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Mathilde L. Silverberg

Date

# The Role of Cultural Distance in HIV Care provision for Young Black Gay, Bisexual and other Men Who Have Sex with Men Living with HIV in Atlanta, GA

By

Mathilde L. Silverberg

Master of Public Health

Hubert Department of Global Health

**Sophia A. Hussen** MD MPH- Committee Chair Assistant Professor - Department of Global Health Rollins School of Public Health, Emory University

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By

Mathilde L. Silverberg

Bachelor of Arts University of Georgia 2016

Thesis Committee Chair: Sophia Hussen MD, MPH

An abstract of A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of Master of Public Health in Global Health 2019

## Abstract

# The Role of Cultural Distance in HIV Care provision for Young Black Gay, Bisexual and other Men Who Have Sex with Men Living with HIV in Atlanta, GA

By Mathilde L. Silverberg

**Background:** Young black gay, bisexual, and other men who have sex with men (YB-GBMSM) are disproportionately impacted by HIV, and often face barriers to engagement in care. There is a paucity of research examining strengths of, and challenges facing HIV service and care providers working with this population. Perceived cultural distance – differences in racial, sexual and/or gender identity relative to the population being served – between patient and provider impacts patients' rating of overall health care quality and trust in providers. Our study aimed to explore HIV care and service providers' perceptions of the impact of their own identities on the care they offer to YB-GBMSM. Additionally, we aimed to learn more about the role of cultural distance in the care YB-GBMSM living with HIV receive in Atlanta, Georgia.

**Methods:** To explore provider experiences working with YB-GBMSM, we conducted 28 qualitative interviews with key informants from healthcare and community-based organizations that serve YB-GBMSM living with HIV in Atlanta, Georgia. Interview domains included descriptions of service provision, personal identity, and cultural competency. We utilized MAXQDA software and rigorous team coding to code the data and analyze it thematically with special attention to racial, sexual, and gender identity of participants.

**Results:** Most (86%) of the key informants were black, 25% were women, and 80% identified as non-heterosexual. Key informants' personal identity characteristics influenced the type of support that they offered to YB-GBMSM. Women often described providing support through nurturing and caregiving methods. Black gay men offered mentorship from personal experiences as a feature of their supportive practices. Participants discussed the need for improving representation of YB-GBMSM among providers, highlighting the role of cultural distance as contributing to gaps in their understanding of the experiences of YB-GBMSM.

**Conclusions:** The racial, sexual, and gender identity of HIV care and service providers influenced their approach and orientation in offering services and support to YB-GBMSM. Efforts to increase the representation of YB-GBMSM in the public health workforce are needed to decrease cultural distance, which can enhance services and ultimately improve engagement in care among YB-GBMSM living with HIV.

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#### **CHAPTER 1: Introduction**

## **1.1 Introduction and Rationale**

Between 2012 and 2016, the annual incidence rate for HIV/AIDS has increased in some groups of people in the United States (US), while remaining stable in the country as a whole [1]. Gay, bisexual and other men who have sex with men (GBMSM) are disproportionately affected by HIV/AIDS compared to other US populations, representing 82% of HIV diagnoses in males and 66% of all diagnoses in the population as a whole [1]. Black men account for the largest number of new HIV diagnoses within MSM population [1]. Additionally, young men ages 13-34 account for 3 out of 4 new HIV diagnoses among Black GBMSM [2]. Over half of the new HIV diagnoses in 2017 were in the South, and half of those diagnoses were in Black Americans. Specifically, in the state of Georgia, the rate of new HIV diagnoses was 24.9 per 100,000, making it the state with the highest incidence rate [3]. The reasons behind these disparities are incompletely understood. Studies examining the role of individual behavior factors have consistently demonstrated that young Black GBMSM (YB-GBMSM) do not engage in individual risk behaviors at higher rates than their non-Black peers [9]. This evidence points to the importance of examining a range of other social determinants that impact the HIV epidemic in YB-GBMSM.

In addition to being at higher risk for acquiring HIV, YB-GBMSM are also at risk for lower rates of engagement in HIV care [9,19]. HIV care is conceptualized as a continuum that includes HIV testing, linkage to care, retention in care, medication adherence, and viral suppression [4]. The HIV care continuum is an instrumental framework for depicting how people living with HIV can maintain a suppressed viral load by adhering to an antiretroviral therapy (ART) regimen. A core component of the HIV care continuum after linking HIV positive individuals to care is retaining these individuals in care to then prescribe to them ART with the hopes of leading to viral suppression. In individuals who are aware of their HIV status, approximately 50% of them are not engaged in regular HIV care [4]. Individuals who are sub-optimally engaged in care have poorer health outcomes [4].

The relationship between people living with HIV and their health care provider plays a critical role in maintaining patient's retention in care across the care continuum [5]. Hightow-Weidman et al. further explored the HIV care continuum for YB-GBMSM. Their findings show being engaged in care is associated with YB-GBMSM having insurance and higher self-efficacy in communication with their care provider [19]. Qualitative work conducted by Mallinson et al. through in-depth interviews with people living with HIV has highlighted the importance of the patient-provider relationship as a critical element for facilitating engagement and retention in care [5]. From the patient perspective, when providers' behavior to patients was validating and the patient felt more like a partner in the relationship, engagement in care was facilitated. The study's participants described wanting a care provider who shows empathy with good communication skills, leading to a positive mutual respect between patient and provider [5].

Other work has highlighted ways in which patient-provider relationships may impact the health of sexual and ethnic minorities differently, and potentially contribute to disparities in health outcomes. Saha and colleagues conducted two studies over the course of two years, both focused on ways to explain the racial and ethnic disparities in HIV care [6-7]. The first focused on the role of *cultural distance* between patient and providers, while the second aimed to learn more about perceived cultural competency of care providers [6-7]. In both studies, providers and patients were surveyed or interviewed to offer insight into the quality of HIV patient care. While past studies have examined the influence of discordant and concordant race and ethnicity in patient provider relationships, Saha and colleagues aimed to expand beyond the patient-provider dyad to understand the larger issues surrounding these interactions [7]. They defined cultural

distance as a continuum used to quantify the cultural differences between patients and their providers.

An instrument developed by Haidet et al. was used to measure patient's perceived cultural distance from their provider [7,22]. The dimensions of cultural concordance and discordance between patient-provider are obtained through this 4-item scale [7]. The items evaluated in the instrument are "patients' perceived similarity to their provider in terms of speech and language, reasoning, communication style and values" [7]. Appendix 1 shows the cultural distance measurement tool utilized to understand patient perceptions on cultural distance between providers [7]. Of note, the scale does not specifically ask questions in regard to racial or sexual orientation differences and how patients perceive these differences with providers. Using this instrument, the research team found that greater cultural distance was associated with lower patient perceived health care quality and less trust in their providers. However, cultural distance was not found to vary between the different racial groups of patients; therefore Saha et al. that racial differences in outcomes were not explained by cultural distance.

Saha et al. also conducted another study focused on cultural competence of HIV care providers in relation to mitigating racial/ethnic health disparities minority populations are experiencing. Specifically, they wanted to understand if the cultural competence of HIV care providers was associated with better care and health outcomes for people living with HIV engaged in care [6]. Additionally, they aimed to explore if cultural competence in providers explained racial disparities found in the health outcomes measured. Cultural competence for this study was defined as "their [providers'] effectiveness in caring for patients from diverse backgrounds" [6]. Provider cultural competence was measured with an instrument Saha et al. developed, shown in Appendix 2, to capture the dimensions of "awareness, attitudes, skills, and behaviors that have been collectively referred to as 'cultural competence'"[6]. Through both patient and provider perspectives, it was seen that providers with a self-perceived higher cultural competence had patients with better care outcomes (higher self-reported self-efficacy and adherence to antiretrovirals). Lower cultural competence of providers was related to disparities in care and health outcomes in populations of racial minorities. When providers had high self-rated cultural competence, patients care and health outcomes among the varying racial and ethnic groups was more equitable [6]. This study highlights the importance of the providers' perspectives on their own cultural competence, which has significant implications for the patients they serve. Although the study does not touch specifically on how cultural competence is related to HIV care engagement for these patients, positive health outcomes found in the study when providers have high levels of cultural competence are examined in other research showing higher levels of engagement in care.

The disparities in HIV care YB-GBMSM are experiencing are complex and closely related to other social determinants impacting care seeking behavior and retention. These topics have been further researched by Hussen and colleagues in Atlanta, who have developed a social capital intervention for YB-GBMSM with the goal to improve HIV care engagement in YB-GBMSM by increasing their social capital [8]. The process of creating the intervention included completing qualitative in-depth interviews with HIV care and service providers working at community-based organizations and clinics. These interviews served as key informant interviews to learn best practices when working with YB-GBMSM.

We sought to explore the experiences of HIV care and service providers working with YB-GBMSM. Specifically, we aimed to understand the roles of cultural competence and personal identity of these providers in the care and support they offer to YB-GBMSM. This study will add to the knowledge on the role of providers in HIV care engagement for YB-GBMSM. This research has the potential to inform cultural competence trainings for both care and service providers who work with groups experiencing disparities in health related to race and sexuality.

