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Pre-Exposure Prophylaxis (PrEP) for HIV Prevention: A Mixed-Methods Study of Sexual Risks and Knowledge, Perceptions, and Willingness of PrEP Use Among African American Women in the South

Jamie Troutman

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by

Jamie Troutman

Bachelor of Arts
University of North Carolina Charlotte, 2010

Master of Public Health
East Carolina University, 2014

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Accepted by:

Lucy Annang Ingram, Major Professor

Alyssa Robillard, Committee Member

Shan Qiao, Committee Member

Bambi Gaddist, Committee Member

Cheryl L. Addy, Vice Provost and Dean of the Graduate School

DEDICATION

This dissertation is dedicated to the inspirational people who lead me here and supported me along the way. First and foremost, I would like to thank my family for their unconditional support and motivation. I could not have accomplished this without your encouragement and love every day. To my parents, thank you for always believing in me, you were my inspiration. To my siblings, your laughter and support provided me with the push I needed to reach the finish line. To Milana, thank you for your companionship, love, and long walks to clear my head. To my husband, our meeting was kismet, and I could not have done this without your love and support along the way. I love you all.

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ABSTRACT

There are approximately 1.1 million people living with HIV in United States, with nearly 40,000 new diagnoses annually. Significant regional and racial disparities are associated with HIV diagnoses — with the South experiencing the greatest burden of HIV and African American women accounting for 60% of new diagnoses among women. Pre-exposure prophylaxis (PrEP) has been designated as an effective tool to prevent HIV transmission among individuals who may be at risk of HIV infection. Earlier PrEP research has focused mainly on at-risk groups such as men who have sex with men (MSM). Previous PrEP research involving African American women included mixed-race and mixed-gender populations, took place in larger, urban cities, and were mainly single-method studies. Given the disproportionate burden of HIV in the South and among African American women, further HIV prevention research is needed in this region and with this at-risk population. Therefore, a sequential, mixed-methods study was conducted to 1) examine the sexual behaviors that put African American women, living in the Southeast, at risk of HIV infection and eligible for PrEP and 2) to explore African American women's current knowledge, perceptions, and willingness of PrEP use for HIV prevention. Data were collected from May 2018 – April 2019 from African American women, 18 years of age or older, who were HIV-negative, and resided in the Southeastern United States. Quantitative data were collected from 413 women, through a confidential, self-administered sexual behavior survey. Four focus groups were conducted, with 27 women, to discuss sexual risk behaviors and PrEP for HIV

prevention. Quantitative results demonstrate African American women are engaging in sexual risk behaviors that make them eligible for PrEP use, with nearly half of eligible women reporting an interest in potential PrEP use. Predictors of PrEP interest among women included younger age (18-35 years), perceived risk of HIV, receiving or giving money for sex, past experience of sexual assault, and comfort with condom negotiation. Qualitative data analyses revealed major themes around 1) sexual risk behaviors linked to HIV and 2) potential PrEP use for HIV prevention. First, several themes emerged highlighting HIV risk behaviors and multi-level factors that influence risk behaviors. These included: 1) lack of condom use; 2) HIV status, disclosure, and testing; 3) sexual partner sharing; 4) cultural and southern influences; 5) perceived societal worth; and 6) health care system and provider experiences impacting health care seeking. Second, several themes emerged which highlighted African American women's thoughts and likelihood of potential PrEP use. These included: 1) knowledge and awareness of PrEP; 2) perceptions of PrEP; 3) willingness to use PrEP; 4) concerns about PrEP; and 5) recommendations to increase PrEP uptake. Study findings are encouraging of PrEP implementation efforts targeting African American women in the South. It is important that future efforts to increase PrEP uptake be relatable to African American women and provide comprehensive information of PrEP use.

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LIST OF ABBREVIATIONS

AIDS ..... Acquired immunodeficiency syndrome

CDC ..... Centers for Disease Control and Prevention

HIV ..... Human immunodeficiency virus

MSM ..... Men who have sex with men

PrEP ..... Pre-exposure prophylaxis

STI..... Sexually transmitted infection

CHAPTER 1

INTRODUCTION

1a. Problem Identification

Despite continuous implementation of behavioral interventions aimed to reduce human immunodeficiency (HIV) transmission and successful antiretroviral therapy (ART) efforts to prolong life expectancy, the United States still experiences an average of 40,000 new HIV diagnoses annually.[1] According to the Center for Disease Control and Prevention (CDC), over 1.1 million people are living with HIV in the United States, and 15% of those infected individuals are unaware that they are infected.[1] Although HIV rates and prevalence are high overall in the United States, many disparities (e.g., geographic, gender, and racial/ethnic) exist among individuals who acquire and are living with HIV.

Geographic variations are apparent in HIV distribution across the United States, with the South experiencing the greatest burden of HIV infection, illness, and death compared to any other region.[2] Approximately 52% of all people living with HIV in the United States reside in southern states, although they only contain one-third of the overall population in the United States.[3]

As of 2017, women accounted for 19% of new HIV diagnoses in the United States, which were attributed primarily to heterosexual sex (86%) or injection drug use (14%).[3] Although rates of HIV diagnoses have declined from 2005 to 2016, there is still a significant racial and ethnic disparity associated with HIV diagnoses. In 2017, African American women accounted for roughly 60% of new cases among women.[3]

Approximately 91% of all new HIV diagnoses among African American women were transmitted through heterosexual contact.[4] In 2015, HIV/AIDS-related illness was among the top leading causes of death for African American women 20-54 years of age.[5] Influential factors such as unknown HIV status, engaging in sexual risk behaviors (i.e., unprotected sex, multiple sexual partners, etc.), previous sexually transmitted infections (STIs), sexual assault, lack of sexual health and HIV prevention knowledge, poor access to health care (i.e., no insurance or geographic barriers), housing status, and alcohol and other drug use contribute to the high rates of HIV among African American women.[6] In addition, African American women are at an increased risk of acquiring HIV due to the high prevalence of HIV in African American women's sexual networks, even if they are in a monogamous relationship.[6]

Current efforts to reduce HIV among African American women in the United States include culturally tailored behavioral interventions aiming to increase routine HIV testing, increase safer sexual practices (e.g., access to condoms, protected sex, reduction of sexual partners, and regular STI screenings), reduce stigma, and increase linkage to care and antiretroviral therapy among HIV positive individuals.[7] However, due to consistent barriers reported by African American women to access condoms and testing, and additional factors such as low education level, intimate partner violence, perceptions of low risk, and high pregnancy rates, additional HIV prevention efforts are needed.

Pre-exposure prophylaxis (PrEP) has been designated as an effective tool to reduce HIV transmission. PrEP means taking a medicine to prevent an infection, prior to being exposed to that infection.[8] PrEP prevents HIV from establishing a permanent infection when an individual is exposed to sex or injection drug use.[8] Although there are

other ways of reducing the chance of HIV infection (e.g., consistent and correct condom use, reducing number of sexual partners, not having sex under the influence, and receiving routine HIV and STI screenings), the once-a-day pill is recommended for HIV-negative individuals who may have trouble doing those things consistently and who want an additional form of protection. PrEP should not replace safer sexual practices, but should be used alongside them for increased effectiveness. Truvada is the pill used for PrEP, which is approved by the Food and Drug Administration (FDA) and contains 2 drugs: 1) tenofovir and 2) emtricitabine.[8] PrEP is highly effective if taken regularly and correctly, but is not 100% effective — it has been found to be 92%-99% effective at preventing HIV in individuals who took it every day, but not effective in individuals who only took it sometimes.[8] Side effects include nausea, diarrhea, abdominal discomfort, and headaches; however, these are uncommon and usually resolve within weeks of initial PrEP use. The cost of Truvada for PrEP is dependent on a person's health insurance. If an individual is commercially insured, Gilead Sciences provides an assistance program that will cover up to $7,200 in co-pays per year.[9] This could mean paying nothing in co-pays per year depending on their insurance. For those who do not have insurance, there are assistance programs available through Gilead Sciences, that could provide PrEP free charge if individuals qualify. [9] Regardless or being insured, underinsured, or uninsured, there are assistance programs available to individuals who are wanting and committed to start taking PrEP.

PrEP has been recommended for heterosexual women and men, men who have sex with men (MSM), transgender individuals, and injection drug users (IDU), who report one or more of the following risk factors: inconsistent condom use, having more

than one sexual partner, having an HIV-positive sex partner, having a recent STI, having an HIV-positive IDU partner, sharing of injection equipment, receiving or exchanging money for sex, using other drugs (e.g., cocaine, meth, stimulants, ecstasy, etc.) in the past 12 months, and having taken post-exposure prophylaxis (PEP) to prevent HIV in the past 12 months.[8]

Past research has examined PrEP knowledge, attitudes, acceptability, and effectiveness among MSM, and high risk heterosexual and international men and women.[10-18] Currently, limited research exists about the knowledge, perceptions, and willingness of PrEP use among African American women in the United States. Additionally, due to the disproportionate burden of HIV and disparities in the South, this region is a primary focus for HIV prevention efforts.[2] Therefore, this sequential, mixed-methods study aimed to investigate African American women's sexual behaviors and networks, and their knowledge, perceptions, and willingness of PrEP use in the Southeast United States.

1b. Conceptual Model

Several major theories and concepts were used to guide our study, so that intrapersonal behaviors, as well as the socio ecological context and relationship dynamics in which these behaviors occur were assessed. The Socio Ecological Model (SEM) [19,20] was used to explain the complex relationship between individual, social, and structural factors and HIV risk. Additionally, the SEM was used to guide the qualitative methods that examined factors that may impact African American women's knowledge, perceptions, and willingness of PrEP use. The SEM model contextualizes individual's behaviors using dimensions that include intrapersonal, interpersonal, community, and

institution/structure to provide a framework that exhibits the interactions between all of these dimensions. Moreover, this model is used in research to explore underlying factors of health disparities and social inequalities, by both biological and social analyses to examine a population's health. [19,20]

The Health Belief Model[21] and Theory of Planned Behavior[22] was also used to guide our study and our understanding of African American women's knowledge, perceptions, and willingness of PrEP use (Figure 1.1). Constructs from the Health Belief Model such as susceptibility to HIV, severity of HIV, benefits of PrEP, perceived barriers to PrEP, and cues to action and self-efficacy to determine participants' readiness and confidence to use PrEP were used to guide our study.[21] In addition, constructs such as attitudes about PrEP, intention to use PrEP, and social and subjective norms regarding HIV and PrEP from the Theory of Planned Behavior were used.[22]

1c. Specific Aims

1c1. Goals and Outcomes of Proposed Research

The primary focus of this proposed research was to 1) examine the sexual behaviors that put African American women, living in the Southeast, at risk of HIV infection and eligible for PrEP and 2) to explore African American women's current knowledge, perceptions, and willingness of PrEP use for HIV prevention.

The expected outcomes of this research are 1) an exploratory summary of the potential role PrEP may play in HIV prevention; 2) an assessment of behaviors that increase HIV risk and impact potential PrEP use; 3) identification of sexual relationship components that may increase risk-level, such as concurrent sexual partnerships, and influence potential PrEP use; 4) an understanding of patient-provider relationships and

the impact it may have on PrEP uptake; and 5) an exploratory summary of current knowledge, perceptions, and willingness of PrEP use among African American women in the Southeast.

1c2. Specific Aims of Proposed Research

Aim 1: To assess perceived risk of HIV infection and sexual behaviors of African American women that put them at risk of HIV and eligible for PrEP use.

Aim 2: Explore knowledge, perceptions, and willingness of PrEP use, sexual activity, and provider relationships among African American women in the Southeastern United States.

> **Research Question 2a:** What are African American women's current knowledge, perceptions, and willingness of PrEP use in the Southeast?
>
> **Research Question 2b:** What impact could African American women's sexual relationships have on sexual risk taking and potential PrEP use in the Southeast?
>
> **Research Question 2c:** What is the relationship dynamic between African American women and their health care providers, and how could this relationship effect the recommendation of PrEP?
>
> **Research Question 2d:** What types of sexual behaviors are African American women engaging in that may put them at risk for HIV infection in the Southeast and that may make them eligible candidates to take PrEP?

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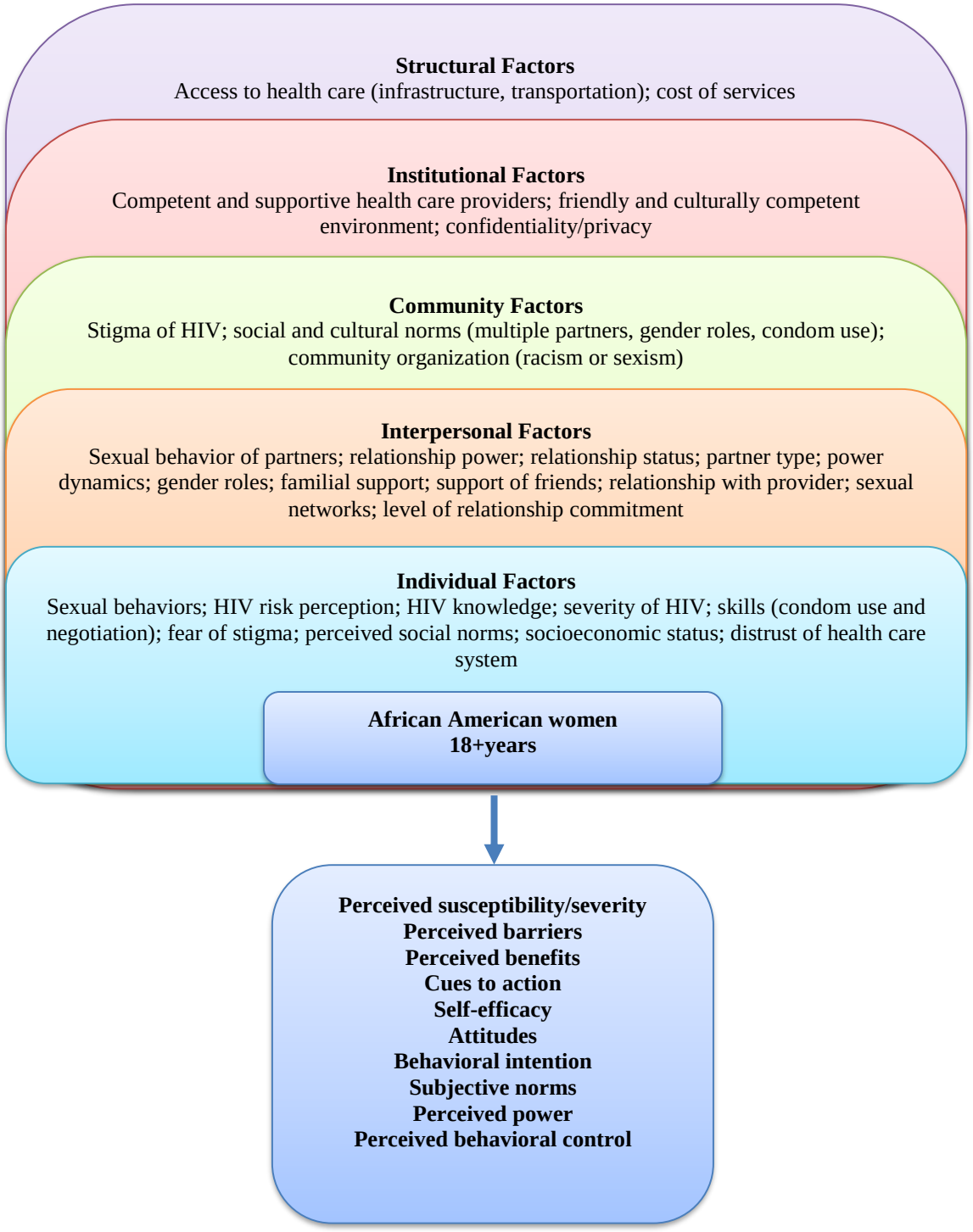

Figure 1.1. Conceptual Model

CHAPTER 2

BACKGROUND

2a. Risk Factors Contributing to HIV among African American Women

African American women, regardless of class, are disproportionately affected by major health crises affecting women in the United States. Specifically, they experience higher rates of sexual and reproductive health disparities compared to white women. African American women continue to represent to the highest proportion of new HIV infections (60%) spread via heterosexual contact.[1,23] Compared to non-Hispanic white women in the United States, the rate of new HIV diagnoses among African American women is 15 times higher.[3] Similarly, African American women demonstrate higher rates of syphilis (21 times greater), gonorrhea (16 times greater), and chlamydia (7 time greater) than white women.[24] African American women also face higher rates of unwanted and unintended pregnancies compared to white women.[25] The HIV disparity, and other sexual health disparities, faced by African American women stem from a variety of behavioral, social, and environmental factors.

Multiple risk factors exist for African American women, such as low socioeconomic status (e.g., lower income, lower education, etc.), drug use, violence victimization, low HIV knowledge, low perceived risk of HIV infection, and risky sexual behaviors (e.g., sex work, multiple sexual partners, history of STIs, engaging in unprotected sex, etc.).[26-34] With risky sexual behaviors having a significant impact on risk of HIV transmission among African American women, it is important to examine factors

(social, cultural, emotional, psychosocial, etc.) that influence their engagement in sexual risk behaviors.

Unique risky sexual behaviors of African American women have been found to increase their risk of acquiring HIV and other STIs.[23,35-37] Studies have demonstrated that risky sexual behaviors unique to African American women include unprotected sex or inconsistent condom use, early age at sexual debut (< 15 years of age), range and sexual activity (oral, vaginal, or anal sex), having concurrent sexual partners, and use of illicit drugs.[35-38] In addition, research proposes interpersonal factors related to African American women's social networks, composition of their sexual relationships, and sexual networks may contribute to their sexual health outcomes.[39] Furthermore, community-level factors such as gender and sex norms/roles and HIV-related stigma have been found to impact HIV risk among African American women.[31,40-53] The following section will discuss factors, occurring at multiple levels, that contribute to increased risk of HIV infection among African American women.

