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# Disparities in HIV/AIDS: Examining Retention in Care and Health Literacy

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An abstract of
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James T. Laney School of Graduate Studies of Emory University
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# Abstract

## Disparities in HIV/AIDS: Examining Retention in Care and Health Literacy

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**Introduction**

Low health literacy and poor retention in care contribute to HIV health disparities among African Americans, but causal pathways have not been examined. We employed an adapted health literacy model to examine the role of health literacy on racial disparities in retention in care and HIV outcomes.

**Methods**

Participants included 699 HIV-positive adults receiving care at one of four HIV clinics in metro-Atlanta, Georgia. We used path analysis to test the mediating effect of 1) health literacy between race (African American vs. non-African American) and retention in care; 2) retention in care between health literacy and HIV viral load; 3) health literacy between sociodemographic indicators and patient-provider interactions. Retention in care was operationalized as 100% visit adherence versus less than 100% visit adherence. Measures included the Short-Test of Functional Health Literacy and the Attitudes Towards the HIV Health Care Provider Scale. Data were collected from 2012 to 2015 through face-to-face interviews. Retention in care and viral load data were abstracted from electronic medical records 24-months post survey.

**Results**

Average participant age was 48 years, with 60% African American and 92% virally suppressed. Non-African American race ($p = .028$) was related to greater health literacy. Greater health literacy led to 100% visit adherence ($p = .002$), which was subsequently associated with viral suppression ($p < .001$). Socioeconomic status ($p = .013$) and cognitive function ($p < .001$) directly influenced health literacy, which then influenced 100% visit adherence and patient-provider interactions ($p < .001$). The model demonstrated good fit (RMSEA = 0.002, SRMR = 0.042, CFI = 0.999, TLI = 1.003).

**Discussion**

Health literacy mediates the relationship between race and retention in care, as well as the effect of race and sociodemographic predictors on patient-provider interactions. Findings suggest causal pathways between retention in care and health literacy for racially disparate HIV populations. Findings from this study highlight areas of research that may expand knowledge of health literacy on disparities in retention in care. Additional implications include the need to provide individualized, patient-centered educational health resources and retention in care interventions that address patient health literacy.

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# CHAPTER 1

## INTRODUCTION

African Americans are disproportionately affected by the Human Immunodeficiency virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) compared with other racial and ethnic groups. African Americans represent the highest percentage of persons living with HIV in the United States, as they comprise 40 percent of the nearly 1.2 million persons living with HIV (Centers for Disease Control and Prevention, 2018a). African Americans also experience the greatest burden of new HIV diagnoses and HIV associated deaths. In 2016, African Americans accounted for 44 percent of the nearly 40,000 new HIV diagnoses (Centers for Disease Control and Prevention, 2016). This is equivalent to 41 new HIV diagnoses per 100,000 persons, which is a seven times higher rate of HIV diagnoses among African Americans than among their White counterparts (Centers for Disease Control and Prevention, 2016). Additionally, while the burden of HIV-associated deaths among all racial and ethnic groups is declining, the incidence of HIV-associated deaths among African Americans remains seven and four times higher compared to White and Hispanic/Latino counterparts, respectively (Siddiqi, Hu, & Hall, 2015). In order to reduce the burden of HIV diagnoses and HIV/AIDS associated deaths among African Americans, it is necessary to understand factors driving this health disparity.

Racial disparities in retention in care also exist. Retention in care refers to whether an individual attends regularly scheduled HIV medical appointments and there is currently no gold standard for its measurement (Mugavero, Westfall, et al., 2012). Formal definitions and measurements by the U.S. Department of Health and Human Services (DHHS) and the Centers for Disease Control and Prevention (CDC) recommend scheduled HIV appointments at set specific intervals. The DHHS suggests that HIV-positive individuals attend at least one HIV medical appointment in a 6-month period with a minimum of 60 days between medical appointments (Health Resource and Services Administration, 2015). The CDC measures retention in care as receiving two HIV viral load laboratory tests at least three months apart (Centers for Disease Control and Prevention, 2018c). While other measures of retention in care are varied, some are based on the number of appointments missed (missed visits) or on the proportion of appointments that were attended out of all scheduled HIV appointments (visit adherence) (Mugavero, Davila, Nevin, & Giordano, 2010). HIV treatment cascades are commonly assembled using the retention in care definition from the CDC. Current publications of this cascade indicate that among the 84 percent of African Americans who are diagnosed with HIV, 59 percent received HIV care, and 46 percent are retained in care (Centers for Disease Control and Prevention, 2017b). Compared to White and Hispanic/Latino populations, retention in care among African Americans is five and two percent lower, respectively (Centers for Disease Control and Prevention, 2017b).

Retention in care is a major contributor to the morbidity and mortality of persons living with HIV, as it is one of the most significant predictors of treatment failure (Lucas, Chaisson, & Moore, 1999; Rastegar, Fingerhood, & Jasinski, 2003) and whether an individual will have a detectable HIV viral load (Berg et al., 2005). To reduce the risk of HIV disease progression and transmission, the Panel on Antiretroviral Guidelines for Adults and Adolescents recommends that all persons living with HIV receive antiretroviral therapy regardless of HIV viral load or CD4 count (Department of Human Health and Services). Among the 46 percent of African Americans who are retained in care, 43 percent are virally suppressed, compared to 57 percent and 48 percent viral suppression among White and Hispanic/Latino counterparts, respectively (Centers for Disease Control and Prevention, 2017b). Poor retention in care limits receipt of antiretroviral therapy and contributes to higher HIV viral loads (Crawford, 2014; Giordano et al., 2007; Mugavero, Amico, et al., 2012) and lower CD4 count (Berg et al., 2005). Non-viral suppression is associated with an increased likelihood of developing comorbidities and AIDS-defining illnesses (Crawford, 2014; Giordano et al., 2007; Park et al., 2007), as well as dying from HIV (Mugavero et al., 2014). Poor retention in care has a negative effect on HIV health outcomes regardless of when persons living with HIV first received antiretroviral therapy. Among individuals in their first year of antiretroviral therapy, those with poor retention in care are more likely to have low CD4 counts, high HIV viral loads, new AIDS-defining illnesses, and increased mortality (Park et al., 2007). Similarly, among individuals with a history of antiretroviral therapy adherence and viral suppression, the odds of viral rebound for those with poor retention in care is 15 times greater than the odds of viral rebound for those with optimal retention in care (Crawford, 2014). Due to the importance of retention in care for effective management of HIV associated symptoms and prolonged life among persons living with HIV, understanding the role of retention in care and contributing factors in HIV health outcomes among African Americans is essential for understanding this disparity.

## Health Literacy is Associated with Disparities in Retention in Care

Emerging evidence suggests that health literacy may contribute to disparities in health outcomes among African Americans living with HIV (Mallinson et al., 2005). The National Academy of Medicine, formerly the Institute of Medicine, defines health literacy as the ability to access, process, and use health information to make informed health decisions (Institute of Medicine of the National Academies, 2004). In 2006, the U.S. Department of Education published a national assessment on adult literacy and found that average health literacy scores among African American adults were 20 percent lower than those among White adults (U.S.

Department of Education, 2006). Additionally, the percentage of African Americans with intermediate levels of health literacy (one level below proficient health literacy; 41 percent) was much lower than that among White adults (59 percent) (U.S. Department of Education, 2006). According to reviews on the effect of health literacy among persons living with HIV, there is limited and inconsistent evidence regarding the association between health literacy and HIV health behaviors and outcomes (Wawrzyniak, Ownby, McCoy, & Waldrop-Valverde, 2013). The Agency for Health Care Research and Quality conducted a review addressing the effects of health literacy on health care utilization and health outcomes among a range of disease states, including HIV. This review found that poor health literacy is associated with decreased knowledge of HIV (Kalichman, Benotsch, et al., 2000; Kalichman & Rompa, 2000; Kalichman, Rompa, & Cage, 2000; Miller et al., 2003) and decreased odds of antiretroviral therapy adherence (Kalichman, Ramachandran, & Catz, 1999; Miller et al., 2003). Additional research suggests conflicting findings regarding the association between health literacy and HIV clinical outcomes, including CD4 count and HIV viral load (Kalichman, Benotsch, et al., 2000; Kalichman & Rompa, 2000).

Even less evidence is available regarding the effect of health literacy on retention in care and its subsequent effect on HIV clinical outcomes. Recent literature suggests that low health literacy is associated with an increased number of missed HIV appointments (Rebeiro et al., 2018). Other research examined the relationship among personal HIV knowledge, visit adherence, and treatment outcomes among adults living with HIV (Jones, Cook, Rodriguez, & Waldrop-Valverde, 2013). Jones et al. (2013) defined personal HIV knowledge as knowledge of one’s CD4 and HIV viral load values. Results indicated that the odds of attending more than 75 percent of regularly scheduled HIV appointments doubled among persons who knew the correct value of their HIV viral load or CD4 count (Jones, et al., 2013). Personal HIV knowledge is also associated with undetectable HIV viral load and increased CD4 count (Jones et al., 2013; Nelsen et al., 2012). Poor health literacy among African Americans combined with the negative effects of health literacy on retention in care and HIV health outcomes suggests that health literacy may contribute to disparities in retention in care among African Americans.

Evidence is emerging regarding causal pathways linking health literacy to health outcomes among racially disparate populations, however, no studies have examined these conceptual pathways for retention in care among racially disparate persons living with HIV. Among HIV-negative populations, current evidence suggests that health literacy mediates the relationship between race and self-reported health status (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Among men presenting with late-stage prostate cancer (Bennett et al., 1998) and among elderly adults (Howard, Sentell, & Gazmararian, 2006) health literacy mediates the relationship between race and self-reported health outcomes. Particularly, poor health literacy partially accounts for poor health outcomes among African Americans, compared to White participants (Bennett et al., 1998; Howard et al., 2006). Among persons living with HIV, current research suggests that health literacy mediates the relationship between gender and antiretroviral therapy adherence and that numeracy—a component of health literacy necessary to understand and use numbers in daily life (Rothman et al., 2006)—mediates this relationship (Waldrop-Valverde, Osborn, et al., 2010). Additionally, in a series of regression analyses, Osborn et al. (2007) found that African Americans were more likely to be non-adherent to antiretroviral therapy regimes than White persons. However, when health literacy was included in the same regression analyses as race, the effects of race diminished by 25% and were no longer significant (Osborn et al., 2007). This finding suggests that health literacy may mediate the relationship between race and antiretroviral therapy adherence. No studies have examined the mediating effect of health literacy on race and retention in care. Disparities in retention in care and health literacy among African Americans, as well as emerging pathways between health literacy and HIV health outcomes, warrant an investigation of causal pathways linking health literacy and racial disparities in retention in care.

## Factors Associated with Health Literacy

Psycho-social factors, including socioeconomic status and cognitive function, shape an individual’s health literacy and may influence retention in care. Socioeconomic status influences whether individuals seek out health information, where they will look, and how that health information will be interpreted (Institute of Medicine of the National Academies, 2004; Pamuk, Makuc, Heck, Reuben, & Lochner, 1998). Socioeconomic status is measured by a variety of indicators, such as education, income, or insurance coverage. From the U.S. Department of Education’s 2003 National Assessment of Adult Literacy, average health literacy among adults living below the poverty threshold was 27 percent lower than average health literacy among adults living 175 percent above the poverty threshold (U.S. Department of Education, 2006). This national assessment also examined health insurance coverage and health literacy and found that average health literacy was higher among adults who received health insurance through an employer, compared to other means of coverage, such as military, privately purchased, Medicare, Medicaid, or no insurance (U.S. Department of Education, 2006). Individuals with Medicare, Medicaid, or no insurance had the lowest average health literacy (U.S. Department of Education, 2006). These statistics are consistent with a large body of research supporting the relationship between low socioeconomic status and poor health literacy (Ayotte, Allaire, & Bosworth, 2009; Mantwill, Monestel-Umaña, & Schulz, 2015; Rikard, Thompson, McKinney, &

Beauchamp, 2016; U.S. Department of Education, 2006). Among persons living with HIV, low socioeconomic status is associated with poor antiretroviral therapy adherence (Burch et al., 2016), as well as poor retention in care. Employment, education, and insurance protect against poor retention in care (Anderson et al., 2018; Hightow-Weidman et al., 2017), while lack of health insurance (Muthulingam, Chin, Hsu, Scheer, & Schwarcz, 2013) and lack of enrollment in Ryan White (Wester et al., 2016) hinder adequate retention in care. Research is lacking regarding causal investigations into the relationships among socioeconomic status, health literacy, and retention in care.

Cognitive function, which includes domains of learning, memory, and executive function directly influences health literacy among persons living with HIV (Vance, Rubin, Valcour, Waldrop-Valverde, & Maki, 2016; Waldrop-Valverde, Jones, Gould, Kumar, & Ownby, 2010; Waldrop-Valverde, Jones, Weiss, Kumar, & Metsch, 2008). Health literacy is correlated with many cognitive domains (Serper et al., 2014), such that when cognitive function is poor, health literacy decreases (Morgan et al., 2015; Vance et al., 2016; Waldrop-Valverde, Jones, et al., 2010; Waldrop-Valverde et al., 2008). The harmful neurocognitive effects of HIV exacerbate the effect of poor cognitive function on health literacy (Grant et al., 1987; Martin et al., 1992; Peavy et al., 1994; Wilkie et al., 2000). Additionally, cognitive function among persons living with HIV may be influenced by demographic factors, such as gender, age, and education, as well as other factors, such as drug use, stress, mental health, and comorbidities (Vance et al., 2016). Research suggests that neurocognitive impairments and low health literacy contribute to poor antiretroviral therapy adherence (Waldrop-Valverde, Jones, et al., 2010; Waldrop-Valverde et al., 2009). Evidence is inconsistent regarding the association between neurocognitive impairments and retention in care. While Jacks et al. (2015) identified a relationship between neurocognitive impairments and retention in care among older adults newly diagnosed with HIV, Waldrop-Valverde, et. al (2014) identified that cognitive impairment was associated with poor retention in care among persons who did not utilize social support networks. Additional research is needed to better clarify the relationship between cognitive function and retention in care, as well as examine these relationships within the context of racial health disparities among persons living with HIV.

The patient-provider relationship is also associated with health literacy and retention in care. Research indicates that poor health literacy is a barrier to effective communication with health care providers (Hironaka & Paasche-Orlow, 2008; Katz, Jacobson, Veledar, & Kripalani, 2007; Kripalani et al., 2010; Williams, Davis, Parker, & Weiss, 2002) and that the quality of the patient-provider communication contributes to antiretroviral therapy adherence (Baker et al., 1996; Kalichman et al., 1999; Mayeaux et al., 1996) and HIV health outcomes (Kalichman & Rompa, 2000). The overall quality of the patient-provider relationship positively influences retention in care (Beach, Keruly, & Moore, 2006; Pettinati, Monterosso, Lipkin, & Volpicelli, 2003) and antiretroviral therapy adherence (Beach et al., 2006; Heckman, Catz, Heckman, Miller, & Kalichman, 2004; Roberts, 2002), particularly among persons who trust (Graham, Shahani, Grimes, Hartman, & Giordano, 2015; Langebeek et al., 2014; Yehia et al., 2015 ) and are positively satisfied with their health care provider (Bodenlos et al., 2007). Persons who believe that their health care providers connect with them (Beach et al., 2006; Flickinger, Saha, Moore, & Beach, 2013; Mallinson, Rajabiun, & Coleman, 2007), listen to (Flickinger et al., 2013; Holzemer et al., 1999; Magnus et al., 2013; Mallinson et al., 2007; Wilson & Kaplan, 2000) and validate them as individuals (Flickinger et al., 2013; Mallinson et al., 2007), and collaborate with them in the health care process (Mallinson et al., 2007) are more likely to be retained in care. Among African Americans, discrimination by health care providers (Bird, Bogart, & Delahanty, 2004), as well as perceptions of racism and mistrust of White health care providers (Benkert, Peters, Clark, & Keves-Foster, 2006) contribute to discomfort in sharing health behaviors, decreased confidence in provider recommendations, and increased likelihood of missing medical appointments (Yehia et al., 2015 ). Although evidence suggests a relationship between health literacy and the patient-provider relationship, as well as the patient-provider relationship and retention in care, examination of their mechanistic relationships may provide further insight into health disparities among African Americans living with HIV.

## Conceptual Framework: Adaption of Paasche-Orlow and Wolf's Health Literacy Model for Retention in Care

This research adapted Paasche-Orlow and Wolf's health literacy model (2007) to inform relationships among health literacy, retention in care, HIV clinical outcomes, and sociodemographic indicators of health literacy. The Paasche-Orlow and Wolf health literacy model focuses on the direct effects of health literacy at three points along the health care continuum: access and utilization of health care, patient provider relationships, and self-care. The primary focus of the present study is on the direct effects of health literacy on access and utilization of health care and patient-provider interactions, as well as their subsequent effects on patient health outcomes. The model, pictured in *Figure 1*, is therefore adapted for this study. This model proposes that patient-level characteristics shape health literacy and that 1) health literacy mediates the relationship between race and access to health services and 2) access to health services mediates the relationship between health literacy and health outcomes.

The Paasche-Orlow and Wolf model recognizes that sociodemographic indicators are strongly associated with health literacy and that it is often challenging to isolate the independent effects of health literacy from these indicators (Paasche-Orlow & Wolf, 2007). However, the authors of the model recognize the importance of the interconnectedness of sociodemographic indicators and health literacy and therefore include them as predictors of health literacy. This study assesses three patient-level characteristics—race, socioeconomic status, and cognitive function—due to their previously described empirically established relationships to health literacy. This research includes race, dichotomized as African-American versus non-African American, to assist in assessing the presence of racial disparities in health literacy and retention in care. In accordance with past research, this study assesses socioeconomic status using insurance/payer status as a proxy (Chen, Moss, Pipkin, & McFarland, 2009; Jain, Schwarcz, Katz, Gulati, & McFarland, 2006; Rebeiro et al., 2018). This study measures episodic memory and executive function, the cognitive domains most likely to be affected by HIV infection in the current antiretroviral therapy era, using well-established and validated neurocognitive assessments (Brandt & Benedict, 2001; D'Elia, Satz, Uchiyama, & White, 1994).

Access and utilization of health care include both patient and system level-factors that influence a patient's ability to initiate or continue with their health care. The model describes this use of health services as "navigation" or "utilization of care" and defines these terms as "all the skills needed to go from one place to another in the pursuit of medical care" (Paasche-Orlow & Wolf, 2007). The present study uses retention in care as a measure of access and utilization of health care. As previously indicated, methods of measuring retention in care continue to evolve and currently there is no gold measurement standard (Mugavero et al., 2010). The present study operationalizes retention in care as visit adherence—the proportion of kept HIV appointments out of all scheduled HIV appointments—as it is one of the most sensitive and specific measures of retention in care available (Mugavero, Westfall, et al., 2012).

Patient-provider relationships include both patient and provider level factors that influence the patient's ability to understand their disease process and to manage daily health care activities. Patient level factors may include knowledge, beliefs, and participation in health care decision making processes, while provider level factors may include communication skills, teaching ability, time, and patient-centered care. The present study assesses the patient's attitudes towards their HIV health care provider on several aspects of the patient-provider relationship, including provider professionalism, provider emotional support, and provider communication abilities (Bodenlos et al., 2004).

The Paasche-Orlow and Wolf model proposes that health literacy, access and utilization of health care, and patient-provider relationships directly influence patient health outcomes. The primary health outcome of interest for the present study is HIV viral load, as it is directly related to retention in HIV care (Crawford, 2014; Giordano et al., 2007; Mugavero, Amico, et al., 2012) and is an established indicator of antiretroviral therapy adherence.

Past research applied the Paasche-Orlow and Wolf health literacy model to a variety of different patient populations, in order to understand the role of health literacy for different phenomena. For example, the model was applied to understand mechanisms linking health literacy to physical activity and self-reported health (Osborn, Paasche-Orlow, Bailey, & Wolf, 2011); to heart failure quality of life (Macabasco-O'Connell et al., 2011); to diabetes self-care and glycemic control (Chandra Y. Osborn, Bains, & Egede, 2010); to dental neglect and oral health status (J. Y. Lee, Divaris, Baker, Rozier, & Vann, 2012); and to patient activation and hospital utilization (Charlot et al., 2017). The health literacy model has not been extensively tested among HIV populations, but it has been adapted to understand the mediating effect of health literacy between race and predictors of antiretroviral therapy adherence (Osborn et al., 2007). Informed by the Paasche-Orlow and Wolf health literacy model, findings from the present study will contribute to an understanding of the model's usefulness for racial disparities in retention in HIV care.

## Research Strategy and Objectives

The goal of the present study is to address research gaps in our understanding of the effects of health literacy on retention in care and HIV clinical outcomes and whether health literacy may contribute to racial disparities among persons living with HIV. The purpose of the study is to utilize an adapted health literacy model (Paasche-Orlow & Wolf, 2007) to evaluate the effect of health literacy on retention in care and its subsequent effect on racial disparities and HIV clinical outcomes. This research is a prospective, observational study, involving 699 persons living with HIV. It is ancillary to a non-experimental longitudinal study (Project READ—R01 MH092284: PI, D. Waldrop-Valverde) that assessed the association between health literacy and antiretroviral therapy discordance on health disparities among persons living with HIV. The parent study recruited participants between June 2012 and December 2015 from four urban outpatient HIV clinics in metro-Atlanta, Georgia, including Grady Health Systems Infectious Disease Program, Emory Healthcare's Infectious Disease Program, and two-independent primary care clinics. The parent study collected data at baseline and six-months for 699 participants. This study used several measures collected by the parent study at baseline, including demographic information, health literacy, cognitive function, and patient-provider interactions. This study collected socioeconomic status, as well as HIV viral load and retention in care collected 24-months following the participant's baseline date in the parent study. Data specifically collected for this study were abstracted from participants' electronic medical records.

Table 1 presents the constructs from the adapted health literacy model, as well as corresponding study variables and measurement strategies. The aims for this study are as follows:

**Aim 1**: *To evaluate the relationship among health literacy (S-TOFHLA), retention in care (visit adherence), and HIV viral load among African Americans with HIV compared to non-African Americans with HIV, controlling for socioeconomic status (insurance) and cognitive function (HVLT-R and CTT).*

**Aim 1a**: *To assess the effect of health literacy on retention in care (visit adherence) and whether this relationship differs by race.*

**Aim 1b**: *To assess the effect of health literacy and retention in care (visit adherence) on HIV clinical outcomes.*

**Aim 2:** T*o examine the effects of patient-provider interactions (ATHCP) on the relationships tested in Aims 1a and 1b.*

## Manuscripts Deriving from This Research

Manuscript 1 is a systematic review of the literature to identify existing disparities in retention in care and their associated determinants of health among adults living with HIV. PubMed/MEDLINE, CINAHL, Sociological Collection, PsychInfo, Cab Direct/Global Health, and the reference list of relevant articles were systematically searched. This review includes quantitative, qualitative, and mixed-methods studies that report on disparities in retention in care and/or factors that aid or impede these disparities. Studies were excluded if the results were unpublished manuscripts or conference abstracts or if they reported only on children or adolescents less than 18 years of age. Case series, case reports, editorials, letter to the editors, commentaries, meta-analyses, systematic reviews, books, and other publications without primary data were also excluded. The quality and risk of bias of all included studies was assessed.

Narrative synthesis methodology and the Determinants of Health within an Ecologic Model were used to summarize disparities in retention in care and their associated factors. This review also includes an assessment of overall robustness of the review process and generalizability of the synthesized findings.

Manuscript 2 evaluates the relationships proposed in aims 1 and 2 by assessing patient and social-level predictors of retention in care among African Americans and non-African Americans living with HIV. In this manuscript, multivariable regression modeling is used to identify whether health literacy, patient-provider interactions, HIV viral load, socioeconomic status, cognitive function, and other demographic variables predict retention in care over a 24-month observation period.

Manuscript 3 also evaluates the relationships proposed in aims 1 and 2 and builds on the findings from Manuscript 2. In manuscript 3, path analysis is used to assess causal relationships among the variables theorized in the adapted Paasche-Orlow and Wolf health literacy model ( *Figure 1*). This manuscript evaluates two predominant mediating relationships. The first is the mediating effect of health literacy on the relationship between race and retention in care and the second is the mediating effect of retention in care on the relationship between health literacy and HIV viral load. This manuscript also tests the effect of socioeconomic status and cognitive function on health literacy, as well as the effect of patient provider-interactions on retention in care and HIV viral load.