### **1.2 Problem Statement**

According to the CDC, Black GBMSM are more impacted by HIV than other groups in the United States [1]. There is a need to understand the role of care and service providers in YB-GBMSM's health outcomes, and to explore how cultural distance and level of cultural competency relate to the care they give. Previous data notes the importance of care providers in the level of engagement in care the patient maintains [6-7]. However, there are few studies examining these topics from the provider's perspective, particularly in relation to their own gender, racial and sexual identity. Additionally, experiences of service providers working with community-based organizations have been explored very little (relative to healthcare providers) to learn from their perspective about the work they do with YB-GBMSM. Through addressing these gaps in knowledge, cultural competency trainings for clinicians and community can be implemented and better informed.

#### **1.3 Statement of Purpose**

The purpose of this qualitative study is to understand the role of cultural competency and personal identity of HIV care and service providers (clinicians, community-based organization staff, and members of academia) in the care they provide to YB-GBMSM in Atlanta, Georgia. This study will aim to explore gender, sexual and racial identity of care and service providers in connection to the care they offer to YB-GBMSM. At this stage in the research, the personal identity of HIV care providers will generally be defined as their gender, racial and sexual

identity. To answer the research question, secondary qualitative data analysis will be conducted on an existing in-depth interview dataset.

## **1.4 Research Questions**

This research study aims to address the following research questions:

a. How do HIV care providers understand cultural competency and cultural distance with respect to their work with YB-GBMSM?

## **1.5 Significance Statement**

The HIV/AIDS epidemic continues to be a critical health issue for many parts of the world. Worldwide in 2017, about 1.8 million were diagnosed with new cases of HIV. In the United States, almost 39,000 new diagnoses occurred in 2017 [1]. The HIV/AIDS crisis disproportionately affects racial and sexual minorities. With the HIV diagnoses rate in YB-GBMSM continuing to be high, more YB-GBMSM living with HIV need to be enrolled and engaged in care. Engaging and retaining HIV patients in care is a challenge because of key social factors. YB-GBMSM are a key population in which HIV is spreading. Research studies focusing on the role care and service providers serve in engaging YB-GBMSM are important. Learning from providers themselves about their cultural competency when interacting with YB-GBMSM can provide new information on how to better train providers to connect with YB-GBMSM and other minority populations.

# 1.6 Definition of Terms

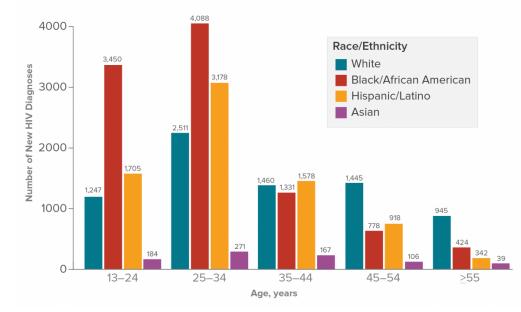
**Cultural distance-** the difference between patients and providers in cultural or ethnic background, including differences in values and communication styles rooted in culture **Cultural competency-** Provider's effectiveness in caring for patients from diverse backgrounds [6]

## **CHAPTER 2: Literature Review**

## HIV in the United States among GBMSM

An estimated 1.1 million people are living with HIV in the United States [1]. Although the incidence of HIV in the United States has remained stable from 2012-2016, it has increased in some demographic groups. HIV/AIDS disproportionally impacts GBMSM. The majority of new diagnoses of HIV in the United States in 2017 were gay and bisexual men [1]. Nearly two-thirds of the diagnoses represented were in by gay and bisexual men and within this demographic, the largest group with new diagnoses was Black GBMSM [2]. Although HIV diagnoses in Black GBMSM remained stable in recent years, they are still the group that is most impacted [1]. HIV incidence rates also vary by region, with the South having the highest HIV diagnoses rate [1]. Georgia is ranked as the state with the highest rate of new infections and Atlanta specifically is third among metropolitan cities in the country for HIV diagnoses [17].

Figure 1. New HIV Diagnoses Among Gay and Bisexual Men by Age and Race/Ethnicity in the US and Dependent Areas, 2017  $^{\rm 2}$ 



Black GBMSM are the demographic most affected by HIV in the United States [2]. Young (13-34 year old) Black GBMSM have the most new HIV diagnoses of any age and race group for men who have sex with men [2]. HIV diagnoses increased 40% in YB-GBMSM ages 25 to 34 between the years 2010 to 2016 [2]. The reasons for this disparity are complex. Social forces such as stigma, homophobia, and discrimination all impact YB-GBMSM in seeking services and connections to receiving adequate quality of healthcare [2]. Higher poverty rates, less access to prevention education and more lead to YB-GBMSM being more likely to have a lack of awareness of HIV status, lower rates of viral suppression, and longer time before linking to care after diagnoses than their counterparts in other racial groups of GBMSM [2].

### **Increased Risk of HIV for Black GBMSM**

Many studies have analyzed HIV risk behaviors as pertains to Black GBMSM to further understand the disproportionate HIV rates impacting them as comparted to their white counterparts. Some contributors to the disparity including individual-level and behavioral risk factors such as substance use, number of sexual partners, acceptance of gay identity, disclosure of sexual identity, and taking ART. However, these behavioral risks factors fail to fully explain the elevated risks of HIV rates in Black GBMSM. Millet and colleagues wanted to further explore these elevated risks and aimed to explain these disparities in HIV infections between Black and White GBMSM [13]. Through their study, they found focusing on behavioral risk factors and behaviors in Black GBMSM will have a limited impact on the elevated HIV rates in Black GBMSM because behavioral risk do not fully explain the disproportionate rates of HIV in Black GBMSM. Millet et al. recommend for researchers to shift their previous focus on risk behaviors to social networks and other areas impacting racial disparities in HIV infections [13]. Their research suggests an area to explore more is the HIV care continuum and the impact of the provider and patient experience on health outcomes [13].

Another study in Washington, DC examined potential explanations for the elevated HIV prevalence in Black GBMSM even though they have lower rates of sexual risk behaviors [9]. Washington DC has one of the highest HIV/AIDS prevalence rates in the United States. Consistent with prior work, they found that Black GBMSM participate in fewer sexual risk behaviors, including having fewer male sex partners, engaging less frequently in intentional unprotected anal sex, and were using condoms more frequently with anal sex [9]. The authors also highlighted social barriers, showing Black GBMSM were less likely to have health insurance, be tested for HIV and disclose their sexual orientation to providers [9]. Both this study and others recommend that the epidemic of HIV in Black GBMSM in the United States is more intricate, involving other factors such as stigma and discrimination leading to the understanding more aspects than behavioral risks should be focused on.

# **HIV Care Continuum**

Researchers began to further investigate other factors than sexual behavioral risks in relation to the disproportionate high prevalence of HIV rates in Black GBMSM. Hightown-Weidman et al. identified barriers YB-GBMSM experience associated with lower rates of engagement in care thus influencing the entire HIV care continuum experience [19]. For example, having health insurance and provider self-efficacy was positively associated with YB-GBMSM being engaged in care [19]. Additionally, in a review of the literature by Maulsby et al., researchers found HIV positive Black MSM may be less likely to engage in care as well as begin and adhere to ART [9]. Lack of engagement in the HIV care continuum may explain the disparities in HIV prevalence Black MSM are experiencing [9]. The HIV Care Continuum is composed of five steps: (i) HIV

Diagnoses, (ii) Linkage to Care, (iii) Engagement in Care, (iv) Prescription and Adherence to Anti-retroviral Therapy (ART), (v) Viral Suppression [4]. To fully benefit from ART, HIV positive patients need to know their status, engage in HIV care, and receive and adhere to their prescribed ART [4]. Although around 75% of individuals recently diagnosed with HIV link to care within six months to a year after diagnoses, only 50% of those with known status engage in HIV care regularly [4]. Without regular engagement in care, HIV patients do not have access to ART and other medicines and general medical services they may need. HIV-positive people have a lower chance of reaching viral suppression when not taking ART [4]. Specifically, in Black GBMSM, modeling completed by Rosenberg et al. in 2010 suggests 24% of Black GBMSM were engaged in care and 16% virally suppressed [19]. In 2015, a CDC Morbidity and Mortality Weekly Report (MMWR) further researched HIV care outcomes in GBMSM. The MMWR showed compared to other racial/ethnic and age groups, Black GBMSM (under age 25) are less likely to be in care within a month of their HIV diagnosis [20]. Additionally, only 45.3% of Black GBMSM ages 20 to 24 who were engaged in care and receiving ART were found to be virally suppressed [20]. Engagement in care through all steps of the HIV care continuum is critical for bettering overall health outcomes for people living with HIV. Previous research has found poor health outcomes are associated with poor engagement in HIV care [4].