2a1. Individual Level Risk Factors

Several factors have been found to contribute to the disparities in the prevalence of HIV among African Americans compared to other groups including young age at sexual debut, low knowledge of HIV, low perceived level of risk of HIV infection, and engagement in riskier sexual practices.[26-28]

Early Sexual Debut

Compared to Hispanic women, African American women report younger ages at sexual debut, and higher rates of experiences of forced or unwanted sex, exchanging sex for money and drugs, and number of sexual partners over a 12 month-period.[35] Early

sexual debut has been found to be associated with negative sexual outcomes such as HIV and STI incidence, unplanned pregnancy, and increased number of sexual partners.[54,55] African American teens, ages 12-19 years, were found to report high rates of early sexual debut and unprotected sexual encounters with multiple partners. In addition, those who reported high rates of substance use and peers engaging in risky behaviors also reported engaging in high rates of risky sexual behaviors.[55] Protective determinants, such as HIV knowledge, sexual self-efficacy, and social support, were low among participants.[55]

HIV Knowledge

HIV knowledge has been found to be a major factor related to the high prevalence rate and racial disparities surrounding HIV among African Americans. Previous research has focused on African Americans' knowledge of HIV, specifically surrounding how it is transmitted, finding consistently low levels among this population group.[56-58] Studies examining the connection between HIV knowledge and risk behaviors associated with HIV have found inconsistent findings. For example, one study examining HIV knowledge among African American women, 17-44 years of age, found the high-risk group scored statistically higher compared to the low-risk group.[59] Therefore, research focusing on increasing HIV knowledge alone is not sufficient to reduce HIV risk behaviors among adult, heterosexual African Americans.

Perception of Risk

Recent research suggests that African Americans may be at higher risk of HIV transmission compared to whites even when their behaviors are normative and low risk.[60] A recent study suggests that African Americans who engage in low-risk behaviors are more likely to engage with high-risk behavior persons compared to whites.[17] This may

cause a false perception of low-risk based on their own personal behaviors, when in actuality, they may be at high-risk based on their partner's behaviors — resulting in situations that contribute to the higher HIV rates among African Americans.[17] Low risk perception has been associated with increased risky behaviors, resulting in increased risk of HIV transmission. Hall [61] examined the psychosocial predictors, perceived susceptibility of HIV-risk, and sociosexuality (tendency for casual, uncommitted sexual relationships) among heterosexual African American women. Overall, the sample was geographically diverse and the majority reported having at least a college degree, an income of at least $45,000 annually, no children and low self-reported rates of STIs. Both sociosexuality (tendency for casual, uncommitted sexual relationships) and perceived susceptibility were significantly associated with engagement in riskier sexual behavior.[61]

Sexual Risk Behaviors

A cross-sectional epidemiological study of HIV-negative, heterosexual African American women living in rural counties within the Southeastern United States, examined sexual risk behaviors of HIV.[35] Specifically, they examined the association between heterosexual anal intercourse, which carries five times the risk of acquiring HIV, compared to unprotected vaginal intercourse among women. Within the past 12 months, 19% had experienced an STI, 87% had engaged in unprotected vaginal intercourse, and 26% had engaged in unprotected anal intercourse — with the majority reporting inconsistent condom use or never using a condom when engaging in anal intercourse.[35] Unprotected anal intercourse was also found to be more likely to occur with partners whom women were currently in a relationship, and less likely with casual partners. With high percentages of heterosexual, African American women engaging in sexual risk

behaviors, specifically unprotected vaginal and anal sex, additional research is needed to better understand individual and interpersonal factors that may contribute to this high risk behavior.

2a2. Interpersonal Level Risk Factors

Partner Type

The composition of African American women's sexual relationships and sexual partner type can impact women's consistent condom use. A recent qualitative study conducted focus groups to explore sexual partnerships, condom perceptions, and condom negotiation among heterosexual, African American women and men.[39] Three types of sexual partnerships were identified: one-night stand, "regular" casual partner, and main partner. Type of sexual acts differed based on the partner type. For example, anal sex was much more likely to occur with a main partner, given a higher perception of intimacy, compared to a one-night stand or "regular" casual partner. Condom negotiation also varied depending on partner type. Both women and men explained that negotiating condom use with a main partner was nearly impossible and would affect the relationship negatively. Females emphasized the difficulty of getting a main partner to use a condom, particularly if alternate forms of birth control were being used. Perrino et al.[62] revealed similar findings, where casual partners were considered to be much easier to discuss condom use with compared to main partners. African American women reported their husbands or boyfriends as their main type or most recent type of sexual partner within the past 12 months; moreover, approximately 50% reported their partner had concurrent female sexual partners within the past 12 months.[35] These findings indicate that type of

sexual partner may influence African American women's participation in sexual risk behaviors and increase their risk of HIV infection.

High-Risk through Partner

Although HIV rates remain alarmingly high among heterosexual, African American women, many report having minimal concern about acquiring HIV.[31] Additionally, many African American women do not believe HIV to be a major health risk directly affecting them.[63] However, a major risk factor of HIV for African American women, is the risky behaviors of their male partners.[64] HIV rates are high and continue to rise among African American males, yet African American women typically select African American males as their partners,[65] inadvertently increasing their risk of HIV infection.

Risky behaviors among African American males, such as concurrent sexual relationships and engaging in sex with other males, indirectly put African American women at risk for HIV.[66] African American women who's sexual partners also engage in MSM behaviors are at increased risk of HIV infection, given African American MSM have the highest rates of HIV/AIDS within the United States, compared to all other racial and behavioral risk groups.[67] Moreover, African American MSM report high rates of bisexual behavior, yet disclosure of these behaviors is less likely compared to all other MSM groups.[34,68-70] African American men, who identify as heterosexual and also engage in same sex behaviors, yet do not reveal this information to their female partners, are referred to as down low or DL.[71] Men, on the down low, are less likely to receive HIV testing compared to those who do not identify as DL.[72]

Women may feel the need to engage in unprotected sex with their male partners in order to keep them as sexual partners, and as a means of competition against other women, so that they may "keep a man".[72] This can be linked to the unbalanced African American male-to-female ratio that exists.[73,74] A significant contributor to this imbalance is the high incarceration rates of African American men.[75] The uneven ratio of men to women results in a shortage of available heterosexual African American male partners and thus engagement in riskier sexual behaviors to ward off other potential female sexual partners.

African American women continue to engage in risky sexual behaviors, such as unprotected sex and alcohol or drug use during sex, despite knowledge of their male partner's simultaneous relationships.[72,76] Conversely, women who perceive themselves to be in a monogamous relationship with their male partner may create a false sense of security, leading to less consistent condom use and in turn an increased risk of acquiring HIV.[77,78] Moreover, African American women's increased HIV risk can be attributed to their male partner's risky sexual behaviors, due to African American men being more likely to participate in sexual relationships outside of marriage or with a secondary partner, compared to African American women.[26,79-83]

Sexual Networks

Women's sexual networks may directly impact their risk for HIV transmission, specifically how partner availability, choice, and behavior may directly and indirectly influence risk-taking behaviors.[84-86] Understanding risk behaviors within African American heterosexual relationships has been growing within the literature, specifically with a focus around simultaneous partnerships.[87,88] Within rural Southeastern

communities, research has found that African American individuals participate in multiple simultaneous sexual partnerships, which are viewed as normative within many of these communities.[89,90] Compared to other women, African American women have frequently been identified as being more likely to engage in concurrent partnerships.[83] Although these partnerships are viewed as normative within the African American community, they have the potential to increase the risk of acquiring HIV and rates of HIV within the community. Contextual factors, such as incarceration rates and poverty, add to an environment that promotes and supports such simultaneous sexual partnerships.[39]

2a3. Community Level Risk Factors

STI Prevalence in the South

The majority of behavioral and epidemiological HIV studies involving African American women focus on women who are at high risk, pregnant, HIV positive, and adolescent females sampled from large, urban settings that have high rates of HIV.[55] Therefore, findings from these studies may not accurately reflect African American women's experiences and risk behaviors that do not represent these groups and who live in more rural settings, specifically in the Southern United States. Lack of awareness, lower education, lack of insurance coverage, higher rates of poverty, higher rates of STIs, and inadequate access to health care services due to rural settings are factors that contribute to the overall HIV epidemic in the South.[91] The HIV epidemic among women residing in the South is known by its high rate of heterosexual transmission, the disproportionate impact on African Americans, the high rates living in rural areas, and numerous high-risk behaviors.[92]

Given the complex relationship between STIs and HIV, research has supported the idea that STI treatment can reduce HIV transmission in the United States.[93] According to the CDC, [94] genital herpes has been found to be a strong risk factor of new HIV infection among African American women. A study in North Carolina,[95] consisting of 109,250 study subjects, with 45% of the subjects at-risk identifying as African American, found the incidence rate higher among African Americans compared to whites and the majority of previously unrecognized HIV patients were detected in public STI clinics. Large racial disparities in HIV and STI rates still exist within the South, however this study demonstrated that access to testing and notification of results can help prevent further transmission of HIV within the community.[95] Unfortunately, access to health care services, due to economic and geographical factors, remains an ongoing barrier to receiving routine HIV and STI testing.

Within the southern United States, HIV transmission has increased among heterosexual, African American women. Given the high STI rates in the south, it is important to examine the multiple factors that may directly and indirectly impact HIV and STI risk among African American women. A review of both qualitative and quantitative data examined sexual network components and social context associations that contribute to the high HIV rate disparity among African Americans.[96] Within the Southern United States, research demonstrates high rates of concurrent sexual partners and dense sexual networks (extent to which members are having sex with one another).[39,96] Research also showed high rates of sexual bridging between high-risk, high-prevalence groups and areas, to lower prevalence areas.[96] When people act as bridges, HIV infected people from higher prevalence areas may travel to lower prevalence areas

where they transmit HIV to a sexual partner in these areas, who in turn may transmit to their sexual partners in this area; conversely, sexual bridging can move from low prevalence to areas of high prevalence.[96] Additionally, research reveals concurrent partnerships and sexual network patterns that increase the likelihood of HIV risk are sustained by racial discrimination, high ratios of women to men, and lack of economic opportunities.[96,97]

Gender and Sex Norms/Roles

Research has suggested that characteristics of women's sexual relationships and social/structural factors could pose as significant determinants of risk for engaging in behaviors that put them at increased risk for acquiring HIV.[34,97-101] Gender-based power scripts, within African American heterosexual relationships, may directly or indirectly influence safer sexual practice among African American women and their primary sexual partners. For example, gender-based power scripts that propose men are more likely to control relationships and sexual activity, and the opinion of infidelity as normal among women, may increase HIV risk among the female within the relationship.[102] Conversely, women who feel they share the power or control within the relationship may perceive this as being more in control of their sexual health practices, which may lead to increased condom use and decreased HIV risk.[103,104]

HIV Stigma for HIV-Positive Individuals

HIV-related stigma has and continues to significantly impact HIV prevention, risk reduction, testing, counseling, disclosure status, and treatment efforts. Compared to men, women seem to be affected more by HIV-related stigma and experience stigma on multiple levels.[105-107] For example, African American women living with HIV

experienced stigma internally, socially, and institutionally—described as existential despair, shunning and callousness, and disregard, respectively.[107] Women living with HIV experience high rates of discrimination due to the stigma associated with the disease, particularly women of color who make up the majority of positive women in the United States and who must combat other isolating social factors, such as racism and poverty.[108]

HIV-related stigma has a noteworthy impact on the South, given the high incidence rate of HIV and culturally conservative views about HIV-transmission.[50,109,110] HIV-related stigma in the South can be attributed to beliefs that HIV is contracted through activities that become "morally abnormal" once associated with HIV (e.g., injection drug use and sexual activity).[111] Women living in the Southeastern United States (Georgia and Alabama), who have experienced HIV-related discrimination, reported high rates of stress, suicidal intention, depressive symptoms, unprotected sexual activity, as well as lower rates of self-esteem, quality of life, and were less likely to receive medical care.[112] A qualitative study examining the effects of HIV-related stigma on psychosocial well-being of HIV positive women living in the Deep South (considered to include Alabama, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, and all or part of the adjacent states of Florida, Virginia, Tennessee, Arkansas, and Texas) found these women to regularly experience, anticipate, and/or internalize stigma.[113] This stigma then leads to experiences of isolation and a threat to self-concept as they determine disclosure status, efforts to keep their status a secret, and think about the future.[113] A systematic review, examining 27 articles pertaining to HIV-related stigma among women living with HIV/AIDS in the Southern US, revealed African American women faced frequent stigma from family and friends, at their workplace, in their

neighborhood, and religious communities.[114] In order to avoid stigma, African American women living in the South reported skipping medication doses while with friends and family, not revealing their HIV status so that they may retain their strong female friendships ("sista" circles), and decreased access to health care due to health care provider stigma.[114] Furthermore, women who already experience social factors and engage in risky behaviors that are highly stigmatized by society (i.e., injection drug use, sex work, single motherhood, poverty, etc.) experience a layering of social stigma; this is particularly true for both African American and rural women.[92,111,115] As a result, the impact of stigma is intensified by racial discrimination and socio-economic inequalities in African American women living in rural areas[114] and should be considered in HIV prevention research.

HIV Stigma for HIV-Negative Individuals

Stigma and discrimination can increase individual's vulnerability to HIV. Populations at high risk of HIV (e.g., African American women) continue to face stigma and discrimination based on their actual or perceived health status, race, socioeconomic status, age, sex, sexual orientation or gender identity, or other grounds.[40] Individuals in high-risk groups, who may already face stigma and discrimination in their daily lives, may be unwilling to risk possible HIV-related stigma in addition to the stigma they already experience. Uninfected family members of HIV-positive individuals have reported experiences of stigma due their association with an HIV-positive family member.[41] For example, older African American women who are caregivers for HIV-positive people reported they do not widely disclose the HIV diagnosis of their loved ones due to the anticipation of HIV-related stigma.[42]

HIV stigma carries severe individual and societal consequences, the most serious being the delay in HIV-testing among at-risk people.[43] Fear of stigma and discrimination is a main reason for not getting tested for HIV.[43-46] Internal and external stigma attached to testing is a major barrier to HIV testing.[47,48] Furthermore, research has demonstrated that stigma and discrimination challenge HIV prevention efforts by making people afraid to seek out HIV information and services, and modalities to lessen their HIV risk, and to adopt safer behaviors so as not to raise suspicion regarding their HIV status.[46] In a study conducted in South Africa, young women reported that stigma stopped them from using PrEP for HIV prevention out of fear of being mistakenly identified as HIV-positive and experiencing discrimination.[49] Women in this study emphasized the importance of taking PrEP secretly so as to preserve their healthy, HIV-negative image; in addition, the women encountered suspicion from community members about why an HIV-negative person would take antiretroviral drugs.[49] Managing social relationships was difficult while participating in the study, women reported hiding their involvement in the study and missing PrEP doses due to fear of social isolation.[49]

HIV-related stigma can be even greater in the South due to the cultural, social, and individual factors specific to the South. For example, social deviance and immorality have been associated with perceptions of HIV infection; this may result in increased stigma among individuals residing in the South, given the higher levels of conservatism and religiosity within the South.[50,51] In addition, research demonstrates that lower levels of HIV knowledge, common in the South, contributes to increased perceived and experienced HIV stigma.[52,53]

2a4. Institutional Level Factors - Patient-Provider Relationship among African American Women

Patient-Provider Trust

Trustworthiness of a provider can greatly impact an individual's acceptance of recommended care, health improvement, loyalty and happiness with a provider and care received, and willingness to allow the provider control within the patient-provider relationship.[116-124] Given the significant impact that provider trustworthiness can have on an individual's health, it is important to consider differences that may arise among different populations that could directly influence their relationship with their provider and thus affect their care received, and health outcomes. Compared to white patients, African American patients have reported lower levels of trust with health care providers.[125,126] Research has discovered a multitude of factors that may cause this difference among African Americans. For example, African Americans' trustworthiness with their health care provider may differ from other population groups given their past mistreatment by health care professionals (e.g., Tuskegee Syphilis Experiment) and ongoing health disparities (e.g., HIV/AIDS).[127-129] Racial discrimination experienced by African Americans has been found to be associated with lower medication adherence, which was partially mediated by trust with their provider — an increase in trust was associated with better medication adherence.[130]

During the 1980's, addressing the HIV/AIDS epidemic was met with challenges — labeling HIV/AIDS as a gay disease caused a mistrust with the health care field among the gay population, leading to a resistance to seek and receive care.[131] A lower level of trust in health care providers has been associated with decreased health care visits

related to HIV and decreased acceptance and use of ART.[132,133] One study, exploring trust levels among HIV-positive African American and white patients found African American patients who reported lack of complete trust in their providers to have lower ART adherence compared to white patients.[134] In addition, not only did African American patients express lower levels of trust with their health care providers, but they were also less likely to be receiving and completely adhering to ART and viral load suppression compared to white patients.[134]

African Americans have expressed several core factors that contribute to distrust in health care and their providers; for example, discrimination in the health care setting and expectations of being experimented on.[135] In a study of 762 African Americans and 1267 whites, examining racial differences in health care system distrust, African Americans had higher rates of health care system distrust which included values distrust (beliefs about honesty, equity, and intentions of the health care system) and higher reports of experiencing discrimination.[136] African American women have reported a variety of factors that influence their distrust with a provider which included interpersonal incompetence, difficulty communicating with foreign physicians, providers being focused on profit, experience of racism, and past history and perceptions about experimentation.[137] Improving the trust level and relationship among African American women and their providers could potentially improve trust levels, resulting in acceptance of provider recommendations for HIV prevention.