## Summary and Scientific Premise

The scientific premise of this study lies in the emerging evidence linking health literacy to HIV disease management. Although African Americans are more likely than other racial and ethnic groups to not attend HIV appointments and to have poor health literacy, few studies have examined the relationship between health literacy and retention in care and no studies have examined this relationship in the context of health disparities. Also, health literacy has been found to mediate the relationship between race and health outcomes, but the mediating effect of health literacy on retention in care among racially disparate populations has yet to be examined. By examining causal pathways between health literacy and retention in care, findings from this study may improve understanding and identification of areas of intervention for health literacy and retention in care among African Americans. The long-term goal of this research and any research thereafter is to minimize health disparities, improve patient outcomes, and reduce rates of HIV transmission.

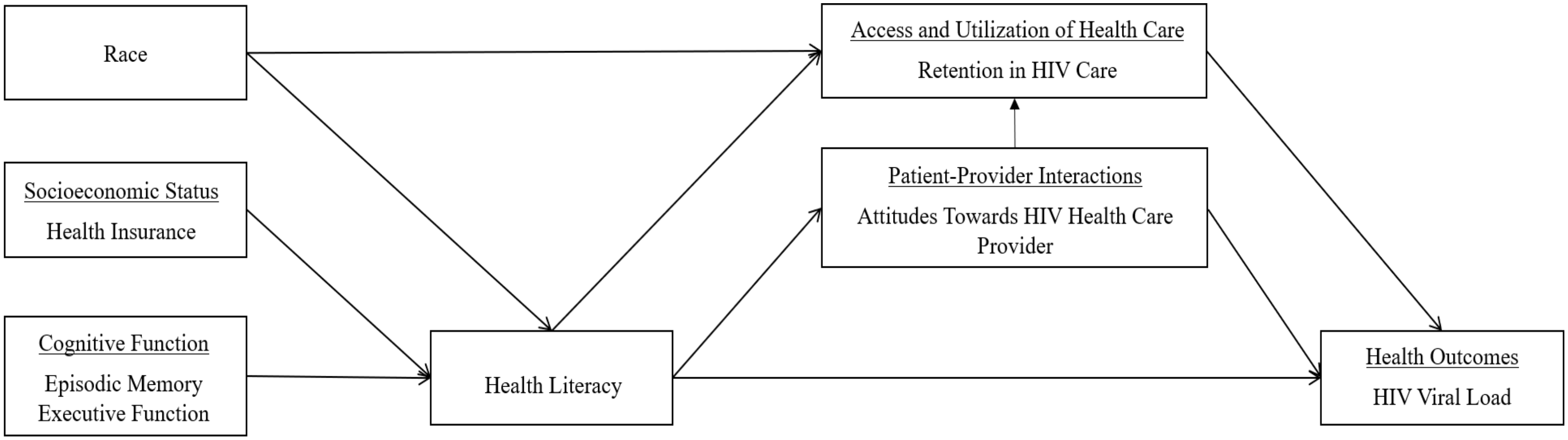


*Figure 1*. Adaption of Paasche-Orlow and Wolf’s Health Literacy Model for Retention in HIV Care

Table 1. Constructs from the Adapted Health Literacy Model with Corresponding Study Variables and Measurement Strategies

| **Construct** | **Variables** | **Measurement Strategy** |
|---|---|---|
| Sociodemographic Characteristics | Race (African American, Non-African American); sex, marital status, sexual orientation, education, age [a] | Demographic Questionnaire |
| Socioeconomic Status (SES) | Health Insurance [b] | *Not Low SES* (Private or Commercial Insurance or Self-Pay); *Low SES* (Ryan White); *Very Low SES* (Medicare/Medicaid)<br>Extracted from electronic medical records |
| Cognitive Function | Cognitive Function [a] | Hopkins Verbal Learning Test-Revised (HVLT-R)*<br>Color Trails Test (CTT) 1 and 2* |
| Health Literacy | Health Literacy [a] | Short-Test of Functional Health Literacy (S-TOFHLA)* |
| Patient-Provider Interactions | Patient-Provider Interactions [a] | Attitudes Towards HIV Health Care Provider (ATHCP)* |
| Access and Utilization of Health Care | Retention in HIV Care [c] | Visit Adherence<br>Extracted from electronic medical records |
| Health Outcomes | HIV viral load [c] | *Viral suppression* (HIV-1 RNA less than 2.3 $\log_{10}$);<br>*Viral non-suppression* (HIV-1 RNA greater than 2.3 $\log_{10}$)<br>Extracted from electronic medical records |

* Validated measurement tool; [a] collected by parent study at baseline; [b] collected by present study at baseline; [c] collected by present study at 24-months post-baseline

# CHAPTER 2

# DISPARITIES IN RETENTION IN CARE AMONG ADULTS LIVING WITH HIV/AIDS: A SYSTEMATIC REVIEW

Health disparities among persons living with HIV continue to be a national priority (Steele, Melendez-Morales, Campoluci, DeLuca, & Dean, 2007; M. B. Williams, Mitchell, & Thomson, 2006), as different health outcomes persist despite general improvements in prevention and treatment. The greatest burden of existing HIV infections are among African Americans especially men who have sex with men (MSM) living in the Southern U.S. (Centers for Disease Control and Prevention, 2016, 2018a). Health disparities may be conceptualized within the spectrum of the HIV care continuum, which is also known as the HIV treatment cascade (Gardner, McLees, Steiner, Del Rio, & Burman, 2011). This continuum follows persons from the time they were diagnosed with HIV, to prescription of antiretroviral therapy, and achievement of viral suppression (Gardner et al., 2011). Within each step of this cascade, differentials in access to care have been recognized, with disparities in linkage and retention in care gaining increased focus.

Among persons living with HIV, 40% are retained in care (Bradley et al., 2014). Retention in care refers to whether an individual attends regularly scheduled HIV medical appointments (Mugavero, Westfall, et al., 2012). Retention in care is critical for the health of persons living with HIV as it is a significant predictor of adherence to antiretroviral therapy and viral suppression (Berg et al., 2005; Rastegar et al., 2003). Failure to attend HIV appointments increases the risk that persons will not initiate or adhere to antiretroviral therapy, thereby increasing risks of morbidity, mortality, and HIV transmission (Metsch et al., 2008; Skarbinski, Rosenberg, Paz-Bailey, & et al., 2015). There is no gold standard of operationalizing retention in care, however, several approaches are commonly used (Mugavero et al., 2010). Underlying each operationalization of retention in care is the assumption that regularly scheduled HIV appointments are made according to treatment guidelines. Treatment guidelines set forth by the Health Resources and Services Administration recommend that a minimum of one HIV appointment occur within a six-month period, with at least 60 days between each appointment (Health Resource and Services Administration, 2015). Additional visit frequency recommendations are available for persons newly diagnosed with HIV or those beginning or modifying an antiretroviral therapy regime. Due to the importance of retention in care for HIV health outcomes, addressing disparities in retention in care is of the upmost importance (Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020, 2008; M. B. Williams et al., 2006).

Critical in understanding disparities in retention in care is recognizing that the term “health disparity” is widely used despite lack of a standardized definition (Steele et al., 2007). Health disparities are commonly defined as differences in the presence of disease incidence, prevalence, health outcomes, mortality, or access to care between populations (Carter-Pokras & Baquet, 2002). These differences are typically categorized into socioeconomic-level determinants, such as age, gender, sexual orientation, disability, race, ethnicity, or geographic location (Carter-Pokras & Baquet, 2002; Centers for Disease Control and Prevention, 2017a; Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020, 2008; U.S. National Library of Medicine). Health disparity is commonly interchanged with similar terms, such as, “health inequality” and “health inequity,” despite nuanced differences in their definitions, which suggest unfairness or avoidability related to a particular outcome (Carter-Pokras & Baquet, 2002). Additionally, other terms, such as “health care disparities” are used to refer specifically to differences in access or availability to heath care facilities and services (U.S. National Library of Medicine). From a measurement perspective, health disparities are defined as a quantity that "separates a group from a specified reference point on a particular measure of health" (Keppel et al., 2005). The reference point is typically pre-specified and the measure of health is usually expressed as a rate, percentage, mean, or other quantitative measure (Keppel et al., 2005).

Given existing disparities in the incidence and prevalence of HIV and the significant effect of retention in care on HIV health outcomes, it is important to identify and address disparities in retention in care within the HIV care continuum. Several systematic reviews have examined predictors of retention in care, but to our knowledge, no reviews have outlined disparities in retention in care. Therefore, this systematic review comprehensively and systematically appraise the literature, with a primary aim of identifying existing disparities in retention in care among adults living with HIV. The secondary aim of this study is to review determinants associated with the identified disparities in retention in care.

## Methods

This systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on July 9, 2018 (Registration Number: CRD42018099914) and was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols 2015 (PRISMA-P; Moher et al., 2015).

### Eligibility Criteria

The major outcome of interest is disparities in retention in care. Studies were included if the retention in care measure reflected an individual's attendance at regularly scheduled HIV appointments, such as through continuous or dichotomous measures of retention in care, including missed visits, visit adherence, visit constancy, visit gap, Health Resources and Services Administration's measure, or other well-defined measure of retention in care (Mugavero, Westfall, et al., 2012). Additionally, studies were included if they referred to disparities as inequities or inequalities and reported disparities as a difference between a group and reference point. For example, disparities may be quantified as a rate, percent, or proportion (Keppel et al., 2005).

Secondary outcomes include determinants that aid or impede disparities in retention in care. Studies may statistically compare the effect of the determinants on retention in care between the health disparate population and reference group. Alternatively, studies may situate their study within the context of a disparity in retention in care and include populations with previously demonstrated disparities in retention in care.

Study inclusion criteria for this review are as follows:

- Non-experimental (e.g. cohort, case-control, cross sectional designs), qualitative, and mixed-method study designs
- Adult participants, 18 years of age or older, and living with HIV/AIDS
- Data collected predominately in the contiguous U.S. and Alaska/Hawaii
- Published in the last 10 years (2008-June 1, 2018)
- Published or translated into English

Studies were also included if participants were health care professionals who cared for adults living with HIV or if participants were key stakeholders for HIV/AIDS populations. Additionally, we included studies with adolescent participants transitioning to adult HIV care providers.

Study exclusion criteria for this review are as follows:

- Experimental and quasi-experimental study designs, case series, editorials, letters to the editor, commentaries, meta-analyses, systematic reviews, books and book chapters, research protocols, and publications without primary data
- Unpublished manuscripts and conference abstracts

## Search Strategy and Identification of Studies

**Search Strategy.** We developed our literature search strategy using Medical Subject Headings (MeSH) and relevant search words related to health disparities, retention in care, and HIV. We utilized appropriate Boolean operators to define relationships between terms in our search strategy. We searched PubMed/MEDLINE, CINAHL, Sociological Collection, PsychInfo, and Cab Direct/Global Health. To ensure as complete a search as possible, we searched for grey literature, specifically, U.S. government funded scientific reports, through the National Technical Reports Library and sought additional citations from the reference lists of included full-text studies.

The primary author developed the specific search strategy with input from the project team and a Nursing Informationist. The primary author then reviewed the literature search strategy according to the PRESS 2015 Guideline Evidence-Based Checklist (McGowan et al., 2016). The detailed search strategy for each database is in Appendix A. We conducted the final literature search on June 1, 2018.

We tracked literature search strategies and search results in a Microsoft Excel document. The Excel document contained the database searched, date of search, search strategy (subject headings and keywords), and number of records retrieved. We exported the final search results from each database into EndNote X8.1 (Clarivate Analytics, 2017), a reference management software, whereby duplicate articles were removed. We then imported the articles along with their full texts into Covidence, an online systematic review management tool (Veritas Health Innovation Ltd., 2019).

**Screening of Articles.** We developed a standardized screening tool containing the inclusion and exclusion criteria to guide the screening of articles. Two independent reviewers reviewed the title, abstract, and full-text of all articles against the standardized tool. We obtained the full-text for articles that meet the inclusion criteria or for which there was uncertainty. The two reviewers resolved discrepancies by discussion; however, if consensus could not be reached, a third independent reviewer made the final determination. The review authors were un-blinded to the article title and authors.

**Quality and Risk of Bias Assessment.** We used the Johns Hopkins Research Evidence Appraisal Tool to assess quality of quantitative, qualitative, and mixed-methods study designs (Dang & Dearholt, 2017). Using this tool, reviewers categorized quantitative studies as high, good, or low quality according to the sufficiency of the sample size for the study design; adequacy of covariate control; validity and reliability of study instruments; consistency and generalizability of results; and consistency of conclusions with results. Reviewers categorized qualitative studies as high/good or low quality according to evidence of author transparency, diligence, verification, self-reflection and self-scrutiny, participant-driven inquiry, and insightful interpretations.

We assessed risk of bias using criteria specific to study design. For quantitative studies, we used criteria developed by the Agency for Healthcare Research and Quality, which examines bias in both intervention and non-intervention studies (Viswanathan et al., 2008). This tool uses the taxonomy for core biases set forth in the Cochrane Handbook (*Cochrane handbook for systematic review of interventions*, 2011) and includes five risk of bias domains—selection bias, performance bias, attrition bias, detection bias, and reporting bias. For qualitative studies, we assessed risk of bias using Cochrane's criteria to critically appraise qualitative studies (Hannes, 2011), which evaluates credibility, transferability, dependability, and confirmability. Reviewers evaluated each qualitative criterion as met if the study authors demonstrated use of a minimum of two evaluation components. Mixed-methods studies were assessed using both tools. We reported risk of bias domain as low, high, or unclear if the study provided insufficient information.

**Data Extraction.** The primary author extracted data from the final studies using data extraction forms developed a priori in Microsoft Excel. Data extracted from each article included the study purpose, study design, data collection time frame, inclusion/exclusion criteria, sample size and setting, sampling and recruitment processes, outcomes measurement, key findings, and limitations.

**Data Synthesis.** We used narrative synthesis to summarize disparities in retention in care and their associated determinants, in accordance with guidelines set forth by Popay et al (Popay et al., 2006). Narrative synthesis utilizes a textual approach to synthesize, compare, and explain findings from studies included in the systematic review. This approach is particularly suited for this systemic review, as it provides guidance for synthesizing findings from a range of study designs. Narrative synthesis methodology involves four main elements: 1) identifying a theoretical model to assist in the interpretation of the review's findings; 2) developing a preliminary synthesis of the findings; 3) exploring relationships within and between studies; 4) assessing the robustness of the evidence.

First, we applied the Determinants of Health within an Ecologic Model (Fielding, Teutsch, & Breslow, 2010). This model allowed us to categorize disparities in retention in care and their associated determinants as biologic characteristics and individual behaviors of persons living with HIV, as interactions between social, family, and community networks, and from broader social, economic, cultural, and physical influences within local, national, and global environments. Secondly, in developing a preliminary synthesis of the findings, we created textual descriptions of all the studies and refined tabulated study details collected during data extraction. To help manage the data synthesis process and to aid in exploring relationships and patterns within and between studies, we then grouped studies based on similar characteristics and whether they identified health disparities or determinants of health disparities. To further aid in identifying patterns and relationships within the data, we utilized concept mapping, as it helps alleviate challenges associated with combining results from different study designs. Lastly, we evaluated the strength of the body of evidence through critically analyzing the overall systematic review methodology, the bias and quality of the evidence, and the synthesis of the evidence. Such an analysis assisted in determining the overall robustness of the review, as well as generalizability of the synthesized findings.

## Results

### Results of the Search

The database search identified 356 unique records published between 2008 and 2018. A search of the grey literature and hand searching the reference lists of included full text studies yielded an additional 6 records, for a total of 361 unique titles and abstracts for screening. Figure 2 provides the PRISMA flow diagram for the literature review screening and selection process. After screening titles and abstracts, we excluded 284 records. We screened the full-text of 78 records against the inclusion and exclusion criteria. We excluded 38 records that did not report on disparities in retention in care or determinants of disparities in retention in care and excluded

7 records that did not meet the study design inclusion criteria. A total of 33 studies were eligible for this review. A description of the characteristics of included studies are in Appendix B.

## Characteristics of Study Methods and Participants

Of the 33 included studies, five reported using a cross sectional study design. Eighteen studies used a cohort design, whereby only one of these studies used a matched cohort design. Ten studies utilized qualitative research methodology. All studies were published between 2009 and 2018. Twenty-two studies were published between 2016 and 2018, nine studies were published between 2012 and 2014, and two studies were published in 2009.

All studies included Black or African Americans living with HIV. One study included non-Hispanic Black Caribbean-born immigrants (Cyrus et al., 2017) and four studies restricted inclusion to Black or African Americans (Messer et al., 2013; Quinn, Reed, Dickson-Gomez, & Kelly, 2018; Sangaramoorthy, Jamison, & Dyer, 2017; Walcott, Kempf, Merlin, & Turan, 2016). Twenty-four studies included Hispanic and Latino persons (Adeyemi, Livak, McLoyd, Smith, & French, 2013; Anderson et al., 2018; Berkley-Patton, Goggin, Liston, Bradley-Ewing, & Neville, 2009; Colasanti et al., 2016; Costa et al., 2018; Dasgupta, Oster, Jianmin, Hall, & Li, 2016; Ghiam et al., 2017; Hall et al., 2013; Hu et al., 2012; Jaiswal, Griffin-Tomas, Singer, & Lekas, 2018; Jaiswal, Singer, Griffin Tomas, & Lekas, 2018; Mauck, Sheehan, Fennie, Maddox, & Trepka, 2018; Messer et al., 2013; Morales-Aleman et al., 2017; Muthulingam et al., 2013; Rebeiro et al., 2016; Rebeiro et al., 2018; Sevelius, Patouhas, Keatley, & Johnson, 2014; Sheehan, Fennie, et al., 2017; Sheehan, Mauck, et al., 2017; Singh et al., 2014; Sohler, Li, & Cunningham, 2009; Sprague & Simon, 2014; Wester et al., 2016) and only three studies restricted study inclusion to Hispanic/Latino persons (Jaiswal, Griffin-Tomas, et al., 2018; Jaiswal, Singer, et al., 2018; Sheehan, Mauck, et al., 2017).

Twenty studies included men who have sex with men (MSM) (Behler, Cornwell, & Schneider, 2018; Colasanti et al., 2016; Costa et al., 2018; Cyrus et al., 2017; Dasgupta et al., 2016; Ghiam et al., 2017; Hall et al., 2013; Hightow-Weidman et al., 2017; Hu et al., 2012; Lesko, Tong, Moore, & Lau, 2017; Mauck et al., 2018; Morales-Aleman et al., 2017; Muthulingam et al., 2013; Rebeiro et al., 2016; Rebeiro et al., 2018; Sheehan, Fennie, et al., 2017; Sheehan, Mauck, et al., 2017; Singh et al., 2014; Sprague & Simon, 2014; Wester et al., 2016), with five studies restricting inclusion to MSM (Behler et al., 2018; Hightow-Weidman et al., 2017; Mauck et al., 2018; Morales-Aleman et al., 2017; Singh et al., 2014). Of these studies, two enrolled only Black MSM (Behler et al., 2018; Hightow-Weidman et al., 2017).

Except for studies who enrolled only MSM, every study included women. Two studies restricted inclusion to women (Anderson et al., 2018; Walcott et al., 2016), two to women of color (Messer et al., 2013; Sangaramoorthy et al., 2017), and one to transgender women (Sevelius et al., 2014).

Additional studies targeted prison releasees (Costa et al., 2018) and low income persons (Jaiswal, Griffin-Tomas, et al., 2018; Jaiswal, Singer, et al., 2018; Sohler et al., 2009; Sprague & Simon, 2014; Walcott et al., 2016).

**Characteristics of Retention in Care Measures**

Studies utilized both laboratory and appointment-based indicators of retention in care. While some studies referred to retention in care as engagement in care or clinic attendance, this systematic review will simplify all terms as retention in care. Laboratory-based definitions commonly measured retention as having at least two CD4 or viral load tests completed at least three months apart within a 12-month period (Adeyemi et al., 2013; Dasgupta et al., 2016; Singh et al., 2014; Wester et al., 2016). One study utilized this definition for a three-year time-period and indicated individuals as consistently retained if they met the retention in care criteria all three years (Dasgupta et al., 2016). Some studies specified collection of CD4 or viral load tests greater than or equal to 90 days apart within a 12-month period (Ghiam et al., 2017; Hu et al., 2012). Other studies utilizing a laboratory-based definition of retention in care focused on the first year of HIV care after receiving a positive diagnosis. One study measured retention in care as greater than or equal to two CD4 or viral load tests completed greater than or equal to three months apart within 12 months of diagnosis (Morales-Aleman et al., 2017). Another study defined retention according to the second and third laboratory tests (Muthulingam et al., 2013). PLWH achieved retention if they completed the second laboratory test within three to six months after entry into care and retention for the third laboratory test if completed within three to six months after the second laboratory test (Muthulingam et al., 2013).

Appointment-based definitions commonly followed a similar format as laboratory-based definitions. Several studies defined retention in care as greater than or equal to two HIV provider visits greater than or equal to 90 days apart within a 12-month period (Colasanti et al., 2016; Costa et al., 2018; Rebeiro et al., 2016; Rebeiro et al., 2018). Only one study using this definition specified HIV provider visits as primary care encounters (Rebeiro et al., 2016). Two studies utilizing a similar appointment-based definition specified that provider visits be completed greater than or equal to three months apart (Jaiswal, Griffin-Tomas, et al., 2018; Jaiswal, Singer, et al., 2018) and three studies did not indicate a time interval between each HIV appointment (Behler et al., 2018; Berkley-Patton et al., 2009; Sohler et al., 2009). Other definitions of retention in care included the number of missed clinic visits in the past year (Anderson et al., 2018; Hightow-Weidman et al., 2017); attendance at one HIV appointment between a specified period (Hall et al., 2013); the number of scheduled and the number of kept HIV care visits in the past year (Sangaramoorthy et al., 2017); being out of care in the past 6 months (Quinn et al., 2018). Lastly, four studies relied upon self-reported attendance at HIV appointments (Behler et al., 2018; Berkley-Patton et al., 2009; Hightow-Weidman et al., 2017; Quinn et al., 2018)

Studies also defined retention in care using a combination of laboratory and appointment data. The most common combined definition measured retention as greater than or equal to two engagement in care opportunities greater than or equal to three months apart in a 12-month period (Cyrus et al., 2017; Mauck et al., 2018; Sheehan, Fennie, et al., 2017; Sheehan, Mauck, et al., 2017). Studies using this definition documented engagement in care if persons had more than one documented lab test, filled a prescription through the AIDS Drug Assistance Program, or had a documented physician visit in the Ryan White database. Two studies assessed retention in care as greater than or equal to two CD4, viral load, or HIV provider visits greater than or equal to 90 days apart (Ghiam et al., 2017; Lesko et al., 2017), with one study specifying an observation period of one year (Lesko et al., 2017).

## Disparities in Retention in Care

The primary outcome of this systematic review was to identify disparities in retention in care and to secondarily identify determinants that aid or impede these disparities. We visually depicted the findings for these primary and secondary outcomes within an adapted Ecologic Model framework (Fielding et al., 2010) in Figure 3. The results of this systematic review are separated by each level within the adapted ecologic model framework first by disparity and then by determinants of retention in care.

**Individual Traits—Race.** Non-Hispanic Blacks and African Americans exhibited an increased risk of poor retention in care, compared to Non-Hispanic Whites (Adeyemi et al., 2013; Althoff et al., 2014; Dasgupta et al., 2016; Ghiam et al., 2017; Hall et al., 2013; Hu et al., 2012; Rebeiro et al., 2018; Sheehan, Mauck, et al., 2017; Wester et al., 2016) and to Hispanics (Dasgupta et al., 2016; Hall et al., 2013). Racial disparities among Non-Hispanic Blacks and African Americans persisted despite adjusted models that controlled for factors such as age, gender, HIV risk group, socioeconomic status, as well as individual and neighborhood factors (Sheehan, Mauck, et al., 2017) and health literacy (Rebeiro et al., 2018).

Several studies also identified racial disparities in retention in care among Hispanics compared to Non-Hispanic Whites (Adeyemi et al., 2013; Ghiam et al., 2017; Hall et al., 2013); however, these findings were not consistent. Two large studies, one utilizing data from 10 U.S. clinical cohorts and another with data from the Los Angeles County Department of Public Health, found that Hispanics (Althoff et al., 2014) and Latinos (Hu et al., 2012), respectively, had a greater likelihood of retention in care compared to Non-Hispanic Whites. However, contradictory findings by Mauck et al. found that Hispanic-Whites were less likely to be retained in care compared to non-Hispanic Whites (2018).

Two studies suggested that racial disparities in retention in care remain over time. Colasanti et al. found that 12 months after enrolling into HIV care, there was no statistically significant difference in retention among Blacks and non-Blacks; however, at 24 and 36-months after enrolling into HIV care, Blacks had significantly lower rates of retention (2016). Dasgupta, et al. found that over a three-year period, Black/African Americans were least likely to be consistently retained in care all three years compared to Hispanics/Latinos and Whites (2016). These findings suggested that racial disparities are likely established in the first one or two years after testing positive for HIV and entering care.