Adding to previous research findings on the importance of the HIV Care Continuum and its impact on overall health, Mallinson and colleagues qualitatively explored the role of providers in patient engagement in HIV care. The patients interviewed for the study were majority Black (51%), with 58% of participants identifying as heterosexual and 26% as homosexual [5]. Demographic information about the providers for these patients was not discussed [5]. Using grounded theory, these researchers explained the cyclical process occurring when people living with HIV engage and fall out of care [5]. During their analysis, researchers found that clients' perspectives on their relationships with providers was a key element impacting the process in which people living with HIV engage and remain in care [5]. The way providers treated and interacted with the patient greatly impacted engagement in care [5]. When providers practiced more validation and viewed the patient as a partner in decisioning making pertaining to care, retention to care was facilitated [5]. Paternalistic behavior from the provider negatively impacted client engagement [5]. Patients desired empathic providers who had strong and impactful communication skills [5]. Mallinson and others' research found the role of the provider to be very important to keep patients in care [5,19]. These authors concluded that role of the provider should be researched further, to learn how these relationships can impact overall HIV health for people living with HIV in order to discover more factors influencing these relationships.

#### Healthcare Experience for YB-GBMSM

As previously mentioned, people living with HIV need to engage at all stages of the HIV care continuum to obtain better overall health. However, many individuals struggle to achieve full engagement across the HIV Care Continuum. Engagement in HIV care for Black GBMSM as mentioned before can be influenced by societal factors. Black GBMSM often feel stigmatized and discriminated against when seeking HIV care because of their race and sexuality [21]. These oppressive conditions such as stigmatization and racism in society have influenced the healthcare experiences of Black GBMSM. Many Black GBMSM struggle to open up about their sexuality to their medical providers because of the fear of increased discrimination [21].

In a study conducted by Malebranche et al., Black GBMSM discussed having a personal connection with their provider was important especially with regard to race, gender and sexuality [21]. Black culture was a very important component many Black GBMSM desired to relate on with providers [21]. They felt if they had a black doctor they could relate more on a personal

level. Aside from wanting to connect on race, sexuality and gender, patients wanted to feel some sort of individual connection to their provider [21].

The above study focused on the effects of provider racial and sexual identity of Black GBMSM from the patient perspective; it is also important to understand how these issues are perceived by the providers themselves. As previously mentioned, many patients desire providers who treat them as partners in decision making [5]. Other research shows shared decision making and communication between patient and providers is associated with positive health outcomes such as adherence to ART [17]. Peek and colleagues developed a conceptual framework to understand shared decision making between Black lesbian, gay, bi-sexual and transgender (LGBT) patients and their providers [17]. The study examined the impact of patient race and sexuality on their patient provider relationships and shared decision making in the clinical setting [17]. Disparities in communication and less shared decision making can contribute to more health disparities in racial and sexual minorities. This study in particular acknowledges that privileges and interactions associated with race, gender and sexual orientation impact not only the patients but providers.

#### **Discordant and Concordant Relationships Between Client and Provider**

More studies have explored into how discordance or concordance of race impacts care satisfaction for patients. One study conducted by LaVeist and others focuses on these phenomena of race concordance and greater satisfaction of care. Although their study did not focus on HIV positive people specifically, it examines a sample of different races to see if race concordance is a predictor in patient satisfaction [15]. In all racial groups, patients that could choose their physician were more likely to have a provider who was race concordant [15]. Additionally, white patients were more likely to be of the same race as their provider [15]. In all racial groups, those who were race concordant with their provider self-reported greater satisfaction with their provider [15]. From this study, it was recommended to increase minority providers as well as training providers how to better interact with patients who are not of the same race [15].

A few years later, Street and colleagues conducted a cross-sectional study to look at the perceptions of patients in relation to demographic similarities with their providers and patient ratings of care quality [12]. Both black and white patients who were racially concordant with their providers reported having more personal and ethnic similarities to their providers [12]. Perceived similarities between patient and providers were impacted by other factors such as patient centered communication used by the provider [12]. As shown by these two studies, the patient-provider relationship is strengthened when patients can see similarities with their care provider in beliefs, values and communication style used by the provider.

#### **Cultural Competence**

As mentioned previously, physicians need to be trained on how to interact with patients who are not of the same race, ethnicity, or sexual orientation. One core way to do this is through cultural competence trainings. Cultural competence can be viewed as a way to address the health disparities that racial minorities are experiencing. Betancourt and others define a culturally competent health care system "as one that acknowledges and incorporates—at all levels—the importance of culture, assessment of cross-cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs" [16]. Many of the previously discussed articles mention communication as a key component in clinical encounters benefitting patient's healthcare experiences. With cultural barriers, clinical encounters can be negatively impacted because communication and trust are affected [16]. These issues often lead to poor adherence and health outcomes because of patient dissatisfaction. When providers are not aware of these cultural and social factors, they can have inherent biases and treat certain patients differently based on their race, culture or social status.

A study by McNeil and others focused on creating a model for cultural competence to better the management of HIV care for Black patients [18]. In their model, cultural competence is a necessary component to provide culturally appropriate care to Black HIV positive patients [18]. The HIV status of patients was considered by providers as another part of dimensionality of culture to be aware of and sensitive to [18]. Providers expressed their belief that HIV status was more stigmatized in Black culture and discussed challenges in connecting with patients due to multiple factors such as emotional distress, societal discrimination, economic hardships and the HIV stigma [18]. Another study, focused on cultural competency in the experiences of HIV positive sexual minority males, highlighted the importance of the social and cultural contexts of sexual identity in the healthcare experiences and treatment of HIV positive sexual minorities [19]. Providers in this study who are more aware of the importance of sexual and social identity of their patients had patients with more medical adherence and care seeking behaviors [19]. Saha and colleagues advance this line of research a step further and evaluate whether cultural competency is associated with better quality of care, providing equitable care and leading to better health outcomes for patients [6]. They found that the quality and equity of care patients received was associated with provider cultural competency [6]. The research suggested enhancing providers cultural competency could lead to reduced disparities in the healthcare quality and outcomes linked to race. In order to measure cultural competency, they developed an instrument to measure the different factors considered to collectively create cultural competency. The scores for providers that had higher levels of cultural competency were seen to be associated with more equitable care across all racial groups examined [6]. When the providers had lower

levels of cultural competency, more racial disparities were seen in receiving ART treatment, viral suppression and the patient's perceptions on their medical adherence [6]. No racial disparities were seen in different health outcomes and engagement when providers had higher cultural competency [6]. Through these numerous studies, the literature shows the importance of understanding the many intersecting identities of patients and a need to increase cultural competency to mitigate racial health care disparities.

## **Cultural Distance**

Cultural distance was used by Saha and others as a measurement to understand the cultural differences between patients and their providers [7]. Cultural distance as defined by Saha et al. is a continuum used to measure the cultural differences between providers and patients [7]. The study aimed to examine whether cultural distance offered explanation for racial disparities in HIV care and if cultural distance was related to the quality of health care people living with HIV receive [7]. It was through the patient perspective that cultural distance was measured as well as their trust in their provider, receiving ART, medical adherence, viral suppression, and rating of healthcare quality received. They found when greater cultural distance was present, patients experienced lower healthcare quality and less trust in providers [7]. Non-white patients were less adherent to their medicine, fewer were virally suppressed, and had lower levels of trust in providers [7]. Ultimately, these researchers concluded that cultural distance between patient and providers negatively impacted trust and perceived quality of care [7]. This study also researched cultural distance to see if it mediated any health disparities in HIV care related to race, the racial disparities in HIV care though were not resolved by having less cultural distance.

Our study aims to expand upon the existing research on healthcare experiences of YB-GBMSM and learn more about the topics of cultural competence and cultural distance from the perspective of HIV care and service providers. Learning about the provider perspective may lead to greater understanding of their perceptions of healthcare disparities and their role in the experiences YB-GBMSM have when seeking care or support.

# **CHAPTER 3: Manuscript**

**Title:** The Role of Cultural Distance in HIV Care provision for Young Black Gay, Bisexual and other Men Who Have Sex with Men Living with HIV in Atlanta, GA

# Abstract

**Background:** Young black gay, bisexual, and other men who have sex with men (YB-GBMSM) are disproportionately impacted by HIV, and often face barriers to engagement in care. There is a paucity of research examining strengths of, and challenges facing HIV service and care providers working with this population. We aimed to learn more about the role of cultural distance in the care YB-GBMSM living with HIV receive in Atlanta, Georgia.

**Methods:** We conducted 28 qualitative interviews with key informants from healthcare and community-based organizations that serve YB-GBMSM. Interview domains included descriptions of service provision, personal identity, and cultural competency. We utilized rigorous team coding to and thematic analysis to identity our results.

**Results:** Most (86%) of the key informants were black, 25% were women, and 80% identified as non-heterosexual. Key informants' personal identity characteristics influenced the type of support that they offered to YB-GBMSM. Women often described providing support through nurturing and caregiving methods. Black gay men offered mentorship from personal experiences as a feature of their supportive practices. Participants discussed the need for improving representation of YB-GBMSM among providers, highlighting the role of cultural distance as contributing to gaps in their understanding of the experiences of YB-GBMSM.

**Conclusions:** The racial, sexual, and gender identity of HIV care and service providers influenced their approach and orientation in offering services and support to YB-GBMSM. Efforts to increase the representation of YB-GBMSM in the public health workforce are needed to decrease cultural distance.