Low HIV-Testing among African American Providers

Alternatively, another influential factor could be that minority groups typically select providers who are similar in racial/ethnic backgrounds;[138,139] however, African

American physicians do not routinely test for HIV because of stigma.[140] In a study surveying 502 African American physicians about HIV testing practices and perceptions, participants reported being concerned that patients 1) may perceive the recommendation to be tested as accusatory or judgmental (57%); 2) would not want to be identified as HIV positive and would be worried that people may find out (48%); and 3) would be offended due to HIV-related stigma that exists (43%).[140] Despite their concern, the majority of African-American physicians (80%) reported that they believe HIV testing should be routine; yet, they reported testing only 37% of their Black patients over the past year, and the majority of the testing was risk-based as opposed to routine. Primary reasons that African American physicians would recommend HIV testing to a patient included multiple sex partners (89%), IDU (85%), sexual assault (83%), sex work (77%), sexual activity (77%), homosexuality (77%), and previous incarceration (70%).

2b. PrEP

Pre-exposure prophylaxis (PrEP) has been labeled as an effective tool to prevent HIV transmission.[8] PrEP prevents HIV from establishing a permanent infection if an individual is exposed through sex or injection drug use.[8] There are other ways of reducing the chance of HIV infection (e.g., safer sex practices); however, the once-a-day pill is recommended for HIV-negative individuals who may have trouble engaging in safer sex practices consistently and who want an added form of protection. PrEP should be used together with safer sexual practices in order to be most effective. PrEP, called Truvada, has been approved by the FDA since 2012 and is recommended by the CDC.[8] PrEP is highly effective (92%-99%) if taken regularly and correctly every day, but is not 100% effective and not effective in individuals who only took it occasionally.[8] PrEP has

been recommended for MSM, transgender individuals, IDU, and heterosexual women and men, that report one or more of the following risk indicators: inconsistent or no condom use, multiple sexual partners, having an HIV-positive sex partner(s), history of a recent STI, having an HIV-positive IDU partner, sharing of injection equipment, commercial sex work, use of other drugs (e.g., cocaine, meth, stimulants, ecstasy, etc.) in the past 12 months, and use of post-exposure prophylaxis (PEP) in the past 12 months.[8]

2b1. MSM and PrEP

It is important to understand knowledge, attitudes, and interest in PrEP among populations with the highest rates of HIV.[11,12,141-146] Given the significantly high HIV disparities in the United States, previous PrEP studies conducted in the US have focused on the MSM population. Knowledge and awareness of PrEP have ranged from low (13%) [11] to moderate (46%).[142] However, the majority of MSM expressed interest in taking PrEP every day as an HIV prevention strategy. In 2007, 227 HIV-negative MSM, recruited through modified respondent-driven sampling, completed an interviewer-administered survey assessing prior PrEP use and awareness, and future intent to use PrEP.[143] Only 19% had previously heard of PrEP prior to the study; however, after participants were educated about the potential of PrEP, 74% reported they intended to use PrEP. MSM were particularly interested in using PrEP if it came at no cost and had no side effects.[143]

Interest in using PrEP among MSM has been associated with cost, side effects, and availability;[143] however, when cost and availability are not an issue, and individuals are accepting of potential side effects, PrEP interest has also been associated with older age, education, intimacy motivations for condomless sex, unprotected anal intercourse

with one or more partners in the past 90 days, and perceived risk of HIV acquisition.[11,144] The US PrEP Demonstration Project, an open-label cohort study assessing PrEP delivery in municipal STI clinics and community health centers in San Francisco, Miami, and Washington, D.C., recruited 1,609 MSM and transgender women to participate.[145] Eligible participants were provided with up to 48 weeks of PrEP. Of the 557 eligible participants, roughly 4% had participated in a prior PrEP study, 3.1% had used PrEP outside of a study, and 15.1% had a sexual partner taking PrEP. The main reasons for enrolling in the study were 'to protect myself against HIV' (66.6%), 'to help fight the HIV epidemic' (14.9%), and 'because my partner has HIV and I want to avoid getting HIV' (10.4%).[145]

Barriers and facilitators of PrEP use have been examined among MSM. Barriers to PrEP uptake include cost of medication, short- and long-term side effects, adverse effects from irregular use or discontinuing PrEP, and accessibility of PrEP.[12] Facilitators of PrEP uptake included protection against HIV infection, reduced concern and fear regarding HIV transmission, the opportunity to engage in unprotected sex, and endorsements demonstrating the effectiveness of PrEP.[12] Golub [146] examined potential barriers and facilitators to PrEP use and their relationship with PrEP acceptability and motivations for adherence among MSM in New York City. The sample included 177 men and 7 transgender women from 18-58 years of age, with the majority identifying as African American (39%) or Latino (22%). The main barriers to PrEP use included health concerns, both long-term effects (78%) and side effects (69%), concerns that PrEP may impact ART medications if the individual were to become infected (65%), and concerns that PrEP is not 100% effective at preventing HIV transmission (63%). Facilitators of

PrEP use found to be most important included no cost to use PrEP (80%), having access to free HIV testing (72%) and sexual health care and monitoring (70%) while on PrEP, and access to personal counseling and support around PrEP use (69%). Both barriers and facilitators predicted PrEP acceptability and motivation for PrEP adherence.

2b2. International PrEP Studies with Women

PrEP is now promoted as an effective HIV prevention strategy and is recommended to individuals who are at high-risk for acquiring HIV. With this new movement of PrEP support, research has been conducted to examine women's knowledge, attitudes, perceptions, acceptability, and support of PrEP. Several international studies have examined potential user groups' willingness and acceptability of PrEP use, revealing significantly high rates. Willingness to use PrEP among female sex workers, MSM, IDUs, serodiscordant couples, and young women was measured in seven countries: Peru, Ukraine, India, Kenya, Botswana, Uganda and South Africa.[13] The majority of participants reported they were willing to consider using PrEP, with 61% reporting they would definitely use PrEP, even when reminded of potential side effects, the need to still use condoms when taking PrEP, and necessary routine HIV testing.[13] Another Kenyan study, examining the acceptability of new ARV-based HIV prevention efforts in rural areas, reported 87% of 5,180 Kenyan women reported willingness to use PrEP.[147]

Fear of side effects is a major factor in whether people chose to use PrEP. Acceptability of daily PrEP use as an HIV prevention strategy was assessed using pre- and post-questionnaires, among 400 Ghanaian women, over a 12 month period.[15] Although several side effects (i.e., gastrointestinal issues, fatigue, and dizziness) were

reported, most women became accustomed to the pill and developed strategies to incorporate pill taking into their daily routine (taking at night, visual cues to remind them to take dosage, incorporating into an existing pill regimen), resulting in a greater than 82% adherence rate throughout the 12-month trial.[15] In addition, overall results demonstrated no increase in risk behavior, as well as a decrease in rates of unprotected sexual activity and number of sexual partners.

2b3. PrEP Studies Among African American Women

Studies conducted in the United States have explored African American women's knowledge, attitudes, perceptions, acceptability, and support of PrEP; however, these studies took place in large, urban cities.[10, 17,18,148-153] Currently, there remains a need to focus specifically on the Southeast, and rural areas within the Southeast, where the burden of HIV incidence is highest amongst African American women. Additionally, many of these studies took place prior to the FDA licensure of PrEP (2012) and the US Public Health Service Guidelines around PrEP provision in 2017, thus perceptions and norms could have changed by this time. A review of PrEP studies involving African American women, with a focus around knowledge, attitudes, perceptions, and acceptability of PrEP, has been provided in the sub-sections to the follow.

2b3a. Knowledge of PrEP

Awareness and knowledge of PrEP among African American women remains low, despite the amount of time that it has been available and promoted as an HIV prevention effort. A study, conducted among STI clinic attendees in South Carolina, from 2009-2010, found low PrEP knowledge rates (8%) among high-risk, heterosexual, African American women.[148] In 2012, a study measuring PrEP knowledge among

women, revealed at-risk, HIV-negative women had 'almost no' awareness of PrEP.[149] A nationwide, online study conducted in 2015 found similarly low levels of prior PrEP knowledge (20%).[150]

A qualitative study of 144 at-risk women in six US cities (New York, Dallas, Atlanta, Newark, Chicago, and New Orleans) was conducted in 2013.[151] Approximately 92% were African American women; roughly one-third were 18-30 years old; 53% were single, divorced or separated; 52% were employed; 47% had annual incomes of $10,000 to $40,000 and 40% had incomes less than $10,000; and 77% were stably housed. Approximately 3.5% reported having multiple sexual partners and 60% had never had an HIV test. Participants were asked questions about their basic awareness and understanding of PrEP. Many participants (90%) had not heard of PrEP and were angry about their lack of awareness; however, most were open to using PrEP once they were educated on the effectiveness, FDA approval, and availability of PrEP for women. Additionally, participants expressed concern about others in their communities being equally unaware of PrEP — participants across all sites brought forth discussion that lack of dissemination of information was influenced by societal devaluation of Black women.[151] Similar to a sentiment shared by many Black women in the US, some participants felt they had not been told about PrEP because people do not care whether Black people get HIV.[154]

2b3b. Attitudes and Perceptions of PrEP

Studies have examined African American women's attitudes and perceptions about PrEP's use and administration, potential effect on sexual activity (i.e., condom use), use as an ideal prevention strategy, and advantages and disadvantages. PrEP testing

requirements were assessed in several studies.[10,18] When asked about their attitudes related to the required HIV testing every three months, many women considered routine and partner testing to be a benefit to PrEP use.[10,18] When asked if they would be able to consistently use condoms while taking PrEP, the majority of women felt that PrEP would not have any positive or negative effect on condom use and viewed PrEP as an additional, not substitute, protection to condoms.[18,151]

Bond [150] conducted a mixed- methods, online, e-health study using quantitative assessments, followed by open-ended questions, to examine the perceived advantages and disadvantages of using PrEP. The sample consisted of 119 African American women; the majority of participants (86%) were between 18-44 years of age; roughly 38% had annual incomes of $20,000 to $49,999 and 44% had incomes greater than $50,000; and 76% were married, in a committed relationship, or currently dating. Advantages identified by study participants included that is was female controlled, an option for women with risky sexual partners, an option for serodiscordant couples, and promoted empowerment and self-efficacy among African American women. Disadvantages included testing burden, side effects, adherence issues, encourages sex with risky partners, increases burden on women, could promote unprotected sex, novelty of the drug, and medical distrust and stigma.

A qualitative study involving 92 HIV-negative women residing in four major cities (Oakland, CA; Memphis, TN; San Diego, CA; Washington, DC) was conducted between March and April 2012.[149] Researchers explored participants' basic understanding of PrEP and attitudes about administration and uptake.[149] Women believed PrEP should be available to all women who are sexually active, regardless of HIV risk.

Although condom use should be combined with PrEP use, most women reported that it was likely that they would not use condoms or have their male partners use condoms.[149]

From 2009-2010, a cross-sectional study was conducted to assess self-perceived risk of HIV infection and attitudes about PrEP among 405 STD clinic attendees in South Carolina.[148] Questions from a self-administered survey assessed attitudes about the use of PrEP, in conjunction with condom use, and knowledge of the use of PrEP to prevent HIV infection. The following survey questions were used: 'If I had to it would be very difficult for me (or my partner) to both use condoms and take daily pills to prevent HIV infection' and 'Have you heard of people who do not have HIV taking AIDS medicines (also known as anti-retrovirals) to keep them from getting HIV?' Only 358 responded to the knowledge about HIV prevention using PrEP; of those, 89% were African American and 159 were females.[148] All females had a high level of agreement with the statement related to difficulty to use both condoms and PrEP to prevent HIV infection.[148]

2b3c. Acceptability, Uptake, and Adherence to PrEP

Studies confirm a strong interest in PrEP among African American women. A study in 2012, conducted five focus groups consisting of 26 African American women, ages 18-50 years, recruited from an inner-city community health center in Boston, Massachusetts, and affiliated HIV testing sites in the Boston area.[10] Participants were asked about their PrEP acceptability and product preference. Overall, participants were interested in using PrEP and preferred the oral PrEP, daily dosage compared to a vaginal microbicide gel.[10]

Social factors have been found to influence women's uptake of PrEP. From 2006-2007, a nationally represented study of 1,509 women, examined the relationship between

socio-demographics, sexual behaviors, and social influences on PrEP uptake.[152] The majority of the random sample was comprised of unmarried African American women (71%) between the ages of 20-45 years. Potential PrEP uptake was measured using the question, 'If there was a pill that you could take once a day, every day, to PREVENT getting HIV, and if this pill caused mild side effects, such as nausea, headaches, and rashes in a small number of people, would you take the pill?' Women with lower educational status (high school education or less), greater lifetime sexual partners (6 or more), provider recommendations supportive of PrEP, and peer norms supportive of PrEP use were more likely to report potential PrEP uptake.[152] Within the study population, African American women were significantly more likely to report potential use of PrEP (aOR=1.76; $p \leq 0.001$), more likely to report use of PrEP if recommended by a health care provider (aOR=1.65; $p \leq 0.001$), less likely to report that they would be embarrassed to ask a health care provider for PrEP (aOR=0.59; $p \leq 0.05$) and more likely to report use of PrEP if their female friends also used PrEP compared to white women (aOR=2.2; $p \leq 0.001$).[152]

A qualitative study was conducted to assess attitudes and service access preferences for PrEP, using mixed-gender focus groups consisting of urban, African Americans ages 18–24 years, at risk for HIV transmission based on their sexual and drug-related behaviors.[18] Focus groups were held in Atlanta, Georgia in 2009. Thirty-five African American women participated in the mixed-gender focus groups. Participants reported significant interest in PrEP associated with its perceived cost, effectiveness, and ease of accessing services and medication near to their homes or by public transportation; a luxury many non-urban residents do not have available to them.

From August to October 2010, a quantitative study was conducted, using anonymous surveys to assess demographics, risk behaviors, and PrEP interest at an STI clinic.[17] There were 494 participants. Of them, 183 women participated in the initial risk assessment and 125 were classified as 'high-risk.' Among the 125 'high-risk' females, 77% were Black and between 26-39 years of age. Only one characteristic or behavior that met the certain risk level (low-, moderate-, or high-risk) was required to classify the participant into that risk level. Characteristics and behaviors included measures such as number of different sexual partners, frequency of condom use, injection drug use, history of STIs, receiving or exchanging money for sex, and their sexual partner's risky behaviors/characteristics. The majority of 'high risk' women reported they would take a pill for PrEP (82%), and they would take it one day before sex (97%) or one hour before sex (96%). The majority of 'high-risk' women also reported that if they were taking the PrEP pill, their condom use would either stay the same (59%) or increase (21%), and their number of sexual partners would stay the same (75%) or lessen (19%).

Researchers in Philadelphia administered surveys to patients undergoing HIV rapid testing, between May 2012 and December 2014, to assess their openness and reason for openness to PrEP.[153] A total of 2,721 females participated, 90% who self-identified as African American. Fear of HIV, interest in prevention, and high risk perception were the top reasons women were open to using PrEP. A comment from a 26 year old African American woman who reported four male sex partners in the previous year simply stated, '…to prevent — rather be safe than sorry'. Recognition of one's HIV risk was often described by a past or current STI, or knowing an HIV-positive individual. A brief comment made by a 21 year old African American woman with syphilis and who

reported one male partner stated, '…because my boyfriend keeps getting stuff…'. However, low risk perception was a main reason for disinterest in PrEP use, with only 8.3% of women reporting moderate or high perceived risk of HIV acquisition.

2b3d. Barriers and Facilitators to PrEP Uptake

Although the promotion of PrEP use and effectiveness has increased, many barriers impacting PrEP uptake still exist. Major barriers to PrEP uptake included lack of trust in the medical system, lack of communication among community members, stigma, cost, side effects, partial effectiveness, low perceived susceptibility to contracting HIV, burden of a daily medication, and reaction of peers to taking HIV medication.[18,149,151] Women recommended several dissemination strategies and locations to inform women, and meet the diverse needs of women, which included schools, peer-to-peer outreach, social and mass media, primary care physicians, obstetricians and gynecologists (OB-GYNs), community-based organizations, and flyering where people gather (e.g., beauty shops).[149,151] Although women have expressed a willingness to turn to their primary care provider for PrEP information and services, the majority of women have not heard about PrEP from their health care providers, even when participants expressed having a strong relationship with their primary care doctors and OB-GYNs.[151] Therefore, in order to increase the likelihood of PrEP uptake among women, we must consider and address common barriers reported, such as lack of communication about PrEP within the community, HIV-related stigma, low perceived risk of HIV infection, distrust in the medical system, and lack of PrEP recommendation or discussion from providers.

2c. Sexual History Assessment

2c1. Missed Opportunities

Routine health care visits can allow for increased opportunities of STI and HIV counseling and screening, which can lead to improved sexual and overall health. Moreover, sexual health discussions between patients and providers can increase and improve STI and HIV counseling and screenings, no matter the reason for the medical visit.[155-157] Unfortunately, sexual health and history discussions are still not routine practice among health care providers,[156,157] and if they are conducted, the provider rarely collects sufficient sexual health histories or the information is not documented in the patient's medical record for future reference.[157-159] Even OB-GYNs, physicians who are in the best situation to address and discuss sexual histories and issues, do not routinely ask about patients' sexual activity (65.6%), sexual problems (40%), or sexual orientation/identity (27.7%).[160] However, recent research has shown that providers are willing to use sexual history tools in clinical practice to support efforts aimed at HIV/AIDS prevention.[161] Providers who deliver medical care to African Americans have been identified as vital partners for efforts that raise awareness and increase regular HIV screening among this population.[162-164] Factors such as stigma, cost, concern regarding reimbursement, and lack of time and training, and discomfort to conduct a sexual health history were reported by providers as barriers to patients receiving regular HIV testing.[165,166]

Missing opportunities to obtain sexual health information from African American patients could be detrimental in the long-run for efforts aimed to increase awareness and HIV testing, and ultimately eliminate the HIV epidemic faced by African Americans.