**Individual Traits—Gender.** Among all races, there was inconsistency regarding gender disparities. While several studies identified females as less likely to be retained in care than males (Rebeiro et al., 2016; Sohler et al., 2009; Wester et al., 2016), other studies suggested greater retention in care among females compared to males (Althoff et al., 2014; Ghiam et al., 2017). Among non-Hispanic Blacks, retention in care was poorer among males compared to females (Dasgupta et al., 2016; Hu et al., 2012; Sheehan, Mauck, et al., 2017) and this finding was also consistent among Mexican and Central American born Latinos (Sheehan, Fennie, et al., 2017).

**Individual Traits—Age.** Consistent evidence suggested that younger age is associated with poorer retention in care than older ages (Adeyemi et al., 2013; Ghiam et al., 2017; Hall et al., 2013; Hu et al., 2012; Rebeiro et al., 2018; Wester et al., 2016) and that older age may be protective for retention in care among all racial and ethnic groups (Mauck et al., 2018). Although individuals as young as 13 years of age and those in their early twenties have poorer retention than older age groups (Adeyemi et al., 2013; Rebeiro et al., 2018) several studies suggested that the likelihood of non-retention may be greatest among persons in their mid-twenties to mid-to-late thirties, compared to persons forty years old and above (Adeyemi et al., 2013; Hall et al., 2013; Wester et al., 2016).

Additionally, studies suggested that disparities in retention in care may exist over time and may be based upon age at enrollment in HIV care. One study, found that retention in care for a third laboratory visit 12 months after initial entry into care was greatest among persons fifty years of age or older at entry into HIV care, compared to persons who enter care at 13-29 years of age (Muthulingam et al., 2013). A study by Colasanti, et al. (2016) had similar findings and found that adults greater than 45 years of age had better retention in care at 12, 24, and 36-months after enrolling in HIV care compared to their younger counterparts. These findings were further supported by Ghiam, et al. (2017) who examined trends in retention in care over a nine-year period and found that longitudinal retention in care is greatest among persons who enter care at 35 years of age or younger and at greater than or equal to 45 years of age, compared to persons who enter care when they are 35-44 years old.

**Individual Traits—HIV Risk Group.** Injection drug users (IDUs) and MSM are at increased risk of poor retention in care, with the risk greatest among IDUs. Evidence consistently suggested lower retention in care among IDUs or individuals with a history of IDU compared to MSM (Althoff et al., 2014; Hu et al., 2012; Lesko et al., 2017; Rebeiro et al., 2018; Wester et al., 2016). One study found that although retention in care among IDUs has increased over time, retention in care among this population remains significantly lower compared to non-IDUs (Lesko et al., 2017).

Compared to heterosexuals, MSM have poorer retention in care (Dasgupta et al., 2016; Ghiam et al., 2017), with additional disparities by race and age. The majority of research indicates poorer retention among non-Hispanic Black MSM compared to non-Hispanic White MSM (Mauck et al., 2018; Wester et al., 2016) and MSM of all other races and ethnicities (Singh et al., 2014). This disparity exists despite controlling for individual and neighborhood level factors (Mauck et al., 2018). However, one study conducted in Florida found that among non-Latino Blacks, MSM were more likely to be retained in care than heterosexuals (Sheehan, Fennie, et al., 2017).

Among MSM, younger individuals are less likely to be retained in care than older individuals. Research suggests that MSM 13-18 years old and 13-24 years old have poorer retention in care than individuals 19-24 years old or greater than 24 years old, respectively (Morales-Aleman et al., 2017; Singh et al., 2014). Further research suggests that retention in care remains poor among MSM 25-34 years old compared to MSM ages 35-44 years (Wester et al., 2016). Additionally, the intersection of race and age may create additional unique disparities in retention in care among MSM, as one study found that White young MSM are less likely to be retained in care than Black/African American young MSM and Hispanic MSM (Morales-Aleman et al., 2017).

**Individual Traits—Incarceration History.** Even though HIV care is interrupted when incarcerated (Sprague & Simon, 2014), research is limited on disparities in retention in care among previously incarcerated persons. One study utilized a propensity-matched cohort study to compare retention in care among PLWH who are reentering the community after release from prison to community controls (Costa et al., 2018). Utilizing Ryan White AIDS Program data from Rhode Island and North Carolina, this study found that persons reentering the community after release from prison have poorer retention in care compared to the community controls. Specifically, the proportion of releasees retained in care in Rhode Island and North Carolina reached 62% and 66%, compared to their respective community controls (91% and 90%).These findings demonstrate a potential disparity in retention in care among previously incarcerated persons, which the authors propose may be related to interrupted HIV care upon reentry into society after release from prison (Costa et al., 2018).

**Individual Traits—Place of Birth.** Although one study found that among all races, foreign-born individuals have better retention in care than U.S. born counterparts (Hu et al., 2012), three studies suggest poorer retention in care among foreign-born individuals. Particularly, one study identified poor retention in care among foreign-born non-Hispanic Blacks and non-Hispanic Whites compared to U.S. born counterparts (Sheehan, Mauck, et al., 2017), with being born in the U.S. protective for retention in care (Mauck et al., 2018). Another study identified that Latinos born in Mexico and Central America, specifically Guatemala and

Honduras, have poorer retention in care compared to Latinos born in the U.S. (Sheehan, Mauck, et al., 2017). Additionally, among Black, Caribbean-born immigrants from Bahamas, Trinidad, Tobago, and Haiti, retention in care is poorer compared to non-Hispanic White counterparts (Cyrus et al., 2017).

**Socioeconomic, Cultural, Environmental, and Political Conditions—Geographic Location.** Within the U.S., disparities in retention in care also exist by geographic location. In regression models adjusting for demographic and HIV risk factors, the percentage of persons retained in care in the West and South lag behind those retained in the Northeast U.S. (Rebeiro et al., 2016). Racial differences by region are also evident with retention in care poorer among Black compared to White persons in the Southern U.S. (Rebeiro et al., 2016). Research in Tennessee suggests that within state disparities may also exist, as persons living with HIV in Nashville are less likely to be retained in care than those in Memphis (Wester et al., 2016). Evidence of disparities within a state's cities or counties is limited.

## Determinants of Disparities in Retention in Care

**Physical and Mental Health.** This review identified health conditions and HIV management as determinants of disparities in retention in care at the physical and mental health level of the adapted ecologic model. A lack of ongoing diagnostic and treatment services for comorbidities (Berkley-Patton et al., 2009), lack of funding assistance for comorbidity treatments (Berkley-Patton et al., 2009), and providers uninformed in managing HIV comorbidities (Sangaramoorthy et al., 2017) deter individuals not only from seeking medical assistance for health conditions, but also from routine HIV care. Additionally, feelings of frustration limit retention in care. Black women living with HIV reported feeling frustrated that they were always at the doctor for comorbid conditions and because of these feelings chose to miss HIV or specialty medical appointments (Sangaramoorthy et al., 2017).

Specific health conditions identified in this review were AIDS diagnosis, mental illness, and substance use. A concurrent AIDS diagnosis was associated with an increased likelihood of retention in care (Cyrus et al., 2017; Mauck et al., 2018; Sheehan, Mauck, et al., 2017). This finding was consistent among non-Latino Blacks (Sheehan, Mauck, et al., 2017), Mexican and Central American born Latinos (Sheehan, Mauck, et al., 2017), and PLWH born in Caribbean countries (Cyrus et al., 2017). One study utilizing surveillance data in Los Angeles, revealed contrary findings (Cyrus et al., 2017). This study reported that among PLWH, lack of retention in care was associated with a concurrent AIDS diagnosis compared to those without a concurrent diagnosis; however, this outcome was not assessed by age, gender, race, or other disparity in retention in care (Cyrus et al., 2017).

Poor mental health was consistently identified as a barrier to HIV management and retention in care (Messer et al., 2013; Quinn et al., 2018; Sevelius et al., 2014; Sprague & Simon, 2014). HIV positive women of color reported that depression and hopelessness hinder engagement in care (Messer et al., 2013). This finding was consistent among Black men living with HIV who also revealed that depression was often exacerbated by other life challenges, which individually and collectively created barriers to HIV care (Quinn et al., 2018). While unmet mental health service needs hindered retention in care (Sevelius et al., 2014), Messer, et al. found that appropriate mental health treatment facilitated improved retention in care (Messer et al., 2013).

Substance use, including drugs and alcohol, was consistently identified as a barrier to retention in care among HIV-positive women (Anderson et al., 2018), women of color (Messer et al., 2013), transgender women (Sevelius et al., 2014), and young, Black MSM (Hightow-Weidman et al., 2017). Among HIV-positive women, alcohol abuse was associated with missing more than one-third of HIV clinic visits (Anderson et al., 2018) and among young, Black MSM, those who did not engage in marijuana or methamphetamine use in the past month were less likely to miss HIV clinic visits than those who recently utilized drugs (Hightow-Weidman et al., 2017). Lack of substance use treatment hindered retention in care (Sevelius et al., 2014), however, receipt of addiction treatment services facilitated retention in care (Messer et al., 2013).

HIV knowledge and coping ability further influenced whether persons attended HIV appointments. An understanding of the importance of continuous HIV care facilitated retention in care, particularly among young adults and HIV positive women of color (Messer et al., 2013; Philbin et al., 2017). For HIV-positive women of color, experience with treatment effectiveness facilitated retention in care (Messer et al., 2013). For example, the use of personal reminder systems and knowing that HIV treatments were effective and would help prevent premature death from HIV were important in retaining women of color in HIV care (Messer et al., 2013; Sangaramoorthy et al., 2017). Conversely, medication side effects and feeling ill hindered retention in care. An additional study, conducted within a diverse Southern health care clinic, suggested that an individual’s health literacy may influence retention in care (Rebeiro et al., 2018). Health literacy affects an individual’s ability to manage their HIV care, as it encompasses an individual’s ability to complete medical forms, as well as read and comprehend written medical information. This study found that although low health literacy was associated with a higher adjusted incidence of missed HIV visits, age and racial disparities were not explained by differences in health literacy scores (Rebeiro et al., 2018).

Coping influenced retention in care of PLWH, especially among persons with a positive outlook on life and hope for the future (Berkley-Patton et al., 2009; Messer et al., 2013; Sangaramoorthy et al., 2017). Having a positive outlook on life helped persons living with HIV identify a "new normal" to their lives and assisted them in overcoming challenges associated with managing their HIV infection (Berkley-Patton et al., 2009). Additionally, HIV-positive women of color identified faith and religion as important for helping them attend HIV appointments (Messer et al., 2013) and major life events, such as a birth or a death, further motivated retention in care (Sangaramoorthy et al., 2017)

**Social, Family, and Community Networks.** This systematic review identified social support and patient-provider relationships as determinants of disparities in retention in care within the social, family and community networks level of the adapted ecologic model. Evidence suggested that peer support among transgender women (Sevelius et al., 2014), family support among women of color (Messer et al., 2013), and overall social support among minorities (Berkley-Patton et al., 2009) facilitated retention in care. Quinn et al. (2018) suggested that relationship issues negatively influenced retention in care by worsening depressive symptoms. No other studies postulated mechanisms by which social support influences disparities in retention in care.

The effect of patient-provider relationships on disparities in retention in care was identified by numerous studies, with consensus on the importance of positive provider and clinic staff relationships as a facilitator of retention in care (Berkley-Patton et al., 2009; Hightow-Weidman et al., 2017; Jaiswal, Griffin-Tomas, et al., 2018; Messer et al., 2013; Sangaramoorthy et al., 2017). PLWH valued health care providers who met with and were accessible to them on a regular basis (Berkley-Patton et al., 2009; Jaiswal, Griffin-Tomas, et al., 2018), practiced effective patient-provider communication (Berkley-Patton et al., 2009; Jaiswal, Griffin-Tomas, et al., 2018), and developed trusting patient-provider relationships (Berkley-Patton et al., 2009; Sangaramoorthy et al., 2017), despite possible historical mistrust among minority groups (Jaiswal, Singer, et al., 2018). Racial and ethnic minorities emphasized patient-centered communication practices as important for retention in care (Jaiswal, Griffin-Tomas, et al., 2018). Minority persons were more likely to reengage or be retained in HIV care if health care providers practiced a more equitable distribution of decision-making by involving them in the decision-making process, ensuring their concerns and opinions were heard and respected, and through promoting a sense of agency (Jaiswal, Griffin-Tomas, et al., 2018). Patient self-efficacy was an additional factor influencing patient-provider communication, whereby high self-efficacy for communicating with health care providers was associated with increased retention in care among young, Black MSM (Hightow-Weidman et al., 2017).

Among transgender women, cultural competence of the health care provider influenced the patient-provider relationship and retention in care (Sevelius et al., 2014). Transgender women reported the need for gender affirming health care where health care providers address them by their preferred name and pronoun and are knowledgeable about trans-related medical issues, such as concurrent HIV management and hormone therapy (Sevelius et al., 2014).

**Living and Working Conditions.** This review identified competing demands, socioeconomic status, transportation, and neighborhood characteristics as determinants of disparities in retention in care at the living and working conditions level of the adapted ecologic model. HIV-positive women of color (Messer et al., 2013), Black men (Quinn et al., 2018), and low income women in the Southern U.S. (Walcott et al., 2016) consistently viewed competing demands as barriers to retention in care (Messer et al., 2013; Quinn et al., 2018; Walcott et al., 2016). Often, individuals lacked basic necessities for living (Walcott et al., 2016), such as food (Sprague & Simon, 2014), housing (Quinn et al., 2018), and employment (Quinn et al., 2018). Persons living with HIV also reported other competing challenges including mental illness, addiction, family responsibilities (Messer et al., 2013), and gender transition-related health care (Sevelius et al., 2014). When competing demands were present, individuals often prioritized these demands over HIV health care (Quinn et al., 2018).

Socioeconomic status encompasses employment, education, health insurance, financial situation, and housing. Findings suggest that while unemployment is a challenge to managing HIV care (Sprague & Simon, 2014), possibly through its effect on depressive symptoms (Quinn et al., 2018), employment is protective against missing HIV appointments among women living with HIV (Anderson et al., 2018). Type of employment may also influence retention in care. For example, engagement in sex work among cis and transgender women not only limits their availability to attend health care appointments during the day (Sevelius et al., 2014), but also places women in situations that foster drug use (Walcott et al., 2016), a previously mentioned determinant of disparities in retention in care. Like employment, education appears to be protective against non-retention in care. Among young, Black MSM, those with a college degree were less likely to miss HIV appointments compared to Black MSM with a high school or equivalent education (Hightow-Weidman et al., 2017). Several studies identified lack of health insurance (Muthulingam et al., 2013) and lack of enrollment in Ryan White (Wester et al., 2016) as barriers to retention in care. Additional studies suggested possible contributions of lack of health insurance on disparities in retention in care among women living with HIV by race and age (Sangaramoorthy et al., 2017; Walcott et al., 2016) and among PLWH by geographic location (Sprague & Simon, 2014). Although lack of health insurance may contribute to disparities in retention in care and having health insurance is associated with retention in care (Hightow-Weidman et al., 2017), insurance challenges for the insured may present additional unique issues. Quinn et al. found that among individuals with insurance, deductibles and co-payments were financially burdensome and created barriers to HIV treatment (2018). Additionally, Philbin et al. (2017) suggested that among adolescents transitioning to adult clinics, switching insurance carriers may deter some adolescents from maintaining continuous health care. Findings suggest that all components of socioeconomic status are interrelated and Walcott, et al. (2016) depicted the interconnectedness among education, income, and insurance status among their sample of low-income women in the Deep South. Their findings identified that poor education reduced the likelihood of women securing high-income jobs or those that offered health insurance, thereby limiting their ability to attend HIV appointments and manage their health (Walcott et al., 2016).

Financial and housing situations are other factors related to socioeconomic status that may disrupt retention in care (Quinn et al., 2018; Sangaramoorthy et al., 2017). Among young, Black MSM, concerns related to the cost of health care was the most commonly reported reason for not attending HIV appointments (Hightow-Weidman et al., 2017). Similarly, Black women 40 years of age and older living with HIV reported high health care costs as a barrier to managing comorbid conditions and that competing financial demands, such as costs for childcare and transportation to and from healthcare clinics, often prevented them from attending HIV appointments. Under financial distress, they also reported borrowing money from family or friends to pay for appointments, rescheduling appointments until they had the money to cover the costs of a copay, or in some instances receiving HIV care from emergency departments, where they would be treated free of charge (Sangaramoorthy et al., 2017). Black men living with HIV reported that during times of financial distress they prioritized their basic needs, including housing and employment, over their health (Quinn et al., 2018).

Several studies identified unstable housing as an additional challenge to managing HIV (Sevelius et al., 2014; Sprague & Simon, 2014; Walcott et al., 2016). Unmet housing needs are the number one service priority for individuals post incarceration (Sevelius et al., 2014) and unstable housing is a significant concern for low income individuals (Walcott et al., 2016), transgender (Sevelius et al., 2014), and racial minorities (Walcott et al., 2016). Unstable housing and homelessness are highly related to financial situation, employment, and health insurance, as well as a contributor to exacerbation of mental health issues (Quinn et al., 2018). Long term housing options for those in need may facilitate improvements in retention in care (Berkley-Patton et al., 2009)

Studies consistently identified transportation as a challenge to retention in care (Hightow-Weidman et al., 2017; Messer et al., 2013; Philbin et al., 2017; Sprague & Simon, 2014; Walcott et al., 2016), including among women of color (Messer et al., 2013; Sangaramoorthy et al., 2017), adolescents transitioning to adult clinics (Philbin et al., 2017), transgender women (Sevelius et al., 2014), and young, Black MSM (Hightow-Weidman et al., 2017). Individuals may have difficulty coordinating transportation to and from HIV appointments (Sangaramoorthy et al., 2017), as transportation options may be limited or unreliable (Philbin et al., 2017), inconvenient (Messer et al., 2013) or cost prohibitive (Messer et al., 2013; Sangaramoorthy et al., 2017). Consequently, individuals may choose to miss HIV appointments rather than contend with transportation issues.

Several studies assessing the effect of neighborhood characteristics and social networks on retention in care suggested that an individual’s neighborhood or social venues may contribute to whether person attend HIV appointments. By examining social venues where young, Black MSM interact, Behler, et al. (2018) characterized social networks to examine whether affiliation with a certain network influenced engagement in care. Findings suggested that young, Black MSM whose social networks were within the Black community were more likely to be retained in care than individuals whose social networks were within the gay community (Behler et al., 2018). This finding was consistent with an additional study which found that among MSM, living in a gay neighborhood was not associated with retention in care (Mauck et al., 2018). Other studies, assessing whether living in rural or urban areas influence retention in care, found contradictory findings. While Cyrus et al. found that living in rural areas was protective for retention in care (2017), Mauck et al. (2018) reported that living in rural versus urban areas was associated with poorer retention in care. These contradictory findings may be explained by differences in study populations.

**Socioeconomic, Cultural, Environmental, and Political Conditions.** At the outermost level of the adapted ecologic model, this review identified stigma, complex care systems, and health care resources as determinants of retention in care. HIV related stigma persists as a barrier to HIV appointment attendance (Philbin et al., 2017; Quinn et al., 2018; Sangaramoorthy et al., 2017; Walcott et al., 2016). Older Black women living with HIV report stigmatization by health care providers who attribute health concerns to HIV (Sangaramoorthy et al., 2017). Others perceive stigma associated with accessing HIV-specific health care facilities and to facilities providing services to persons of lower socioeconomic status (Walcott et al., 2016). Persons living with HIV may perceive that by attending the aforementioned health care facilities there is an increased likelihood of unwanted HIV status disclosure (Quinn et al., 2018; Walcott et al., 2016) or community associated stigma (Walcott et al., 2016). Among gay and bisexual men, overlapping stigmas from multiple marginalized identities may create a particularly negative effect on disparities in retention in care (Quinn et al., 2018).

Persons living with HIV described difficulty navigating complex health care systems and challenges accessing health care resources as additional barriers to retention in care (Philbin et al., 2017; Sangaramoorthy et al., 2017; Sevelius et al., 2014). Transgender women reported that navigating health systems was not worth the trouble, resulting in missed health care opportunities (Sevelius et al., 2014). Among adolescents transitioning to adult HIV clinics and among older Black women with multiple comorbidities, poor coordination of care and lack of data sharing between providers and clinics hindered retention in care (Philbin et al., 2017; Sangaramoorthy et al., 2017). Additionally, frequent clinic staff turnover (Messer et al., 2013), inconvenient clinic locations (Hightow-Weidman et al., 2017), and rescheduling of appointments by health care clinics (Messer et al., 2013) further contributed to poor retention in care. Due to state and federal budget cuts (Berkley-Patton et al., 2009), HIV community resources are limited (Berkley-Patton et al., 2009). However, among resources that are available, persons living with HIV may be unaware of or have a difficult time accessing such resources (Walcott et al., 2016). Structured and easily accessible HIV health care services may facilitate improvements in retention in care (Sprague & Simon, 2014).

## Quality and Risk of Bias of Included Studies

We summarized the quality and risk of bias assessments for quantitative and qualitative studies in Tables 2 and 3, respectively. We provide the risk of bias assessments for all studies with authors' support for judgement in Appendix C.

Due to the inclusion of qualitative and quantitative studies in this systematic review, we utilized quality and risk of bias tools for each respective study type. We found that among the quantitative studies (n = 24) only one was low quality (Sangaramoorthy et al., 2017) and all other studies were either good or high quality. This low-quality study was the only mixed-methods study design. We also found that ten quantitative studies exhibited low risk for all criteria, thereby having no areas of high risk or unclear risk of bias (Anderson et al., 2018; Costa et al., 2018; Ghiam et al., 2017; Hu et al., 2012; Morales-Aleman et al., 2017; Muthulingam et al., 2013; Rebeiro et al., 2016; Sheehan, Fennie, et al., 2017; Sheehan, Mauck, et al., 2017; Sohler et al., 2009). Among the qualitative studies (n = 10), half were low quality and the other half were good/high quality. All qualitative studies exhibited areas for high risk of bias. One study had high risk of bias in only one domain (Berkley-Patton et al., 2009), whereas another study exhibited high risk of bias in all four domains (Jaiswal, Griffin-Tomas, et al., 2018).

## Discussion

To our knowledge, several systematic reviews have examined predictors of retention in care, but no reviews have outlined disparities in retention in care or their associated determinants. This systematic review identified a total of 33 eligible studies and utilized an adapted Determinants of Health Ecologic Model to first identify disparities in retention in care and to secondarily identify determinants that aid or impede these disparities. Identified disparities included race, gender, age, HIV risk group, incarceration history, and place of birth, as well as disparities by U.S. geographic location. Within the adapted Ecologic Model, this review identified determinants of disparities in retention in care at each level. At the physical and mental health level, determinants included health conditions, HIV knowledge, and coping. At the social, family, and community networks level, adequate social support and patient-provider relationships facilitated retention in care. Competing demands, socioeconomic status, transportation, and neighborhood characteristics individually and collectively created significant barriers to retention in care at the living and working conditions level of the model. Finally, at the social, health care and geographic environments level, HIV-related stigma, complex care systems, and difficulty navigating complex health care systems and resources contributed to disparities in retention in care.

Consistent with our findings, previous systematic reviews of the literature identified mental health comorbidities as predictors of retention in care (Bulsara, Wainberg, & Newton-John, 2018; Geter, Sutton, & Hubbard McCree, 2018; Rooks-Peck et al., 2018). Persons living with HIV with mental health symptoms or a mental health diagnosis had a lower odds of retention in care (Rooks-Peck et al., 2018) and substance users exhibited the highest attrition in HIV care than other populations (Bulsara et al., 2018). Rooks et al. (2018) found that the effect of mental health symptoms and mental health diagnoses on retention in care depended on health insurance status, thereby suggesting a possible mechanism by which predictors of socioeconomic status may influence mental health and retention in care (Rooks-Peck et al., 2018). Also consistent with our findings, other published systematic reviews suggest that the patient-provider relationship and social support are critical factors for retention in care, particularly Black women with HIV (Geter et al., 2018; Lambert, Mugavero, Najjar, Enah, & Guthrie, 2018), and that dissatisfaction with HIV care and treatment services may be related to a lack of patient-provider communication (Geter et al., 2018).

Although previously published reviews of the literature support findings from this systematic review, additional research is necessary particularly where evidence is limited or emerging. First, a greater understanding of disparities in retention in care will assist in understanding populations most at risk of HIV complications and viral transmission. Future areas of research identified by this review include investigation of disparities in retention in care between cis and transgender PLWH, as well as between previously incarcerated persons and community controls. Second, further research on determinants of disparities in retention in care will assist in developing innovative strategies and interventions to enhance retention in care. Areas that may benefit from further research, include, but are not limited to, the effect of neighborhood and social network characteristics on disparities in retention in care, the role of health literacy on disparities in retention in care, as well as methods of health care delivery that maximize accessibility to healthcare care clinics and available resources.