Key Words: HIV/AIDS, patient-provider relationship, cultural distance Word Count: 241/250

# Introduction

Between 2012 and 2016, the annual incidence rate for HIV/AIDS has increased in some groups of people in the United States (US), while remaining stable in the country as a whole [1]. Gay, bisexual and other men who have sex with men (GBMSM) are disproportionately affected by HIV/AIDS compared to other US populations, representing 82% of HIV diagnoses in males and 66% of all diagnoses in the population as a whole [1]. Black men account for the largest number of new HIV diagnoses within MSM population [1]. Additionally, young men ages 13-34 account for 3 out of 4 new HIV diagnoses among Black GBMSM [2]. Over half of the new HIV diagnoses in 2017 were in the South, and half of those diagnoses were in Black Americans. Specifically, in the state of Georgia, the rate of new HIV diagnoses was 24.9 per 100,000, making it the state with the highest incidence rate [3]. The reasons behind these disparities are incompletely understood. Studies examining the role of individual behavior factors have consistently demonstrated that young Black GBMSM (YB-GBMSM) do not engage in individual risk behaviors at higher rates than their non-Black peers [9]. This evidence points to the importance of examining a range of other social determinants that impact the HIV epidemic in YB-GBMSM.

In addition to being at higher risk for acquiring HIV, YB-GBMSM are also at risk for lower rates of engagement in HIV care [9,19]. HIV care is conceptualized as a continuum that includes HIV testing, linkage to care, retention in care, medication adherence, and viral suppression [4]. The HIV care continuum is an instrumental framework for depicting how people living with HIV can maintain a suppressed viral load by adhering to an antiretroviral therapy (ART) regimen. A core component of the HIV care continuum after linking HIV positive individuals to care is retaining these individuals in care to then prescribe to them ART with the hopes of leading to viral suppression. In individuals who are aware of their HIV status, approximately 50% of them are not engaged in regular HIV care [4]. Individuals who are suboptimally engaged in care have poorer health outcomes [4].

The relationship between people living with HIV and their health care provider plays a critical role in maintaining patient's retention in care across the care continuum [5]. Hightow-Weidman et al. further explored the HIV care continuum for YB-GBMSM. Their findings show being engaged in care is associated with YB-GBMSM having insurance and higher self-efficacy in communication with their care provider [19]. Qualitative work conducted by Mallinson et al. through in-depth interviews with people living with HIV has highlighted the importance of the patient-provider relationship as a critical element for facilitating engagement and retention in care [5]. From the patient perspective, when providers' behavior to patients was validating and the patient felt more like a partner in the relationship, engagement in care was facilitated. The study's participants described wanting a care provider who shows empathy with good communication skills, leading to a positive mutual respect between patient and provider [5].

Other work has highlighted ways in which patient-provider relationships may impact the health of sexual and ethnic minorities differently, and potentially contribute to disparities in health outcomes. Saha and colleagues conducted two studies over the course of two years, both focused on ways to explain the racial and ethnic disparities in HIV care [6-7]. The first focused on the role of *cultural distance* between patient and providers, while the second aimed to learn more about perceived cultural competency of care providers [6-7]. In both studies, providers and patients were surveyed or interviewed to offer insight into the quality of HIV patient care. While past studies have examined the influence of discordant and concordant race and ethnicity in patient provider relationships, Saha and colleagues aimed to expand beyond the patient-provider dyad to understand the larger issues surrounding these interactions [7]. They defined cultural

distance as a continuum used to quantify the cultural differences between patients and their providers.

An instrument developed by Haidet et al. was used to measure patient's perceived cultural distance from their provider [7,22]. The dimensions of cultural concordance and discordance between patient-provider are obtained through this 4-item scale [7]. The items evaluated in the instrument are "patients' perceived similarity to their provider in terms of speech and language, reasoning, communication style and values" [7]. Appendix 1 shows the cultural distance measurement tool utilized to understand patient perceptions on cultural distance between providers [7]. Of note, the scale does not specifically ask questions in regard to racial or sexual orientation differences and how patients perceive these differences with providers. Using this instrument, the research team found that greater cultural distance was associated with lower patient perceived health care quality and less trust in their providers. However, cultural distance was not found to vary between the different racial groups of patients; therefore Saha et al. that racial differences in outcomes were not explained by cultural distance.

Saha et al. also conducted another study focused on cultural competence of HIV care providers in relation to mitigating racial/ethnic health disparities minority populations are experiencing. Specifically, they wanted to understand if the cultural competence of HIV care providers was associated with better care and health outcomes for people living with HIV engaged in care [6]. Additionally, they aimed to explore if cultural competence in providers explained racial disparities found in the health outcomes measured. Cultural competence for this study was defined as "their [providers'] effectiveness in caring for patients from diverse backgrounds" [6]. Provider cultural competence was measured with an instrument Saha et al. developed, shown in Appendix 2, to capture the dimensions of "awareness, attitudes, skills, and behaviors that have been collectively referred to as 'cultural competence'"[6]. Through both patient and provider perspectives, it was seen that providers with a self-perceived higher cultural competence had patients with better care outcomes (higher self-reported self-efficacy and adherence to antiretrovirals). Lower cultural competence of providers was related to disparities in care and health outcomes in populations of racial minorities. When providers had high self-rated cultural competence, patients care and health outcomes among the varying racial and ethnic groups was more equitable [6]. This study highlights the importance of the providers' perspectives on their own cultural competence, which has significant implications for the patients they serve. Although the study does not touch specifically on how cultural competence is related to HIV care engagement for these patients, positive health outcomes found in the study when providers have high levels of cultural competence are examined in other research showing higher levels of engagement in care.

The disparities in HIV care YB-GBMSM are experiencing are complex and closely related to other social determinants impacting care seeking behavior and retention. These topics have been further researched by Hussen and colleagues in Atlanta, who have developed a social capital intervention for YB-GBMSM with the goal to improve HIV care engagement in YB-GBMSM by increasing their social capital [8]. The process of creating the intervention included completing qualitative in-depth interviews with HIV care and service providers working at community-based organizations and clinics. These interviews served as key informant interviews to learn best practices when working with YB-GBMSM.

We sought to explore the experiences of HIV care and service providers working with YB-GBMSM. Specifically, we aimed to understand the roles of cultural competence and personal identity of these providers in the care and support they offer to YB-GBMSM. This study will add to the knowledge on the role of providers in HIV care engagement for YB-GBMSM. This research has the potential to inform cultural competence trainings for both care and service providers who work with groups experiencing disparities in health related to race and sexuality.

## Methods

### Context

The purpose of this qualitative study is to understand the influence of personal identity of HIV care and service professionals (care providers, community members, and members of academia) on their ability to provide care to YB-GBMSM. We defined the "personal identity" of HIV care providers as referring to their gender, racial and sexual identity. To answer the research question, secondary qualitative data analysis was conducted on an existing interview dataset. The data utilized for this research was originally collected for a larger mixed-methods study, "Social Capital and Engagement in Care among Young Black Men who have Sex with Men Living with HIV" in Atlanta, Georgia [8]. HIV care and service providers were interviewed as key informants to assist in the development of a social capital intervention designed for HIV positive YB-GBMSM.

#### **Participants**

In order to gain HIV care and service providers' perspectives to assist in the development and design of a program to increase social capital in YB-GBMSM in Atlanta, 28 in-depth interviews (IDIs) were conducted with key informants. The key informants were healthcare and service providers in the Atlanta community, who were nominated by study staff members, colleagues, and members of our youth advisory board (YAB) based on their perceived skill and experience in interacting with YB-GBMSM. The key informants not only varied in occupation but also age, gender, race, sexual orientation, education and years involved in the HIV field. The key informants included clinicians, community- based organization workers, health department employees, research staff, professors, and nonprofit workers. The inclusion criteria for the key

informants were that they had experience working with YBMSM in a clinical or communitybased organization setting and were able and willing to verbally consent to participate in an indepth interview.

## Design

The research team developed a semi-structured IDI guide focusing on the key informants' experiences working with YBMSM (Appendix 3). The interviews took place at the key informant's place of work, the Grady Infectious Disease Program clinic, other mutually agreed upon locations in the community or over the telephone and were conducted by members of the research team. Before beginning the interview process, informed consent was given by the key informants and after completing the interview, they received a \$50 gift card. The interviews were digitally recorded, transcribed verbatim, and imported into MAXQDA (VERBI software, Berlin, Germany), a qualitative data analysis software program. Upon importing the interviews into MAXQDA, the interviews were coded and analyzed. The study was approved by the Grady Research Oversight Committee and the Emory University Institutional Review Board. Researchers conducting secondary analysis were also granted IRB

# approval.

#### Thematic Analysis

We conducted a thematic analysis to find patterns in the data. The analytic process for secondary analysis began by de-identifying the dataset, writing memos, then developing codes. Through an iterative process of reading transcripts, writing memos about repeating themes, and discussing codes within the study team, a codebook was developed and agreed upon. Code definitions were applied, discussed and refined as needed until inter-coder agreement was achieved. The codebook consists of both inductive and deductive codes. The next step in analyzing the coded data was to write a thick description on the strongest inductive code, to discover the depth, breadth, context and nuance of the central phenomenon being analyzed. The themes and codes were compared across the key informants' gender, age, sexuality, race, age and profession. After comparison of codes and themes, conceptual diagrams were created to explain major concepts.

