. This suggests that health literacy may mediate the relationship between race and retention in care (Baron & Kenny 1986). Findings from this study are analogous to Osborn, et al. (2007) and Waldrop-Valverde, et al. (2018) who found a mediating effect of health literacy between race and HIV medication adherence. Additional research is needed to further test whether health literacy mediates the relationship between race and visit adherence. Such work would provide further insight on the mechanisms underlying health literacy's contributions to racial disparities in retention in care.

Among PLWH with less than 100% visit adherence and controlling for race, a patient's attitudes towards their HIV health care provider was a significant predictor of percent visit adherence. The current study found that as patients viewed their health care providers more favorably, percent visit adherence decreased. This finding is unexpected given that the quality of the patient-provider relationship has been shown to positively influence retention in care (Beach, et al., 2006; Pettinati, Monterosso, Lipkin, & Volpicelli, 2003). However, the effect of patient attitudes towards the health care provider and percent visit adherence may be partially explained by findings from Lee et al. (2017). Specifically, health care providers who gave their email address to patients were more likely to communicate with their patients outside of the health care clinic and patients reported greater satisfaction with their health care (Lee, 2017). It is possible that among participants in the present study, those with a good patient-provider relationship may communicate with their health care provider via email or other means outside of the HIV clinic and may rely less on attending patient appointments to manage their HIV.

Among persons with less than 100% visit adherence, additional significant predictors of visit adherence were age and marital status. Consistent with a large body of previous research (Adeyemi, Livak, McLoyd, Smith, & French, 2013; Ghiam et al., 2017; Hall et al., 2013; Hu et al., 2012; Mauck, Sheehan, Fennie, Maddox, & Trepka, 2018; Rebeiro, et al., 2018; Wester et al., 2016), older age was associated with greater visit adherence. Additionally, PLWH who were previously married and currently married or living with a partner had lower percent visit adherence than PLWH who were single or never married. Waldrop-Valverde, et al. (2014) similarly found lower percent visit adherence among PLWH who were married. Family responsibilities from marriage and marital-like relationships may present unique demands that are perceived as more important than attending an HIV appointment (Messer et al., 2013; Sangaramoorthy, Jamison, & Dyer, 2017). Poor visit adherence among PLWH who were previously married may be partially explained by findings from Ironson et al. (2017) who found that separation or divorce is associated with increased viral load and anxiety over time. Research is necessary to further understand the effect of marital status on retention in care.

The findings from this study should be interpreted with the limitations inherent to the retrospective nature of this study. First, data were collected from four different HIV clinics in Metro-Atlanta and we were unable to identify clinical care outside of one of our four recruiting clinics. Second, due to the conservative retention in care cut-off (100% versus <100% visit adherence) this study may have inaccurately represented individuals who are sufficiently retained in care to be virally suppressed. Third, this study was unable to capture additional predictors that may greatly influence racial disparities in retention in care. Finally, findings from this study may have limited generalizability.

Conclusions

Findings suggest that health literacy may help explain disparities in retention in care among African Americans. Further research is needed to understand mechanisms underlying health literacy's contributions to racial disparities in retention in care, as well as the contributions of other modifiable predictors, such as the patient provider relationship. Researchers should leverage path analytic techniques to further examine whether significant relationships identified in this study may be explained through mediation by a third variable. Such knowledge would then assist researchers and public health officials in developing interventions that target these predictors, with a goal of improving health equity and minimizing disparities.

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Table 1.

Participant Characteristics

	Total (n = 634)		<100% Visit Adherence (n = 395)		100% Visit Adherence (n = 239)		
	N	**%**	**n**	**%**	**n**	**%**	**p-value**
Race							
African American	383	60.41	256	64.81	127	53.14	.0036[a]
Non-African American	251	39.59	139	35.19	112	46.86	
Sex/Gender							
Identify Male	440	69.62	266	67.68	174	72.80	.1748[a]
Identify Female	192	30.38	127	32.32	65	27.20	
Marital Status							
Single/Never Married	360	56.78	228	57.72	132	55.23	.0233[a]
Previously Married	135	21.29	93	23.54	42	17.57	
Married/Living with Partner	139	21.92	74	18.73	65	27.20	
Sexual Orientation							
Heterosexual	248	39.12	163	41.27	85	35.56	.1540[a]
Other	386	60.88	232	58.73	154	64.44	
Insurance/SES							
Not Low SES	219	36.26	126	33.16	93	41.52	.0085[a]
Low SES	112	18.54	64	16.84	48	21.43	
Very Low SES	273	45.20	190	50.00	83	37.05	
Education							
<High School	90	14.20	68	17.22	22	9.21	.0002[a]
High School/GED	173	27.29	120	30.38	53	22.18	
>High School	371	58.52	207	52.41	164	68.62	
Viral Load							
Not Suppressed	53	8.44	42	10.91	4	1.70	<.0001
Suppressed	575	91.56	343	89.09	231	98.30	

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	Total (n = 634)		<100% Visit Adherence (n = 395)		100% Visit Adherence (n = 239)		
	N	%	n	%	n	%	p-value
	Mean	SD	Mean	SD	Mean	SD	p-value
Age (years)	47.97	9.90	47.62	9.45	48.57	10.60	.2400[b]
Years Since HIV Diagnosis	15.49	8.55	14.72	8.67	16.77	8.20	.0041[b]
STOFHL	91.43	11.85	90.33	11.93	93.23	11.51	<.0027[c]
ATHCP	86.90	13.13	87.42	12.96	86.07	13.38	.2113[c]
Cognitive Function	41.44	8.31	40.90	8.17	42.33	8.48	.0368[b]

Note. SD = standard deviation; SES = socioeconomic status [not low SES = private insurance or self-pay, low SES = Ryan White, very low SES = Medicare/Medicaid]; GED = graduate equivalency degree; S-TOFHLA = Short Test of Functional Health; ATHCP = Attitudes Towards HIV Care Provider

[a] = Pearson's chi-squared test

[b] = Student's t-test

[c] = Mann Whitney test

Table 2.