Patient difficulty navigating health care systems and accessing available HIV resources present opportunities for providers and clinics to translate findings from this systematic review, in order to improve the delivery of health care and ultimately HIV health outcomes. Providers may begin addressing disparities in retention in care at an individual, community, and state or federal level. Providers should begin or continue assessing individual mental health and substance use issues, connecting patients to social workers and other resources for assistance in addressing basic needs, and advocating for essential federal and state HIV resources. Health care clinics also have opportunities for improved data sharing as a mechanism to streamline care between providers within and across different health care systems.

This systematic review is not without limitations. Study level differences in defining and measuring retention in care limit our ability to interpret the prevalence of disparities. Because our objective was to identify disparities in retention in care and their associated determinants within the U.S., it is not representative of other geographic locations, such as Africa, where a large proportion of the HIV epidemic is situated. Additionally, as the literature search was restricted to the past 10 years, to the English language, the U.S., and adult populations, articles that fell outside of these criteria were excluded. While the search strategy was thorough and conducted by two reviewers, it is also possible that relevant articles were unintentionally omitted. This review is also limited by the quality and risk of bias of the included studies. Only ten quantitative studies exhibited low risk for all bias criteria. Half of the qualitative studies were low quality, with all qualitative studies demonstrating high risk for one or more bias criteria. These findings are not surprising due to the complexity of disparities in retention in care and the evolving nature of the research. Nevertheless, findings from this review should be viewed within the context of the quality and risk of bias of its included studies.

## Conclusion

Disparities in HIV/AIDS continue to be a national priority (Steele et al., 2007; M. B. Williams et al., 2006) and are garnering attention as improvements across the care continuum are necessary to meet prevention and care goals (Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020, 2008). This review comprehensively and systematically identified existing disparities in retention in care and their associated determinants. Evidence from this review suggests that additional research is necessary to further identify existing disparities, particularly where evidence is limited or emerging. Researchers should employ innovative, yet strong research methodologies, to better understand determinants of disparities in retention in care that are unique to health disparate populations and that may be targeted through appropriate individual, clinic, community, state, or federal level interventions. Such research would benefit from the development of or agreement on a gold standard for defining and measuring retention in care. Providers and health care clinics may help create structured health care services that support HIV health care and disease management, particularly among populations with disparities in retention in care. This review identified several practical approaches that providers and health care clinics could take to help address disparities in retention in care, such as improving provider communication and patient decision-making practices and de-fragmenting complex health care systems. Additionally, researchers, providers, and inter-disciplinary care partners should collaborate with persons living with HIV and community stakeholders to develop innovative interventions that mitigate determinants of disparities in retention in care. Ultimately, developments in research and health care will assist in reducing disparities in retention in care and will improve HIV health outcomes.

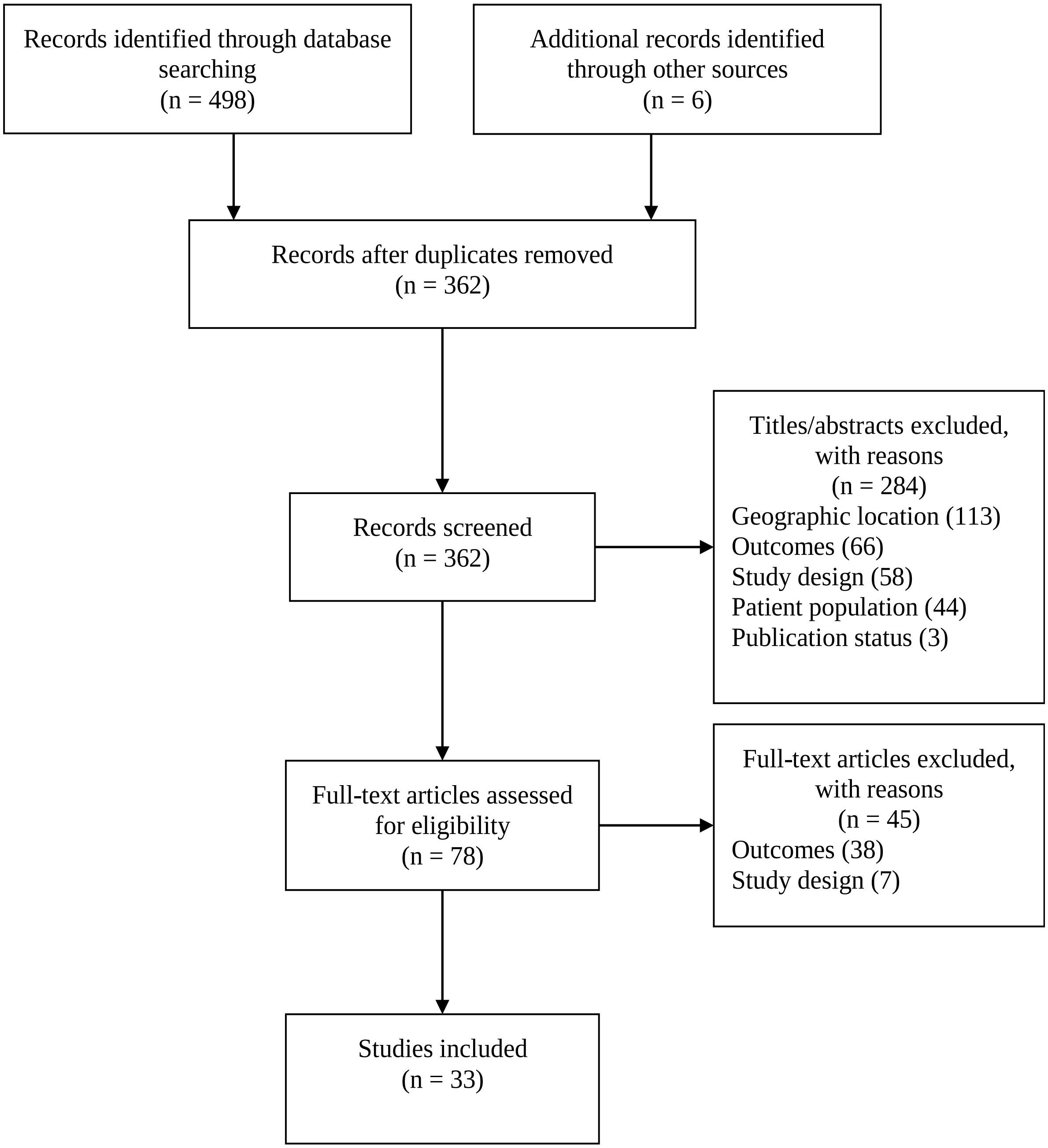


*Figure 2*. PRISMA Literature Flow Diagram.

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

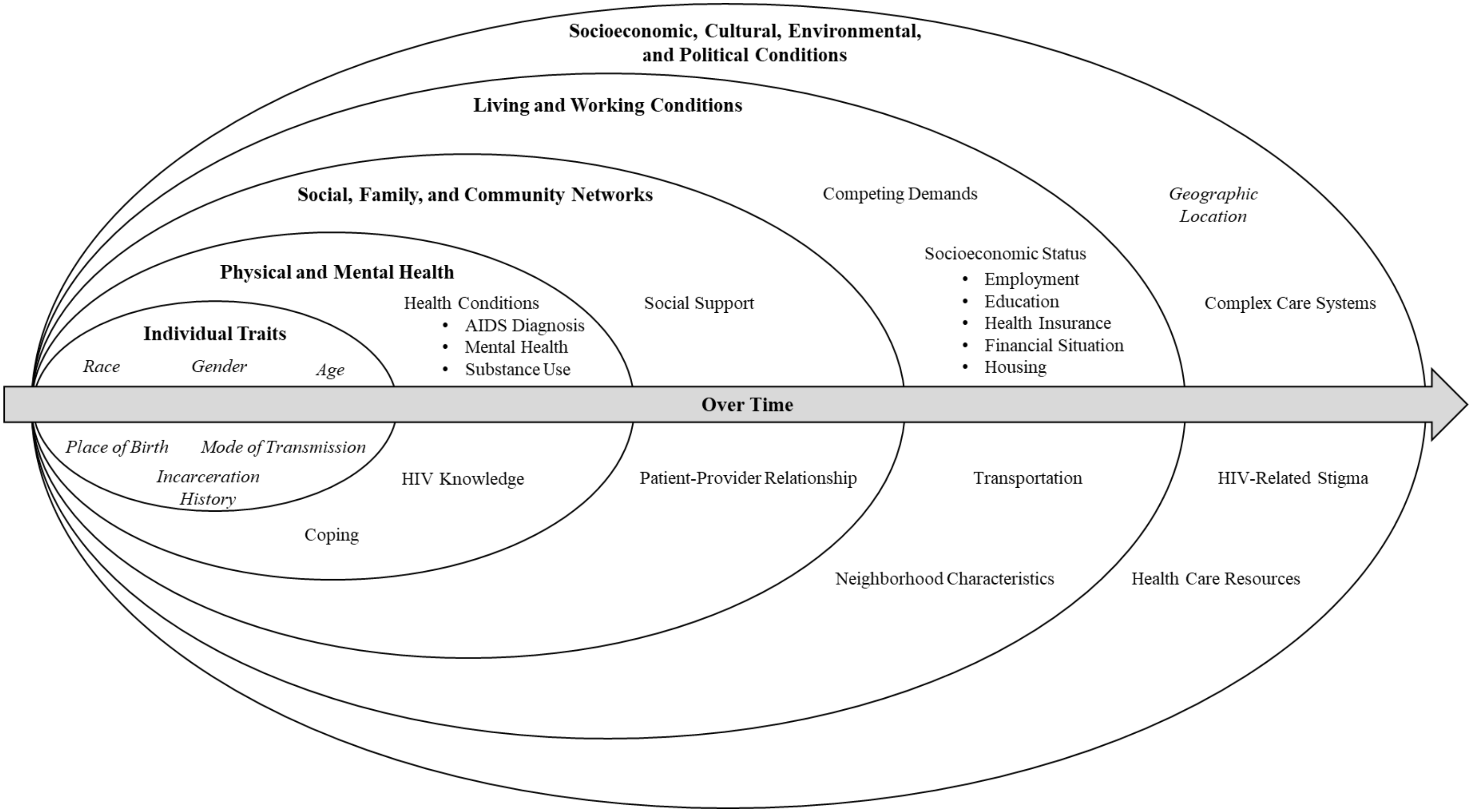


*Figure 3*. Disparities in Retention in Care and Determinants of Disparities Within an Adapted Ecologic Framework.

Italicized words refer to disparities in retention in care; Adapted from: Fielding, J., Teutsch, S., & Breslow, L. (2010). A Framework for Public Health in the United States. Public Health Reviews, 32(1), 174-189. doi:10.1007/BF03391597

Table 2. Quality and Risk of Bias Summary for Quantitative Studies

| | | Quality Rating | Uniform application of inclusion/exclusion criteria (selection bias) | Similar recruitment strategy for control group (selection bias) | Control for confounding and modifying variables (selection bias) | Rule out of unintended exposure (performance bias) | Appropriate handling of missing data (attrition bias) | Consistent assessment and implementation of measures (detection bias) | Reporting of prespecified outcomes (reporting bias) |
|---|---|---|---|---|---|---|---|---|---|
| Adeyemi | 2013 | Good | + | N/A | + | ? | ? | + | + |
| Althoff | 2014 | High | + | N/A | + | + | ? | + | + |
| Anderson | 2018 | Good | + | N/A | + | + | + | + | + |
| Behler | 2018 | Good | ? | N/A | + | ? | + | + | + |
| Colasanti | 2016 | High | + | N/A | + | + | - | + | + |
| Costa | 2018 | High | + | + | + | + | + | + | + |
| Cyrus | 2017 | Good | + | N/A | + | + | + | + | - |
| Dasgupta | 2016 | High | + | N/A | - | ? | + | + | + |
| Ghiam | 2017 | High | + | N/A | + | + | + | + | + |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Hall | 2013 | Good | + | N/A | + | ? | ? | + | + |
| Hightow-Weidman | 2017 | Good | ? | N/A | + | ? | + | + | + |
| Hu | 2012 | Good | + | N/A | + | + | + | + | + |
| Lesko | 2017 | High | + | N/A | + | + | ? | + | + |
| Mauck | 2018 | Good | + | N/A | + | + | ? | + | + |
| Morales-Aleman | 2017 | Good | + | N/A | + | + | + | + | + |
| Muthulingam | 2013 | Good | + | N/A | + | + | + | + | + |
| Rebeiro | 2016 | High | + | N/A | + | + | + | + | + |
| Rebeiro | 2018 | High | + | N/A | + | + | - | + | + |
| Sangaramoorthy | 2017 | Low | ? | N/A | - | - | + | + | + |
| Sheehan, Fennie | 2017 | High | + | N/A | + | + | + | + | + |
| Sheehan, Mauck | 2017 | High | + | N/A | + | + | + | + | + |
| Singh | 2014 | High | + | N/A | + | ? | + | + | + |
| Sohler | 2009 | Good | + | N/A | + | + | + | + | + |
| Wester | 2016 | High | + | N/A | + | + | ? | + | + |

*Note.* + indicates low risk of bias; - indicates high risk of bias; ? indicates unclear risk of bias; High quality: consistent, generalizable results, adequate control, definitive conclusions, consistent recommendations based on comprehensive literature review; Good quality: reasonably consistent results, some control, fairly definitive conclusions, reasonably consistent recommendations based on fairly comprehensive literature review; Low quality: little evidence with inconsistent results, conclusions cannot be draw (Dang & Dearholt, 2017). Low quality studies are shaded grey in the table.

Table 3. Quality and Risk of Bias Summary for Qualitative Studies

| | | Quality Rating | Consistency between representation of data and views of participants studied (credibility) | Transferability of research findings to other specific settings (transferability) | Logical, traceable, and clearly documented process of research (dependability) | Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) |
|---|---|---|---|---|---|---|
| Berkley-Patton | 2009 | Low | - | + | - | - |
| Jaiswal, Griffin-Tomas | 2018 | Low | - | - | - | - |
| Jaiswal, Singer | 2018 | Low | + | - | + | - |
| Messer | 2013 | High/Good | + | - | + | - |
| Philbin | 2017 | High/Good | + | - | + | - |
| Quinn | 2018 | High/Good | + | + | - | - |
| Sangaramoorthy | 2017 | High/Good | + | + | - | - |
| Sevelius | 2014 | Low | + | - | - | - |
| Sprague | 2014 | Low | + | + | - | - |
| Walcott | 2016 | High/Good | + | - | + | - |

*Note*. + indicates low risk of bias; - indicates high risk of bias; High/Good Quality: Evidence of some or all of the following are found in the study: Transparency (descriptions of how information was documented, how data was reviewed by others, how themes and categories were formulated); Diligence (rereading data to check interpretations, corroborating evidence with multiple sources); Verification (ensuring methodologic coherence); Self-Reflection and Self-Scrutiny (awareness of the researcher's experiences, background, and prejudices on the analysis and interpretations); Participant-driven inquiry (participant involvement in shaping scope and breadth of questions, analysis and interpretations give voice to participants); Insightful Interpretation (Linking of data and knowledge to relevant literature); Low Quality: Studies exhibit few if any of the features for high/good quality studies (Dang & Dearholt, 2017). Low quality studies are shaded grey in the table.

# CHAPTER 3

## PREDICTORS OF DISPARITIES IN RETENTION IN CARE AMONG AFRICAN AMERICANS AND NON-AFRICAN AMERICANS LIVING WITH HIV

African Americans are disproportionately affected by HIV compared to other racial and ethnic groups in the United States (U.S.). African Americans accounted for 44% of all new HIV diagnoses in 2016, even though they comprised only 12% of the United States population (Centers for Disease Control and Prevention, 2018a). Moreover, African Americans constitute 42% of the nearly 1.1 million persons living with HIV in the U.S., making up the largest racial/ethnic group living with diagnosed HIV (Centers for Disease Control and Prevention, 2016). Additionally, while the incidence of HIV-associated deaths is declining among all racial and ethnic groups, the death rate among African Americans remains higher than among White and Hispanic/Latino persons (Siddiqi et al., 2015). In fact, African Americans are seven and four times more likely to die from HIV compared to White and Hispanic/Latino counterparts, respectively (Centers for Disease Control and Prevention, 2016).

Retention in care predicts HIV mortality among persons living with HIV (Giordano et al., 2007; Mugavero et al., 2014) and disparities in retention in care among African Americans may be one contributor to poor health outcomes among this population. Approximately 46% of African Americans are retained in care, which is 5% fewer than the proportion of White persons who are retained in care (Centers for Disease Control and Prevention, 2017b). In addition to mortality, retention in care is one of the most significant predictors of treatment failure (Rastegar et al., 2003). Retention in care is associated with elevated viral loads (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). Since 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). U.S. Department of Education surveys found that average health literacy is 20% lower among African American adults compared to White adults (U.S. Department of Education, 2006). Emerging research indicates that low health literacy is associated with increased missed HIV appointments (Jones et al., 2013; Rebeiro et al., 2018). One study found that the likelihood of a person attending 75% of their regularly scheduled HIV appointments doubled among those who knew the correct value of their CD4 and HIV viral load values (Jones et al., 2013). Low health literacy is also associated with decreased overall knowledge of HIV (Kalichman, Benotsch, et al., 2000) and decreased odds of antiretroviral therapy adherence (Kalichman et al., 1999; Miller et al., 2003; Waldrop-Valverde, Jones, et al., 2010). These findings suggest that health literacy may contribute to disparities in retention in care among African Americans

The contributing effect of health literacy on disparities in retention in care should not be examined in isolation, as health literacy is shaped by a variety of factors, including socioeconomic status (Mantwill et al., 2015) and cognitive function (Serper et al., 2014). 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 persons living with HIV (Vance et al., 2016; Waldrop-Valverde, Jones, et al., 2010; Waldrop-Valverde et al., 2008) and is subject to the negative effects of HIV infection on various cognitive domains (Grant et al., 1987; Martin et al., 1992; Peavy et al., 1994; Wilkie et al., 2000).

Health literacy and retention in care are associated with the patient-provider relationship. Poor health literacy may be a barrier to effective patient-provider communication (Katz et al., 2007; Kripalani et al., 2010; Williams et al., 2002), while poor patient-provider communication may contribute to antiretroviral therapy non-adherence (Baker et al., 1996; Kalichman et al., 1999) and poor HIV health outcomes (Kalichman & Rompa, 2000). Conversely, quality patient-provider relationships may positively influence retention in care (Beach et al., 2006) and antiretroviral therapy adherence (Beach et al., 2006; Roberts, 2002), particularly among persons who trust (Beach et al., 2006; Flickinger et al., 2013) and are satisfied with their health care provider (HCP) (Bodenlos et al., 2004).

Although African Americans are less likely than other racial and ethnic groups to attend HIV appointments and to have poor health literacy, few studies have examined the relationship between health literacy and retention in care and even fewer have examined these relationships in 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 is to evaluate patient and social-level predictors, including health literacy, on retention in care among African Americans living with HIV compared to non-African Americans living with HIV.

## Methods

This study is ancillary to a non-experimental longitudinal study that examined the association between health literacy and disparities in medication discordance among African Americans and non-African Americans living with HIV. The parent study recruited participants from four outpatient HIV-clinics in the urban metro-Atlanta, Georgia area between June 2012 and December 2015. Eligibility criteria included attendance at a minimum of one scheduled HIV medical appointment in the nine months prior to the baseline study visit at one of the recruiting clinics and a current prescription for antiretroviral therapy for at least the past six months. Exclusion criteria included acute intoxication, as determined by a breath alcohol test, inability to read or write English, visually or hearing impaired, or plans to move out of the Metro-Atlanta area within six months after baseline. As cognitive impairments are common among persons living with HIV and such impairments may hinder informed consent, the parent study administered a consent post-test that assessed each participant's ability to provide informed consent by assessing comprehension of study procedures, risks, benefits, and other important study related information. Participants who were unable to correctly answer post-test questions after three attempts were excluded from the study.

Data for the parent study was collected at baseline and six-months for 699 HIV-positive adults in private offices at each of the recruiting clinics or in the study team's private offices at Emory University. Study personnel administered questionnaires via an Audio Computer-Assisted Self-Interviewing (ACASI) System. Participants used headphones connected to a computer to listen to instructions, questions, and responses that were digitally recorded into the ACASI system. The corresponding text was simultaneously displayed on a computer monitor. Participants then entered their response to each question directly into the computer using a keyboard and mouse. Previous research suggests that the use of ACASI for data collection leads to greater disclosure of sensitive information and that participants are more likely to disclose risky behaviors compared to face-to-face interviews (Perlis, Des Jarlais, Friedman, Arasteh, & F Turner, 2004; Ghanem, Hutton, Zenilman, Zimba, & Erbelding, 2005). This ancillary study used several baseline measures collected by the parent study, including demographic information, HIV viral load, health literacy, cognitive function, and patient-provider interactions. Additional measures added for this study included retention in care and participant socioeconomic status (SES). Emory University's Institutional Review Board approved the parent and ancillary study.

## Measures

**Demographic Information** included participant reported race, sex, marital status, sexual orientation, education, age, and time since HIV diagnosis. We collected insurance data from the participant's electronic medical record for an HIV visit closest to the participant's baseline interview date. We used insurance as a proxy for SES, as previous research indicates a relationship between the use of this proxy and poor HIV-related outcomes (Chen et al., 2009; Jain et al., 2006). Consistent with prior published HIV research (Rebeiro et al., 2018), we categorized participant insurance/SES as "not low SES" if using private or commercial insurance or if self-pay; "low SES" if receiving Ryan White (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** was measured using the Short-Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). The S-TOFHLA contains two prose passages and four numeracy items. The 36-items in the two prose passages measure reading comprehension by omitting every fifth to seventh word in a health-oriented text passage and asks the reader to select the appropriate word from a list of four possible choices. The passages for the S-TOFHLA are from instructions for an upper gastrointestinal x-ray series, the patient rights and responsibilities section of the Medicaid application form, and a standard hospital informed consent form. The four numeracy items assess ability to comprehend directions for taking medicines, monitoring blood glucose, and keeping clinic appointments. 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** was assessed using the Hopkins Verbal Learning Test Revised (HVLT-R) (Brandt & Benedict, 2001) and the Color Trails Test (CTT) 1 and 2 (D'Elia et al., 1994). The HVLT-R is a verbal list learning task that includes three learning trials and a delayed free recall trial. CTT 1 and 2 measure attention and mental flexibility, a component of executive functioning. For CTT 1 and 2, participants use a pencil to sequentially connect colored circles containing numbers, but for CTT 2, participants alternate between different colored circles. This 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** were evaluated using the Attitudes Towards the HIV Health Care Provider Scale (ATHCP) (Bodenlos et al., 2004). ATHCP is a 19-item scale that assesses patient attitudes towards their HIV health care provider. This patient-reported scale 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) with total scores ranging from 19 to 114. Higher total scores indicate a more positive attitude toward the HIV health care provider. Past research indicates that ATHCP has acceptable internal consistency ($\alpha = 0.69$) and correlates well with measures of patient satisfaction ($r = 0.59$) (Bodenlos et al., 2004). The Cronbach coefficient alpha for the ATHCP for participants in this study was 0.92.

**Viral Load** was obtained 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 electronic medical records. We dichotomized viral load as virologically suppressed or virologically non-suppressed. Consistent with the Centers for Disease Control (Centers for Disease Control and Prevention, 2018b), we defined viral suppression as HIV-1 RNA values less than 2.3 $\log_{10}$ and viral non-suppression as HIV-1 RNA values greater than 2.3 $\log_{10}$. An HIV-1 RNA value of 2.3 $\log_{10}$ corresponds to a viral load of 200 copies/mL.

**Retention in Care** was measured as visit adherence. We calculated visit adherence as the proportion of kept HIV appointments out of all scheduled HIV appointments (Mugavero, Westfall, et al., 2012) over a 24-month period. From the electronic medical records, we extracted outpatient appointments with an HIV primary care provider who has prescribing authority, including physicians and advanced care providers, over a 24-month post-baseline observation period. We collected the date of the visit, the clinic location for the appointment, the health care provider's name, and the status of the HIV appointment, for example, completed, cancelled/missed, or no-show. We did not include specialty HIV care visits, nursing visits, and laboratory visits. To calculate percent visit adherence, we utilized visits with a completed status to represent kept HIV appointment and completed, missed, and no-show visits to calculate the number of scheduled HIV appointments.