### Results

## Sample Description

The sample of 28 key informants ranged between the ages of 22 and 62 (Table 1) with an average age of 36.5 years (standard deviation = 9.57 years). The majority of participants (86%) identified as non-heterosexual, 80% of participants identified as Black and 25% as female. Some participants self-reported HIV status during the course of their interviews- 25% identified as HIV positive, the rest identified as HIV negative or did not discuss their HIV status. Most participants (23) had at least a bachelor's degree, and the remaining had completed high school and, in some cases, some college as well. Key informants work in a variety of positions at the following work spaces: health clinics, academic institutions, health departments, non-profits, and other community-based organizations. Key informants had been working in the field of HIV from 1 to over 30 years.

In relation to our research questions, the following major themes emerged: *(i) identity in the work (ii) orientation and approach to YB-GMSM,* and *(iii) support.* Within each theme, we also identified various subthemes and categories.

# **Cultural Distance**

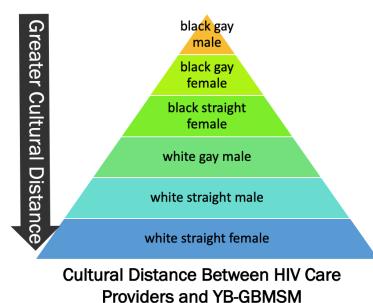


Diagram 1. Cultural Distance Between HIV Care Providers and YB-GBMSM

Cultural distance, as noted by Saha et al. to measure HIV positive patients' cultural differences from their providers, was seen as an important concept discussed in the key informants' interviews [7]. Although the HIV care and service providers interviewed did not mention cultural distance by name, many providers expressed the differences of racial, sexual, and gender identity between themselves and the YB-GBMSM they support as factors that distanced them from relating to their clients/patients. Diagram 1 depicts our conceptualization of the spectrum of cultural distance and where the providers interviewed are on the spectrum in relationship to the YB-GBMSM they work with. Cultural distance increases from top to bottom of the pyramid with the providers that identity as white straight females at the bottom with the greatest level of cultural distance to the YB-GBMSM. The positionality of providers on the cultural distance pyramid was based in the interviews with key informants and their perceptions of the distancing their racial, sexual and gender identity differences impact their ability to relate to their YB-GBMSM clients. Providers' that identified as white straight females have the greatest cultural distance

from YB-GBMSM as they do not have any overlapping identities. The following quote demonstrates the distance one of the white straight female providers felt and how she interacted differently with the YB-GBMSM than other providers who have less cultural distance. Interestingly, she viewed her cultural distance from the YB-GBMSM she works with as a strength. Since she was not a part of the black or LGBTQ community, she was able to approach them with an open mind.

But I think that because I work with the patient population that by and large is nothing like me, I think that has actually helped me in that I don't hold any preconceived notions because I haven't ever really had this type of intimate exposure to the patient population. So I'm not really coming to it with any kind of bias because my community didn't look like this community. My family didn't look like this community. I certainly had, you know, friends and family that could fit individual demographics of the community but, like, this isn't what my community looked like...Um, and I think I definitely can see a difference in how I interact with my patients versus, um, and, obviously again, not every individual person in this building, but like, I think I can see differences in the way that my black colleagues work with this patient population with the way my, um, LGBT colleagues work with this patient population and I think that - and I see this certainly with my direct coworker who, um, identifies pretty much opposite to everything that I, other than being female, um, in terms of sexual identity, race, um, socioeconomic upbringing, we are like complete opposites (White Straight Female, 30)

Providers further up towards the top of the pyramid have more overlapping aspects of identity

leading to less cultural distance. A provider who identifies as a black gay man explained in his

interview how being part of the Black GBMSM community allows providers to better serve the

population by connecting and understanding them.

there's a lot of people in this field that have no clue about what it feels like to be the patient. And without that knowledge or understanding, you'll never really be able to adequately, you know, service that population (Black Gay Male, 32)

Race was shown as the component of identity that was strongly connected to limiting cultural distance between providers and YB-GBMSM. A black gay female provider described how being

black is an instrumental part of her work in the HIV field as she is working for her community, the black community.

Oh! I'm black!! So, I think being black, I mean I can relate to black people. So it's like I said, it's all about community... I think it makes it more relatable too. Like, because you don't just see it as work in most aspects. Now it's, okay like this is what I'm doing for my homey. You know this is what I'm doing for this person...So you know this is what I'm doing from my heart, from my passion, from my soul to give. So I would definitely say that black lives matter. And because of that, because I am black, I do not want to see anybody in my community of black people in despair. I don't want to see them discouraged, I don't want to see them oppressed, I don't want to see them anything negative, I want to uplift them, so. (Black Gay Female, 29)

The majority of providers discussed their identity and the role it played in informing their work. The self-described gender, racial and sexual identities of providers often enforced the reason for why they were in the HIV field, and informed their approaches towards working with YB-GBMSM.

Many providers mentioned the importance of being aware of one's identity when working with YB-GBMSM, and the impact it could have on this work and relation to YB-GBMSM. All providers often discussed a lack of focusing on the influence racial, gender and sexual identity have in this work. Acknowledging the importance of identity allowed providers to reflect on how to better approach and engage the YB-GBMSM community in the care and services they were offering.

I don't think - I don't think we acknowledge enough that, um, that race and sexuality and gender expression, um, and all those kinds of intersections of identity, I don't think we acknowledge enough that they matter, that they matter and they shape our experience and they shape the way that we navigate the world... Um, and I think that's a big piece of what's missing. And if you, as a provider, um, especially if you're from a different race, a different socioeconomic class, if you can't acknowledge that you don't even, you know, at baseline, um, you can't even understand the way that your patients navigated in the world and you can't even understand the they acompletely different experience from you and, an experience that you will never understand, right? Then if we can't even acknowledge that piece, then we're missing a chunk, right? (Black Gay Female, 33)

Some providers found that even if they had less cultural distance, they could still feel distance and a difference from their clients due to the great diversity within this community.

Now, the challenge that I've had in some cases is, um, I guess sometimes I can come off a little bit too masculine for a lot of my more feminine clients and they'll come in and they'll be thinking they're dealing with a straight guy, so they'll kind of keep it together for a little while until they look around my room. I try to make my room open and, and they can see something in here that will make you know, well, maybe he might be. And then as we talk, I may say something and they'll be like, 'Okay, he is gay.' The moment that they get that grin, and I can always see it, they open up, they just start talking. (Black Gay Male, Care Resource 43)

Other providers (particularly those who are non-Black) may appear to be further distanced in identity from the YB-GBMSM they work with but still feel a close connection to them either because of their ability to empathize or feeling they truly listen to their clients or patients. They acknowledged that they cannot truly understand the experiences their patients and clients go through because of the greater levels of cultural distance. One provider who is a white gay male explained his perceived understanding of his identity influencing his work:

So this is sort of complicated and it's something that I have kind of had to learn. So I'm gay and that allows, you know, a limited bit of identification with that population. But you know it's very limited because I'm, well not young anymore and, I'm not black. And the thing that I have learned over the past like however, many years that I've been doing this, is the experience of growing up as a middle-class white guy, white gay guy, is very different than the experience of growing up black and gay and that it's really not the same. So there's some, you know, there's some common causes, there's some identification but, you know, it's not all the same (White Gay Male,48)

Providers with less cultural distance found their identity to be a powerful asset to their work and allows them to engage more with their clients and patients because they feel a true understanding to what their clients experience. These providers saw their shared identities with their clients as a strength, allowing the YB-GBMSM to "see themselves" more in the field of HIV prevention/treatment.

And me being African-American, I think it helps when, uh, people see themselves when they walk in the door. Um, it helps when anybody can come in and, and see a black man sitting up there talking about HIV and knowing some things. But, especially when people see themselves, because I'm, I'm, I'm listening a little bit closer when I see myself. (Black Gay Male, 43)

Only one provider felt that his identity did not inform his work in the field of HIV prevention

when working with YB-GBMSM:

Um, I don't think that that has an effect. I mean, I'm African American and most of the people I connect with are African American. But, I mean at the end of the day, I don't - I don't see color and whether it's in a room full of African Americans, Indians, Asians, um, my story doesn't change, my approach doesn't change. (Black Gay Male, 33)
Overall, being aware of one's cultural distance from YB-GBMSM was discussed among

providers as a critical step in HIV prevention and treatment work.

### **Types of Support Provided**

Participants emphasized different aspects of support that they provided to YB-GBMSM as a part of their work. The types of support varied largely in accordance with their cultural distance from the patients/clients.

A spectrum of support was created to display where providers with specific identity combinations (gender identity, sexuality, and race) in this data were in the spectrum of support. Three different aspects of support were discussed in detail: empowerment, empathy and guidance.