Due to the increasing rate of heterosexual transmission of HIV/AIDS among African American women, culturally-sensitive sexual histories should be obtained at first contact, at every health care system point of entry (i.e., community health centers, emergency rooms, and family planning).[167] Gathering a sexual history should be a routine component of obtaining a medical history; providers should not make assumptions or imply judgment, but should determine the patient's understanding of sexual matters and ask questions related to types of sexual engagement (oral, vaginal, anal), types of sexual partners (male, female, transgender), number of sexual partners, condom use, birth control methods, injection drug , alcohol, and other drug use, STI history, pregnancy history, and private familial sexual practices (i.e., rape, physical abuse, incest, etc.).[167]

2c2. PrEP Guidelines Recommend Sexual History Assessment

According to the CDC PrEP guidelines, a sexual history assessment is recommended as part of the eligibility process for PrEP. Providing a sexual history assessment can potentially raise patients' awareness of consequences that come from risk behaviors, and increase sexual risk reduction motivations and greater risk sensitization.[168,169] Sexual history taking could have a direct impact on patients' understanding and willingness to use PrEP. A study in the United States examined comprehension of PrEP educational information, among 157 young people of color, from February 2012 to April 2014.[170] Participants completed a one-time, in-person visit where they received educational messages about PrEP, were asked about their sexual behaviors in the past 30 days, and self-reported demographic measures. Participants were asked to report type of sexual activity (anal or vaginal intercourse; protected or unprotected) by partner type (casual or main) for each of the past 30 days. Participants were also asked

about heavy alcohol use and any substance use for each of the past 30 days. Engaging in a sexual history prior to receiving PrEP education was associated with increased odds of message comprehension among participants (aOR=2.23; 95% CI: 1.06–4.72) — demonstrating the important role sexual history taking can have on an individual's understanding of PrEP, the potential benefits of using PrEP, and ultimately their decision to use PrEP.

2d. Significance

2d1. PrEP uptake rates remain low despite research supporting efficacy and national recommendations. The majority of current HIV prevention strategies for African American women include culturally tailored health messages and behavioral strategies;[7] however, additional HIV prevention efforts are needed. PrEP has been designated as an effective tool to prevent HIV transmission.[8] Although there is increasing support for the use of PrEP as an HIV prevention strategy for high-risk individuals, uptake and adherence remain low. Particularly, rates remain low among African American women. Research has begun to examine knowledge, attitudes, and likelihood to use PrEP among potential user groups, [10,17,18,148-153] however, further research is needed to examine African American women's awareness, perceptions, and willingness to use PrEP.

2d2. This research will provide a geographical focus on the Southeast where HIV rates are highest among African American women. Given the high rates of HIV in the southern United States, particularly among African American women, it is important to continue developing HIV prevention efforts aimed to reduce the disparities faced by this population. However, there is limited understanding of risk behaviors and factors associated with sexual risk behaviors linked to HIV among African American women

residing in the Southern United States, in the face of increasing HIV rates among this population and within this geographical area.[91] Our study aims to provide information that can inform future HIV prevention strategies so that they are effective and consider factors unique to African American women residing in the Southeast region.

2d3. Perceived risk of HIV and risk behaviors, across all risk groups will be assessed. Low perceived risk of HIV has been found to be associated with increased risk behaviors and increased risk of HIV transmission; yet, perceived risk may not actually reflect the behaviors individuals are engaging in.[17,60,61] For example, women who engage in low-risk behavior with high-risk partners may have a false sense of risk.[35] This is especially true for African American women who report high rates of their male partners having concurrent sexual partners and male partners who are also MSM, as well as difficulty negotiating safer sexual practices with their primary sexual partner.[63,64] Therefore, further research is needed to explore additional prevention strategies for African American women who experience convoluted sexual relationships and who may not be able to discuss condom use or use PrEP due to partner resistance.

2d4. Research examining patient-provider discussions of sexual history and provider recommendation of PrEP is needed. Providers are presented with unique opportunities to obtain sexual health histories and information from their patients.[155-157] This information can be used to educate patients on their HIV risk and to recommend HIV prevention strategies such as PrEP.[168,169] Yet opportunities that could greatly impact the reduction of HIV health disparities among African Americans are still being missed.[156,157] This research aims to increase awareness about whether providers are asking patients about

their sexual behaviors at routine visits and if eligible women are being recommended PrEP as an HIV prevention tool by their providers.

2e. Innovation

This research is innovative in several ways. First, previous PrEP research has primarily focused on international populations or MSMs when conducted in the United States. [11,12,141-146] Research that has been conducted around PrEP and African American women in the United States, has focused on urban and inner-city women (e.g., New York, Chicago, Dallas, San Diego, and Washington D.C.), has included mixed-gender and -race study populations (e.g., African American males or white females), and have been single method studies.[10,17,18,148-153] This research focused only on African American women, residing in the rural Southeast, using a mixed-methods approach.

Second, the majority of PrEP research involving African American women took place prior to the FDA approval of Truvada as PrEP in 2012 and the US Public Health Service Guidelines around PrEP provision in early 2017. [10,17,18,148-153] Knowledge, awareness, perceptions, and acceptability around PrEP is likely to have changed given both the time passed and increased national support and promotion of PrEP for HIV prevention. Our study provides current PrEP-related views among African American women, which can be assessed to determine if knowledge, perceptions, and willingness of PrEP use has increased since receiving FDA approval and the updated national provision guidelines.

Third, many studies have focused on MSM and African American MSM given the high prevalence of HIV among these populations; [11,12,141-146] however, African American women experience high rates of HIV, as well as engage in sexual relations

with individuals who engage in MSM behaviors. Given the high rates of heterosexually-transmitted HIV among African American women in the United States and their complex sexual relationships that include MSM partners, our study provides a unique insight into risk factors that increase risk of HIV infection and affect potential PrEP use.

Lastly, our study provides insight into health care provider practices with African American women. Sexual health history-taking by health care providers can increase individuals' perceived HIV risk, and has been found to impact PrEP uptake among MSM.[170] Specifically, this research examined whether health care providers are 1) taking sexual histories of patients during routine medical visits and 2) using routine visits as an opportunity to recommend PrEP among African American women reporting high risk behaviors.

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CHAPTER 3

METHODS

3a. Overview

The overall objective of the proposed research was to 1) explore African American women's current knowledge, perceptions, and willingness of PrEP use for HIV prevention and 2) examine the sexual behaviors that put African American women, living in the Southeast, at risk of HIV infection.

The expected outcomes of this research were 1) an exploratory summary of the potential role PrEP may play in HIV prevention; 2) an assessment of behaviors that increase HIV risk and impact potential PrEP use; 3) identification of sexual relationship components that may increase risk-level, such as concurrent sexual partnerships, and influence potential PrEP use; 4) an understanding of patient-provider relationships and the impact it may have on PrEP uptake; and 5) an exploratory summary of current knowledge, perceptions, and willingness of PrEP use among African American women in the Southeast.

Participants included African American women, ages 18 years or older, who were HIV negative, and resided in the Southeastern United States. Our study was conducted using a sequential, mixed-methods approach that consisted of a quantitative sexual behavior survey (n = 413), followed by focus groups (n = 27 participants) to examine PrEP knowledge, perceptions, and willingness of PrEP use. A diagram demonstrating the sequential study design has been provided (Figure 3.1).

Survey data were used to provide a more comprehensive portrait of the women who participated. Data were used to examine the relationship between a range of sociodemographic variables, sexual behaviors, and socio-economic influences on potential PrEP awareness, acceptability, and uptake.

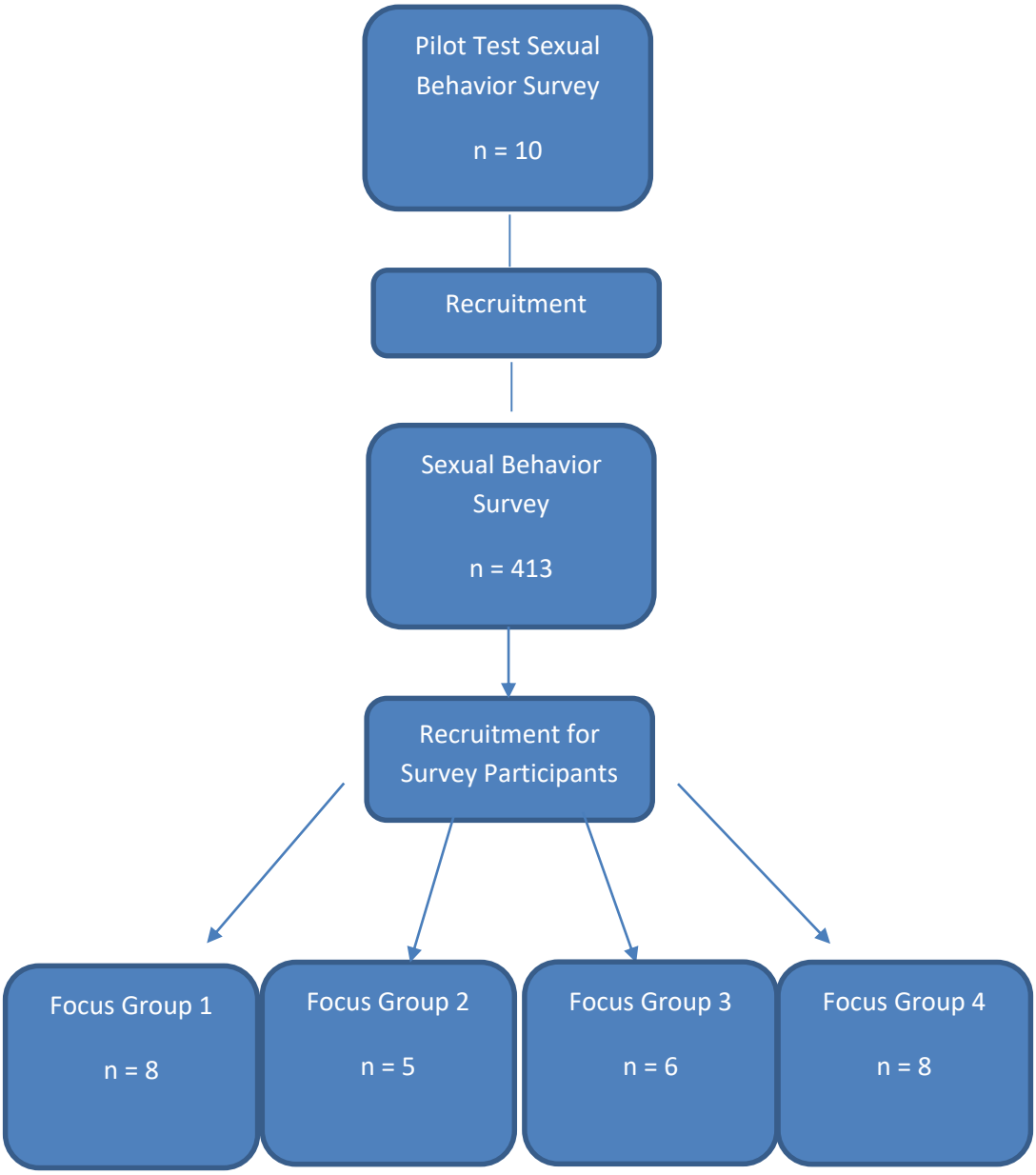

Figure 3.1. Study Design

3b. Study Setting

Given the mixed-methods approach, the study setting was in the Southeastern United States and consisted of an online environment/internet and in-person sites. Previous studies have included populations within the Southeastern United States, and have defined the geographical area by including the following states: Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee. Although there is no official definition of the Southeastern United States by the Census Bureau, the American Association of Geographers defines the Southeastern United States as Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee, Maryland, Virginia, and West Virginia.[171] For the purpose of our study, we recruited participants from the Southeastern United States, which included the following states: South Carolina, North Carolina, Georgia, Alabama, and Florida. Overall, the majority of study participants resided in South Carolina.

The quantitative sexual behavior survey was delivered and accessed remotely through a link provided via email or social media. Community stakeholders and gatekeepers were used to promote and help in distributing information about the study via organizational listservs and social networks. The qualitative focus groups were conducted in Columbia, South Carolina, at the Wright Wellness Center (WWC) dba South Carolina HIV Council (SCHC); a local non-profit organization focused on HIV prevention and treatment services. The selection of the location for the focus groups was driven by interest in each state during the quantitative methods and funding availability.

3c. Sample

In order to generate a confidence level = 95% and a margin of error of ± 5%, a quantitative sample size of approximately 384 was calculated to estimate a single population parameter. Previous qualitative studies examining knowledge, perceptions, and willingness of PrEP use were used to determine the focus group sample size for our study.[10,18,144-147]

A total sample of 413 participants completed the survey. Four focus groups, consisting of 5-8 participants were conducted. Rules for data saturation were used to guide the qualitative phase of this research. Data saturation is considered achieved when there was no new data, no new themes, no new coding, and the ability to replicate the study. [172] Although we did not reach saturation, we saw re-occurring themes brought up multiple times in each of the focus groups.

3d. Eligibility and Recruitment

Eligibility criteria for study participation included women who (1) self-identified as African American or Black, (2) were18 years of age or older, (3) self-reported as HIV negative, and (4) resided in the Southeastern United States (South Carolina, North Carolina, Georgia, Alabama, or Florida). Although the study focused on heterosexual women, women who identified as bisexual were also included in the study sample given the high risk women may acquire by engaging in sexual activities with their male partners. Additionally, women who identified as homosexual and report females as their primary sex partners were eligible to take the survey so that we could report on the sexual behaviors of these women; however, they were not be eligible for focus group participation.

A number of various recruitment strategies and sources were used to garner interest in the study and to obtain participants. Initial recruitment efforts included entities and opportunities such as the Columbia Housing Authority, faith-based organizations, and community outreach events to ensure class, socioeconomic status, and geographic diversity were evenly distributed across the sample population. Potential participants were recruited from state and local organizations, groups, and institutions. Leadership and professional organizations (e.g., National Coalition of 100 Black Women) and African American sororities (e.g., Alpha Kappa Alpha and Delta Sigma Theta) were targeted for recruiting potential participants. In addition, potential participants were recruited from local and non-local colleges and universities (University of South Carolina, Benedict College, Allen University, and University of North Carolina at Charlotte). Lastly, participants were recruited during local health fairs and HIV testing and outreach events in the community.

Wright Wellness Center (WWC) was used to recruit potential participants. WWC is a non-profit organization that aims to address HIV prevention, early intervention, and treatment service gaps in South Carolina. WWC provides services that include, but are not limited to: HIV and other STI screenings, STI treatment, HIV positive peer navigation and linkage to care, and medical case management, treatment referrals, transportation, and HIV positive supports groups.

News about the study opportunity was disseminated using email and social media platforms (Facebook and Twitter) to recruit potential participants. Participants had the chance to receive a $50 incentive, provided they complete the sexual behavior survey. A drawing for two $50 Visa gift cards was held at the end of the quantitative data

collection. Additionally, participants were eligible for a $25 incentive, by participating in a focus group. Following the completion of the sexual behavior survey, participants were asked if they were interested in participating in a focus group related to HIV prevention. If interested, participants were asked to provide their email address so that they may be contacted about the future dates and times for each focus group.

Focus group participants were recruited from the sexual behavior survey sample (N=413). Potential focus group participants were considered ineligible if they did not complete the sexual behavior survey. Of the 413 participants who completed the sexual behavior survey, 193 said they were interested in participating in a future focus group and provided their contact information. Emails were sent to the potential participants with information about the upcoming focus groups. Of the 193 potential participants, 42 women responded with RSVPs to one of the four proposed focus groups. The 42 potential participants were sent a total of five confirmation and reminder emails prior to the focus group, with all 42 confirming their attendance the week of their scheduled focus group. Expected attendance for each focus group ranged from 9-12 participants. Ultimately, 27 women showed up and participated across the four scheduled focus groups.

Of the 27 focus group participants, many either worked in the field of HIV or in the health field. We unintentionally recruited participants from the HIV and health field, given that participation in the focus groups was self-elected. This may bias our focus group results; however, we were cognizant of this when presenting our results and reported this as a potential limitation of our study. Conversely, our specific sample allowed us to present perspectives and experiences unique to African American women,

who work in the HIV and health field, around HIV risks and prevention methods, such as PrEP.

3e. Measures

Descriptions of the measures used for the study are outlined in detail below categorized under quantitative and qualitative methods.

3e1. Sociodemographic Characteristics

The socio-demographic measures were comprised of participants' self-reported age, education, income, insurance status, relationship status, religiosity, sexual identity, and current profession/field of work. This information was obtained as part of the sexual behavior survey and prior to focus group participation.

3e2. Quantitative – Sexual Behavior Survey

A self-administered questionnaire was used to assess both perceived HIV risk and engagement in sexual risk behaviors. Perceived risk of contracting HIV was measured using a single item. The item was similar to other studies measuring HIV risk perception: "Do you think you have no risk, a small risk, a moderate risk or a great risk of getting HIV?"[173-175]

Additional sexual and risk behaviors were assessed to gather a thorough understanding of participants' sexual histories and behavior patterns. We used the terminology "sexual risk behavior" to examine sexual behaviors that increased women's risk of HIV. Use of the term "sexual risk behavior" allowed us to intentionally focus on the behavior and not the person, by using past terminology like "risky sexual behaviors."