Logistic Regression on Characteristics of PLWH with 100% Visit Adherence Compared to PLWH with Less Than 100% Visit Adherence (N = 634)

	Model 1			Model 2			Model 3		
Variable	**OR**	**95% CI**	**p-value**	**OR**	**95% CI**	**p-value**	**OR**	**95% CI**	**p-value**
Age	1.01	1.00, 1.03	0.124	1.02	1.00, 1.03	0.094	1.01	1.00, 1.03	0.109
Race									
African American	REF	REF		REF	REF		REF	REF	
Non-African American	**1.56**	**1.10, 2.20**	**0.044**	1.42	1.00, 2.02	0.106	1.39	0.97, 1.99	0.123
Sex/Gender									
Identify Male	REF	REF		REF	REF		REF	REF	
Identify Female	0.98	0.61, 1.56	0.932	1.00	0.62, 1.61	0.999	0.997	0.62, 1.61	0.991
Marital Status									
Single/Never Married	REF	REF		REF	REF		REF	REF	
Previously Married	0.76	0.49, 1.20	0.117	0.75	0.48, 1.18	0.152	0.75	0.48, 1.19	0.158
Married/Living with Partner	1.44	0.96, 2.16	0.142	1.41	0.94, 2.12	0.164	1.41	0.93, 2.12	0.167
Sexual Orientation									
Heterosexual	REF	REF		REF	REF		REF	REF	
Other	1.09	0.69, 1.70	0.730	1.05	0.66, 1.66	0.849	1.04	0.66, 1.65	0.863
Viral Load									
Not Suppressed	REF	REF		REF	REF		REF	REF	
Suppressed	0.89	0.50, 1.60	0.668	0.89	0.50, 1.60	0.678	0.89	0.50, 1.60	0.681
S-TOFHLA				**1.02**	**1.00, 1.04**	**0.024**	**1.02**	**1.00, 1.04**	**0.016**
ATHCP							0.99	0.98, 1.00	0.167
R^2	0.04			0.05			0.07		

Note: 100% visit adherence was coded as 1 and <100% visit adherence was coded as 0; REF = reference group; OR = Odds Ratio; CI = confidence interval; S-TOFHLA = Short Test of Functional Health; ATHCP = Attitudes Towards HIV Care Provider; This study tested the interaction effect of race on significant predictor variables (insurance and S-TOFHLA) in model 3 and found that interaction effects were not significant.

Table 3.

Linear Regression on Characteristics of Percent Visit Adherence among PLWH with Less Than 100% Visit Adherence (N = 395)

	Model 1			Model 2			Model 3		
Variable	**β**	**95% CI**	**p-value**	**β**	**95% CI**	**p-value**	**β**	**95% CI**	**p-value**
Age	**0.15**	**0.05, 0.24**	**0.004**	**0.14**	**0.05, 0.24**	**0.004**	**0.14**	**0.04, 0.23**	**0.007**
Race									
African American	REF	REF		REF	REF		REF	REF	
Non-African American	0.06	−0.04, 0.16	0.203	0.07	−0.03, 0.17	0.180	0.06	−0.04, 0.16	0.225
Sex/Gender									
Identify Male	REF	REF		REF	REF		REF	REF	
Identify Female	0.05	−0.07, 0.17	0.430	0.05	−0.07, 0.17	0.441	0.05	−0.08, 0.17	0.465
Marital Status									
Single, Never Married	REF	REF		REF	REF		REF	REF	
Previously Married	**−0.14**	**−0.25, −0.04**	**0.009**	**−0.14**	**−0.25, −0.04**	**0.009**	**−0.14**	**−0.25, −0.04**	**0.008**
Married/ Living with Partner	**−0.12**	**−0.22, −0.02**	**0.024**	**−0.11**	**−0.22, −0.01**	**0.026**	**−0.12**	**−0.22, −0.02**	**0.023**
Sexual Orientation									
Heterosexual	REF	REF		REF	REF		REF	REF	
Other	−0.02	−0.15, 0.10	0.707	−0.02	−0.15, 0.10	0.729	−0.03	−0.15, 0.10	0.674
Viral Load									
Not Suppressed	REF	REF		REF	REF		REF	REF	
Suppressed	0.08	−.02, 0.17	0.117	0.08	−0.02, 0.17	0.122	0.08	−0.02, 0.18	0.109
S-TOFHLA				−0.03	−0.13, 0.08	0.632	−0.02	−0.12, 0.08	0.754
ATHCP							**−0.10**	**−0.20, −0.01**	**0.037**
Adjusted R^2	0.05			0.05			0.06		

Note: REF = reference group; CI = confidence interval; S-TOFHLA = Short Test of Functional Health; ATHCP = Attitudes Towards HIV Care Provider; This study tested the interaction effect of race on significant predictor variables (age, marital status, ATHCP) in model 3 and found that interaction effects were not significant.