#### **Empowerment**

Empowerment was identified as an important aspect of support and was more commonly cited by Black and/or gay providers in describing their support of YB-GBMSM. Specifically, empowerment manifested as mentorship, community, and personal connection. The theme of *mentorship* came up primarily from older black gay and bisexual men, who discussed acting as mentors for the next generation of community leaders. The majority of these older black gay and bisexual male providers reflected on not having had support from older generations growing up, and stated that this experience motivated them to do this work and serve their community. At the same time, they acknowledged generational differences and used mentoring as a way to bridge this divide:

So I'd rather mentor you and not try to tell you how to do it or what to do exactly, but maybe give you some advice and you can take it or not, but it's your part of the struggle right now, it's your battle. So it's your generation that you're fighting for. So I want to help in any way. But also acknowledging the differences between when I was in your shoes and where I am right now. (Black Gay Male, 48)

Providers described empowerment as a type of support in reference to giving YB-GBMSM strength to carry on through the tough times and serving as a source to always rely on. They felt it was necessary to be a source of strength due to the many times YB-GBMSM are often unsupported in different aspects of their lives. One provider, who was a Black gay man, expressed a lack of support seen from the larger Black community for the Black LGBTQ community as a driver for why he wanted to empower the black gay community which he refers to as "his community". Only Black providers mentioned empowerment in discussing the support they aim to give YB-GBMSM. Those who practiced this type of support aim to encourage, uplift, inspire and want to insure the whole black community which they define as their community is never "in despair". Many Black providers aimed to empower and mentor YB-GBMSM, so they can in turn begin to support themselves and uplift others:

I'm dealing with a lot of those same barriers that they're dealing with but I think I'm providing an example of how to get through. And that presents to them a good – gives them strength and gives them support and, you know, empowerment to realize you know, if he's saying that he's doing it, I can do it too. That's how I bring that to the table. (Black Gay Male, 27)

#### <u>Empathy</u>

Empathy was identified as a core form of support and was described by HIV care providers with greater cultural distance as the main way they supported and connected with YB-GBMSM. It is critical to note even when provider's race, gender or sexual orientation varied from that of the YB-GBMSM, they were still empathetic to the experiences of the YB-GBMSM. By giving support as a form of empathy, providers were better equipped to listen to the YB-GBMSM. Providers often reflected on how they would feel if they were in the same position and imagine the type of support they would hope to receive:

...I'm not a black gay man. So I don't know what they experience but I try to be empathetic and at least be someone that they can have confidence that I'm there to listen to them and to take their concerns, their worries, their fears seriously and try to direct them to existing services...(White Straight Male, 35)

Providers who mentioned being empathetic described themselves as diligent listeners and thus being able to support YB-GBMSM with specific needs. Many who expressed empathy for the YB-GBMSM community had similar racial or sexual orientation to them. Through having a similar identity, providers could more easily empathize due to sharing experiences and community with YB-GBMSM or having family members live shared experiences. Female providers often expressed empathy in a maternal or nurturing way. Many female providers mentioned their naturally warm personality, or being a mother, as a driver for the empathy they gave to their YB-GBMSM clients.

I'm a black woman and I'm a mother with a son. And I can't imagine what would possess some mothers, not many that I know, but I hear the stories, right? But I just think about how much I love my son and I couldn't imagine my son being treated the way that I know a lot of people are treated. So a lot of it is personal. I'm a black woman, a mom, I got a kid. And to see so many broken, you know, to see young people who are broken and who don't have access to their mothers or don't have access to families or whatever, that's a problem... And so I think that, to me, always try to look from that caring perspective as a, probably as a mom first. (Black Straight Female, 45)

### <u>Guidance</u>

The last form of support found was guidance. Guidance was described as a type of support the providers offered as a means to help YB-GBMSM navigate through the unfair events happening in their lives. Those who offered guidance aimed to be givers and offer up a service or recommendation. Providers gave guidance to fill the gaps in support YB-GBMSM experience. They gave guidance by first being a listener and then acting as a linker. Through acting as listeners, providers gave support by listening to YB-GBMSM's concerns and then linking them to the proper care they need. As linkers, providers hope to link YB-GBMSM to proper care and a variety of services of benefit to them. The majority of providers who support YB-GBMSM by serving as listeners and linkers were men.

#### **Cultural Competence**

Regardless of personal cultural distance from YB-GBMSM, providers highlighted several important related to cultural competence that informed their work and/or their recommendations with respect to YB-GBMSM.

### Recognizing the diversity of YB-GBMSM

The impact of the diversity of YB-GBMSM on approaching both health care and service needs in the community was a theme that participants discussed frequently. Diversity within the YB-GBMSM population was described as a strength of the community by many. Black gay male providers mentioned the diversity of this community as critical to be aware of when working in providing HIV care and services.

We are the most creative and brilliant folks on this earth. Um, and so I think that holds us together. I think our strength is also in our diversity. What's good about it is our diversity. Like the different facets that we represent. Like, how many different subpopulations there are within black gay cultures. Um, yeah, we're like a patchwork of all different types, shapes, sizes, interests, talents, strengths... kind of our diversity and kind of our strength, and you have to approach everybody a little bit differently. Like, you can't come in assuming... and, it's insulting, like most people will do when you just say, 'Oh, you're black and gay so I'm going to make X, Y, Z assumption about you.' (Black Gay Male, 48)

#### Importance of Representation

Providers with more cultural distance referenced gaps in services YB-GBMSM do not receive such as having community support, inspiration in the community and representation in at their place of work. Many Black gay male providers cited these gaps as reasons they became engaged in the HIV field. Virtually all providers discussed the need to have more representation of YB-GBMSM in the care and service organizations that serve them, as a way to better the care and support YB-GBMSM currently receive. Many providers felt that engaging YB-GBMSM into the care and service workforce would be a way to increase cultural competency in the work environment and with the community.

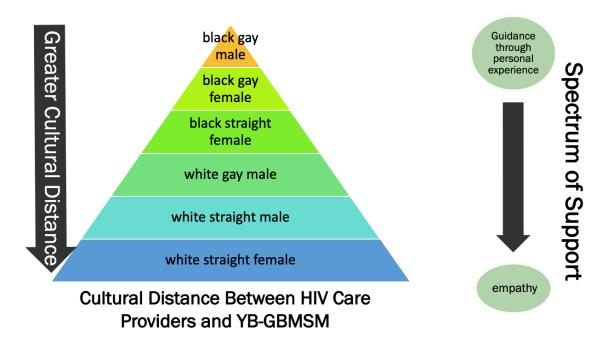
I feel like cultural competency is like everything that we've been talking about. Like, you know, not only creating programs for black gay men, but creating the programs by black gay men for black gay men... doing things in a way that involves the world view of the community that you're doing it for (Black Gay Male, 38)

However, I don't think any of us have efficiently insured that, from top down, there's representation of those people being studied or intervened on within an organization. That happens to nonprofits, that happens in, that happens everywhere, right? So I think I'm not saying that you have to be black and gay to be able to intervene in the lives of black or gay males, not saying that. But I do think that you can add more substance and experience to a person's experience and there is something to say when you walk into a place and you see faces that look like you because that gives you this next level of hope, maybe inspiration, that you can get to a point. (Black Straight Female, 45)

## Discussion

We examined the role of personal identity (gender identity, sexual identity and racial identity) of HIV care and service providers in their perceived ability to provide care to YB-GBMSM in Atlanta. Additionally, researchers aimed to explore the influence of cultural competency and cultural distance in the work of HIV care and service providers. We found HIV care and service providers' approach to working with and caring for YB-GBMSM is influenced by cultural distance and understandings of cultural competency, which in turn impacts the type of support they offer to YB-GBMSM.

The support offered from HIV care and service providers was associated with the cultural distance between the providers and YB-GBMSM and resulted in a spectrum of support given.



### Figure 3: Cultural Distance Pyramid in Relationship to the Spectrum of Support

All providers offered support in a variety of capacities and the support they gave fell on a spectrum in regard to their level of shared experiences or identity in relation to the YB-GBMSM they worked to provide care to in their respective positions. Patient-provider identity

concordance has been researched primarily through the lens of overall health outcomes and often not specifically looking at HIV patients' part of a specific demographic such as YB-GBMSM. The primary characteristic of research has been focused on gender and racial identity [10-11]. Many of these studies are based in the theory of Intersectionality. Intersectionality is a concept originally used by Kimberlé Crenshew to describe the way in which gender and race interact "shaping the multiple dimensions" of experiences for Black women [22]. Her original work on Intersectionality Theory has contributed to research to understand engagement on the HIV care continuum for Black HIV positive individuals. One study conducted by Freeman et al. employs intersectionality theory but just focuses on gender, race, and socioeconomic status as the characteristics to examine intersectionality with HIV care engagement [23]. YB-GBMSM have multiple dimensions of their lives in which they face discrimination or are labeled as minorities. Our research is adding an intersectional perspective to the concept of cultural distance by engaging in provider's intersectionality of identity and the role this intersection has when working with YB-GBMSM.