The following measures were used: number of sexual partners, consistency of condom use, history of STIs, accepting or providing money for sex, intravenous drug use

(IVDU), sex with an HIV-positive individual, and sex with an MSM within the past 12 months. The identified sexual behaviors were used to create a PrEP eligibility risk score for participants. The risk score and categorization method was based on previously used and validated risk categorization tools.[17,153,176]

3e3. PrEP Eligibility Risk Score

Survey participants' sexual behaviors were summed and categorized to determine PrEP eligibility. Risk behaviors used to determine PrEP eligibility were guided by the CDC[177] and previous research,[178] and were used to categorize participants as no risk, low risk, and medium-high risk. Selected risk behaviors were summed to create a three level risk scale: 0 (no risk), 1 (low risk), and >1 (medium-high risk). The following seven risk factors were used to determine risk group and PrEP eligibility: 1) sex with an MSM (yes or no); 2) intravenous drug use (yes or no); 3) history of STIs (yes or no); 4) having sex with an HIV-positive individual (yes or no); 5) accepting or providing money for sex (yes or no); 6) consistent condom use during vaginal or anal sex; and 7) multiple vaginal and/or anal partners (>1). Indicators 1-5 were dichotomized and coded as 0 (no risk) and 1 (risk). Consistent condom use was measured using a Likert scale ranging from 1 (Always), 2 (Most of the time), 3 (Sometimes), and 4 (Never). Answers of 1 (Always) were coded as 0 for no risk and answers 2-4 (Most of the time, Sometimes, Never) were coded as 1 for risk. Multiple partners was coded as 0 (no risk) for participants answering 0-1 and coded 1 (risk) for participants answering >1 for either vaginal or anal sex. All risk factors were measured over the past 12 months. The potential risk scores could range from 0-7.

The remaining survey items were used to measure participants' knowledge, awareness, and willingness of PrEP use. In addition, the sexual behavior survey included items related to the dynamics of participants' sexual relationships and experiences of sexual assault.

3e4. Quantitative – Cognitive Testing of Sexual Behavior Survey

The sexual behavior survey was assessed through cognitive testing using a small sample (n=10) representative of the intended study sample. This included African American women, ages 18 years or older, who self-reported as HIV-negative, and resided in the Southeastern United States. Cognitive testing of the sexual behavior survey took place in person and electronically, to account for potential respondents' availability and to test the quality of the online version. In addition to the sexual behavior survey, respondents were asked evaluative questions that assessed the length of the survey and clarity of the questions being asked. Respondents were given the opportunity to provide feedback and recommendations for the survey. Responses from the survey were reviewed, analyzed, and adjustments were made to finalize the sexual behavior survey prior to administering to the entire sample population.

3e5. Qualitative – Focus Group

Sociodemographic measures were collected using a self-administered survey and included age, education, income, insurance status, relationship status, sexual identity, and profession. Focus groups explored topics that included, but were not limited to HIV-negative, African American women's: 1) knowledge, awareness and understanding of PrEP; 2) attitudes about PrEP usage for themselves and others; 3) perceptions of PrEP's impact on future sexual behaviors (i.e., condom use); 4) stigma related to PrEP use; 5)

willingness to use PrEP; 6) likelihood of recommending PrEP to their sexual partners; 7) likelihood of PrEP uptake and adherence, given the behavioral requirements and financial obligations; 8) current relationship with their provider, focusing on patient-provider discussions around sexual history and behaviors, and provider recommendations of PrEP use; 9) past and recent sexual activity behaviors; and 10) experiences and composition of sexual relationships. A topical guide for focus groups was developed using the specific aims of the study to determine key questions and topics that should be included. Prior to use, the research team reviewed the topical guide and provided recommendations. The topical guide was then adjusted accordingly, where it was then reviewed and approved by the research team for focus group use.

3f. Data Collection

3f1. Quantitative

Targeted emails were sent and social media messages were posted with information for potential participants to learn about the study; a hyperlink to the questionnaire was provided in the email or social media post. If interested, potential participants were informed that by following the hyperlink they are agreeing to enroll in the study; however, they were not guaranteed eligibility. A screener survey was incorporated into the beginning of the questionnaire to assess study eligibility. The screener survey required participants to 1) identify as female; 2) identify as African American or Black; 3) be 18 years of age or older; 4) self-report HIV-negative status; and 5) currently reside in the Southeast before proceeding to complete the survey. Based on the screener survey, ineligible participants were automatically exited from the survey. Once eligibility was determined, eligible participants were provided with an electronic

informed consent disclaimer prior to starting the survey questions. Eligible participants completed a questionnaire on sociodemographic information, perceived risk of acquiring HIV, and engagement in sexual risk behaviors. SurveyMonkey[179] was used to screen potential participants for eligibility and administer, collect, and store the sexual behavior survey. Approval of the Institutional Review Board, at the University of South Carolina, was obtained prior to implementing any study procedures.

The survey required participants to self-report sociodemographics and sexual behaviors. Previous studies have demonstrated that mode of survey administration (in-person versus online) did not influence disclosure of sexual behaviors.[180,181]

Surveys were also administered in-person at local health fairs and outreach events in the community. Eligible participants were asked if they were interested in taking a survey about their sexual behaviors and HIV risk. Interested participants were asked to read the informed consent form prior to taking the survey, informing them about the survey content and that by proceeding to take the survey would count as their consent to participate in the study.

3f2. Qualitative

Participants, who successfully completed the sociodemographic and sexual behavior survey, were eligible to participate in the targeted focus groups. Eligible participants were emailed and asked if they were interested in participating in a focus group to discuss an innovative HIV prevention method called PrEP. Four focus groups, consisting of 5-8 participants, were conducted. Each focus group lasted approximately 90 minutes each and took place in Columbia, South Carolina.

All participants were required to sign an informed consent form prior to focus group initiation. Before beginning the focus groups, participants completed a self-administered sociodemographic survey. Participants also received basic informational handouts about PrEP (i.e, effectiveness, side effects, requirements, etc.) during the focus group.

A topical guide was developed and used as an instrument to help facilitate the focus group discussion and ensure the likelihood of all essential topics being discussed. The focus group moderator used the topical guide while conducting the focus groups to guide discussions and aid in probing when needed. In addition, a designated note taker was present during each focus group to capture quotes, non-verbal cues from participants, key points and themes for each question, potential follow-up questions that could be asked, and additional ideas or thoughts that may be significant. Participants received a $25 incentive, which was distributed at the end of the focus group meeting. Food and drinks were provided during each focus group.

3g. Data Management

3g1. Quantitative

Each participant was assigned a unique participant identification number for the quantitative sexual behavior survey. A secure email account and social media accounts (Facebook and Twitter) were used for our study to inform potential participants of the study and to provide the hyperlink to access the sexual behavior survey. Survey data were collected using SurveyMonkey[179] and remained confidential at the individual level. Data were exported into a secure database by a trained research member, and was stored on a password-protected server on a secure computer network.

3g2. Qualitative

A digital tablet was used to record audio of the focus groups; the tablet had a secure password and only held the audio recordings until they were uploaded to a password-protected server on a secure computer network. Once uploaded, the audio files were deleted from the tablet. The audio files were transcribed and analyzed using NVivo (version 12), and transcriptions were saved to the same secure network as the audio files.

3h. Data Analysis

3h1. Quantitative

Data from the sociodemographic and sexual behavior survey were analyzed using SPSS version 25 statistical software (IBM Corp., Armonk, NY). Sociodemographic characteristics were examined and stratified by risk categorization. Risk categorization was determined by summing and categorizing risk factors reported in the sexual behavior survey. Participants were categorized as no risk, low risk, and medium-high risk to determine PrEP eligibility for quantitative analyses. Additional risk behaviors were examined and presented as frequencies to provide an overview of participants' current and former sexual behaviors.

Bivariate analysis was used to examine the relationship between sociodemographic characteristics, sexual risk behaviors, and potential PrEP eligibility and interest. Variables found to be associated with PrEP interest ($p<.20$) were considered for logistic regression models. Associations between PrEP interest and potential predictors were investigated using multivariate logistic regression models. P values less than 0.05 were considered statistically significant.

3h2. Qualitative

Focus groups were recorded, transcribed, and analyzed to identify underlying themes using NVivo (version 12) qualitative data analysis software. Initially, the principal investigator conducted a content analysis of the focus group transcriptions using a sensitizing framework. From there, a codebook was developed to guide the data analysis and further analyze identified themes. All transcripts were double-coded; results were compared and the codebook was reviewed then agreed upon by the research team for finalization. Once coded, co-occurring and frequently occurring codes were reviewed by interview questions to determine predominant themes within the interview guide. Themes, similar and different, between each focus group were compared.

Two community gatekeepers were recruited and assisted with focus group moderation as note-takers. The selected individuals were representative of the sample population (African American women) and served as a liaison to help facilitate the discussions when needed. The note-takers were provided with the opportunity to analyze data to assist in discovering underlying themes; one note-taker aided in the coding and discussion of focus group themes.

CHAPTER 4

RESULTS

MANUSCRIPT 1.

Eligibility and key factors associated with potential PrEP use among African American women in the South

Prepared for: *AIDS and Behavior*
Jamie Troutman, Lucy Annang Ingram, Shan Qiao, Bambi Gaddist, Alyssa Robillard

ABSTRACT

Introduction: HIV diagnoses remain disproportionately high among African American women in the South. Pre-exposure prophylaxis (PrEP) is a novel HIV prevention method that can be highly effective for eligible candidates. Our study examined PrEP eligibility and potential factors associated with potential PrEP use among African American women in the South.

Methods: We recruited 413 women who were 18 years of age or older, identified as African American or Black, were HIV-negative, and resided in the Southeastern United States. Participants completed a sexual behavior survey that was used to assess their perceived HIV risk, sexual risk behaviors, and sociodemographics. Participants sexual risk behaviors were summed and categorized to create a 3-risk value scale, categorizing participants as no risk, low risk, or medium-high risk. Risk groups were assessed to determine associations between sociodemographics, sexual risk behaviors, and PrEP interest.

Results: Overall, 324 participants were eligible for PrEP. Participants who had experienced a previous STI (OR=2.60; p=0.019), inconsistent condom use (OR=2.38; p= 0.022), having multiple sexual partners (OR=2.09; p=0.001), exchanging or receiving money for sex (OR=2.20; p= 0.047), and perceived HIV risk of small and moderate (OR=; $p \leq 0.001$) were more likely to be interested in PrEP use. In multivariate analyses, ages 18-35 years, perceived HIV risk, receiving or giving money for sex, past experience of sexual assault, and comfort with condom negotiation were found to be predictors of PrEP interest.

Conclusion: African American women are reporting risk behaviors that make them eligible for PrEP, as well as an interest in PrEP use for HIV prevention. Future PrEP implementation efforts should consider 1) all risk groups as potential candidates for PrEP use and 2) potential predictors of PrEP use when determining if a woman is ready and willing to take PrEP. It is also important for future efforts to understand predictors of non-interest to determine potential areas to promote interest.

Key Words: HIV prevention, PrEP eligibility, PrEP use, African American women

INTRODUCTION

Given the high rate of HIV diagnoses and heterosexual transmission, risk of HIV infection is still a concern among women in the United States. In a national survey of heterosexual women at risk of HIV infection, 26% of HIV-negative women reported engaging in anal sex without a condom, and 93% reported engaging in vaginal sex without a condom in the past 12 months.[182] Receptive sex has been found to be riskier than insertive sex, meaning women are at a higher risk of HIV infection during vaginal or anal sex compared to their male partners.[183,184] Previous STIs, having multiple sexual partners, and exchanging sex for money or drugs increase women's risk of HIV infection; in addition, some women may be unaware of their risk of HIV due to risk acquisition through their male partners, and may not use condoms.[23] Moreover, low perception of HIV risk has been found to be associated with increased risk behaviors.[61,148,185]

In 2017, women represented 20% of new HIV diagnoses in the United States, respectively.[23] Women of color, specifically African American women are disproportionately at risk and impacted by HIV. African American women accounted for the majority (60%) of new HIV diagnoses among women, yet they only represent 13% of the population.[186] Of the new HIV infections among African American women, approximately 91% were transmitted through heterosexual contact.[4]

The majority of new HIV infections (52%) occur in the Southern United States and similarly disproportionately vary by race.[187] Of the new HIV infections attributed to heterosexual contact among women in the United States, nearly 58% resided in the South.[3] African American women accounted for 70% of new HIV diagnoses attributed to heterosexual contact among women in the South.[3]

Previous and current prevention efforts to reduce HIV risk and diagnoses among African American women have focused on culturally-tailored interventions aimed at reducing sexual risk behaviors.[7] However, African American women continue to face barriers that impact their ability to engage in safe sex practices. Pre-exposure prophylaxis (PrEP) is a once a day pill that has been found to be 90% effective at preventing HIV among HIV-negative, high-risk individuals.[8] In a systematic review examining factors that may affect PrEP implementation for women in the United States, findings demonstrated an interest in PrEP use among women.[188] Among the studies reviewed, between 51%-97% of women were willing to try PrEP; however, only 0%-33% had ever heard of PrEP.[188]

Previous research has examined PrEP interest and willingness to use PrEP among potential user groups such as MSM and high-risk individuals in the United States. PrEP interest has been found to be associated with education, older age, condomless anal sex with one or more sexual partners in the past three months, and perceived risk of HIV infection among MSM. [11,144] A recent study examined motivations for openness to PrEP among an urban-clinic population, consisting of over 90% African American respondents.[153] Younger age, higher perceived risk of HIV, previous HIV testing, greater number of sexual partners annually, and Black race were found to be predictors of openness to PrEP.[153] Other mixed-gender cohorts of all or predominantly African American participants have found significant PrEP interest to be associated with effectiveness, low cost, ease of accessibility,[18] gender, age, and number of sexual partners in the past 90 days.[148]

In a study comprised of a nationally representative sample of unmarried white and African American women, ages 20-44 years, researchers found women with lower education, greater lifetime of sexual partners, provider recommendations for PrEP, and peer norms supportive of PrEP to be more likely to report potential PrEP uptake.[152] Another mixed-race study examined PrEP acceptability among young adult females, 18-35 years of age, seeking reproductive health services at selected family planning clinics in Baltimore.[189] PrEP acceptability was significantly associated with commercial sex work and being Black. A study taking place from 2014-2015, estimated PrEP eligibility and assessed PrEP knowledge and acceptability among at-risk women in the Southern United States.[178] Of the 225 women, 83.1% identifying as Black, 72 women were eligible for PrEP. In this study, factors significantly associated with PrEP eligibility included: medium-to-high self-perceived risk of HIV (aOR 6.76; 95% CI: 3.26 to 14.05), history of sexual violence (aOR 4.52; 95% CI: 1.52 to 17.76), and having less than a high school education (aOR 2.56; 95% CI: 1.22 to 5.37. Sixty-three of the PrEP eligible participants and 173 of the total sample expressed willingness to consider PrEP use for reasons such as having more control/protection from HIV, mistrust in sexual partners, recommended by a provider, and having an HIV-positive partner.

Inconsistent or no condom use, commercial sex work, recent STI, intimate partner violence, living in a high prevalence area with HIV, and having a sexual partner with unknown HIV status or who engages in MSM behavior are factors associated with HIV risk among women.[190] Understanding potential influences of behavioral and sociodemographic factors on PrEP interest and use, among at-risk groups, is an important step to preventing HIV. Although previous research has examined potential predictors of

PrEP interest and use, study samples included MSM, mixed-gender, and mixed-race populations. To fill this gap, and to expand upon the current limited research around African American women's readiness and interest in PrEP use for HIV prevention, our study examined African American women's risk eligibility and key factors associated with interest in PrEP use for HIV prevention in the South.

METHODS

Study Population and Recruitment

Our study used targeted sampling to recruit African American women residing in the Southern United States. Eligibility criteria included women who 1) identified as African American or Black, 2) were 18 years of age or older, 3) reported an HIV negative status, and 4) were currently living in one of the following states: Alabama, Florida, Georgia, North Carolina, or South Carolina. Participants were recruited through a wide range of locations and channels from May 2018 to March 2019, for either in-person survey or online survey administration. Recruitment locations included a local HIV/AIDS service organization, non-profit organizations, community health fairs, HIV testing outreach events, local women's conferences, and local historically black colleges and universities (HBCUs). Online survey recruitment used listservs and social media platforms targeting African American leadership and professional organizations, sororities, HBCUs, and universities located in North Carolina and South Carolina.

Study Protocol

Surveys were administered online and in-person. Online survey participants were recruited using targeted emails and social media posts, informing potential participants of the study and eligibility criteria. A link to the survey was provided and participants were

screened with eligibility questions prior to them taking the survey. If eligible, participants were informed that by proceeding to take the survey that they were providing consent to participate in our study. In-person paper surveys were administered by the principal investigator, where participants were given information about the survey and provided informed consent prior to taking the survey. Participants were also informed of potential risks or harms by participating in this study. All surveys were confidential and took 10-15 minutes to complete. Participants who completed the survey were entered into a drawing for one of two $50 Visa gift cards available. We received approval for all study protocols from the University of South Carolina's Institutional Review Board.