## Statistical Analysis

First, we assessed missing data patterns and calculated descriptive statistics. Due to low response rates for some categorical variables, we combined categories to have adequate cell sizes (sex/gender [male or female]; marital status [single/never married, previously married, or married/living with partner]; sexual orientation [heterosexual or other]; education [less than high school, high school/GED, or greater than high school]). Within the female sex/gender category were 16 transgender women who did not play a statistically significant role in the analysis. We removed participants from the data set who reported “other” for their marital status (n = 5), as we were unable to appropriately categorize these individuals into one of the three marital status categories. We also removed participants with no scheduled HIV appointments during the 24-month post-baseline follow-up period (n = 48). Examination of missing data revealed data missing at random for cognitive function (1.24%), ATHCP (0.77%), sex/gender (0.31%), insurance/SES (4.64%), and baseline viral load (0.93%). We performed multiple imputation for missing data using all study variables to create ten imputed data sets. We performed multiple imputation in Mplus using the IMPUTE command, which utilizes Bayesian estimation models (Muthén & Muthén, 1998-2017; Rubin, 1987; Schafer, 1997).

Examination of visit adherence descriptive statistics revealed a non-parametric distribution and the presence of two unique visit adherence groups. The first group included participants who attended 100% of their scheduled HIV appointments and the second group included participants who attended less than 100% of their scheduled HIV appointments. Data was parametrically distributed among participants with less than 100% visit adherence. The distribution of the visit adherence data for all participants and for participants with less than 100% visit adherence is in *Figure 4*. Based on this finding, we conducted the remaining statistical analyses with a binary visit adherence outcome comparing participants with 100% visit adherence versus less than 100% visit adherence, as well as with a continuous visit adherence outcome among participants with less than 100% visit adherence only. In the following analyses, we coded 100% visit adherence as 1 and less than 100% visit adherence as 0.

Next, we conducted bivariate analyses of predictors of visit adherence between participants with 100% and less than 100% visit adherence. Predictors of visit adherence included demographic characteristics, health literacy, cognitive function, patient provider interactions, and viral load. We utilized Pearson's Chi-squared test for categorical variables, Student's t-test for parametrically distributed predictor variables, and Mann-Whitney test for non-parametrically distributed predictor variables.  We also conducted Pearson and Spearman correlations.

Finally, we performed multivariable logistic regression analyses comparing participants with 100% visit adherence to participants with less than 100% visit adherence. We also conducted multivariable linear regression analyses using a continuous measure of percent visit adherence for participants with less than 100% visit adherence. We performed a sequential, block-wise regression that first examined the effects of demographic characteristics. We then included insurance/SES followed by S-TOFHLA and ATHCP. The final step tested the moderating effects of race on significant predictor variables. Since we used multiple imputation for missing data, the regression analyses used the DATA TYPE = IMPUTATION command in Mplus. This command performs the regression analyses for each of the ten imputed data sets and then averages parameter estimates and standard errors. We used SAS Studio software version 3.71 for descriptive and bivariate statistics and Mplus version 8.2 for multiple imputation and multivariable regression.

# Results

## Sociodemographic Characteristics of Study Participants

The parent study included 699 participants. Of these, 646 participants were included in this analysis. Detailed participant characteristics are in Table 4. Participant racial groups included African Americans (60%) and non-African Americans. Among non-African Americans, 81% identified White/non-Hispanic, 6% identified Hispanic/Latino, and 13% identified with another race, such as Asian, Native American/Alaska Native, or biracial. Most participants identified male (70%), were single or never married (57%), and had greater than a high school education (59%). Nearly 92% of participants were virally suppressed and were living with HIV for an average of 16 years. Participant ranged in age from 20 to 83 years, with a mean age of 48 years. Among participants with 100% visit adherence compared to participants with less than 100% visit adherence, there were significant differences by race ($\chi^2$[1, 646] = 7.24, *p* = .007), marital status ($\chi^2$[2, 646] = 8.42, *p* = .015), insurance ($\chi^2$[2, 607] = 8.92, *p* = .008), education ($\chi^2$[2, 646] = 17.10, *p* < .001), time since HIV diagnosis (*t*[612] = -2.82, *p* = .005), S-TOFHLA (*t*[644] = -3.35, *p* < .001), and cognitive function (*t*[636] = -2.32, *p* = .021). Additionally, health literacy among African Americans (mean ± SD: 88.59 ± 13.74) was statistically significantly lower than the health literacy of non-African Americans (mean ± SD: 94.96 ± 8.29; *t*[644] = -6.68, p<.001).

Participants with 100% visit adherence had an average of 8.29 ± 5.64 scheduled appointments over the 24-month period (range: 1- 33). Participants with less than 100% visit adherence averaged 15.36 ± 12.47 appointments over the 24-month period (range: 1 - 122). Among participants with less than 100% visit adherence, percent visit adherence ranged from 0% to 98% with a mean percent visit adherence of 75%. Most participants with less than 100% visit adherence were African American (64%). Percent visit adherence for African Americans (74%) was less than percent visit adherence for non-African Americans (76%), however, this difference was not statistically significant (*t*[405] = -1.30, *p* = .193).

Bivariate analyses between health literacy, education, and cognitive function suggested issues of multicollinearity. Spearman correlations suggested that health literacy was significantly correlated with education (*r* = 0.49, *p* < .001*)* and cognitive function (*r* = 0.42, *p* < .001). Additionally, education and cognitive function collectively explained 33% of the variance in health literacy (*F* = [3, 634] = 103.26, *p* < .001). Due to concerns of multicollinearity, the multivariable logistic and linear regressions performed in this study did not include education or cognitive function.

## Logistic Regression on Characteristics of Participants with 100% Visit Adherence Compared to Participants with less than 100% Visit Adherence

We conducted multivariable logistic regression to identify significant predictor variables of visit adherence. The full logistic regression results are in Table 5. In model 1, race was the only significant predictor of visit adherence, whereby the odds of 100% visit adherence among non-African Americans was 1.48 times the odds of 100% visit adherence among African Americans (*OR* = 1.48, 95% CI = 1.11, 1.97, *p* = .027). In model 2, both race (*OR* = 1.42, 95% CI = 1.06, 1.90, *p* = .046) and insurance/SES (*OR* = 0.63, 95% CI = 0.46, 0.87, *p* = .021) were significant predictors of 100% visit adherence. In the fully adjusted model that included S-TOFHLA and ATHCP (model 3), insurance/SES and S-TOFHLA were the only variables significantly associated with visit adherence. The odds of 100% visit adherence was 35% lower among persons with very low SES compared to persons with not low SES when controlling for other predictors (*OR* = 0.65, 95% CI = 0.48, 0.92, *p* = .030). Findings also suggested that for each unit increase in S-TOFHLA, the odds of 100% visit adherence increased by 2% when controlling for all other model variables (*OR* = 1.02, 95% CI = 1.01, 1.04, *p* = .012). We also tested the interaction effect of race on significant predictor variables in model 3 (insurance/SES and S-TOFHLA) and found that none of the interaction effects were significant. Model 3 explained only 7% of the variance in visit adherence among PLWH with 100% and less than 100% visit adherence.

### Linear Regression on Characteristics of Percent Visit Adherence among Participants with Less Than 100% Visit Adherence

In order to understand factors associated with less than perfect visit adherence, we performed multivariable linear regression analysis. The full linear regression is in Table 6. Age and marital status were statistically significant predictors of visit adherence in all models. 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 ($\beta$ = 0.14, 95% CI = 0.06, 0.22, *p* = .006). Findings also indicated that persons who were previously married ($\beta$ = -0.13, 95% CI = -0.22, -0.05, *p* = .012) or currently married/living with a partner ($\beta$ = -0.12, 95% CI = -0.20, -0.04, *p* = .018) had lower percent visit adherence compared to persons who were single or never married. After testing the interaction effect of race on significant predictor variables in model 3 (age, marital status, ATHCP) we found that none of the interaction effects were significant. Model 3 explained only 7% of the variance in percent visit adherence among participants with less than 100% visit adherence.

## Discussion

This study evaluated patient and social-level predictors of visit adherence among African Americans living with HIV compared to non-African Americans living with HIV. We assessed predictors of visit adherence among persons who achieved 100% visit adherence and among persons with less than 100% visit adherence. The study sample consisted of persons living with HIV within the Southern U.S. who were predominately African American, male, non-heterosexual, very low SES, and virally suppressed. Among participants with less than 100% visit adherence participants attended an average of 73% of their regularly scheduled HIV appointments. African Americans and non-African Americans attended an average of 74% and 76% of their scheduled HIV appointments.

In multivariable logistic regression analyses that only included demographic characteristics, this study found significant differences by race among participants with 100% visit adherence. African Americans were less likely than non-African Americans to have 100% visit adherence. Consistent with current literature (Jones et al., 2013; Rebeiro et al., 2018), this study also found that health literacy was a significant predictor of 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 finding suggests that health literacy may mediate the relationship between race and 100% visit adherence. This is a similar finding to health literacy and antiretroviral therapy adherence research (Osborn et al., 2007), which found that African Americans were more likely to be non-adherent to antiretroviral therapy than White counterparts. Yet, when Osborn, et al. (2007) included health literacy in the same regression model as race, the significant effects of race diminished. This suggested a mediating effect of health literacy on the relationship between race and antiretroviral therapy adherence (Osborn et al., 2007). Although findings from the current study suggest a possible mediating effect of health literacy on race and

100% visit adherence, additional research using path analyses is necessary to test pathways that may link these variables.

The current study also found that SES, as measured by insurance, was the only demographic/socioeconomic predictor of 100% visit adherence. Findings indicated that the odds of 100% visit adherence was lower among persons with very low SES compared to persons with not low SES.  This finding is consistent with other research that utilized insurance as a proxy for socioeconomic status (Rebeiro et al., 2018). Past research indicates that lack of health insurance (Muthulingam et al., 2013) and lack of enrollment in Ryan White (Wester et al., 2016) are barriers to retention in care, whereas having health insurance is associated with greater retention in care (Hightow-Weidman et al., 2017).

Among persons with less than 100% visit adherence, significant predictors of visit adherence included age and marital status. Older age was associated with greater visit adherence, which aligns with findings from research conducted among a diversity of racial and ethnic groups (Adeyemi et al., 2013; Ghiam et al., 2017; Hall et al., 2013; Hu et al., 2012; Mauck et al., 2018; Rebeiro et al., 2018; Wester et al., 2016). Additionally, participants who were previously married and those who were currently married or living with a partner had lower percent visit adherence than participants who were single or never married. Waldrop-Valverde, et al. (2014) demonstrated similar results, finding that percent visit adherence was lower among persons who were married. Family responsibilities from marriage and marital-like relationships may present unique demands that compete with an individual’s ability to attend HIV appointments (Messer et al., 2013). For example, child care and competing financial demands may outweigh the perceived importance of attending an HIV appointment (Sangaramoorthy et al., 2017). Poor visit adherence among participants 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. Further research is necessary to further clarify findings of the effect of marital status on retention in care.

## Study Limitations

The findings from this study should be interpreted in regard to its limitations. First, percent visit adherence may not accurately represent all patient appointments that were scheduled and kept. 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. Patient HIV appointments may have also been misclassified as a completed, missed, or no-show visit. Differences in each clinic’s scheduling practices made it difficult to accurately categorize HIV appointments into the broad categories of completed, missed, and no-show, which were used to calculate percent visit adherence. Additionally, percent visit adherence may provide a biased estimate of retention in care, as persons with few scheduled HIV appointments will have a lower percent visit adherence compared to persons with a greater number of scheduled HIV appointments who miss the same number of appointments.

Second, this study may provide an overestimation of retention in care. Inclusion criteria for the parent study was a minimum of one scheduled HIV medical appointment and a current prescription for antiretroviral therapy within a specified time period. While these inclusion criteria are appropriate for the purposes of the parent study, they favor individuals who regularly attend HIV appointments. As a result, the findings from the present study may over estimate actual retention in care.

Third, this study was unable to capture additional predictors of visit adherence. The final logistic and linear regression models accounted for 7% of the variance in visit adherence, suggesting that other model predictors are needed. A patient’s ability to keep an HIV appointment is influenced by a diversity of different socio-demographic factors, such as transportation or proximity to the HIV care clinic and may even be influenced by whether a patient communicates with his or her health care provider via email or other means. Additional research would benefit from capturing this information to determine its effect on visit adherence.

Finally, findings from this study may not be generalizable to populations outside of Georgia or the Southern U.S. Our sample’s race and gender distributions were comparable to HIV infected populations in Georgia. However, due to data limitations, we are unable to address how the study sample relates to populations most affected by HIV, such as injection drug users or men who have sex with men.

## Implications for Future Research

Retention in care is one of the most significant predictors of HIV treatment failure and has substantial implications for the morbidity and mortality of persons living with HIV, particularly among African Americans. Further research is necessary to understand specifically how significant predictors of retention in care contribute to disparate health outcomes, with a particular focus on modifiable predictors, such as health literacy and patient provider relationships. Future research 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 provide researchers with an understanding of the mechanisms underlying the relationship between patient and social level factors and retention in care, thereby informing the development of interventions targeted at reducing racial and ethnic health disparities.

Table 4. Participant Characteristics (N = 646)

| | Total (n = 646) | | <100% Visit Adherence (n = 407) | | 100% Visit Adherence (n = 239) | | |
|---|---|---|---|---|---|---|---|
| | N | % | n | % | n | % | *p-value* |
| Race | | | | | | | |
| African American | 387 | 59.91 | 260 | 63.88 | 127 | 53.14 | .007[a] |
| Non-African American | 259 | 40.09 | 147 | 36.12 | 112 | 46.86 | |
| Sex/Gender | | | | | | | |
| Identify Male | 448 | 69.57 | 274 | 67.65 | 174 | 72.80 | .170[a] |
| Identify Female | 196 | 30.43 | 131 | 32.35 | 65 | 27.20 | |
| Marital Status | | | | | | | |
| Single/Never Married | 366 | 56.66 | 234 | 57.49 | 132 | 55.23 | .015[a] |
| Previously Married | 140 | 21.67 | 98 | 24.08 | 42 | 17.57 | |
| Married/Living with Partner | 140 | 21.67 | 75 | 18.43 | 65 | 27.20 | |
| Sexual Orientation | | | | | | | |
| Heterosexual | 256 | 39.63 | 171 | 42.01 | 85 | 35.56 | .106[a] |
| Other | 390 | 60.37 | 236 | 57.99 | 154 | 64.44 | |
| Insurance/SES | | | | | | | |
| Not Low SES | 221 | 35.88 | 128 | 32.65 | 93 | 41.52 | .008[a] |
| Low SES | 116 | 18.83 | 68 | 17.35 | 48 | 21.43 | |
| Very Low SES | 279 | 45.29 | 196 | 50.00 | 83 | 37.05 | |
| Education | | | | | | | |
| <High School | 93 | 14.40 | 71 | 17.44 | 22 | 9.21 | <.001[a] |
| High School/GED | 175 | 27.09 | 122 | 29.98 | 53 | 22.18 | |
| >High School | 378 | 58.51 | 214 | 52.58 | 164 | 68.62 | |
| Viral Load | | | | | | | |
| Not Suppressed | 54 | 8.44 | 33 | 8.21 | 21 | 8.82 | .787[a] |
| Suppressed | 586 | 91.56 | 369 | 91.7 | 217 | 91.81 | |
| | Mean | SD | Mean | SD | Mean | SD | *p-value* |
| Age (years) | 48.03 | 9.89 | 47.72 | 9.45 | 48.57 | 10.60 | .292[b] |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Years Since HIV Diagnosis | 15.51 | 8.54 | 14.77 | 8.65 | 16.78 | 8.20 | .005[b] |
| STOFHL | 91.14 | 12.26 | 89.92 | 12.53 | 93.23 | 11.51 | <.001[c] |
| ATHCP | 86.91 | 13.03 | 87.41 | 12.82 | 86.07 | 13.68 | .174[c] |
| Cognitive Function | 41.32 | 8.38 | 40.74 | 8.27 | 42.33 | 8.48 | .021[b] |
| Scheduled Appointments | 12.74 | 11.01 | 15.36 | 12.47 | 8.29 | 5.64 | <.001[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 5. Logistic Regression on Characteristics of Participants with 100% Visit Adherence Compared to Participants with Less Than 100% Visit Adherence (N = 646)

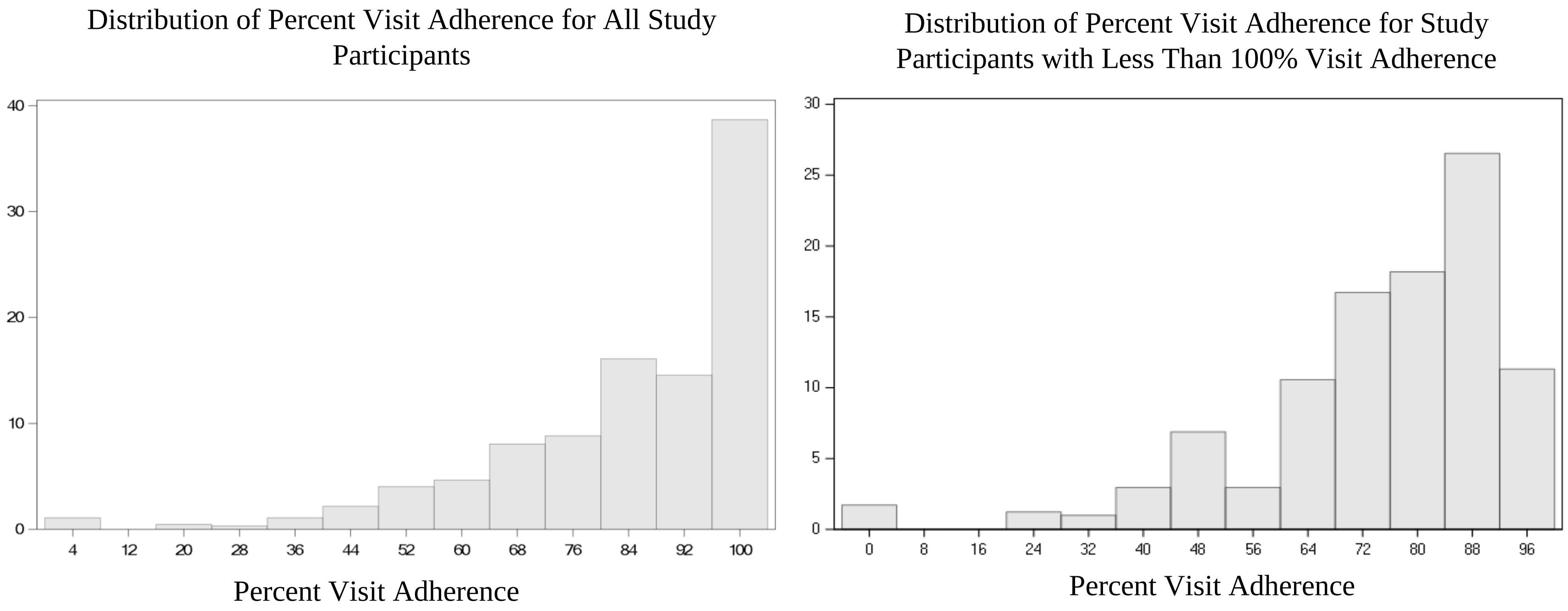
| | Model 1 | | | Model 2 | | | Model 3 | | |
|---|---|---|---|---|---|---|---|---|---|
| Variable | OR | 95% CI | p-value | OR | 95% CI | p-value | OR | 95% CI | p-value |
| Age | 1.01 | 1.00, 1.03 | 0.146 | 1.01 | 1.00, 1.03 | 0.101 | 1.02 | 1.00, 0.13 | .089 |
| Race | | | | | | | | | |
| African American | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Non-African American | **1.48** | **1.11, 1.97** | **0.027** | **1.42** | **1.06, 1.90** | **0.046** | 1.28 | 0.95, 1.72 | .181 |
| Sex/Gender | | | | | | | | | |
| Identify Male | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Identify Female | 1.01 | 0.68, 1.49 | 0.969 | 1.04 | 0.70, 1.54 | 0.867 | 1.04 | 0.70, 1.55 | .877 |
| Marital Status | | | | | | | | | |
| Single/Never Married | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Previously Married | 1.01 | 0.68, 1.49 | 0.969 | 1.04 | 0.70, 1.54 | 0.867 | 1.04 | 0.70, 1.55 | .877 |
| Married/Living with Partner | 1.01 | 0.68, 1.49 | 0.969 | 1.04 | 0.70, 1.54 | 0.867 | 1.04 | 0.70, 1.55 | .877 |
| Sexual Orientation | | | | | | | | | |
| Heterosexual | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Other | 1.16 | 0.80, 1.98 | 0.522 | 1.11 | 0.76, 1.11 | 0.661 | 1.05 | 0.72, 1.55 | .828 |
| Viral Load | | | | | | | | | |
| Not Suppressed | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Suppressed | 0.88 | 0.54, 1.43 | 0.678 | 0.85 | 0.52, 0.86 | 0.583 | 0.88 | 0.53, 1.42 | .671 |
| Insurance/SES | | | | | | | | | |
| Not Low SES | | | | *REF* | *REF* | | *REF* | REF | |
| Low SES | | | | 0.99 | 0.67, 1.45 | 0.951 | 0.96 | 0.66, 1.44 | .875 |
| Very Low SES | | | | **0.63** | **0.46, 0.87** | **0.021** | **0.65** | **0.48, 0.92** | **.030** |
| S-TOFHLA | | | | | | | **1.02** | **1.01, 1.04** | **.012** |
| ATHCP | | | | | | | 0.99 | 0.98, 1.00 | .130 |
| Adjusted $R^2$ | 0.03 | | | 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; SD = standard deviation; SES = socioeconomic status (not low SES = private insurance or self-pay, low SES = Ryan White, very low SES = Medicare/Medicaid); 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 6. Linear Regression on Characteristics of Percent Visit Adherence among Participants with Less Than 100% Visit Adherence (N = 407)

| | 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** | **0.07, 0.23** | **0.003** | **0.15** | **0.07, 0.23** | **0.003** | **0.14** | **0.06, 0.22** | **.006** |
| Race | | | | | | | | | |
| African American | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Non-African American | 0.08 | 0.00, 0.16 | 0.095 | 0.08 | 0.00, 0.16 | 0.100 | 0.09 | 0.00, 0.17 | .086 |
| Sex/Gender | | | | | | | | | |
| Identify Male | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Identify Female | 0.03 | -0.07, 0.13 | 0.582 | 0.04 | -0.07, 0.14 | 0.572 | 0.03 | -0.07, 0.13 | .608 |
| Marital Status | | | | | | | | | |
| Single, Never Married | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Previously Married | **-0.13** | **-0.22, -0.04** | **0.014** | **-0.13** | **-0.22, -0.04** | **0.016** | **-0.13** | **-0.22, -0.05** | **.012** |
| Married/ Living with Partner | **-0.12** | **-0.20, -0.04** | **0.017** | **-0.12** | **-0.20, -0.04** | **0.020** | **-0.12** | **-0.20, -0.04** | **.018** |
| Sexual Orientation | | | | | | | | | |
| Heterosexual | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Other | -0.04 | -0.15, 0.06 | 0.509 | -0.04 | -0.15, 0.06 | 0.518 | -0.04 | -0.15, 0.06 | .520 |
| Viral Load | | | | | | | | | |
| Not Suppressed | *REF* | *REF* | | *REF* | *REF* | | *REF* | *REF* | |
| Suppressed | 0.08 | 0.00, 0.16 | 0.098 | 0.08 | 0.00, 0.16 | 0.093 | 0.08 | -0.00, 0.16 | .104 |
| Insurance/SES | | | | | | | | | |
| Not Low SES | | | | *REF* | *REF* | | *REF* | *REF* | |
| Low SES | | | | 0.03 | -0.06, 0.13 | 0.554 | 0.02 | -0.07, 0.12 | .661 |
| Very Low SES | | | | 0.01 | -0.09, 0.10 | 0.915 | -0.01 | -0.10, 0.09 | .907 |
| S-TOFHLA | | | | | | | -0.05 | -0.13, 0.03 | .333 |
| ATHCP | | | | | | | -0.09 | -0.17, -0.02 | .051 |
| Adjusted $R^2$ | 0.05 | | | 0.05 | | | 0.07 | | |

Note: REF = reference group; OR = Odds Ratio; CI = confidence interval; SD = standard deviation; SES = socioeconomic status (not low SES = private insurance or self-pay, low SES = Ryan White, very low SES = Medicare/Medicaid); 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.



Distribution of Percent Visit Adherence for All Study Participants

Distribution of Percent Visit Adherence for Study Participants with Less Than 100% Visit Adherence

*Figure 4.* Distribution of Percent Visit Adherence for All Study Participants and for Participants with Less Than 100% Visit Adherence

# CHAPTER 4

# A PATH ANALYSIS OF PATIENT AND SOCIAL-LEVEL FACTORS ON HEALTH LITERACY AND RETENTION IN CARE AMONG AFRICAN AMERICANS AND NON-AFRICAN AMERICANS LIVING WITH HIV

Although African Americans comprise only 12% of the United States (U.S.) population (Centers for Disease Control and Prevention, 2018a), African Americans represent the greatest proportion of persons diagnosed and living with HIV among all racial and ethnic groups. In 2016, African Americans accounted for 44% of all new HIV diagnoses (Centers for Disease Control and Prevention, 2018a) and of the nearly 1.1 million persons living with HIV in the U.S., 42% were African American (Centers for Disease Control and Prevention, 2016). African Americans are also more likely to die from HIV than other racial and ethnic groups, with the likelihood of death from HIV seven and four times greater than that among White and Hispanic/Latino counterparts, respectively (Centers for Disease Control and Prevention, 2016).