Our findings suggest the importance of understanding provider gender, racial and sexual identity and the way these identities enhance or challenge their work. Community-based organization (CBO) service providers offer critical services in HIV prevention and treatment directly impacting individuals and their communities. There is little knowledge on the relationship between CBO service providers' relationships with YB-GBMSM and any implications concordance of identity may have on the way YB-GBMSM receive these services. Additionally, much of the research on concordant provider-patient relationships focuses on the perspective of the patient. To offer a more complete view of the processes our research aimed to gain more insight on the provider perspective [10,12]. Many providers stressed how critical these components of identity are when working with a demographic such as YB-GBMSM whose racial and sexual identity interact greatly with the health disparities they encounter and systemic structural issues impacting their overall wellbeing [9,13-14]. Providers who are more aware of the role their gender, racial and sexual identity play at work can better understand how these components impact their positionality at work with patients and clients of concordant or discordant identities. These findings fill gaps in knowledge about the role of additional components of identity not just racial and gender identity in relation to provider and patient or client relationships.

As seen in previous literature, our analysis suggests providers having shared identity and experiences to their clients and patients can enhance the relationship in patient-provider dyad [10-12,15]. Providers who have shared experiences as their patients found their work was enhanced and more impactful. They found it allowed their clients to "see themselves" while increasing the connection between themselves and their clients. Providers with different experiences believed their patients would have a better experience working with providers who had more similar experiences to that of YB-GBMSM. Different perspectives from the side of the provider on supporting YB-GBMSM are needed as well because multiple types of support to care for YB-GBMSM are valuable. The strength of shared experiences between providers and patients and the positive relationship with patients that providers feel is present in their work, displays the positive outcomes of minimizing cultural distance as Saha and colleagues discuss in their work [7]. Our results suggest increasing the Black MSM presence the HIV care and service provider workforce has the potential to improve YB-GBMSM engagement in care. Providers with greater cultural distance from their patients were still found to feel a very strong connection amid identity differences. These providers often focused on empathy in their interactions with YB-GBMSM. Through these strong levels of empathy, providers felt they listened and learned from their patients and were more attuned to client needs. Although

providers acknowledge the differences between themselves and their patients, they found they needed greater cultural competency to understand their patients' stories and experiences. Our findings suggest that, through an increased self-perceived level of cultural competency, providers could practice moral imagination and reflect on how it may feel to be in the position of an HIV positive YB-GBMSM in society. These findings add to previous research exploring cultural competency and the role it plays in HIV prevention work [6,16].

Our findings on cultural distance added nuanced to the existing body of research on cultural distance. Our secondary data analysis utilized qualitative data while Saha et al. was a quantitative study using an instrument to measure cultural distance [7]. Additionally, the instrument used in the previous study does not ask any questions regarded to gender, racial or sexual identity but rather it focused on patient-provider communication. The analysis conducted with our data expanded on the concept of cultural distance by directly asking providers about their gender, racial and sexual identity in relation to their work and clients. The biggest difference between our study and other cultural distance research focused on HIV care was the focus on providers. Previous studies do not inquire about the provider perspective on cultural distance or how these cultural differences between themselves and patients may impact patient care. We focused exclusively on the provider perspective allowing us to explore more about cultural distance through the provider lens to add to patient perspective driver studies.

There is more existing research pertaining to cultural competence in relation to HIV care and service providers and their patients than cultural distance. Saha and others also explored the role of cultural competence of HIV care providers and HIV care outcomes [6]. Again, Saha and colleagues research utilized an instrument to measure cultural competency quantitatively while we examined it through qualitative data. The equity and quality of HIV care patients received was associated with provider cultural competency [6]. Our findings both add to and supplement their conclusion that negative healthcare outcomes may be reduced by augmenting provider cultural competency. Many of the providers in our study discussed the need to increase cultural competency training and expectations for those working in HIV prevention with the hopes YB-GBMSM will receive more culturally appropriate care. The research we conducted added to the perspective's providers have on the importance of cultural competency in this work. Additionally, our findings offer specific knowledge on working with YB-GBMSM whereas sexuality was not discussed in the previous study.

Although the terminology of cultural distance was not explicitly stated, the concept of cultural distance as described by Saha and collogues was frequently discussed [7]. Many of the HIV care and service providers discussed minimizing the distance in racial and sexual identity would lead to more opportunity for the YB-GBMSM they care for to relate to the provider and hopefully as a result, new levels of support would be reached. Our results suggest having more cultural distance creates less opportunity for the provider to relate to the patient's life experiences linked to these specific identity components. Since providers in the field of HIV prevention have varying levels of cultural distance, cultural competency trainings must increase and be effectively executed so those with discordant identity are more away of how their identity may impact their relationship with the YB-GBMSM they care for.

Motivations for providers of different cultural distance to work in HIV were complementary and added more information to the importance of providers in the HIV care continuum. Providers with discordant identities to YB-GBMSM often discussed gaps they see in the lives of YB-GBMSM including lack of role models in the YB-GBMSM community or lack of support from the black and LGBTQ communities. Since these providers have increased cultural distance, they are aware they cannot fully fill these gaps. However, providers with less cultural distance from that of their YB-GBMSM patients and clients can fill these gaps of not having enough black gap

male role models and representation in these spaces were YB-GBMSM seek treatment and services. Many of the providers with more shared experiences and identity expressed trying to mitigate these gaps of experiences for YB-GBMSM is precisely why they are engaged in this work.

This study of HIV care and service providers working with YB-GBMSM in Atlanta adds to the body of knowledge existing about cultural distance and cultural competency. It offers more information guiding the orientation and approach providers with increased or decreased cultural distance to YB-GBMSM may take when working with this population. All these factors of identity feed into the type of support providers offer to YB-GBMSM. Through this research, cultural competency trainings may be better informed and implemented for both care and service providers who work with groups experiencing disparities in health related to race and sexuality. As a result of this new knowledge, public health interventions aimed to increase provider cultural competency, and awareness and importance of gender, racial and sexual identity in this work can be better informed.

# Limitations

There are several limitations to this study. As a secondary analysis, the study is limited in that the researcher was not part of the original study design including designing the research instrument and selection of interview participants. Therefore, the data is subjected to interpretation by a researcher who was not present for the process of data collection and instrument design. Certain demographic information about the providers such as self- reported HIV status, specific years in the field of HIV prevention and previous work before working in HIV field are unknown and may have added rich comparisons and information. Much of the demographic information available for these participants was gathered directly from the interviews. Additionally, key informants were purposively selected through recommendations by patients and clients with the hope they would have good recommendations for developing an intervention for YB-GBMSM. As a result, representation from less culturally competent/aware providers who may not have positive relationships with their clients and patients are not represented here.

### Conclusions

Gender, racial and sexual identity of HIV care and service providers influenced their approaches to working with YB-GBMSM. The discordance or concordance of their identity in relation to the YB-GBMSM they work to support has public health implications in the support YB-GBMSM receive and the potential positive relationships between providers and YB-GBMSM. Our results suggest decreasing cultural distance between providers and YB-GBMSM leads to more understanding of the YB-GBMSM experience and greater capacity to support one's community due to shared lived experiences. Future research in the topic of cultural distance should be conducted to better understand health outcomes when less cultural distance is present between providers and YB-GBMSM. HIV prevention and care should focus on enhancing cultural competency training of providers and increasing the number of providers in this field who closely relate with YB-GBMSM.

Demographic Characteristic	Total Sample (n=28)
Age:	
Age Range	22-62
Median	34
Race: n (%)	
Black	24 (85.71%)
White	4 (14.29%)
Education Level: n (%)	
Some College	4 (14.29%)
Bachelor's Degree	8 (28.57%)
Advanced Degree	15 (53.57%)
High School Diploma	1 (3.57%)
Years in the field of HIV prevention:	
Year range	1-30
HIV Status: n (%)	
Positive	7 (25%)
Negative	6 (21.43%)
Unknown	15 (53.57%)

### **CHAPTER 4: Recommendations**

This study aimed to understand the role of personal identity of HIV care and service providers in their perceived ability to provide care to the YB-GBMSM community in Atlanta. Our research explored cultural competency and cultural distance and the importance of these concepts in working with YB-GBMSM. Through this research, more insight has been gained on how to improve the care YB-GBMSM receive from HIV care and service providers. Our findings offer information on the challenges HIV care and service providers face when they experience concordance or discordance of identity with YB-GBMSM. More exploration of public health interventions, research and recommendations come as a result of the public health implications of this study. The following recommendations are aimed to promote the strengthening of the cultural competency among HIV care and services providers as well as greater understanding about cultural distance and the impact their gender, racial and sexual identity may have on the YB-GBMSM for whom they support and care for. These recommendations build upon existing initiatives and recommendations from the providers interviewed for this research project.

# 1. More Research

A main finding of our study was the understanding by many of the HIV care and service providers that being aware and knowledgeable about the impact of one's identity and the influences identity may have when working with YB-GBMSM is critical. Since the participants in our study were purposively selected based on their positive relationships and connections with the YB-GBMSM they work with, more research is needed on these topics with providers of varying levels of connection with their patients and clients. Further research with more providers will allow not only potential validity in results but also offer more knowledge from providers will less connections with YB-GBMSM to learn how to more positively influence these relationships in constructive ways. Additionally, there is a lack of knowledge on the role community based organizations (CBO) and how service providers at these organizations influence the lives of YB-GBMSM. The majority of the participants in this study with less cultural distance to the YB-GBMSM worked at CBOs. Adding to the knowledge base about CBO service providers and the impact these relationships have of YB-GBMSM would complete this research. With our current findings, more research would be beneficial and should be invested in to understand HIV care and service providers' perspectives even more to learn recommendations they may have in how to approach cultural distance and identity differences.