Measures

The survey measured demographic data, participants' perceived risk of HIV infection, sexual behaviors, and PrEP awareness and interest. Demographic information included age, education, income, insurance status, relationship status, and sexual identity. A single item was used to measure participants' perceived risk of HIV infection: "Do you think you have no risk, a small risk, a moderate risk or a great risk of getting HIV?" Measures used to assess participants' sexual risk behaviors and PrEP eligibility, were defined using the 2017 CDC guidelines[177] and previous research,[178] and included the following: number of sexual partners, frequency of unprotected sex, history of STIs, accepting or providing money for sex, intravenous drug use (IVDU), sex with an HIV-positive individual, and sex with an MSM within the past 12 months. Overall PrEP interest was measured using two PrEP-related items: 1) Would you be interested in taking PrEP once a day if it had no-to-few side effects, to prevent HIV? (yes/no/not sure) and 2) Would you be interested in taking PrEP if it were free of charge or only a small charge, to

prevent HIV? (yes/no/not sure). If a participant reported 'yes' for at least one of the two PrEP items, they were categorized as 'interested in PrEP.'

Data Analysis

Survey data were used to assess sexual risk behaviors, perceived HIV risk, and initial interest in PrEP use. Participants were examined and stratified by risk categorization based on their self-reported risk behaviors from the survey. Participant's sexual risk behaviors were summed and then categorized as no risk, low risk, or medium-high risk. The risk categorization method was modeled after previously used and validated risk categorization tools.[17,153,176] Participant's risk profile was assessed using the following seven risk factors: 1) having sex with an MSM within the past 12 months (yes or no); 2) intravenous drug use (IVDU) in the past 12 months (yes or no); 3) history of STIs in the past 12 months (yes or no); 4) having sex with an HIV-positive individual in the past 12 months (yes or no); 5) accepting or providing money for sex in the past 12 months (yes or no); 6) inconsistent condom use during vaginal or anal sex in the past 12 months; and 7) multiple vaginal and/or anal partners in the past 12 months. Answers to the above indicators were dichotomized as 0 (no risk) and 1 (risk). A Likert scale ranging from 1 (Always) to 4 (Never) was used to measure condom use. For the condom use indicator, risk was coded as 0 for answers of 1 (always use a condom) and 1 for answers of 2-4 (Never, sometimes, or most of the time use a condom). The item for multiple sexual partners was coded 0 for answer $\leq$ 1and coded 1 for answers >1 for either vaginal and/or anal sex.

The result of the risk score for each participant was used to categorize participants into a three-risk value scale: 0 (no risk), 1 (low risk), and >1 (medium-high risk).

Initial exploratory and descriptive analyses were conducted to determine data distribution of demographics, sexual behaviors, and PrEP eligibility, awareness, and interest. Bivariate analysis was performed using chi-square tests or Fisher's exact test to determine associations between sociodemographic information, sexual behaviors, and PrEP eligibility and interest. All *p* values less than 0.05 were considered statistically significant. Logistic regression models were used to investigate the effect of age, relationship status, sexual identity, risk behaviors for PrEP eligibility, and perceived HIV risk upon the interest in PrEP use. Multivariate logistic regression models were used to investigate associations between interest in PrEP and potential predictors. All statistical analyses were conducted using SPSS version 25 (IBM Corp., Armonk, NY).

RESULTS

A total of 497 surveys were completed, however, the final sample size was N=413. This reflected a screening of the inclusion/exclusion criteria, which resulted in a total of 84 incomplete or ineligible survey participants. Of the 413 participants, the average age was 34.39 years, ranging from 18-70 years. The majority of participants (89.1%) reported attending some college or university or higher. Seventy-one percent of participants reported that they were currently employed, with 36.9% reporting an income less than $5000, 11.3% reporting $5,000 - $20,000, 21.6% reporting $21,000-$40,000, 18.0% reporting $41,000-$60,000, and 12.3% reporting $61,000 or higher annually. Over four-fifths (82.1%) of participants reported having health insurance. Most participants resided in South Carolina (88.5%), with the remaining participants residing in North Carolina, Georgia, and Florida. Participants were predominantly single (66.0%) and

identified as heterosexual (84.6%), with the remaining participants identifying as bisexual (8.9%), homosexual (5.5%), or other (1.0%).

HIV Risk and PrEP Eligibility

The majority of participants believed they had no risk of getting HIV (53.7%). Of the remaining participants, 37.4% reported a small risk, 6.9% reported a moderate risk, and 2.0% reported a great risk of contracting HIV.

Using the risk score, participants were categorized as no risk (21.5%), low risk (47.0%), and medium-high risk (31.5%). Risk scores ranged from 0-4. A total of 324 participants were eligible for PrEP through their reported risk behaviors. Risk-group demographics, perceived HIV risk, and PrEP eligibility and interest are provided in Table 4.1. When compared to other age groups, participants 18-24 years were more likely to be categorized as medium-high risk ($p<0.001$). Compared to the low risk group, no risk and medium-high risk participants were significantly less likely to have health insurance. The majority of single participants were categorized as low risk or medium-high risk; however, the percentage of single participants did not differ significantly between risk groups. Married participants were more likely to be categorized as low risk. As expected, medium-high risk participants were more likely to report experience of an STI, sex with an HIV-positive person, accepting or providing sex for money, lack of condom use, and multiple sex partners within the past 12 months compared to low risk participants. Medium-high risk participants reported significantly lower rates of no perceived HIV risk (32.3%) compared to no risk (70.8%) and low-risk (58.2%) participants. Medium-high risk participants were more likely to be interested in PrEP if it had no-few side effects

(38.5%) or no-small cost (58.5%). There were no significant differences in employment status and sexual orientation, between risk groups.

PrEP Awareness and Interest

Approximately 59% of participants had never heard of PrEP. When asked about potential PrEP interest, 27.9% of participants reported they would be interested in taking PrEP if there had little to no side-effects, with 40.5% not interested and 31.6% not sure. When asked if participants would be interested in PrEP if it were free or only a small charge, 45.7% were interested and 54.3% were not interested. Overall, roughly 45% of participants were interested in potential PrEP use, with the remaining 55% answering not interested or unsure of interest. Of the 41% that had heard of PrEP (166), only 5 participants (3.0%) had been recommended PrEP by a provider, 3 participants (1.8%) had ever taken PrEP, and 43 participants (26.4%) knew someone that had taken PrEP.

Participants between the ages of 18-24 years (OR=3.17; 95% CI=1.58, 6.34; $p \leq 0.05$) and 25-34 years (OR=2.81; 95% CI=1.29, 6.10; $p \leq 0.05$) were much more likely to potentially use PrEP compared to participants 35 years or older. Participants who reported being married were significantly less likely (OR=0.26; 95% CI=0.14, 0.49; $p \leq 0.05$) to use PrEP compared to participants who were currently single. The majority of heterosexual participants (56.7%) were not interested in PrEP use; however, the majority of bisexual participants (63.9%) were interested in PrEP use. Compared to participants who reported no risk for their self-perceived HIV risk, participants who reported a small risk (OR=2.77; 95% CI=1.80, 4.27; $p \leq 0.05$) and moderate risk (OR=6.35; 95% CI=2.58, 15.67; $p \leq 0.05$) were more likely to be interested in PrEP use.

Interest in PrEP among Eligible Participants

A total of 324 participants reported behaviors that increased their risk of HIV infection. Low risk participants (n=194) and medium-high risk participants (n=130) were grouped to represent PrEP eligible participants. Among PrEP eligible participants, 45.1% reported an interest in PrEP use. The majority of participants who were interested in PrEP use were comfortable discussing HIV testing with their partner (92.5%) and condom use with their partner (94.5%; $p<.05$). Participants reporting an experience of sexual assault were more likely to be interested in PrEP compared to participants who had not (OR=2.10; 95% CI=1.28, 3.41; p=0.003).

The majority of risk behavior criteria for PrEP eligibility were associated with PrEP interest ($p<0.05$). Participants who had experienced a previous STI within the past 12 months were 2.6 times more likely to be interested in PrEP (95% CI=1.17, 5.72; p=0.019). The likelihood of PrEP interest was increased by sexual risk behaviors, which included engaging in vaginal or anal sex without a condom (OR=2.38; 95% CI=1.13, 5.00; p=0.022) and having multiple sexual partners (OR=2.09; 95% CI=1.33, 3.29; p=0.001). Participants who reported exchanging or receiving money for sex had 2.20 times higher odds than participants who did not engage in commercial sex work (95% CI=1.01, 4.80; p=0.047). Participants who perceived their HIV risk to be small and moderate were approximately 3 times (95% CI=1.79, 4.75; $p\leq 0.001$) and 9 times (95% CI=3.05, 24.65; $p\leq 0.001$) more likely to be interested in PrEP than participants who believed they had no risk of HIV infection. Participants between the ages of 18-24 (95% CI=1.55, 9.85; p=0.004) years and 25-34 years (95% CI=1.36, 10.03; p=0.010) were approximately four times more likely to be interested in PrEP compared to participants

35 years of ages and older. Among the PrEP eligible participants, younger age (18-35 years), perceived HIV risk, receiving or giving money for sex, past experience of sexual assault, and comfort with condom negotiation were found to be predictors of PrEP interest (Table 4.2).

Risk behaviors for PrEP eligibility were similar among participants 18-24 years (n=130) and 25-34 years (n=58). High rates of inconsistent condom use were reported among participants' ages 18-24 years (87.7%) and 25-34 years (91.4%). Participants 18-24 years reported a higher rate of multiple sex partners (62.3%) compared to participants 25-34 years (36.2%). HIV risk perception varied between age groups. The majority of participants (55.8%) 18-24 years of age reported no perceived risk of HIV infection, while the majority of participants (67.2%) 25-34 years of age reported a small-great risk of HIV infection. Most participants within each age group were single. Approximately 85% of participants 18-24 years of age were single, with the remainder of participants reporting they had a partner. Forty-four women (75.9%), 25-34 years of age, were single, followed by 15.5% were married, 6.9% had a partner, and 1.7% were divorced. There were no significant differences in condom use and relationship status among each age group. However, single participants, 18-24 years of age, reported high rates of inconsistent condom use (86.5%) similar to single participants 25-34 years (93.2%). Overall, 56.2% of participants 18-24 years of age and 55.2% of participants 25-34 years of age were interested in PrEP.

DISCUSSION

Our study examined African American women's risk eligibility for PrEP and factors associated with potential PrEP use for HIV prevention. The results demonstrate

that PrEP interest still remains low among African American women of all risk groups; however, higher-risk participants reported slightly higher rates of PrEP interest compared to the low risk participants. Medium-high risk participants reported lower rates of perceived HIV risk compared to the no and low risk groups. Similar studies have found individuals who engage in risk behaviors to have a lower perception of HIV risk compared to those who report less risk behaviors.[148] Future efforts to increase PrEP use should consider the difference between actual risk behavior and perceived HIV risk so as to increase the likelihood of PrEP uptake and adherence among high-risk individuals.

Previous research suggests that women at high risk of HIV infection, including those with multiple sexual partners and lower educational status, were more likely to use PrEP.[152] Among these women, African American women were more likely to report potential PrEP use compared to white women. In addition to having multiple sexual partners, we discovered additional risk factors and behaviors associated with interest in PrEP use among African American women which included inconsistent condom use, previous STI, receiving or exchanging money for sex, experiences of sexual assault, and self-efficacy in condom negotiation skills. These findings have important implications for public health efforts aimed to increase targeted PrEP recommendations for high-risk, African American women.

Our PrEP eligible sample consisted primarily of women, 18-24 years of age (40.1%) and 25-34 years of age (18.0%). This population was found to have a greater interest in PrEP use compared to all other ages in our study. High rates of inconsistent condom use were reported within these age groups; however, participants 18-24 years of age reported higher rates of having multiple sex partners. Additionally, participants 18-24

years of age reported very low perceptions of HIV risk, with the majority reporting they believed to have no risk of HIV infection. Overall, the majority of this age group was interested in potential PrEP use. The combination of multiple risk factors, low perception of HIV risk, and interest among women 18-24 years makes this population an ideal candidate for PrEP. PrEP implementation efforts should heavily target younger adults who have shown a significant interest in PrEP use.

Fear of HIV, younger age, high perceived risk of HIV, inconsistent condom use, greater numbers of sexual partners and HIV testing have been shown to be predictors of openness to PrEP among African American men and women.[153] Our study was able to investigate predictors of PrEP interest solely among African American women. Similar to the previous study, we found younger age and perceived HIV risk to be predictors of African American women's PrEP interest. In addition, we discovered predictors that may be only specific to African American women and included exchanging or receiving money for sex, experiences of sexual assault, and self-efficacy with condom negotiation. These predictors have been found to have higher rates among women compared to men, and may potentially create a sense of powerlessness or relinquishment of control when experienced. A study examining PrEP acceptability among female sex workers in a high-prevalence city, found women who had experienced recent violence or sexual assault from their clients to be significantly more likely to be interested in PrEP, compared to those who had not experienced violence.[191] Previous research has shown PrEP to be viewed as an HIV prevention option that can promote empowerment and self-efficacy to women and their sexual health.[150] These gender-focused predictors should be considered when determining if a woman could be interested and a candidate for PrEP.

Our study has several limitations. First, the survey collected self-reported data, which could be a limitation given the sensitivity of the questions asked (e.g., sexual behaviors, STI history, and experience of sexual assault). Participants may have provided more socially desired responses. Additionally, we cannot account for non-response data. The sample may have been biased due to the recruiting locations used for study enrollment. These included health fairs, women's empowerment conferences, and a local HIV/AIDS service organization. The sample may have included participants who were more proactive in their health practices and improving their overall well-being. Additionally, our data collection took place in the South, where the HIV incidence is relatively higher; therefore, our current findings may not be generalizable to other geographic areas. Additional research is needed to accurately assess risk factors associated with potential PrEP use and successful PrEP uptake among African American women in the South.

Strengths of this study include a sample that was 1) large in size, 2) drawn from areas with a high HIV prevalence, and 3) inclusive of all age groups.

CONCLUSION

In order to increase PrEP uptake, we must determine the level of PrEP interest and potential motivators of PrEP use among at-risk populations and communities. We found a moderate level of PrEP interest among eligible African American women in the South, despite low awareness of PrEP. Largely, younger women, ages 18-34 years, showed greater interest in potential PrEP use compared to older women. Our findings present potential predictors of PrEP interest and use, which included age, perceived HIV risk, commercial sex work, experience of sexual assault, and condom negotiation skills among African American women. It is also important for future efforts to understand

predictors of non-interest to identify potential areas to cultivate interest. Overall, future efforts to increase PrEP uptake among African American women should consider their initial interest, as well as our suggested predictors of interest, to effectively implement PrEP as an HIV prevention option in high prevalence communities. .

Table 4.1. Distribution of demographics, HIV risk perception, and PrEP eligibility and interest, stratified by risk group

Characteristics	No Risk (n = 89)		Low Risk (n = 194)		Medium-High Risk (n = 130)		p[a,b]
Age Group							<0.0001[a]
18-24	25	(28.1)	55	(28.4)	75	(57.7)	
25-34	12	(13.5)	40	(20.6)	18	(13.8)	
35-44	12	(13.5)	32	(16.5)	14	(10.8)	
45-54	14	(15.7)	37	(19.1)	14	(10.8)	
55-70	23	(25.8)	21	(10.8)	7	(5.4)	
Education							0.019[a]
6^{th}-8^{th} grade	0	(0.0)	0	(0.0)	1	(0.8)	
9^{th}-12^{th} grade	10	(11.2)	12	(6.2)	21	(16.2)	
Some college or university	39	(43.8)	93	(47.9)	71	(54.6)	
Bachelor's degree	18	(20.2)	37	(19.1)	18	(13.8)	
Higher education	20	(22.5)	47	(24.2)	18	(13.8)	
Employment							0.078[a]
Employed	61	(68.5)	140	(72.2)	88	(67.7)	
Unemployed	17	(19.1)	43	(22.2)	38	(29.2)	
Retired	6	(6.7)	5	(2.6)	1	(0.8)	
Disabled	3	(3.4)	2	(1.0)	3	(2.3)	
Income							0.001[a]
Less than $5,000	26	(29.2)	59	(30.4)	62	(47.7)	
$5,000-$20,000	8	(9.0)	17	(8.8)	20	(15.4)	
$21,000-$40,000	22	(24.7)	44	(22.7)	20	(15.4)	
$41,000-$60,000	19	(21.3)	38	(19.6)	15	(11.5)	
$61,000	11	(12.4)	31	(16.0)	7	(5.4)	
Health Insurance							<0.0001[a]
Yes	84	(94.4)	161	(83.0)	89	(68.5)	
No	5	(5.6)	29	(14.9)	39	(30.0)	
Relationship Status							<0.0001[a]
Single	56	(62.9)	111	(57.2)	101	(77.7)	
Married	14	(15.7)	52	(26.8)	6	(4.6)	
Partner	3	(3.4)	18	(9.3)	12	(9.2)	
Divorced	13	(14.6)	7	(3.6)	8	(6.2)	
Widowed	2	(2.2)	1	(0.5)	2	(1.5)	
Sexual Orientation							0.268[a]
Heterosexual	74	(831)	163	(84.0)	104	(80.0)	
Homosexual	5	(5.6)	11	(5.7)	6	(4.6)	
Bisexual	6	(6.7)	14	(7.2)	16	(12.3)	
Other	1	(1.1)	0	(0.0)	3	(2.3)	
PrEP Eligibility Criteria							
Sex with MSM	NA	NA	0	(0.0)	2	(1.5)	0.160[b]
IDVU	NA	NA	0	(0.0)	0	(0.0)	
Experience of STI	NA	NA	4	(2.1)	26	(20.0)	<0.0001[b]
Sex with HIV+ Person	NA	NA	0	(0.0)	6	(4.6)	0.004[b]
Accepting/providing money for sex	NA	NA	5	(2.6)	25	(19.2)	<0.0001[b]

Lack of condom use	NA	NA	164	(84.5)	126	(96.9)	<0.0001[b]
Multiple sexual partners	NA	NA	21	(10.8)	113	(86.9)	<0.0001[b]
Perceived HIV Risk							<0.0001[a]
No risk	63	(70.8)	113	(58.2)	42	(32.3)	
Small risk	19	(21.3)	67	(34.5)	66	(50.8)	
Moderate risk	4	(4.5)	10	(5.2)	14	(10.8)	
Great risk	0	(0.0)	2	(1.0)	6	(4.6)	
PrEP interest if no-few side effects							0.001[a]
Yes	19	(21.3)	43	(22.2)	50	(38.5)	
No	30	(33.7)	92	(47.4)	41	(31.5)	
Unsure	37	(41.6)	54	(27.8)	36	(27.7)	
PrEP interest if no-small cost							<0.0001[a]
Yes	36	(40.4)	69	(35.6)	76	(58.5)	
No	48	(53.9)	117	(60.3)	50	(38.5)	

Data are in number (%)

[a] Compare between no risk, low risk, and medium-high risk groups.