A contributor to the morbidity and mortality of HIV among African Americans is poor retention in HIV care. African Americans are less likely than White and Hispanic/Latino persons to attend regularly scheduled HIV appointments (Centers for Disease Control and Prevention, 2012). Poor retention in care is one of the most significant predictors of antiretroviral treatment failure (Rastegar et al., 2003) and is associated with elevated HIV viral load (Crawford, 2014; Giordano et al., 2007; Mugavero, Amico, et al., 2012), lower CD4 count (Berg et al., 2005), as well as increased likelihood of developing AIDS-defining illnesses (Crawford, 2014; Giordano et al., 2007; Park et al., 2007) and dying from HIV (Mugavero et al., 2014). Due to the significance of retention in care on HIV outcomes, understanding factors that contribute to poor retention in care may ultimately assist in improving HIV health disparities among African Americans.

A growing body of evidence suggests a link between health literacy —the ability to access, process, and use health information—and retention in care (Mallinson et al., 2005). In health literacy surveys among adults in the U.S., average health literacy scores among African Americans were 20% lower than those among White adults (U.S. Department of Education, 2006). Low health literacy is associated with missing HIV appointments (Jones et al., 2013; Rebeiro et al., 2018), decreased knowledge of HIV (Kalichman, Benotsch, et al., 2000), and decreased likelihood of antiretroviral therapy adherence (Kalichman et al., 1999; Miller et al., 2003). Poor health literacy among African Americans combined with its negative effects on retention in care and HIV health outcomes suggests that health literacy may contribute to disparities in retention in care among African Americans.

Health literacy is shaped by a variety of factors, such as socioeconomic status (Mantwill et al., 2015) and cognitive function (Serper et al., 2014). Socioeconomic status influences whether individuals seek out health information, where they will look, and how they will interpret health information (Institute of Medicine of the National Academies, 2004). Cognitive function, which includes domains of learning, memory, and executive functioning, is influenced by the negative neurologic effects of HIV (Grant et al., 1987; Martin et al., 1992; Peavy et al., 1994; Wilkie et al., 2000) and is directly associated with health literacy (Vance et al., 2016; Waldrop-Valverde, Jones, et al., 2010; Waldrop-Valverde, et al., 2008).

Health literacy is also associated with the patient-provider relationship and evidence suggests a direct effect of the patient-provider relationship on retention in care (Beach et al., 2006). Poor health literacy minimizes effective communication between PLWH and their care provider (Katz et al., 2007; Kripalani et al., 2010; Williams et al., 2002), which contributes to antiretroviral therapy non-adherence (Baker et al., 1996; Kalichman et al., 1999) and poor HIV health outcomes (Kalichman & Rompa, 2000).

Evidence is emerging regarding causal pathways linking health literacy to health outcomes among disparate populations, but no studies have examined these pathways for retention in care among racially disparate persons living with HIV. Among men living with late-stage prostate cancer and among elderly adults, health literacy mediates the relationship between race and self-reported health outcomes, with health literacy partially accounting for poorer health outcomes among African Americans compared to their White counterparts (Bennett et al., 1998; Howard et al., 2006). Within the HIV literature, current research suggests that health literacy mediates the relationship between gender and antiretroviral therapy adherence (Waldrop-Valverde, Jones, et al., 2010). Research also suggests that health literacy mediates the relationship between race and antiretroviral therapy adherence (Osborn et al., 2007; Waldrop-Valverde, Osborn, et al., 2010). Due to disparities in retention in care and health literacy among African Americans, and due to emerging casual pathways between health literacy and health outcomes, examination of pathways linking health literacy and retention in care may identify potentially modifiable contributors associated with HIV health disparities.

This research adapted Paasche-Orlow and Wolf’s health literacy model (Paasche-Orlow & Wolf, 2007) to inform relationships among health literacy, retention in care, HIV clinical outcomes, and sociodemographic indicators of health literacy. The Paasche-Orlow and Wolf health literacy model focuses on the direct effects of health literacy at three points along the health care continuum: access and utilization of health care, patient provider relationships, and self-care. The primary focus of the present study is on the direct effect of health literacy on access and utilization of health care and patient-provider interactions, as well as their subsequent effects on patient health outcomes (*Figure 1*). This model proposes that 1) patient-level characteristics shape health literacy; 2) health literacy mediates the relationship between race and access to health services; 3) access to health services mediates the relationship between health literacy and health outcomes; 4) health literacy influences the patient-provider relationship. This study adapted the model to include socioeconomic status and cognitive function as patient-level characteristics, retention in care as a measure of access to health services, HIV viral load as the health outcome of interest, and patient attitudes towards the health care provider (HCP) as an indicator of the quality of the patient-provider relationship. The purpose of this study is to examine the role of health literacy on disparities in retention in care and HIV clinical outcomes by assessing the relationships among the variables theorized in the adapted Paasche-Orlow and Wolf health literacy model.

## Methods

This study is ancillary to a non-experimental longitudinal study, which recruited participants from June 2012 to December 2015 from outpatient HIV clinics in metro-Atlanta, Georgia. Inclusion criteria for the parent study included attendance at a minimum of one scheduled HIV medical appointment in the last nine months and a current prescription for antiretroviral therapy for at least the past six months. The parent study excluded participants if they were acutely intoxicated as determined by a breath alcohol test, unable to read or write English, visually or hearing impaired, or planned to move out of the Metro-Atlanta area within six-months of the baseline study visit. In order to assess comprehension of study procedures, risks, benefits, and other important study related information, the parent study administered a consent post-test prior to participants signing the consent form. Participants were excluded if unable to correctly answer post-test questions after three attempts.

The parent study collected data at baseline and six-months for 699 participants. Participants completed study questionnaires in private offices at the recruiting clinics using the Audio Computer-Assisted Self-Interviewing System (ACASI). Trained study personnel collected additional study assessments (health literacy and cognitive function). This study used several measures collected by the parent study at baseline, including demographic information, health literacy, cognitive function, and patient-provider interactions. This study collected HIV viral load, socioeconomic status (SES), and retention in care data from participant electronic medical records (EMR).

## Measures

**Race** was collected via participant self-report at baseline. This study categorized race as African American versus non-African American.

**Socioeconomic Status (SES)** was assessed using insurance as previous research indicates a relationship between insurance as a proxy for SES and poor HIV-related outcomes (Chen et al., 2009; Jain et al., 2006). We collected insurance data that was closest to the baseline interview date from the participant's electronic medical record. Consistent with prior published HIV research (Rebeiro et al., 2018), we categorized participant SES as "not low SES" if using private or commercial insurance or self-pay; "low SES" if receiving Ryan White (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).

**Cognitive Function** was assessed using the Hopkins Verbal Learning Test Revised (HVLT-R) (Brandt & Benedict, 2001) to measure episodic verbal learning and the Color Trails

Test (CTT) 1 and 2 (D'Elia et al., 1994) to measure executive cognitive function. The HVLT-R measures verbal learning and memory by using verbal list learning tasks, which include three learning trials and a delayed free recall trial (Brandt & Benedict, 2001). CTT 1 and 2 measures attention and mental flexibility, a component of executive functioning. For CTT 1 and 2, participants use a pencil to sequentially connect colored circles containing numbers and for CTT 2, participants must alternate between different colored circles in numeric order. We created a continuous measure of cognitive function for analysis by averaging the baseline T-scores for HVLT-R, CTT 1, and CTT 2.

**Health Literacy** was measured using the Short-Test of Functional Health Literacy (S-TOFHLA), which consists of two prose passages and four numeracy items. The prose passages assess reading comprehension by omitting every fifth to seventh word in a health passage and asking the reader to identify the appropriate word from a list of four possible choices. Health passages are from an upper gastrointestinal series, the patient's rights and responsibilities section of the Medicaid application form, and a standard hospital informed consent form. The numeracy items assess numerical abilities by asking questions related to medication directions, blood glucose monitoring, and clinic appointments. The S-TOFHLA score is the cumulative percent correct for the prose passages and numeracy items. Previous research shows acceptable internal consistency ($\alpha = 0.68$) and correlation of the S-TOFHLA to other measures of health literacy (Baker et al., 1999).

**Patient-Provider Interactions** were measured with the Attitudes Towards the HIV Health Care Provider Scale (ATHCP) (Bodenlos et al., 2004). ATHCP is a 19-item scale that assesses patient's attitudes toward their HIV health care provider, particularly the provider's professionalism and emotional support towards the patient. Participants scored each item on a 6-

point Likert scale (1 = strongly disagree to 6 = strongly agree). Total scores range from 19 to 114 and higher scores indicate more positive attitudes towards the HIV health care provider. ATHCP has acceptable internal consistency ($\alpha = 0.69$) and correlates well with other measures of patient satisfaction ($r = 0.59$) (Bodenlos et al., 2004). The Cronbach's alpha for participants in this study was 0.92.

**Access and Utilization of Health Care** was measured using retention in care, which was operationalized as visit adherence. Visit adherence is expressed as a percentage and is defined 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. We extracted all outpatient appointments with an HIV primary care provider who has prescribing authority, including physicians and advanced care providers. We excluded specialty HIV care visits, nursing visits, and laboratory visits. We collected the date and location of the appointment, the health care provider's name, and status of the appointment, such as completed, cancelled/missed, or no-show. We used appointments with a completed status to represent kept HIV appointments and we totaled appointments with completed, cancelled/missed, or no-show status to represent total scheduled HIV appointments.

The **health outcome** of interest was HIV viral load. We obtained participant HIV viral load laboratory data from each participant's electronic medical record. We collected a single HIV-1 RNA viral load value and laboratory collection date that corresponded closest to the participant's 24-month post baseline date. We categorized viral load as virologically suppressed or virologically non-suppressed. We defined viral suppression as HIV-1 RNA less than 2.3 $\log_{10}$, which corresponds to a viral load of 200 copies/mL. This definition of viral suppression is consistent with the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 2018b).

**Covariates** known to be associated with the variables in the adapted health literacy model include sex, marital status, sexual orientation, education, and age. The parent study used a demographic questionnaire administered at baseline to collect these demographic covariates.

## Statistical Analysis

Preliminary analyses of all study variables included descriptive statistics, an examination of missing data patterns, and bivariate analyses. We combined categories for some categorical variables to have adequate cell sizes (sex/gender [male or female]; marital status [single/never married, previously married, or married/living with partner]; sexual orientation [heterosexual or other]; education [less than high school, high school/GED, or greater than high school]). We removed participants who reported “other” for their marital status, as we were unable to appropriately categorize these individuals into one of the marital status categories. Participants with no scheduled HIV appointments during the 24-month post-baseline follow-up period ($n = 48$) and participants missing HIV viral load data ($n = 14$) were dropped from the data set. Examination of missingness identified data missing at random for cognitive function (1.24%), ATHCP (0.77%), insurance/SES (4.64%), and sex/gender (0.31%). We performed multiple imputation for variables with missing data in Mplus using the IMPUTE command, which utilizes Bayesian analysis (Muthén & Muthén, 1998-2017; Rubin, 1987; Schafer, 1997). We used all study variables for imputation and created ten imputed data sets. We conducted bivariate analyses in order to identify variables likely to be indicators of the endogenous variables. Variables were considered potential covariates if they had a significant correlation ($p < .05$) with the endogenous variables and were appropriately controlled for when modeling the hypothesized relationships.

We checked data for distributional assumptions and independence of observations using histograms and residual plots. Descriptive statistics of the visit adherence variable revealed a non-parametric distribution and the presence of two unique visit adherence groups—participants who attended 100% of their scheduled HIV appointments and participants who attended less than 100% of their scheduled HIV appointments. Due to the presence of these two unique groups, we conducted the analysis using a binary visit adherence outcome that compared participants with 100% visit adherence to those with less than 100% visit adherence.

We performed path analysis in Mplus using theta parameterization to test the relationships hypothesized in the adapted health literacy model. Since we used multiple imputations, we used the DATA TYPE = IMPUTATION command. This command performed the specified path analysis for each of the ten imputed data sets. The IMPUTATION command then pooled parameter estimates over the set of analyses and calculated standard errors using the average of the standard errors and between analysis parameter estimate variation (Muthén & Muthén, 1998-2017; Schafer, 1997). The path analysis controlled for covariates that had a significant association with endogenous variables. The focus of the path analysis was on the statistical significance of the pathways and model goodness of fit. We assessed goodness of fit using Root Mean Squared Residual (RMSR), Standardized Root Mean Squared Residual (SRMR), Comparative Fit Index (CFI), and Tucker-Lewis Index (TLI). The RMSR and SRMR suggest relatively good model fit when they are less than 0.06 and 0.08, respectively, and the CFI and TLI suggest good model fit when they are greater than 0.95 (Hu & Bentler, 1999). We performed preliminary analyses using SAS Studio software, version 3.71, and conducted multiple imputation and path analysis in Mplus version 8.2.

## Results

The participant sample size for this study is 699. After eliminating participants with no scheduled HIV appointments during the 24-month post-baseline follow-up period (n = 48), those missing HIV viral load data (n = 14), and those with “other” marital status (n = 5), the final total sample size was 632 participants. Descriptive statistics of all study variables for the non-imputed data set are detailed in Table 7. Of these participants, the majority were African American (60%), single/never married (57%), very low SES (45%), and had greater than high school education (59%). Most participants identified male (70%). There were 16 transgender women in the female sex/gender category, however, they did not play a statistically significant role in the analysis. The mean age of participants was 48 years (SD = 9.93) and on average participants were living with HIV for 16 years (SD = 8.53). Most participants were virally suppressed (93%) and attended less than 100% of their scheduled HIV appointments (63%). Overall, health literacy scores were high. On average, participants correctly answered 91% of reading comprehension and numeracy portions of the S-TOFHLA. African Americans exhibited significantly lower health literacy (89%) compared to non-African Americans (95%; $t[630] = -6.52$, $p < .001$).

Over the 24-month period, participants with 100% and less than 100% visit adherence had 8.36 ± 5.66 (range: 1- 33) and 15.48 ± 12.46 (range: 1 - 122) scheduled HIV appointments, respectively. Participants with less than 100% visit adherence attended an average of 75% of their scheduled HIV appointments (range: 0-98%). African Americans comprised most participants with less than 100% visit adherence (64%) and attended an average of 74% of their scheduled HIV appointments. This is compared to 77% attendance among non-African Americans ($t[395] = -1.67$, $p = .09$).

Bivariate analyses between health literacy, education, and cognitive function suggested issues of multicollinearity. Spearman correlations suggested that health literacy is significantly correlated with education ($r = 0.49$, $p < .001$) and cognitive function ($r = 0.42$, $p < .001$). Additionally, education and cognitive function collectively explain 33% of the variance in health literacy ($F = [3, 634] = 103.26$, $p < .001$). Due to concerns of multicollinearity, education was not included as a covariate in the path analysis. Additional bivariate Pearson and Spearman correlations identified that age ($r = -0.08$, $p = .046$), sex/gender ($r = -0.15$, $p < .001$), and sexual orientation ($r = 0.21$, $p < .001$) are significantly correlated with S-TOFHLA and that age is also significantly correlated with viral load ($r = 0.19$, $p < .001$). No covariates were significantly correlated to visit adherence or ATHCP. Consequently, the path analysis controlled for the effect of age, sex, and sexual orientation on S-TOFHLA and for the effect of age on viral load.

Findings from the path analysis are in *Figure 5*, which includes standardized beta coefficients, standard errors, and p-values. Non-African American race ($\beta = 0.100$, $p = .028$) and higher cognitive function ($\beta = 0.367$, $p < .001$) are related to higher health literacy and higher health literacy is related to 100% visit adherence ($\beta = 0.141$, $p = .002$). Higher health literacy is also related to more favorable attitudes towards the HIV health care provider ($\beta = 0.124$, $p < .001$). Low and very low SES is related to higher health literacy ($\beta = -0.092$, $p = .013$), which is subsequently associated with 100% visit adherence ($\beta = 0.141$, $p = .002$) and more favorable attitudes towards the HIV health care provider ($\beta = 0.124$, $p < .001$). Additionally, higher health literacy is related to 100% visit adherence ($\beta = 0.141$, $p = .002$) and 100% visit adherence is related to viral suppression ($\beta = 0.470$, $p < .001$). Race and attitudes towards the HIV health care provider were not directly related to 100% visit adherence ($\beta = 0.105$, $p = .055$ and $\beta = -0.093$, $p = .052$, respectively). Health literacy and attitudes towards the HIV health care provider were not directly related to viral suppression ($\beta = 0.115$, $p = .066$ and $\beta = -0.085$, $p = .240$, respectively). Significant covariates include non-heterosexual orientation on S-TOFHLA ($p = .043$) and age on viral load ($p < .001$). All other covariates were non-significant. The model demonstrated good fit (RMSEA = 0.002, SRMR = 0.042, CFI = 0.999, TLI = 1.003) and explains 21.3% of variance in health literacy, 38.0% of variance in viral load, 4.3% of variance in visit adherence, and 1.5% of the variance in attitudes towards the HIV health care provider.

## Discussion

This study adapted a health literacy model by Paasche-Orlow and Wolf to examine the role of health literacy on racial disparities in retention in care and HIV clinical outcomes. This study evaluated two primary mediating relationships. The first was the mediating effect of health literacy on the relationship between race and retention in care and the second was the mediating effect of retention in care on the relationship between health literacy and HIV viral load. This study also tested the effect of socioeconomic status and cognitive function on health literacy, as well as the effect of retention in care on patient-provider interactions and viral load. The study sample included participants from the Southern U.S. who were predominately African American, male, and very low SES, with an average age of 48 years. Although most participants were virally suppressed (93%), nearly two-thirds of participants failed to attend all scheduled HIV appointments.

To our knowledge, this study is among the first to examine causal pathways linking health literacy to health outcomes among racially disparate persons living with HIV. Our results suggest that consistent with the adapted health literacy model, health literacy explains the relationship between race and retention in care. Specifically, non-African Americans had greater health literacy and were more likely to attend 100% of scheduled HIV appointments. This finding supports previous research which found a relationship between health literacy and retention in care (Jones et al., 2013; Rebeiro et al., 2018). Findings are also similar to studies that examined the mediating role of health literacy between race and antiretroviral therapy adherence (Osborn et al., 2007; Waldrop-Valverde, Osborn, et al., 2010). In a series of regression analyses, Osborn et al. (2007) found that African Americans were more likely to be non-adherent to antiretroviral therapy regimes than White counterparts. When health literacy was included in the same regression model as race, the effects of race diminished by 25% and were no longer significant, suggesting a mediating effect of health literacy on the relationship between race and antiretroviral therapy adherence. Additionally, Waldrop-Valverde et al. (2010) found that numeracy—a component of health literacy necessary to understand and use mathematical operations in daily life—drove the mediating effect of health literacy on race and antiretroviral therapy adherence (Waldrop-Valverde, Osborn, et al., 2010). Consistency between findings from this study among racially disparate persons living with HIV and those from other studies on health literacy and antiretroviral therapy adherence hold promise that health literacy is a significant contributing factor to health disparities in retention in care among African Americans living with HIV.

We also found that health literacy mediates the relationship between other sociodemographic predictors of health literacy—cognitive function and socioeconomic status—and retention in care. Greater cognitive function was related to higher health literacy, which was then associated with 100% visit adherence. This finding supports the established relationship between cognitive function and health literacy (Ownby, Acevedo, Waldrop-Valverde, Jacobs, &

Caballero, 2014; Serper et al., 2014; Vance et al., 2016; Waldrop-Valverde, Jones, et al., 2010; Waldrop-Valverde et al., 2008). Findings also support research indicating a relationship between neurocognitive impairment and poor retention in care among older adults newly diagnosed with HIV (Jacks et al., 2015), but are inconsistent with other research suggesting no direct relationship between neurocognitive impairment and retention in care (Waldrop-Valverde et al., 2014). Discrepancies in study findings may be associated with the retention in care observation period. Waldrop-Valverde, et. al (2014) examined retention in care over a 28-week period, while Jacks et al. (2015) and the current study utilized a 12-month and 24-month follow-up period, respectively.

Additionally, low and very low SES was related to higher health literacy, which led to an greater likelihood of 100% visit adherence. The relationship between socioeconomic status and health literacy is contrary to the body of research on socioeconomic disparities and health literacy among persons living with HIV (Ayotte et al., 2009; Mantwill et al., 2015; Rikard et al., 2016; U.S. Department of Education, 2006). The participants for this study are predominately very low SES, virally suppressed, and have been living with HIV for nearly 16 years. Therefore, it is possible that among persons with very low SES, the number of years spent managing their HIV infection has a positive effect on their overall health literacy. Other explanations for the association between low SES and high health literacy include variations in methods of operationalizing SES, such as monthly or annual income or financial situation. Further study on the relationship between health literacy, SES, and retention in care among PLWH is warranted.

Results also showed that health literacy is directly associated with patient attitudes towards the HIV health care provider. Consistent with past research (Beach et al., 2006; Katz et al., 2007; Kripalani et al., 2010; Williams et al., 2002), higher health literacy was subsequently associated with more favorable attitudes towards the HIV health care provider.

Our results indicated that retention in care mediates the relationship between health literacy and HIV viral load. Particularly, higher health literacy is related to 100% visit adherence, which is subsequently related to viral suppression. These findings were expected, considering that overall, health literacy was high among this sample; that 93% of participants were virally suppressed; and that the average visit adherence was 73% among participants with less than 100% visit adherence. The relationship between higher health literacy and 100% visit adherence supports Jones et al. (2013) and Rebeiro et al. (2018) who found that higher health literacy is associated with attending more than 75% of regularly scheduled HIV appointments and with decreased numbers of missed HIV appointments, respectively. The effect of 100% visit adherence on viral suppression is also consistent with research indicating a direct relationship between retention in care and viral load (Crawford, 2014; Giordano et al., 2007). Our results did not suggest a direct relationship between health literacy and viral suppression and the literature on this relationship remains inconsistent (Kalichman & Rompa, 2000; Kalichman, Rompa, et al., 2000).

The adapted Paasche-Orlow and Wolf model explained 21% and 38% of the variance in health literacy and viral load, respectively, while only explaining 4% and 2% of the variance in visit adherence and attitudes towards the HIV health care provider, respectively. The Paasche-Orlow and Wolf model utilized medical and public health literature on health literacy to identify direct pathways between health literacy and health outcomes and was not developed specifically for HIV. Paasche-Orlow and Wolf recognized that additional associations may influence the variables and the pathways in the model and that future research is necessary to elucidate these relationships. The variables included in the adapted health literacy model explain a small proportion of the variance in visit adherence and attitudes towards the HIV health care provider and future research utilizing this model would benefit from considering and including additional variables.

## Study Limitations

Findings from this study should be interpreted within its limitations. First, percent visit adherence may inaccurately represent scheduled and kept patient appointments. Due to differences in each clinic's scheduling practices, appointments may have been misclassified as completed, missed, or no-show, categories which were used to calculate percent visit adherence. Percent visit adherence may also provide a biased estimate of retention in care, as participants with few scheduled appointments may have a disproportionately lower percent visit adherence if they miss a visit compared to persons with many scheduled appointments. Second, viral load and appointment data were collected from four HIV recruiting clinics in Metro-Atlanta and we were unable to gather data from clinics outside of these primary sites. As a result, this may have led to a decreased estimation of percent visit adherence and contributed to missing data for visit adherence and HIV viral load. Third, this study did not collect data on additional predictors of visit adherence, such as transportation, proximity to the HIV clinic, or patient-provider dynamics. Such information may help explain a greater percentage of the variance in retention in care. Finally, study findings may not be generalizable to populations outside of Metro-Atlanta Georgia or the Southern United States. This study provides limited information on populations most heavily affected by HIV, such as men who have sex with men, injection drug users, or transgender persons.

## Implications for Future Research

Primary findings from this study show that health literacy mediates the relationship between race and retention in care, a new finding in this area, and that retention in care subsequently influences HIV viral load. Socioeconomic status and cognitive function directly influence health literacy, which then influences retention in care and patient-provider interactions. Health care providers may find it beneficial to assess health literacy, as well as predictors of health literacy, particularly cognitive function and SES, in order to provide more targeted and individuated HIV health outcomes. To minimize racial disparities in retention in care, future research should focus on developing interventions for retention in care that account for patient level differences in health literacy. In developing these interventions, it may be beneficial to understand additional modifiable factors that may influence health literacy and retention in care. Through addressing health literacy issues and their effect on HIV outcomes, these interventions should ultimately improve patient outcomes and reduce morbidity and mortality of HIV among health disparate populations.