### 2. Cultural Competency Trainings

The majority of providers who mentioned their varying places of work noted that cultural competency was either not something present at work or the trainings currently in place did not suffice or were not firmly enforced or monitored. A key theme from our analysis was the role cultural competency plays in understanding YB-GBMSM and the cultural distance a provider may experience from the YB-GBMSM community they aim to support. Cultural competency trainings that keep in mind the concept of cultural distance, fostering open and honest dialogue, and growth between providers and YB-GBMSM could positively influence the health outcomes of YB-GBMSM living with HIV. These trainings should be required for all HIV care and service providers who work to support YB-GBMSM even if the capacity in which they do so may seem minimal. We propose these trainings be led by YB-GBMSM in order to have their perspective in understanding services they need and how to approach and relate to them more effectively. Participants did express they felt it may not be possible to be fully culturally competent towards a community unless they are part of the community. These cultural competency trainings

would aim to further push understanding of the YB-GBMSM community and hopefully lead to better connections between providers and YB-GBMSM.

These trainings should start at the beginning of HIV care and service providers careers in the field of HIV prevention. Positive provider-patient relationships are important for health outcomes and exposing providers to cultural competency trainings at the beginning of their careers could positively impact and strengthen their connections with patients as well as emphasize the importance of these issues in HIV prevention work.

#### 3. Engagement of YB-GBMSM

Our analysis showed overwhelming recommendations to engage YB-GBMSM more in the HIV care and services provided to them. Engaging YB-GBMSM to have more people representing their community working in the positions of HIV care and service providers has the potential to positively affect YB-GBMSM experiences overall when seeking HIV care and services in Atlanta. A few participants who were part of the YB-GBMSM community mentioned feeling both tokenized in their current position or they were only working there to recruit more YB-GBMSM for studies. More effort needs to invested into the YB-GBMSM currently working in HIV prevention work to keep them engaged and encourage those who may be interested to be involved to learn more about how they can help their communities in this work. The previous recommendations would help in engaging YB-GBMSM by creating more culturally competent work environments in which YB-GBMSM may want to continue working in, feeling valued and more confident in their careers and contributions in HIV prevention.

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# **Appendix 1: Cultural Distance Scale**

## **Cultural Distance Scale:**

- 1. The way my doctor and I speak is \_.
- 2. The way my doctor and I reason about problems is \_.
- 3. My doctor and I have \_ styles of communication.
- 4. My doctor and I have general values in life.

Response options: very similar (1), moderately similar (2), slightly similar (3), slightly different (4), moderately different (5), very different (6).

# **Appendix 2: Self-Rated Cultural Competence Instrument for Primary Care Providers**

Table 5. Self-Rated Cultural Competence Instrument for Primary Care Provider	Table 5.	Self-Rated	Cultural	Competence	Instrument f	for Primary	Care Provider
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	ltems	Domains
Awareness	1. I understand the distinctions between the concepts of race, ethnicity, and culture.*	Concept of Culture
and Attitudes		Delene (Contractor I Contract
	3. Understanding a patient's culture is vital to providing effective health care.*	Relevance of Sociocultural Context
	<ol> <li>Physicians can provide excellent care without knowing much about a patient's social environment. (R)</li> </ol>	
	5. Finding out where patients live and work is an essential aspect of the medical history.*	
	6. Family and friends are as important to a patient's health as doctors are.	
	7. Health care providers should not ask patients about personal matters like religion and	
	spirituality. (R)	
	8. The social history rarely contributes much to how I care for my patients. (R)	
	9. Minority patients in the U.S. as a whole receive lower quality health care than white patients.	Disparities in Health and Health Car
	10. Being white affords people many privileges in the U.S. that minorities don't have.	1
	11. I am familiar with most of the lay beliefs about disease that my patients have.	Diverse Beliefs and Behaviors
	12. Lay beliefs about disease and treatments are an impediment to good medical care. (R)	
	13. I am not interested in hearing patients' folk beliefs about their illnesses. (R)	
	14. Working with patients from different cultural backgrounds is an exciting part of being	
	a doctor.	
	15. Physicians can learn a lot from patients about providing good medical care.*	
kille and	16. I have little patience for people who believe in "wives' tales" over science. (R) 17. I am comfortable asking patients from different cultural backgrounds about their	Cross-Cultural Care
Skills and Behaviors	beliefs and customs.*	Cross-Cultural Care
chaviors	18. I know where to find information about prevalent beliefs and health practices of different	
	cultural groups.	
	19. I feel less than competent working with patients from cultural backgrounds different	
	from mine. (R)	
	20. I am equally effective in caring for minority patients as I am in caring for white patients.	
	21. I ask all my patients about complementary and alternative therapies they may be using.	
	22. I feel comfortable adapting my approach to patient care for patients from different	
	cultural backgrounds.*	
	23. I'm uncomfortable letting patients believe things about their disease that I don't believe	Patient-Centered Communication
	are true. (R)	
	24. I am good at negotiating treatment plans with skeptical patients.*	
	25. I always try to find out what patients think is the cause of their illness. 26. I try to maintain professional distance from my patients when caring for them. (R)	
	20. I try to maintain professional distance from my patients when caring for them. (K) 27. I try to involve patients in decisions about their health care as much as I can.	
	27. I uy to involve patients in decisions about their nearth care as hiden as I can.	

scale included 20 instances up to be a scale ranging from strongly asagree to strongly agree. (1) indicates tients with reverse-could response \*Not included in final scale

# **Appendix 3: In-Depth Interview Guide**

# **In-depth Interview Guide: Key Informants**

Thank you so much for agreeing to talk with me today. As you know, we are in the process of developing a program, or intervention, to help young Black gay/bisexual and other men who have sex with men (MSM) living with HIV. We are specifically interested in learning about how their <u>social connections, relationships and networks</u> might be used to help them engage in medical care. At the same time, we are interested in learning about your experiences with this population more broadly. Although we do not expect to discuss personal or sensitive information about you personally, please rest assured that your name (or your organization's name) will not be connected to your interview responses or printed in any publications or documents that may result. So you know, I will be recording our conversation, so that we can be sure capture everything that you say. Do you have any questions before we begin?

- 1. Tell me a little bit about yourself.
- 2. Tell me about your job.
  - a. *Probe* Describe how you personally interact with HIV-positive young Black MSM in the work setting.
  - b. *Probe-* Describe how (*organization name*) works with HIV-positive young Black MSM.
- 3. Tell me about any volunteering or community work that you do in which you interact with YBMSM.
  - a. *Probe* Describe how you interact with HIV-positive young Black MSM in the community setting, outside of work.
- 4. What do you see as the main strengths that young Black MSM possess?
  - a. Probe What are common strengths you see in individuals you interact with?
  - b. *Probe* What are strengths you see in the Black gay community as a whole?
- 5. What do you see as the main strengths that HIV-positive individuals possess?
  - a. *Probe* What are common strengths you see in individuals you interact with?
  - b. *Probe* What are strengths you see in the HIV-positive community as a whole?
- 6. What do you see as the key obstacles facing HIV-positive young Black MSM?
  - a. *Probe* What are common obstacles that you see facing the individuals you interact with?
  - b. *Probe* What are obstacles that you see facing the Black gay community as a whole?
- 7. How do the strengths and challenges that you've just described inform your work with HIV-positive young Black MSM?
- 8. HIV-positive young Black MSM are not a homogeneous group. Can you speak a little about diversity within this group, and how that impacts the work in this community?

- 9. How do you think that healthcare facilities and AIDS service organizations in Atlanta are doing in terms of meeting the needs of HIV-positive young Black MSM?
  - a. *Probe:* What are organizations in Atlanta doing well?
  - b. *Probe:* What could be done better?
  - c. Probe: How do the different organizations and facilities in Atlanta work together?
- 10. Talk about cultural competence, with respect to young Black MSM, at [*organization name*].
  - a. *Probe:* What do you think you do well? What could be better?
  - b. *Probe*: What training do people there get about working with Black youth? LGBT youth? HIV-positive individuals?
  - c. *Probe*: How do you think other ASOs and healthcare facilities compare to (*organization name*) on this issue?
- 11. What do you think is missing from our collective approach towards caring for HIVpositive young Black MSM?
  - a. Probe: Why are we failing to keep young Black MSM engaged in care?
- 12. What local, state or national policies do you think have the biggest impact (positive or negative) on the HIV-positive young Black MSM who you work with? Please discuss these policies and their impact.

*Read out loud:* As I mentioned earlier, we are particularly interested in building social connections among young Black MSM, and helping them to use these social network connections as a way to improve their engagement in HIV care.

- 13. What do you think of this idea?
- 14. What tips do you have for us, based on your own experiences, successes and challenges in the past?
- 15. What obstacles do you anticipate for us in trying to create and implement this type of program?
- 16. What recommendations do you have for recruiting and engaging youth in this population?

Thank you so much for your time! Is there anything else you'd like to share?