[b] Compare between low risk and medium-high risk group

Table 4.2. Predictors of PrEP interest among eligible candidates (n=324)

Predictor Variable	Odds Ratio	95% CI	p Value
Age			
18-24	7.05	2.32-21.43	0.001
25-34	5.10	1.60-16.22	0.006
35-44	1.77	0.52-6.05	0.360
45-55	2.02	0.61-6.67	0.251
55-70	1 (Referent)		
Perceived HIV risk			
No risk	1 (Referent)		
Small risk	2.97	1.70-5.19	<0.0001
Moderate risk	8.83	2.76-28.22	<0.0001
Great risk	4.07	0.82-20.27	0.086
Gave or exchanged money for sex			
No	1 (Referent)		
Yes	2.82	1.20-7.27	0.031
Experience of sexual assault			
No	1 (Referent)		
Yes	1.92	1.09-3.37	0.023
Comfortable with condom negotiation			
No	1 (Referent)		
Yes	2.72	1.09-6.77	0.032

MANUSCRIPT 2

Influences on African American women's sexual risk in the South: support for promoting PrEP

Prepared for: *AIDS Patient Care and STDs*
Jamie Troutman, Lucy Annang Ingram, Alyssa Robillard, Shan Qiao, Bambi Gaddist

ABSTRACT

Introduction: HIV rates remain high among African American women in the Southern United States. Although HIV prevention methods such as PrEP have been designated as affective HIV prevention tools, multi-level factors (i.e., individual, social, and structural) continue to contribute to the increased risk of HIV among African American women. We sought to understand the multi-level factors that influence HIV risk behaviors and the potential role PrEP may play in HIV prevention for African American in the South.

Methods: We collected qualitative data (4 focus groups; N=27) from a sample of HIV-negative, African American women, 18 years of age or older, who resided in the Southern United States. The Socio Ecological Model (SEM) and Health Belief Model (HBM) were used to guide our study. Focus group recordings were transcribed verbatim and double coded, using an agreed upon codebook developed by the research team. Common themes were discussed and analyzed further post coding.

Results: The following three themes were identified around sexual risk behaviors linked to HIV: 1) lack of condom use; 2) HIV status, disclosure, and testing; and 3) sexual partner sharing. Three additional themes were identified around influences that impact sexual risk: 1) cultural and "southern" influences; 2) perceived societal worth; and 3) health care system and provider experiences impacting health care seeking. Participants also provided robust discussions around PrEP as an HIV prevention method.

Conclusion: Understanding both sexual risk behaviors linked to HIV and multi-level factors that impact risk behaviors may improve targeted HIV prevention efforts like PrEP. Our findings support PrEP implementation efforts among African American women in the South.

INTRODUCTION

Approximately one-fifth of new HIV diagnoses are among women in the United States.[3] Among women diagnosed, African American women represent the majority of new HIV diagnoses (60%), with 91% of African American women contracting HIV through heterosexual contact.[4] In 2017, the rate of new HIV diagnoses among African American women was 15 times higher than non-Hispanic white women and 5 times higher than that of Hispanic women.[192] Of the 7,401 new HIV diagnoses in 2017 among women, 4,010 were living in the Southern United States. Of these cases, African American women's HIV diagnoses were 11 times higher compared to non-Hispanic white women and 4.5 times higher compared to Hispanic women in the South.[192]

Pre-exposure prophylaxis (PrEP) has been promoted and designated as an effective method to prevent HIV infection.[8] Despite increasing support for PrEP as an HIV prevention tool, rates of uptake and adherence remain low. Previous research studies around PrEP in the United States have focused mainly on men who have sex with men (MSM). [11,12,141-146,193-197] In addition, the majority of PrEP advertisements and promotions have targeted the MSM population. Although MSMs of any race have the highest risk of HIV infection, African American women are considered the second most vulnerable group for HIV infection.[1] While African American women are not considered the traditional risk population for PrEP, the high rates and risk of HIV infection suggests this population is worth focusing on for PrEP eligibility and use.

Awareness and knowledge of PrEP among African American women remains low.[188] Low risk perception of HIV infection has been found to be a significant barrier to PrEP uptake.[198] Engagement in sexual risk behaviors (i.e., sex without a condom,

multiple sexual partners, intravenous drug use, and alcohol dependence) and recent sexually transmitted infection (STI) diagnosis contribute to the high rates of HIV among African American women.[6,35] However, other social and structural factors have been found to be associated with increased risk of HIV infection among African American women. Lack of HIV prevention knowledge, [56-58] sexual networks, [39,96,199] unknown HIV status of self and partner,[6] incarceration,[200] low ratio of male to females, [73,74] poor access to health care,[6,201] and mistrust in the health care system[202] may add to the increase in HIV risk among African American women.

A recent study examined individual, dyadic, network, and community level factors that concurrently contribute to the HIV epidemic among women in the United States.[203] Using a socio-ecological framework, researchers identified four levels of factors that contribute to HIV vulnerability: 1) individual factors (e.g., risk taking, substance use, and HIV/STI awareness); 2) dyadic factors (e.g., sex exchange, interpersonal social support, and intimate partner violence); 3) network factors (e.g., sexual concurrency and organizational social support); and 4) community factors (e.g., poverty, discrimination, gender imbalances, community violence, unstable housing).

A nuanced understanding of the social and structural influences that may contribute to increased risk of HIV infection can provide insight for promoting alternative HIV prevention options, like PrEP.[204] Previous PrEP research focused on MSM,[205-207] included mixed-race female samples,[151,152,203] and took place in larger, urban cities.[10,149,152,203] With consistently high HIV rates among African American women and within the Southern United States, further research is needed to understand the individual, social, and structural influences that increase risk of HIV infection. In addition, research

examining the effect of potential PrEP use on factors that increase risk of HIV infection among an overlooked risk population, specifically African American women, is needed. This qualitative study explored 1) HIV risk behaviors and the individual, social, and structural factors that impact them, and 2) the potential role PrEP may play in HIV prevention among African American women in the Southern United States.

METHODS

Overview

A sequential, mixed-methods study conducted from May 2018 to April 2019 assessed current influences on African American women's HIV risk and PrEP eligibility. To be eligible for the overall study, participants must have been HIV-negative females, identifying as Black or African American, 18 years of age or older, and currently living in in the Southeastern United States. Following completion of a quantitative survey, participants were asked to report their willingness to participate in a future focus group. This study focuses on findings from the focus groups.

Recruitment and Procedures

Given the location of the research team (South Carolina) and the high rates of HIV diagnoses in the surrounding states, [187] we selected the following targeted states for recruitment: South Carolina, North Carolina, Georgia, Alabama, and Florida. Information and eligibility criteria about the study was disseminated through Facebook and Twitter, emails to targeted professional and leadership organizations (e.g., National Coalition of 100 Black Women), African American sororities, historically black colleges and universities (HBCUs) and other colleges and universities located in the study eligible states. Additionally, participants were recruited at local health events and conferences,

targeted HIV testing events, and an HIV/AIDS service organization. Upon completion of the online and in-person survey, participants were entered into a drawing for a chance to win one of two $50 incentives.

Survey participants were asked about their interest in participating in a future focus group about HIV prevention. If interested, participants were asked to provide their contact information so that they may be contacted with future focus group dates and times. Although survey participants were recruited from states in the South, focus group participants were only representative of South Carolina. Therefore, this paper reports data only from the qualitative focus groups and on a sample of women from South Carolina.

A total of four focus groups were conducted, consisting of 5-8 participants per session. Each focus group was conducted by a trained facilitator and included a note taker, who had been selected to represent the study population. All focus groups were conducted at the local HIV/AIDS service organization used for participant recruitment and lasted approximately 90 minutes. All participants signed an informed consent form, which informed participants of potential risks or harms by participating in this study, and completed a brief demographic survey prior to the start of the session. Participants were given a $25 gift card at the end of the session. Food and drinks were provided to focus group participants.

Sociodemographic data on participants were collected prior to the focus group and included age, education, income, insurance status, relationship status, sexual identity, and current profession/field of work. The Socio Ecological Model (SEM) [19,20] and Health Belief Model (HBM) [21] were used to develop a topical discussion guide. The SEM model was used to develop focus group questions examining the relationship between

individual, social, and structural factors that impact HIV risk. Constructs such as susceptibility to HIV, severity of HIV, and benefits of PrEP were developed using the HBM and were used to guide our study. The topical guide was used by the moderator and note taker during each focus group to ensure all focus groups covered the same general topics and stayed within the proposed time frame. Focus group questions explored African American women's 1) past and current sexual behaviors, 2) experiences and dynamics of their sexual relationships, 3) experiences with their providers focused on discussions around sexual history taking and HIV prevention service, and 4) PrEP's potential role in HIV prevention. All study procedures were approved by the Institutional Review Board at the University of South Carolina.

Data Analysis

Audio recordings of each focus group was transcribed verbatim, reviewed for accuracy, and uploaded into NVivo for data management and analysis. A preliminary codebook was developed by the principal investigator (PI) using an inductive approach during the initial coding of the transcripts. Two additional researchers, along with the PI, used the agreed upon codebook to analyze and apply codes to the focus group transcripts. All transcripts were double-coded. Researchers met post coding to clarify and discuss themes discovered.

Focus group discussions focused around past and current sexual behaviors, dynamics of sexual relationships, provider experiences related to sexual history taking and HIV prevention, and PrEP for HIV prevention. Three main themes emerged around sexual risk behaviors linked to HIV which included 1) lack of condom use, 2) HIV status, disclosure, and testing, and 3) sexual partner sharing. From the risk behavior discussions,

three additional themes emerged around influences that impact sexual risk: 1) cultural and "southern" influences, 2) perceived societal worth, and 3) health care system and provider experiences impacting health care seeking. In addition, participants discussed the potential role PrEP could play in preventing HIV, given the significant factors that influence sexual risk behaviors and put African American women at an increased risk of infection. Emergent themes identified in the focus groups are presented below.

RESULTS

Table 4.3. Participants' Demographic Characteristics (n=27)

	Percentage	n
Education		
9^{th}-12^{th} grade	7.4	2
Some college or university	33.3	9
Bachelor's degree	18.5	5
Higher education	40.7	11
Employment		
Employed	96.3	26
Disabled	3.7	1
Income		
Less than $5,000	14.8	4
$5,000-$20,000	14.8	4
$21,000-$40,000	33.3	9
$41,000-$60,000	25.9	7
$61,000	11.1	3
Health Insurance		
Yes	81.5	22
No	18.5	5
Relationship Status		
Single	59.3	16
Married	14.8	4
Partner	7.4	2
Divorced	14.8	4
Widowed	3.7	1
Sexual Orientation		
Heterosexual	92.6	25
Bisexual	7.4	2
Profession		
HIV field	37.0	10
Health field	22.2	6
Other	29.6	8
Student	11.1	3

A total of 27 women participated in the focus groups. Participants' age ranged from 20-67 years with an average of 39.15 years. (See Table 4.3 for participant data.)

Sexual Risk Behaviors Linked to HIV

Lack of Condom Use

The majority of participants said they did not use a condom when they engaged in sex to prevent HIV or STIs. Participants were more concerned about becoming pregnant than contracting HIV or other STIs, and considered themselves to be "protected" if they were on birth control. Participants discussed how they initially used protection when they enter into a relationship, but how they stop after a while, with the mention that African American men are "very resistant to use condoms." Other reasons for not using a condom included condoms causing irritation or yeast infections and putting on a condom took too much time. One participant who agreed that using condoms could be difficult while in a relationship noted, "It's a hard battle. Let's be honest, condoms don't feel good; it doesn't feel natural."

The dynamics of the relationship can play a major role in whether condoms are used during sex. Some women mentioned that condom negotiation was difficult because women did not want to be confrontational out of fear of rejection or how their partner may react. One participant stated, "If I don't have unprotected sex, he won't come back." Another participant commented on how African American women use unprotected sex as a way to "keep their man" saying, "And if my man says that we are not using protection then I will abide by it because they are few, far, and in-between…because they refuse to go outside of race." Other women said women are scared to ask about their sexual partner's status and they allow men to have too much power in the relationship.

Participants also thought that assuming they are in a monogamous relationship led to no condom use, even though all participants expressed how common it was for their partners to have other sexual partners simultaneously. One participant mentioned:

> I'm married and I'm faithful to my husband, and I will assume that he's faithful. It's the assumption. I'm not gonna put my lifeline on it, but I would just assume that he's loyal because I'm loyal. That's why I don't use condoms.

HIV Status, Disclosure, and Testing

Participants were aware and informed of the current HIV epidemic among African American men and women, and expressed concern about knowing the status of their sexual partners' status given the high rates of HIV among African American men. One participant stated:

> It makes me more cautious and makes me even more cautious with them [African American men], um, compared to anybody else. That's why I advocate for knowing what the status is between, not just myself, but for the other person considering to do sexual activity with me. I want to protect myself and that is my preference dating wise, so that's why it's a concern for me.

Some women were insisting on knowing their partner's status; however, the majority of women were not confirming their partner's status before engaging in sexual activity. Some women stated that they will ask their partner their status, but they do not insist on looking at their test results and that they will just accept a verbal confirmation. Several participants discussed how that was an issue because of the dishonesty that exists in the community about people's results. Participants mentioned that men are printing off fake results or using old results to show their negative status to women who take the initiative to ask. One participant responded, "It's dangerous out there."

Participants stated that there is a lack of transparency and consistency in regards to testing and results. Participants believed that women are not getting tested consistently and that the timeframe between HIV screenings varied too much for women and their partners. One participant commented on the time between testing could be "two weeks, two months, or two years." In addition, participants said their partners are hesitant to go and get tested together because they don't want them to know that they've been having sex with other people.

Sexual Partner Sharing

Perceived as a common practice. The majority of participants said that they had experienced or knew of someone who had experienced their male partner "cheating" or openly having other sexual partners. Participants discussed how most Black women don't talk about their relationships or about partners cheating or having other sexual partners — one participant went on to say, "The lack of communication only amplifies their risk." Another woman commented that, "Black women are too trusting." Some participants agreed with this comment while others said women in general are too trusting.

According to participants, sexual partner sharing or men having multiple sexual partners is considered the norm in most relationships for African American women and in the African American community. All participants agreed that African American communities are accustomed to "sharing" with one participant noting, "Most Black households have a female head because most households are sharing men." The women also said that either they know about it or they act like they don't know about it, while one women commented, "Nine times out of ten you know, and he know you know." Several participants mentioned that women are accepting of it for reasons such as

needing stability, financial dependence, and because they want to keep their partner. One woman responded, “Do I wanna like get rid of you and be out on the street, and be homeless…or am I just gonna stay here and deal with this you know?” Another participant observed that in these situations we rarely consider that the woman may also have other sexual partners if she knows her main sexual partner is “cheating”, which only increases her risk more. However, most participants did not report having additional sexual partners in combination with their main partner.

Lack of available men. A major issue expressed by participants was that the ratio of Black men to women was very low and due to this they are more open to and accepting of sharing their partners. Several participants commented that they believe there are more same sex relations among Black women due to the lack of available Black men and/or women not wanting to share their partner. One participant noted, “So I still tend to see a lot of women taking on men roles, starting to love one another; just wanting to have somebody to love or either we're willing to share.” A common comment made in reference to the lack of available Black men among participants was that all Black men were incarcerated, deceased, or gay. One woman added:

> With the existence of Black men, there are less choices for Black women; particularly young black women. There's about eleven to one ratio in some cities in this country, and so there's less men. Yeah, because its share or have nothing, because between what is an eligible black man who is not on drugs, got a job, not sleeping on his mama couch, got a record and can't get a job, that's not gay, and that ain’t switched over to a white woman, Chinese woman or German woman…okay, there ain’t much left.

Open to multiple partner relations. According to several participants, another influence on sexual partner sharing is that African American women are becoming more open sexually and with their sexuality. One participant shared, “Just open sexuality

period. It's more open and acceptable now to be bisexual. And marriages…I've not known, but heard where marriages have open, open marriages where the husband can sleep with whomever he wants and the wife can sleep with whomever she wants. Just open sexuality." Several participants agreed and discussed that open marriages in the Black community are becoming more and more prevalent — both when accepted and known by the woman and not accepted and not known by the woman. These participants noted that there is still risk involved, whether the woman is aware of the open relationship or not. One woman shared

> I'm married, but you know, we're open. So like, if we have a threesome with another female it's like he's not really putting himself at risk. I'm putting myself at risk because even though you're using a condom with a female, like because of unwanted pregnancy, I mean, you're using the same condom on her as you're using on me. So it's like I'm exposing myself to her bodily fluid and anybody she slept with. So literally I'm taking the risk of getting everything…he's not taking the risk on none of them. How many people are going to have sex in a threesome and change the condom every time you move from each female? You're not. So it's like you're at risk.