Table 7. Participant Characteristics (N = 632)

| | Total (N = 632) | |
|---|---|---|
| | N | % |
| Race | | |
| African American | 382 | 60.44 |
| Non-African American | 250 | 39.56 |
| Sex/Gender | | |
| Identify Male | 438 | 69.52 |
| Identify Female | 192 | 30.48 |
| Marital Status | | |
| Single/Never Married | 359 | 56.80 |
| Previously Married | 138 | 21.84 |
| Married/Living with Partner | 135 | 21.37 |
| Sexual Orientation | | |
| Heterosexual | 251 | 39.72 |
| Other | 381 | 60.28 |
| SES/Insurance | | |
| Not Low SES | 217 | 36.05 |
| Low SES | 113 | 18.77 |
| Very Low SES | 272 | 45.18 |
| Education | | |
| <High School | 89 | 14.08 |
| High School/GED | 171 | 27.06 |
| >High School | 372 | 58.86 |
| Viral Load | | |
| Not Suppressed | 47 | 7.44 |
| Suppressed | 585 | 92.56 |
| Visit Adherence | | |
| <100% Visit Adherence | 397 | 62.82 |
| 100% Visit Adherence | 235 | 37.18 |
| | Mean | SD |
| Age (years) | 48.05 | 9.93 |
| Time Since HIV Diagnosis (years) | 15.57 | 8.53 |
| S-TOFHLA | 91.17 | 12.28 |
| ATHCP | 86.96 | 13.00 |
| Cognitive Function | 41.32 | 8.38 |

*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.

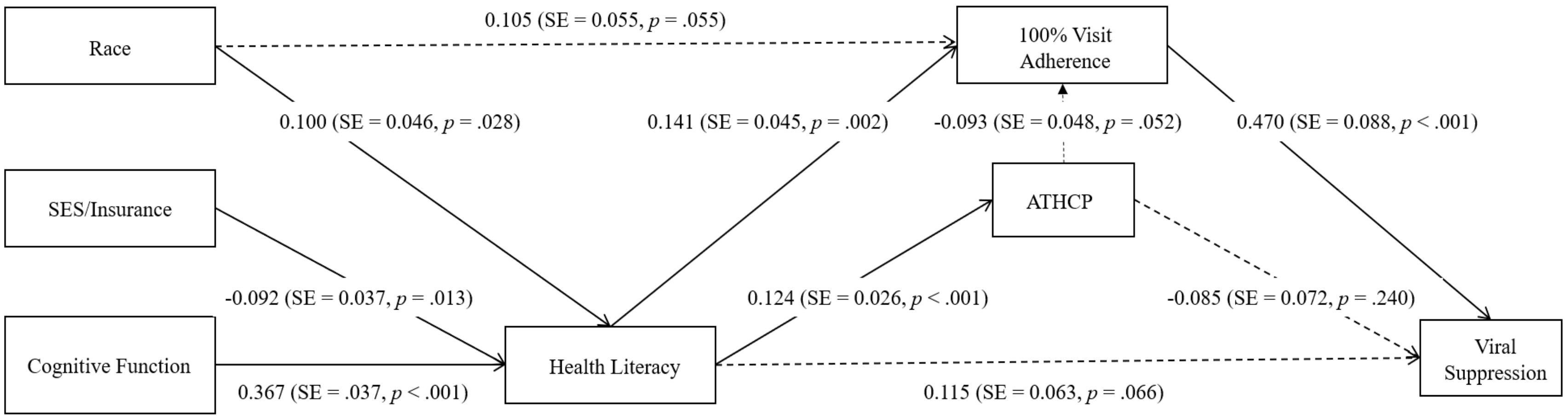


*Figure 5.* Path Analysis of Direct Effects of Patient and Social-Level Factors on Health Literacy and Retention in Care (N = 632). Model controls for the effect of age, sex, and sexual orientation on S-TOFHLA and the effect of age on viral load. Significant covariates include the effect of sexual orientation on S-TOFHLA (p = .043) and the effect of age on viral load (p<.001). Standardized beta coefficients are presented. Dashed and solid lines represent paths that are non-significant and significant, respectively. SE = standard error; SES = socioeconomic status; ATHCP = Attitudes Towards HIV Care Provider. Coding for categorical variables are as follows: race is 0 = African American, 1 = Non-African American; visit adherence is 0 = <100% visit adherence, 1 = 100% visit adherence; viral load is 0 = not suppressed, 1 = suppressed; SES/Insurance 0 = not low SES, 1 = low SES, 2 = very low SES

# CHAPTER 5

# SYNTHESIS

Retention in care is one of the most significant predictors of HIV treatment failure and has substantial implications for the morbidity and mortality of persons living with HIV. Disparities in retention in care exist among African Americans living with HIV and poor health literacy may exacerbate the negative effects of poor retention in care on HIV health outcomes. This study sought to address gaps in our understanding of the effects of health literacy on retention in care and HIV clinical outcomes among African Americans. Findings indicate that non-African Americans had higher health literacy compared to African Americans. Higher health literacy led to a greater likelihood of 100% visit adherence, which was subsequently associated with viral suppression. Socioeconomic status and patient cognitive function were related to retention in care and attitudes towards the HIV health care provider through the mediating effect of health literacy.

Strengths of this research include its novel approach to understand causal pathways linking health literacy to retention in care.  First, to the author's knowledge, this study is among the first to examine causal pathways linking health literacy to retention in care and HIV health outcomes among racially disparate persons living with HIV. While past research suggested a mediating effect of health literacy on race and antiretroviral therapy adherence, this study is among the first to assess the role of health literacy in explaining racial differences in retention in HIV care.  Second, this is the first study to the author's knowledge to adapt the Paasche-Orlow and Wolf health literacy model for retention in HIV care. Previous research adapted and tested this model for a variety of disease processes including, but not limited to, heart failure, diabetes, and hospitalization. HIV research has used the model to understand the relationship between health literacy and antiretroviral therapy adherence, but no previous research has applied the model to disparities in retention in care. Third, this research presents methodologic strengths that enhance the reliability of study findings. This study assessed retention in care over a 24-month period. Compared to studies that measure retention in care over a 6 or 12-month period, the 24-month observation period minimizes overestimation of successful retention in care and viral suppression (Colasanti et al., 2015). Longitudinal measures of retention in care also offer insight into long-term patient behaviors of appointment attendance, whereby individuals may become more regular users of HIV care or experience appointment attrition over time (Baligh R. Yehia et al., 2012). Additionally, our statistical analyses were adequately powered. Rules-of-thumb sample size estimates for structural equation modeling suggest that sample sizes greater than 200 and 400 decrease the likelihood of model non-convergence and improper solutions, respectively (Boomsma & Hoogland, 2001). Therefore, our sample size of 699 minimized risk of model non-convergence and improper solutions and allowed for adequate detection of a small effect size.

## Study Limitations

Findings from this study should be interpreted within its limitations. Percent visit adherence may inaccurately represent scheduled and kept patient appointments. Data were collected from four different HIV clinics in Metro-Atlanta and we were unable to identify care received from outside of one of our four recruiting clinics. Among the recruiting clinics, differences in each clinic’s scheduling practices made it difficult to accurately categorize HIV appointments into the broad categories of completed, missed, and no-show, which were used to calculate percent visit adherence. As a result, HIV appointments may have been misclassified, which would influence the percent visit adherence calculation. Also, percent visit adherence may provide a biased estimate of retention in care. Among persons who miss the same number of appointments, percent visit adherence will be lower among persons with fewer scheduled HIV appointments compared to persons with a greater number of scheduled HIV appointments.

Next, the variables included in the adapted health literacy model are in no way exhaustive. Many factors influence and are a consequence of health literacy and retention in care. Transportation, proximity to the HIV care clinic, and communication with the health care provider outside of the clinic are a few additional factors that may influence the variables in this study but were not assessed.

Lastly, findings from this study may not be generalizable to populations outside of Georgia or the Southern U.S. Our sample's race and gender distributions were comparable to HIV infected populations in Georgia. Due to limitations in the dataset, we were unable to determine how the study sample relates to populations most affected by HIV, such as injection drug users, men who have sex with men, or transgender persons. Also, since this study categorized race as African American and non-African American, we were unable to pinpoint a specific race for which the findings among non-African Americans are most applicable. However, since the majority of non-African Americans were White/non-Hispanic (81%), with a small proportion identifying as Hispanic/Latino (6%) or other race (13%), it is likely that findings from this study for non-African Americans are most applicable to White/non-Hispanics.

## Study Implications

This research supports the U.S. Department of Health and Human Services' (DHHS) initiative to end the HIV/AIDS epidemic (Fauci, Redfield, Sigounas, Weahkee, & Giroir, 2019). In the State of the Union Address on February 5, 2019, President Donald J. Trump announced his administration's goal to end the HIV/AIDS epidemic in the United States by 2030. Through this initiative, the DHHS strives to reduce the number of new HIV infections by 75% within 5 years and by 90% within 10 years. In the initial phases, this initiative will focus on geographic hotspots in which approximately 50% of new HIV diagnoses are reported and will focus on four major components: early diagnosis of new HIV infections; treatment of HIV infection to prevent viral spread; HIV exposure prophylaxis; rapid detection and response to clusters of HIV infections. While this plan is ambitious, it holds promise as new resources will be available to rally efforts among health care providers, public health officials, researchers, and politicians in targeted efforts to eliminate new HIV diagnoses. Working in parallel to the White House's action plan to eliminate HIV is the National Action Plan to Improve Health Literacy (United States Department of Health and Human Services, 2010) and the Action Plan to Reduce Racial and Ethnic Health Disparities (Department of Health and Human Services, 2011). The National Action Plan to Improve Health Literacy envisions providing Americans with accurate, accessible, and understandable health information; delivering person-centered health care and services; and supporting lifelong learning and skills to promote health (United States Department of Health and Human Services, 2010). The Action Plan to Reduce Racial and Ethnic Health Disparities envisions a nation free of disparities in health and health care (Department of Health and Human Services, 2011). The findings from this research have significant implications for future research, clinical practice, and health care policy. These implications align with the above action plans from the DHHS, as they promote scientific advancement and innovation to achieve their respective visions; promote changes in the health care system and the nation's health care infrastructure; promote advances in health care and health.

## Implications for Research

The findings from this research highlight several areas of research that build on the methodology and results of this study. These areas of research have the potential to expand knowledge of the role of health literacy on disparities in retention in care, with the long-term goal of minimizing health disparities, improving health literacy, and optimizing health outcomes for all persons living with HIV. These areas of research are summarized below:

1) *Expanding and testing the health literacy model* may provide a greater understanding of the significant relationships identified in this study. The adapted health literacy model explained only 4% of the variance in visit adherence and 2% of the variance in patient attitudes towards the HIV health care provider. By capturing and including additional predictors of visit adherence and patient attitudes towards the HIV health care provider, we may be able to expand this model's predictive capability for retention in care among racially disparate populations. Additionally, due to the limitations associated with percent visit adherence, it may be beneficial to test the adapted health literacy model using alternative operationalization of retention in care. Formal definitions from the DHHS and the Centers for Disease Control and Prevention may provide study findings that are more readily applicable to recommended benchmarks. Less formal operationalizations of retention in care, such as missed visits or gaps in care may be more advantageous for clinicians and researchers and would offer yet another approach and insight into additional components of HIV health care attendance that contribute to retention in care (Mugavero et al., 2010).

    Findings from this study, in addition to previous research that tested the Paasche-Orlow and Wolf health literacy model for antiretroviral therapy adherence, suggests that this model may be beneficial to understand relationships among predictors of racial disparities for a variety of HIV care outcomes. In addition to further expanding the health literacy model for disparities in retention in care, future research should consider this model when assessing the effect of health literacy in other HIV health disparities.

2) *Identifying levels of percent visit adherence that are associated with optimal patient outcomes* may expand our knowledge of retention in care. This study categorized percent visit adherence as 100% visit adherence compared to less than 100% visit adherence due to the presence of two unique visit adherence groups. It is assumed that attending 100% of scheduled HIV appointments is ideal and superior to missing HIV appointments, as greater retention in care is associated with viral suppression, antiretroviral therapy adherence, and other advantageous HIV treatment outcomes. Yet, no study has identified whether this assumption is true or if levels of visit adherence less than 100% are associated with similar HIV treatment outcomes. Conducting this area of research would have significant implications for HIV treatment and it may provide patients, health care providers, and researchers with a more achievable level of visit adherence.
3) *Examining this study's finding on the association between low socioeconomic status and higher health literacy* may identify possible mechanisms driving this relationship. This finding is contrary to current HIV literature, which suggests that patients of low socioeconomic status also have low health literacy. It is possible that the use of insurance as a proxy for SES resulted in inconsistent findings within the literature, as other studies use more common measures of SES, including monthly or annual income or an assessment of financial situation. It is also possible that health literacy increases over time following a patient's initial diagnosis with HIV, as this present study included patients who have been managing their HIV infection for an average of 16 years. Further research on the relationship between socioeconomic status, health literacy, and retention

in care may reveal findings that further build upon our understanding of the modifiability of health literacy.

4) *Developing interventions that address modifiable predictors of retention in care* may help minimize racial HIV health disparities. Researchers should place emphasis on predictors of retention in care, such as health literacy and patient-provider relationships, as these are modifiable unlike race. Interventions that focus on patient-provider communication strategies that are culturally sensitive and that are effective for patients of all health literacy levels may be most beneficial. Interventions could target areas of health literacy associated with retention in care, such as personal knowledge of one's CD4 and HIV viral load values (Jones et al., 2013). Interventions could also more broadly focus on areas of HIV care management associated with health literacy, including overall knowledge of HIV (Kalichman, Benotsch, et al., 2000; Kalichman & Rompa, 2000; Kalichman, Rompa, et al., 2000; Miller et al., 2003) or adherence to antiretroviral therapies (Kalichman et al., 1999; Miller et al., 2003). Other more novel interventions may harness technology to allow for patient-provider communication and care management outside of the HIV health care clinic. Through addressing health literacy issues and their effect on HIV outcomes, these interventions may ultimately improve patient outcomes and reduce morbidity and mortality of HIV among health disparate populations.

## Implications for Health Care Providers

Findings from this study have several implications for health care providers surrounding health literacy and disparities in retention in care. One primary finding demonstrated that a patient's health literacy is a significant predictor of later retention in care and that differences in this relationship exist by race. Building on this finding, collaboration between health care providers and public health practitioners would aid in the development of accurate, understandable, and accessible educational resources for persons living with HIV. These resources should be culturally sensitive and available to all persons, including those from a diversity of races and ethnicities and lower socioeconomic circumstances. These resources would support patients as informed consumers of health care and assist in improving health literacy.

Health care providers may also find it beneficial to incorporate patient health literacy assessments as standard of care. Health literacy assessments would offer health care providers valuable information to aid in the development of communication and treatment strategies to meet the individual health literacy needs of patients. Such strategies may enhance patient engagement in health care and decision-making processes, strengthen patient-provider relationships, and improve HIV health outcomes, including retention in care. While these strategies would likely benefit all persons living with HIV, they would be particularly beneficial for African Americans and other racial and ethnic groups who experience poor health literacy.

Collaboration between health care providers and transdisciplinary teams would aid in the development of technologies that promote patient care in communities where health disparities are prevalent. One example includes telehealth which could virtually link patients living with HIV to specialized health care providers and would offer health care in communities where access to providers are limited. Another beneficial use of technology is the development of interoperable electronic medical record systems which would allow for electronic sharing of patient data across different electronic medical record systems and among health care providers. This capability has the potential to improve HIV disease management and monitoring of health care utilization. Use of technology may expand the current reach of health care, in order to alleviate patient, health care, and societal level challenges associated with access to HIV health care.

## Implications for Health Policy

Government and policy-based efforts are also critical for improving health literacy, minimizing disparities in retention in care, and eliminating new HIV diagnoses. These policies set the stage for national HIV priorities and have significant implications for access and delivery of health care. Findings from this study highlight the continued need for federal support to end HIV by 2030 and for the National HIV/AIDS Strategy, in order to ensure that every person diagnosed with HIV has access to high quality health care, receives antiretroviral therapies, and maintains viral suppression (Fauci et al., 2019; White House Office of National AIDS Policy, 2015). Efforts to reduce disparities in HIV and improve outcomes among persons living with HIV requires an increase in the accessibility and affordability of health care through expansion of Medicare/Medicaid, and supplemental insurance, including Ryan White. These efforts also require improved access to health care services through an increase in the number of HIV health care clinics located in underserved communities. Providing incentives to physicians, advanced practice nurse practitioners, physicians assistants and specialized care providers may increase the number of health care providers working in communities with HIV health disparities. Improved access to health care services also requires provision of care coordination to assist persons living with HIV in navigating the complex health care systems. Identifying and mapping areas experiencing greatest HIV health disparities, as proposed in the DHHS's plan to end HIV, may assist in maximizing efforts and providing targeted assistance. Government organizations should also coordinate their efforts with local disparity reduction activities and collaborate with city and community planning to address basic needs of persons living with HIV. Addressing access to affordable transportation, housing, food security, and child care are a few basic needs that support a patient’s ability to attend regularly scheduled HIV appointments and contribute to disparities in retention in care.

This research also emphasizes the need to address health literacy not only of persons living with HIV, but of all persons in the U.S. Policies can support improved communication of health and safety information to the public. This requires the development of information that is culturally sensitive, understandable for all persons, and readily accessible. A wide range of organizations and individuals are responsible and must commit to improving communication of health and safety information, including health care providers, clinics, and systems, insurance providers, and drug and device manufactures. These policies should support health care providers, organizations, and researchers in their efforts to address and improve health literacy. Government support of health literacy may even extend beyond the realm of health care. To ultimately improve the health literacy of all persons, we need targeted efforts to incorporate health and science curriculum into educational settings. Since youth can easily access health information, educational settings can assist them in building the knowledge and skills necessary to be informed consumers of health information, which will carry through into adulthood.

The implications summarized above are in no way exhaustive, but instead highlight major areas of focus for researchers, health care providers, and health policy makers. Society wide efforts must continue to address disparities in retention in care and health literacy among persons living with HIV. Collaboration is a key component as no one intervention or discipline can address the complexity of problems contributing to disparities in retention in care and health literacy. Through sustained focus, we can achieve the goals of eliminating racial disparities in retention in care and health literacy and improving the health of all persons living with HIV.

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# Appendix A

## Search Strategy

Database: Pubmed

((((("Healthcare Disparities"[Mesh]) OR "Health Status Disparities"[Mesh]) OR (health status disparit* OR healthcare disparit* OR disparities health OR health disparit* OR racial disparit* OR racial ethnic disparit* OR disparit* OR healthcare disparit* OR socioeconomic disparit* OR rural health disparit* OR lgbt health disparit* OR mental health disparit* or gender inequalit* OR health inequalit* OR income inequalit* OR social inequalit* OR socioeconomic inequalit* OR social determinants health OR inequalit*))) AND (retention OR retention in care OR visit adherence OR appointment adherence OR missed visit OR missed clinic visits OR missed appointment visit OR missed appointment OR visit constancy OR engagement OR engagement in care OR care engagement)) AND ((("Acquired Immunodeficiency Syndrome"[Mesh]) OR "HIV"[Mesh]) OR (HIV OR acquired immunodeficiency syndrome OR AIDS OR acquired immuno-deficiency syndrome OR acquired immune deficiency syndrome OR human immunodeficiency virus OR human immunodeficiency virus infection OR HIV AIDS OR HIV infection OR HIV-infected patients OR HIV-positive persons OR AIDS patient))

Filters: English, last 10 years (2008-2018)

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Database: CINAHL (Ebsco Interface)

(((MH "Health Status Disparities") OR (MH "Healthcare Disparities")) OR (health disparit* OR health status disparit* OR healthcare disparit* OR gender inequalit* OR disparit* health OR racial disparit* OR racial ethnic disparit* OR disparit* OR socioeconomic disparit* OR rural health disparit* OR lgbt health disparit* OR mental health disparit* OR health inequalit* OR income inequalit* OR social inequalit* OR socioeconomic inequalit* OR social determinants health OR inequalit*)) AND (retention OR retention "in" care OR visit adherence OR appointment adherence OR missed visits OR missed clinic visits* OR missed appointment visit OR missed appointment OR visit constancy OR engagement OR engagement "in" care OR care engagement) AND ((MH "Acquired Immunodeficiency Syndrome") "OR" "OR" (MH "Human Immunodeficiency Virus") OR (MH "HIV-Infected Patients") OR (MH "AIDS Patients") OR (AIDS OR HIV OR acquired immune deficiency syndrome OR HIV-infected patients OR AIDS patients OR HIV-positive persons OR AIDS OR HIV infection OR HIV AIDS OR human immunodeficiency virus infection OR acquired immuno-deficiency syndrome OR acquired immunodeficiency syndrome))

Filters: English, last 10 years (2008-2018)

---

Database: Sociological Collection (Ebsco Interface)

( DE "GENDER inequality" OR gender inequalit* OR health status disparit* OR healthcare disparit* OR disparit* health OR health disparit* OR racial disparit* OR racial ethnic disparit* OR disparit* OR socioeconomic disparit* OR rural health disparit* OR lgbt health disparit* OR mental health disparit* OR health inequalit* OR income inequalit* OR social inequalit* OR socioeconomic inequalit* OR social determinants health OR inequalit* ) AND ( retention OR retention in care OR visit adherence OR appointment adherence OR missed visit OR missed clinic visit OR missed appointment visit OR missed appointment OR visit constancy OR engagement OR engagement in care OR care engagement ) AND ( (DE "HIV-positive persons") OR (DE "AIDS (Disease)") OR HIV-positive persons OR HIV-infected patients OR AIDS OR AIDS patients OR HIV infection OR HIV AIDS OR HIV OR human immunodeficiency virus

OR human immunodeficiency virus infection OR acquired immuno-deficiency syndrome OR acquired immune deficiency syndrome OR acquired immunodeficiency syndrome )

Filters: English, last 10 years (2008-2018)

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Database: Global Health (CABI)

((disparity OR disparit* OR “Gender inequalit*” OR “health status disparit*” OR “healthcare disparit*” OR “health disparit*” OR “racial disparit*” OR “racial ethnic disparit*” OR “socioeconomic disparit*” OR “rural health disparit*” OR “lgbt health disparit*” OR “mental health disparit*” OR “health inequalit*” OR “income inequalit*” OR “social inequalit*” OR “socioeconomic inequalit*” OR “social determinants” OR “health inequalit*”) AND (Retention OR “retention in care” OR “visit adherence” OR “appointment adherence” OR “missed visit” OR “missed clinic visit” OR “missed appointment” OR “visit constancy” OR engagement OR “engagement in care” OR “care engagement”) AND (AIDS OR HIV OR “HIV infection” OR “human immunodeficiency virus” OR “human immunodeficiency virus infection” OR “acquired immune deficiency syndrome” OR HIV/AIDS OR “HIV-positive persons” OR “HIV-infected patients” OR “AIDS patients” OR HIV AIDS OR “acquired immuno-deficiency syndrome” OR “acquired immunodeficiency syndrome”))

Filters: English, last 10 years (2008-2018)

# Appendix B

## Description of Studies Included in the Systematic Review of the Literature

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| Adeyemi, 2013 | Cross-sectional | Chicago, Illinois | EMR | ≥ 13 years old; ≥ 1 clinic visit at the CORE center | N = 4,577<br>Age range = 13-59 years old<br>74% Male<br>65% Non-Hispanic Black<br>20% Hispanic | ≥ 2 HIV RNA measurements in 2010 |
| Althoff, 2014 | Cross-sectional | 10 United States clinical cohorts | NA-ACCORD | ≥ 1 HIV care visit from 1/2008-6/2008 | N = 35,324<br>49% ≥ 50 years old<br>83% Male<br>45% Black | Attended ≥ 1 HIV care visit from 1/2008 – 6/2008 and visits ≥ 90 days apart in each of the next 3 semesters from 1/1/2008-12/31/2009 |
| Anderson, 2018 | Cross-sectional | Baltimore, Maryland | Clinical relationship<br>Recruitment period 3/2014-11/2015<br>EMR | Female; ≥ 18 years old; HIV-positive; patient at clinic for at least last year; reported being in intimate relationship in past years | N = 239<br>Age range = 24-66 years old<br>100% Female<br>86% African American<br>3% Hispanic | Proportion of missed scheduled outpatient clinic visits in the past year, including specialty HIV visits |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| Behler, 2018 | Cohort | Chicago, Illinois | Respondent driven sampling/ seed recruitment<br>Recruitment period 6/2013-5/2014 | Identified as black or African American; born male; 16-29 years old; reported ≥ 1 male sex partner within last 24 months; resides or spends most of time in a Black community area | N = 618<br>Mean age = 24 years old<br>100% Black/African American<br>100% MSM<br>62% Gay | Self-reported attendance at ≥ 2 HIV visits in past years |
| Berkley-Patton, 2009 | Qualitative | Kansas City, Missouri | Key stakeholders:<br>directories of local service organization<br>HIV-positive persons:<br>recruited from 2 infectious disease clinics | HIV-positive persons:<br>Self-reported access to HIV services ≥ 2 times per year; onfor ≥ 9 months; stable viral load; overcame barriers to care | Key stakeholders<br>N = 12<br>33% Male<br>HIV-positive persons<br>N = 18<br>44% Male<br>56% African American<br>17% Hispanic | Self-reported access to HIV services ≥ 2 times per year |
| Colasanti, 2016 | Cohort | Atlanta, Georgia | EMR | ≥ 16 years old; confirmed HIV infection; enrolled in Infectious Disease Program in 2010 | N = 655<br>Age range = 16-≥ 65 years old<br>78% Male<br>83% African American<br>4% Hispanic<br>54% MSM | Attended 2 provider visits ≥ 90 days apart within a 12-month period |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| Costa, 2016 | Matched Cohort | Rhode Island & North Carolina | Releasees:<br>Bureau of Justice Statistics' National Corrections Reporting Program<br>Community controls:<br>Ryan White Services Report | Releasees:<br>Receiving Ryan White assistance; released from prison between 1/1/2010-12/31/2013<br>Community controls:<br>Propensity score matching to releasees | N = 245<br>North Carolina:<br>Mean Age = 42 years old<br>81% Male<br>79% Black<br>1% Hispanic<br>18% MSM<br>Rhode Island:<br>Mean age = 44 years old<br>84% Male<br>33% Black<br>17% Hispanic<br>53% MSM | Attended 2 provider visits ≥ 90 days apart within a 12-month period |
| Cyrus, 2017 | Cohort | Florida | Florida Department of Health eHARS | ≥ 13 years old; Florida resident; diagnosed with HIV between 2000-2014 | N = 56,119<br>70% Male<br>10% Caribbean-born Black<br>40% US born-Black<br>46% MSM | ≥ 2 engagement in care opportunities ≥ 3 months apart in 2015<br>Engagement in care = evidence of ≥ 1 documented lab test; prescription filled through AIDS Drug Assistance |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | | | | Program; or physician visit documented in Ryan White databases |
| Dasgupta, 2016 | Cohort | 12 United States jurisdictions | NHSS | ≥ 13 years old; diagnosed with HIV in 2010; alive in 12/2013 | N = 9,824<br>77% Male<br>54% Black<br>17% Hispanic<br>61% MSM | ≥ 2 CD4 or viral load tests ≥ 3 months apart in within a 12-month period, assessed annually for 2011, 2012, and 2013<br>Consistently retained = retention in care for all three years |
| Ghiam, 2017 | Cohort | Nashville, Tennessee | EMR | ≥18 years old; > 1 medical visit at Vanderbilt Comprehensive Care Clinic between 1/1/2004-12/31/2013 | N = 4,641<br>Median age = 38 years old<br>77% Male<br>38% Black<br>5% Hispanic<br>52% MSM | Laboratory definition: ≥ 2 CD4 or viral load tests ≥ 90 days apart<br>Laboratory and appointment definition: ≥ 2 CD4 or viral |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | | | | load tests or HIV provider visit ≥ 90 days apart |
| Hall, 2013 | Cohort | 46 United States and District of Columbia | NHSS; MMP | ≥ 13 years old at diagnosis | N = 1,148,200<br>33% 45-54 years old<br>76% Male<br>44% Black<br>19% Hispanic<br>52% MSM | Attended ≥ 1 HIV appointment between 1/1/2009-4/30/2009 |
| Hightow-Weidman, 2017 | Cross-sectional | North Carolina | Flyers; online advertisements; word of mouth<br>Recruitment period 11/2013-10/2015 | 18-30 years old; biologically male; self-identify as Black; live in North Carolina; access to mobile device; any of the following: condom less anal sex with male, anal sex with >3 male partners; exchange of money, gifts, shelter, drugs for anal sex with male partner; anal sex while under influence of drugs or EtOH | N = 193<br>Mean age = 25 years old<br>100% Black<br>100% MSM<br>71% Gay | Self-reported number of missed HIV care appointments |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| Hu, 2012 | Cohort | Los Angeles County, California | Los Angeles County Department of Public Health eHARS | ≥ 13 years old; reported to eHARS between 1/31/2012-12/31/2009 | N = 37,325<br>48% 13-44 years old<br>88% Male<br>22% African American<br>39% Latino<br>75% MSM | ≥ 2 viral load tests ≥ 90 days apart in 2009 |
| Jaiswal, Griffin-Tomas, 2018 | Qualitative | New York City, New York | Telephone calls<br>Purposive sampling from parent study (recruited during inpatient hospital stay overnight or longer for untreated HIV)<br>Recruitment period 7/2015-5/2016 | HIV-positive; low income; Black or Latino | N = 27<br>Age range = 28-55 years old<br>41% Male<br>78% Black, non-Hispanic<br>22% Hispanic/Latino | Attended ≥ 2 scheduled HIV visits ≥ 3 months apart within a 12-month period |
| Jaiswal, Singer, 2018 | Qualitative | New York City, New York | Telephone calls<br>Purposive sampling from parent study (recruited during inpatient hospital stay overnight or longer for untreated HIV) | HIV-positive; low income; Black or Latino | N = 27<br>Age range = 28-55 years old<br>41% Male<br>78% Black, non-Hispanic<br>22% Hispanic/Latino | Attended ≥ 2 scheduled HIV visits ≥ 3 months apart within a 12-month period |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | Recruitment period 7/2015-5/2016 | | | |
| Lesko, 2017 | Cohort | Baltimore, Maryland | Johns Hopkins HIV Clinical Cohort | ≥ 18 years old; HIV-positive; enrolled in Johns Hopkins outpatient HIV clinic since cohort inception (1995-2012); ≥ 1 outpatient HIV clinic visit or ≥ 1 CD4 or viral load between 2000-2012 | N = 4,602<br>Mean age = 40 years old<br>66% Male<br>75% Black<br>26% MSM | ≥ 2 clinical visits or HIV specific laboratory measurements > 90 days apart between 1/1 and 12/31 or present year |
| Mauck, 2018 | Cohort | Florida | Florida Department of Health eHARS | ≥ 13 years old; MSM or MSM/IDU reported mode of HIV transmission | N = 29,156<br>40% non-Hispanic White<br>29% non-Hispanic Black<br>31% Hispanic<br>96% MSM | ≥ 2 engagement in care opportunities ≥ 3 months apart in 2015<br>Engagement in care = evidence of ≥ 1 documented lab test; prescription filled through AIDS Drug Assistance Program; or |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | | | | physician visit documented in Ryan White databases during 2015 |
| Messer, 2013 | Qualitative | North Carolina | Posters; clinical relationship<br>Purposive sampling | HIV-positive; women of color | N = 30<br>100% women<br>70% >40 years old<br>86% African American<br>7% Hispanic | N/A |
| Morales-Aleman, 2017 | Cohort | District of Columbia | eHARS | 13-29 years old; diagnosed with HIV between 2005-2012; alive in 2013; MSM reported mode of transmission | N = 910<br>49% 19-24 years old<br>73% Black/African American<br>10% Hispanic<br>100% MSM | ≥ 2 CD4 or viral load tests ≥ 3 months apart within 12 months of diagnosis |
| Muthulingam, 2013 | Cohort | San Francisco, California | San Francisco HIV/AIDS Reporting System | ≥ 13 years old; diagnosed with HIV between 1/1/2009-12/31/2012; reported to San Francisco Department of Public health through 2012 | N = 862<br>30% 40-49 years<br>90% Male<br>15% Black<br>21% Hispanic<br>68% MSM | Retention in care for 2nd visit: 2nd laboratory test within 3-6 months after entry into care<br>Retention in care for 3rd visit: 3rd |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | | | | laboratory test within 3-6 months after 2nd laboratory test |
| Philbin, 2017 | Qualitative | 14 ATN clinical sites in United States<br>10 adult clinics to which ATN youth transition | Email; telephone calls<br>Purposive sampling | Medical and social service providers; transitioned adolescents from ATN sites or received adolescents at adult clinics | Clinic providers at adolescent clinics<br>N = 30<br>Clinic providers at adult clinics<br>N = 28 | N/A |
| Quinn, 2018 | Qualitative | Milwaukee, Wisconsin | Outreach in community settings and online | ≥ 18 years old; HIV-positive; self-identify as Black; out of care ornon-adherent | N = 23<br>Age range = 20-55 years old<br>100% Male<br>100% Black<br>83% Gay/Bisexual | Out of care: Not receiving HIV care in the previous 6 months |
| Rebeiro, 2016 | Cohort | 12 United States clinical cohorts | NA-ACCORD | ≥ 18 years old; ≥ 1 HIV primary care visit between 1/2000-12/2010 | N = 78,993<br>37% 40-49 years<br>83% Male<br>44% Non-Hispanic Black<br>11% Hispanic<br>34% MSM | ≥ 2 HIV primary care visits ≥ 90 days apart within a calendar year; subspecialty visits were not included in this definition |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| Rebeiro, 2018 | Cohort | Nashville, Tennessee | EMR | ≥18 years old; > 1 medical visit at Vanderbilt Comprehensive Care Clinic between 1/1/2004-12/31/2013 | N = 508<br>Mean Age 39 years<br>72% Male<br>45% Non-Hispanic Black<br>3% Hispanic<br>46% MSM | ≥ 2 healthcare provider visits in the calendar years of interest > 90 days apart |
| Sangaramoorthy, 2017 | Qualitative | Prince George's County, Maryland | Purposive sampling; participant referral; case manager and outreach worker referral | ≥ 40 years old; HIV-positive; female; self-identify as Black; live in Prince George's County | N = 35<br>Age range 40-71 years old<br>100% Female<br>100% Black | Number of HIV-related care visits scheduled in the past year; number of kept HIV-related care visits |
| Sevelius, 2014 | Qualitative | San Francisco Bay Area, California | Purposive sampling from cross-sectional survey of transgender women; snowball sampling; street-based recruitment | ≥ 18 years old; born male, identify as female; self-reported HIV diagnosis | N = 44<br>48% 50-59 years old<br>76% African American/Black<br>12% Latina | N/A |
| Sheehan, Fennie, 2017 | Cohort | Florida | Florida Department of Health eHARS; | ≥ 13 years old; meet CDC's HIV case definition during 2000-2014; | N = 65,735<br>68% 25-49 years old<br>71% Male | ≥ 2 engagement in care opportunities ≥ |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | 2009-2013 American Community Survey | list Florida as most current state of residence; alive at end of 2015 | 48% Non-Latino Black<br>24% Latino<br>47% MSM | 3 months apart in 2015<br>Engagement in care = evidence of ≥ 1 documented lab test; prescription filled through AIDS Drug Assistance Program; or physician visit documented in Ryan White databases during 2015 |
| Sheehan, Mauck, 2017 | Cohort | Florida | Florida Department of Health eHARS; 2009-2013 American Community Survey | ≥ 13 years old; Latino or Hispanic; meet CDC's HIV case definition during 2000-2014; list Florida as most current state of residence; alive at end of 2015 | N = 12,106<br>74% 25-49 years old<br>83% Male<br>6% Black Latino<br>100% Latino<br>61% MSM | ≥ 2 engagement in care opportunities ≥ 3 months apart in 2015<br>Engagement in care = evidence of ≥ 1 documented lab test; prescription filled through |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | | | | AIDS Drug Assistance Program; or physician visit documented in Ryan White databases during 2015 |
| Singh, 2014 | Cohort | 19 United States jurisdictions | NHSS; MMP | ≥ 13 years old at diagnosis; MSM; diagnosed through 12/31/2009; alive on 12/31/2009 | N = 10,093<br>34% 45-54 years old<br>33% Black/African American<br>20% Hispanic<br>100% MSM | ≥ 2 CD4 or viral load tests ≥ 3 months apart during 2010 |
| Sohler, 2009 | Cohort | Manhattan & the Bronx, New York | Convenience sample; EMR | ≥ 18 years old; living in single room occupancy hotel; HIV-positive | N = 444<br>50% <45 years old<br>76% Male<br>56% non-Hispanic Black<br>32% Hispanic | ≥ 2 HIV related primary care visits over a 6-month period |
| Sprague, 2014 | Qualitative | Birmingham & Tuscaloosa, Alabama | Purposive sampling | Accessingthrough AIDS Drug Assistance Program | N = 25<br>Age range 20-52 years old<br>72% Male<br>64% African American<br>4% Hispanic | N/A |

| Last Name, Year | Study Design | Location | Recruitment Strategy or Data Source | Inclusion Criteria | Sample Size and Characteristics | Retention in Care Measure |
|---|---|---|---|---|---|---|
| | | | | | 32% MSM | |
| Walcott, 2016 | Qualitative | Alabama | Flyers<br>Purposive sampling; snowball sampling | Stakeholders:<br>≥ 19 years old; reside in Alabama<br>Women living with HIV:<br>19-64 years old; self-reported low socioeconomic status; seeking care at recruitment site | N = 46<br>Mean age = 45 years old<br>100% Female<br>89% Black/African American | N/A |
| Wester, 2016 | Cross-sectional | Tennessee | Tennessee Department of Health eHARS | Reported to eHARS | N = 8,458<br>33% 45-54 years old<br>73% Male<br>56% non-Hispanic Black<br>4% Hispanic<br>47% MSM | ≥ 2 CD4 or viral load tests ≥ 3 months apart in 2013 |

*Note.* EMR = electronic medical records; HIV = human immunodeficiency virus; RNA = ribonucleic acid; NA-ACCORD = North American AIDS Cohort Collaboration on Research and Design;= antiretroviral therapy; MSM = men who have sex with men; eHARS = Enhanced HIV/AIDS Reporting System; NHSS = National HIV Surveillance System; MMP = Medical Monitoring Project; ATN = Adolescent Medicine Trials Network

# Appendix C

## Risk of Bias Assessments with Authors' Support for Judgement

Adayemi, 2013

*Risk of Bias*

| *Bias* | *Bias Rating* | *Support for Judgment* |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from electronic medical records |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate logistic regression models |
| Rule out of unintended exposure (performance bias) | Unclear | No exclusionary criteria indicated |
| Appropriate handling of missing data (attrition bias) | Unclear | Handling of missing data not specified |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from electronic medical records |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Althoff, 2014

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from NA-ACCORD US Clinical Cohorts |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate poisson regression models |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of Veterans Aging cohort and Kaiser Permanente Northern California cohort |

| | | |
|---|---|---|
| Appropriate handling of missing data (attrition bias) | Unclear | Handling of missing data not specified |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from NA-ACCORD US data set |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Anderson, 2018

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Interested participants were screened for eligibility |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate logistic regression models |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals prescribed antiretroviral therapy within the past year, not HIV-positive, or not receiving HIV care at study clinic |
| Appropriate handling of missing data (attrition bias) | Low | Complete cases included in analysis |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent survey administration and data extraction from electronic medical records |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Behler, 2018

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Unclear | Screening of participants for eligibility was not indicated<br>Data obtained from electronic medical records |

| | | |
|---|---|---|
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate longitudinal logistic regression models |
| Rule out of unintended exposure (performance bias) | Unclear | No exclusionary criteria indicated |
| Appropriate handling of missing data (attrition bias) | Low | Imputation of missing data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent survey administration and data extraction from electronic medical records |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Berkley-Patton, 2009

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | High | Verbatim quotes |
| Transferability of research findings to other specific settings (transferability) | Low | Contextual background information<br>Study participant details/demographics |
| Logical, traceable, and clearly documented process of research (dependability) | High | No evaluation techniques for dependability |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Colasanti, 2016

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from electronic medical records |

| | | |
|---|---|---|
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate logistic regression models |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals who were perinatally exposed but uninfected, enrolled in research trials, or misclassified as new clinic enrollees |
| Appropriate handling of missing data (attrition bias) | High | Missing viral load data was classified as not suppressed |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from electronic medical records |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Costa, 2018

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Releasee data obtained from Bureau of Justice Statistics National Corrections Reporting Program; Community control data obtained from Ryan White Services Report data |
| Similar recruitment strategy for control group (selection bias) | Low | Community control data obtained from Ryan White Services Report data |
| Control for confounding and modifying variables (selection bias) | Low | Propensity score matching used to match releasees with community controls |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals who did not have adequate follow-up time to meet the retention definition |
| Appropriate handling of missing data (attrition bias) | Low | 12 participants with missing race or housing were excluded from analysis |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from data sources |

| | | |
|---|---|---|
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Cyrus, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Florida Department of Health’s Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted odds ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals diagnosed under 13 years of age or in a correctional facility |
| Appropriate handling of missing data (attrition bias) | Low | Exclusion of missing data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | High | Non-statistically significant findings were not reported |

Dasgupta, 2016

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from National HIV Surveillance System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | High | No control for confounding or modifying variables through analysis or other approaches |
| Rule out of unintended exposure (performance bias) | Unclear | No exclusionary criteria indicated |

| | | |
|---|---|---|
| Appropriate handling of missing data (attrition bias) | Low | Imputation of missing data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from national HIV Surveillance System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Ghiam, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from electronic medical records |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted risk ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of observations in a patient's calendar year of death |
| Appropriate handling of missing data (attrition bias) | Low | Exclusion of missing viral load data; imputation of missing socioeconomic status |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from electronic medical records |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Hall, 2013

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from National HIV Surveillance System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |

| | | |
|---|---|---|
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved stratification of outcomes |
| Rule out of unintended exposure (performance bias) | Unclear | No exclusionary criteria indicated |
| Appropriate handling of missing data (attrition bias) | Unclear | Handling of missing data not specified |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from National HIV Surveillance System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Hightow-Weidman, 2017
*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Unclear | Screening of participants for eligibility was not indicated |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate logistic regression |
| Rule out of unintended exposure (performance bias) | Unclear | No exclusionary criteria indicated |
| Appropriate handling of missing data (attrition bias) | Low | Complete cases included in analysis |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent survey administration |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Hu, 2012
*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|

| | | |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Los Angeles County Department of Public Health's Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted hazard ratios and adjusted prevalence ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals with most recent address outside of Los Angeles County |
| Appropriate handling of missing data (attrition bias) | Low | Imputation of missing data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Jaiswal, Griffin-Tomas, 2018

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | High | Verbatim quotes |
| Transferability of research findings to other specific settings (transferability) | High | Study participant details/demographics |
| Logical, traceable, and clearly documented process of research (dependability) | High | Peer Review |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Jaiswal, Singer, 2018

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|

| | | |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Debriefing<br>Outside auditor validation of findings |
| Transferability of research findings to other specific settings (transferability) | High | Study participant details/demographics |
| Logical, traceable, and clearly documented process of research (dependability) | Low | Peer Review<br>Audit Trails |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Lesko, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Johns Hopkins HIV Clinical Cohort |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved probability weighted log-binomial regression models |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals not actively enrolled in care at Johns Hopkins University clinic |
| Appropriate handling of missing data (attrition bias) | Unclear | Handling of missing data not specified |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Johns Hopkins HIV Clinical Cohort data set |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Mauck, 2018

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|

| | | |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Florida Department of Health's Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted prevalence ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals with most recent address outside of Florida and those who died before 2015 |
| Appropriate handling of missing data (attrition bias) | Low | Handling of missing data not specified |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Messer, 2013

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Peer debriefing<br>Verbatim quotes<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | High | Study participant details/demographics |
| Logical, traceable, and clearly documented process of research (dependability) | Low | Peer debriefing<br>Interrater reliability<br>Triangulation of findings<br>Audit trails |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Morales-Aleman, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|

| | | |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate logistic regression |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals without U.S. census socio-structural information |
| Appropriate handling of missing data (attrition bias) | Low | Complete cases included in analysis |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Muthulingam, 2013

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from San Francisco HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved multivariate logistic regression |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals for whom only a year of diagnosis was available |
| Appropriate handling of missing data (attrition bias) | Low | Exclusion of missing viral load data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Philbin, 2017

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | High | No evaluation techniques for transferability |
| Logical, traceable, and clearly documented process of research (dependability) | Low | Peer debriefing<br>Field notes<br>Interrater reliability |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Quinn, 2018

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | Low | Study participant details/demographics<br>Contextual background information |
| Logical, traceable, and clearly documented process of research (dependability) | High | No evaluation techniques for dependability |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Reberio, 2016

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|

| | | |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from NA-ACCORD US Clinical Cohorts |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted Poisson regression models |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of classical prospective cohorts and exclusion of inpatient visits and laboratory only visits from retention in care measures |
| Appropriate handling of missing data (attrition bias) | Low | Imputation of missing CD4+ count data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from NA-ACCORD |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Rebeiro, 2018

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from electronic medical records |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted Poisson regression models |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals whose health literacy data was not available in the electronic medical records |
| Appropriate handling of missing data (attrition bias) | High | Missing data not imputed |
| Consistent assessment and implementation of measures (detection bias) | High | Consistent data extraction from electronic medical records |

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| Reporting of prespecified outcomes (reporting bias) | High | All prespecified outcomes reported |

Sangaramoorthy, 2017

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | Low | Study participant details/demographics<br>Contextual background information |
| Logical, traceable, and clearly documented process of research (dependability) | High | Triangulation of methodologic approaches |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Sangaramoorthy, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Unclear | Screening of participants for eligibility was not indicated |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | High | No control for confounding or modifying variables through analysis or other approaches |
| Rule out of unintended exposure (performance bias) | High | No exclusionary criteria indicated |
| Appropriate handling of missing data (attrition bias) | Low | Missing data replaced with mean scores from appropriate subscales |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent survey administration |

| | | |
|---|---|---|
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Sevelius, 2014

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | High | Study participant details/demographics |
| Logical, traceable, and clearly documented process of research (dependability) | High | Debriefing |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Sheehan, Fennie, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Florida Department of Health’s Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted odds ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals whose reported current ZIP code population is zero and individuals diagnosed in a correctional facility |
| Appropriate handling of missing data (attrition bias) | Low | Exclusion of individuals with missing retention in HIV care |

| | | |
|---|---|---|
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Sheehan, Mauck, 2017

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Florida Department of Health’s Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted odds ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of individuals whose reported current ZIP code population is zero and individuals diagnosed in a correctional facility |
| Appropriate handling of missing data (attrition bias) | Low | Exclusion of individuals with missing or unspecified/unknown country of birth |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Singh, 2014

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from National HIV Surveillance System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |

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|---|---|---|
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved stratification of outcomes |
| Rule out of unintended exposure (performance bias) | Unclear | No exclusionary criteria indicated |
| Appropriate handling of missing data (attrition bias) | Low | Data were statistically adjusted for missing HIV transmission categories |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from National HIV Surveillance system |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Sohler, 2009

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Interested participants were screened for eligibility; data obtained from electronic medical records |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved stratification of outcomes and adjusted odds ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of participants intoxicated at time of recruitment |
| Appropriate handling of missing data (attrition bias) | Low | Imputation of missing data |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent survey administration and data extraction from electronic medical records |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |

Sprague, 2014

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|

| | | |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | Low | Study participant details/demographics<br>Contextual background information |
| Logical, traceable, and clearly documented process of research (dependability) | High | Triangulation of findings |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Walcott, 2016

*Risk of Bias*

| Bias | Bias Rating | Evaluation Techniques Used |
|---|---|---|
| Consistency between representation of data and views of participants studied (credibility) | Low | Verbatim quotes<br>Peer Debriefing<br>Independent analysis of data by more than one reviewer |
| Transferability of research findings to other specific settings (transferability) | High | Study participant details/demographics |
| Logical, traceable, and clearly documented process of research (dependability) | Low | Triangulation of findings<br>Peer Review |
| Confirmability of findings through grounding of analysis in data and examination of audit trails (confirmability) | High | No evaluation techniques for confirmability |

Wester, 2016

*Risk of Bias*

| Bias | Bias Rating | Support for Judgment |
|---|---|---|
| Uniform application of inclusion/exclusion criteria (selection bias) | Low | Data obtained from Enhanced HIV/AIDS Reporting System |
| Similar recruitment strategy for control group (selection bias) | N/A | N/A |

| | | |
|---|---|---|
| Control for confounding and modifying variables (selection bias) | Low | Statistical analysis involved adjusted prevalence ratios |
| Rule out of unintended exposure (performance bias) | Low | Exclusion of Memphis Transitional Grant Area |
| Appropriate handling of missing data (attrition bias) | Unclear | Handling of missing data not specified |
| Consistent assessment and implementation of measures (detection bias) | Low | Consistent data extraction from Enhanced HIV/AIDS Reporting System |
| Reporting of prespecified outcomes (reporting bias) | Low | All prespecified outcomes reported |