Unaware of multiple partner relations. Participants also discussed that some women are not aware that their husband or partner has other sexual partners so they do not take extra precaution or practice safe sex with their husband or partner. One participant reflected on her mentality before she got married saying, "I used to say 'as long as he ain't bringing nothing home to me, I don't care.' I don't know about it; just don't let me find out. That was my mentality. Hey, do what you want to do." While another woman shared a story about a friend who was married, but unaware of her husband having other sexual partners, which led to her contracting HIV:

> My girlfriend, her husband was stepping out. And with him stepping out, because he wasn't honest with her about his stepping out or in order to have an open relationship, he did it in secrecy. And doing it in secrecy, he didn't use

> protection. He ended up getting HIV and he infected her. How she found out was because he was still having sex with her, and he was still having sex with other females. But how she found out was when she found the medication.

MSM behavior. The majority of participants commented that many Black men are having other sexual partners that are male — noting that there is "a lot of secrecy" in the African American community around this occurrence and that these men are considered to be on the "down low" or "undercover." One participant commented on how the secrecy impacts their sexual health, stating:

> What I found out is that we have a lot of men, now African American men, who are now sleeping with other men; unbeknown and unknowing to the women. And they are clearly unaware. The rates of STDs or STIs have definitely increased. It's because the young men are sleeping with other men and they're also sleeping with women, and they're not notifying their partners.

Although the majority of participants reported a high frequency of men engaging in MSM behavior, interestingly the discussion around MSM was not as robust as we anticipated.

Factors Influencing Sexual Risk

Cultural and "Southern" Influences

Many cultural influences emerged when discussing influential factors on sexual risk behaviors among African American women. All participants commented or agreed that living in the South, particularly in the "Bible Belt," impacted how they act and conduct themselves sexually — many participants stating that African American women are more conservative in their communication, attitudes, and beliefs around sex in the South. Most participants said that sex was not discussed when they were growing up and that their parents did not provide them with information or have conversations "about sex

and how to navigate through sex." If their parents happened to discuss sex it was only focused on preventing pregnancy and just not engaging in sex; no discussions were had around HIV. Several participants mentioned that their parent/s threatened to "beat" them if they had sex or became pregnant, which only "spiked their interest more" and led to participants engaging in sex without any knowledge about safe sex practices. One woman stated, "Must be good if you wanna beat me; must be real good. Let me go see how good it is." Several women also said that their comfort level with their sexuality growing up was very low, given the conservative environment they grew up in and lack of conversations had around sex. One participant reflected on the historical events that impacted their perceptions of sex and how it has evolved over time, indicating:

> Really, when you dig deep under the surface, the African American community as a whole is very conservative sexually, because we were very deeply based in the church. You know, so we have very conservative ideas, particularly when it comes to same sex relationships, and when it comes to sexual relationships outside of marriage. All of those things that we have been culturally ingrained with, even though our reality has been just the opposite, which was to try to encourage us to breed when it was free labor. Once they started had to pay us, we got too many children. You know, now we have too many. They never said 'she had too many during slavery,' but once things changed, then it became you have too many [children]. So I think with the onset of the birth control pill, women of all races and all backgrounds got more sexual freedom. And so the experimentation started and we started to be able to not have to worry about being pregnant, and you had the freedom to enjoy it.

Religion and the church. Twenty-five of the participants considered themselves to be a religious or spiritual person. The majority of participants brought up the point that they, as well as most African American women, are deeply based in the church. These participants emphasized that the connection to church impacts how sex is viewed, discussed, and addressed among African American women. Although a great deal of time

is spent at the church and the HIV epidemic is most prevalent among African Americans, rarely do they have sermons or conversations around sex and HIV due to those topics still being considered "taboo". Most participants agreed that this is a missed opportunity by the church and that more conversations need to be had in a place where people are easily accessible and open to listening. One participant stated:

> I think, I think there's a ways to go because of stigma and things of that nature. Within the African-American community, at some point, we're going to have to come to a realization that what used to work is not always going to work. So we have to do different things and you've got people in your congregations that are doing it. So do you want souls? Do you want them to be there or do you not? We have to start having those hard conversations, those taboo conversations.

Some participants discussed having a religious outlook on having sex and who they have sex with, by saying that people you have sex with also "carry" their previous partners with them. One woman used the term "soul-tie" which she described as having a "connection to everything the person you have had sex with has ever done and had sex with." She elaborated on how this idea made her more aware and take on more responsibility to safeguard her health by stating:

> People you allow, not only into your life, but into your body, everything that they ever touch is in you. For me, that was one of my biggest concepts. And once I got that, I was like, so everything, every person that they've ever touched and that person has ever touched, has definitely penetrated my body and my soul. And I decided that I wanted to be more responsible; not only with my health, but with myself, with my sex, with my spiritual being. I just had to protect that first.

Sexist repercussions. Several women also agreed that there is a lack of communication due to sexist repercussions. For example, one participant discussed how her daughter became pregnant, and the church asked her to "step down from the choir,"

yet the young male father was allowed to continue his involvement with the church and the choir. She continued by stating, “Some of these repercussions keep us from talking. Keep us from getting information. Keep us at risk for HIV, for unplanned pregnancy, for STDs, or all of those things that are caused by the same thing — unprotected sex, unprotected sex.”

Gender roles. Many participants felt that gender roles are still prevalent in the South and in the African American community. Several participants mentioned that culturally, it’s believed that the man owns the woman’s body. One woman mentioned the fact that you still have to have your husband’s permission to get your “tubes tied” in South Carolina. Participants felt that the gender roles and power dynamics in their relationships could lead to riskier sexual behaviors and having less control over their bodies and what happens to them. Many participants agreed that they “allow men to have too much power in the relationship,” while one participant argued that women have to demand respect, and in turn protect themselves by saying:

> So I mean, if you demand somebody to respect you, or use a condom, or go get tested…if this person really wants to be with you, they're going to do that. A person only does what we allow them to do. And when you give people too much power or control, you know, they're not gonna respect you or not gonna appreciate anything.

Perceived Societal Worth

Some participants expressed that the value of sexuality in African American women is different and undervalued compared to other races and ethnicities. These participants felt that Black women’s value and desirability is at times diminished by the culture that we live in. One woman responded, “The value placed on Black women’s sexuality, by society, is not at the prime rate.” Another participant further described how

the difference in value among Black women compared to other women impacts their ability to find a Black male partner, who they don't have to share, and lessens certain opportunities to move up in society, stating:

> Like I said, with the difference [difference in value], we're more likely to share because the devaluation of the Black woman. Most other, and particularly our men, have married into every other nationality there is. There are very few other nationalities that married Black women that aren't famous, aren't rich, aren't somebody. You don't see Chinese men marrying Black women. You don't see you [Black women] if you look in the NBA and the NFL. How many of them married to white women versus how many white players married to a sister? If we get to the NBA, we got to play damn ball ourselves. You know, we don't have those same opportunities because there's not that same value on our beauty, on our sexuality, on our body shapes.

Other participants believed that African American women may also use their body sexually to increase self-esteem, for power or for survival, or to find their identity — however, this increases their risk by 1) having multiple sex partners, 2) having sex for money, and 3) influencing what they believe their role in the bedroom to be or what acts are expected of them in the bedroom. Some participants emphasized how this is a greater issue when the woman does not practice safer sex, with one woman saying:

> The self-esteem that they might get or the self-identity that they might get, from becoming who they want to become in the bedroom or on the street, puts them at risk. They don't know how to protect themselves or they're not using condoms, you know, to protect themselves.

Health Care System and Provider Experiences Impacting Health Care Seeking

When asked about their relationship with their provider and experiences with the health care system, participants had several discussion points around distrust with the health care system, continued barriers to access, and a lack of discussion around sexual history and HIV services.

Continued distrust with the health care system. Many participants expressed that distrust still exists among African Americans and the health care system; some women believing that there is still information withheld from them in regards to their health. One woman commented, “If you want to control a person or people, you control their access to health information.” Many women agreed that they do not receive the most relevant and up-to date health information in the African American community and that lack of information can impact their health by influencing their preventive actions and treatment decisions. Additionally, participants mentioned that most Black women do not have a regular doctor or insurance. One participant summarized the distrust and lack of access by saying:

> A lot of Black people, and Black women, don't even have a doctor. They don't have a job that offers insurance. They don't have insurance. We didn't expand Medicaid in this city. They don't even go to the doctor. And then from our cultural background, hospitals, doctors, and medicine still isn't as widely accepted, or they may experiment again on us. We've been guinea pigged to death. We've been researched to death. And we always go back to the Tuskegee study.

Lack of sexual history taking among providers. For the women who reported going in for routine screenings, the majority reported that their providers did not ask questions about their sexual history; if they were asked, it was not in detail. Several women believed that providers are afraid to ask about their “sex life” which they found surprising given the high prevalence of HIV in the African American community. One participant commented: “And you would think, nowadays, they would ask that question because you're seeing so many people getting HIV and all these STDs. You would think that that would be something that doctors would be asking their patients now, but they still not doing it.” Some participants expressed that

sex is still “taboo” to discuss in the South, even with health care providers, and that providers are hesitant to ask questions about sexual activity because, “They're afraid what you're going to say if they ask you because they may not typically believe or morally agree with what you're going to tell them. So they just not even going to ask.” Another participant responded: “As soon as providers realize you identify or engage in behaviors outside of their moral compass, then they ignore it and do not discuss risks that could be associated with those factors.”

Negative experiences of HIV testing and perceived HIV stigma among providers. Participants discussed their frustration with how HIV testing is not part of the testing panel when they go in for their regular doctor visits or for the “Well Woman’s” visit. Participants noted that many women believe when they go to their doctor or gynecologist that they get tested for HIV, which leads them to believe that they did their HIV screening and their results came back negative. Additionally, participants complained that you have to make additional appointments to get screened for HIV/STDs because they do not offer it during a normal doctor’s visit, and many women are less likely to go back for that additional appointment.

Several participants believed that providers do not like to test for HIV and instead send them to other HIV-focused clinics to get tested, resulting in multiple appointments. Participants believed that providers did not want to have the responsibility to tell the patient they are positive and have to get them into treatment. One participant commented, “I must say it, some are not going to do it [test for HIV] because that means, if you have something, they got to put you in treatment. So they rather for you to come to one of these places [HIV/AIDS service organization] and get it done. That way they don't have

to be bothered with you." These participants also believed that providers are not sensitive to people testing positive — one participant saying, "They just give you your results and send you on your merry way." Some women also believed that providers are insensitive because they felt the providers were judging how someone contracted HIV; participants felt that providers think they must have done something "wrong" to contract HIV when it could have been out of their control. One woman commented on how they felt a provider would react to her testing positive to HIV saying, "Doctors lookin' at you all dirty, like I don't want to handle you, I don't want to deal with you."

A minority of participants mentioned having good experiences with their health care provider, reporting that they asked thorough questions about their sexual history and that they were genuinely concerned about their sexual health. However, several women reported having experiences with their provider that were negative. For example, one participant said when she asked her provider about getting tested that the provider asked her if "everything was ok with their marriage?" Several other women mentioned similar experiences where their provider assumed they didn't need to be tested because they were married or in a long-term relationship. Another participant shared:

> When they're doing my blood work, for like my panel and everything from my kidneys and stuff, I just be like, can you check me for any STDs and HIV and everything? Then they just groan and they'd be like, 'Why, are you still with the same partner?'

PrEP's Potential Role for Prevention among African American Women

Participants said that PrEP could be beneficial to women who may have difficulty negotiating condom use with their partner. Several women thought PrEP would provide an added step of protection against HIV, if their partner did not want to use condoms or if

they believed their partner had other sexual partners. Participants believed that with the high prevalence of sexual partner sharing and non-monogamous relationships within the African American community, PrEP could protect women who may have "concerns" about their sexual partner. One woman stated, "I think it would be a benefit to them, especially if they knew that was going on or they had a feeling something wasn't right. I think that would be a good idea to use PrEP. At least I would." Participants also mentioned that PrEP could be beneficial to women who may acquire their risk through their partner, referring to situations where a partner may secretly have other sexual partners or who maybe engaging in MSM behavior on the "down low." One participant commented, "Even if you're not high risk, you still want her to take it [PrEP] because you may be monogamous, but your partner may not be; because you got a lot of men that like to do that…undercover."

The majority of participants believed that PrEP could provide a sense of empowerment to African American women who want to take control back over their bodies and provide themselves with a means of protection. One woman said, "It'll be more that I'm protecting myself, and I'm not leaving that up to anybody else." Several participants felt that taking PrEP would allow them to take their "power back" and be in control of their own sexual health and well-being.

None of the participants had been told about PrEP by a provider; however, several participants stated they would be interested in taking PrEP if it was recommended by their provider. Some participants stated that they didn't think their provider even knew about PrEP and that most providers miss opportunities because they are not educated on how to take their sexual histories or how to address HIV. One participant commented,

"Well you know what, when it comes to the doctors, it's the fact that not only PrEP, but HIV in general, taking a sexual history, and those types of subjects are not taught in residency and in med school."

Most participants had heard of PrEP, however, they did not feel like PrEP promotions or advertisements were relatable to them. The majority of participants felt that PrEP was targeted only to MSMs, which led African American women who may be eligible less likely to seek out PrEP for HIV prevention. Regardless, the majority of participants advocated for PrEP use among African American women who may be at risk of HIV infection and also for anyone who is HIV negative and may be at risk of infection. One participant said:

> Anybody can purchase it [PrEP], but a lot of people aren't aware that anyone can purchase it. As long as you put a billboard sign saying you got to be negative, as long as you're HIV negative, and you want to purchase PREP, you have the availability to purchase PrEP. But it's been marketed so much to MSM, and for MSM, that a lot of people believe that is only for men who have sex with men. But it's not. It's for anybody in the general population, who is HIV negative, and feels that they may be at risk or high risk.

DISCUSSION

From these focus groups, African American women reported multi-level factors that continue to put them at risk of HIV infection. Behavioral factors included lack of condom use, lack of HIV status, disclosure, and testing, and sexual partner sharing. Influential factors that were associated with risk behaviors included cultural and southern influences, perceived societal worth, and health care system and provider experiences impacting health care seeking.

Our study provided insight into the multiple factors that interact to contribute to African American women's HIV risk in the South. Similar to a previous study, [203] we

presented data that demonstrated intersecting factors, across multiple levels that operated similarly among women living in the same geographic area. Participants reported factors that had the potential to interact and influence their HIV risk, particularly among women residing in the South. Our findings support PrEP as a potentially effective and beneficial tool to prevent HIV by addressing socio-ecological factors that affect HIV risk among African American women.

Lack of condom use during sex was considered a risk behavior that most women engaged in; however, participants provided justifications for this continued behavior which mainly included the assumption of being in a monogamous relationship, a tactic used to "keep" their partner, and resistance from their partner. In a recent study examining condom use among African American women and men, female participants reported condom negotiation being close to impossible with their main partner and could significantly, negatively impact their relationship. [39] Participants from our study reported engaging in sex without a condom even when they were aware that their partner may have other sexual partners. Similarly, African American women have reported engaging in sex without a condom despite knowledge of their partner's other sexual partners and as a means to "keep a man". [72,76] Our study also discovered issues that African American women are facing around disclosure status from their partners. Several participants reported that males within the African American community are providing false negative results to women when asked about their HIV status, causing a lack of transparency and accuracy of status. These reported risk factors (i.e., no or inconsistent condom use, sexual partner sharing, and unknown HIV status) support PrEP eligibility and use among African American women.

Sexual partner sharing was highly reported among participants, and was considered to be a risk behavior that increased risk of HIV infection. Many women described the practice of sexual partner sharing as being "accepted" in the African American community. Although the term "acceptance" was used among participants, we questioned whether the term "tolerance" was better suited for the experiences participants described. According to our participants, sexual partner sharing is a practice that has become common and expected within the African American community. It is also a practice that allows African American women to procreate and build families with African American men. The normality and positive outcomes have made African American women tolerant of sexual partner sharing, but likely far from accepting. We speculate that, if given the choice, African American women would choose not to share their partners and to have monogamous relationships. Future research should further examine the difference between acceptance and tolerance of sexual partner sharing.

Cultural influences significantly impacted participant's sexual risk behaviors. The majority of participants felt that women in the South had a conservative outlook on sex, which did not reduce their risk behavior, but made women less likely to have conversations around sex and safe sex practices. Lack of communication about sex, sexual risk behaviors, and negative sexual outcomes was influenced by the role of religion and church, potential sexist repercussions that may be faced, and gender roles still occurring in the South. Participants felt that these influences impacted their knowledge of safe sex practices and ability to protect their sexual health, resulting in "secrecy" of sexual activity and increased HIV risk amongst African American women.

Efforts to increase PrEP awareness and uptake should target predominantly female frequented areas and establishments to be most effective.

Focus groups revealed there to be a continued distrust with the health care system among African American women, which impacts their access and ability to receive routine and preventive care (e.g., HIV screening). Moreover, providers are continuing to miss opportunities to ask about patient's sexual history and recommend routine HIV testing and PrEP, regardless of the patient's current relationship status among those who do seek sexual health screenings. While provider recommendations of PrEP remain very low, there should be focus around increasing the amount of African American women who initially seek sexual health screenings. In an earlier study, at-risk women suggested that PrEP afforded an opening for patients and providers to improve their communication about HIV prevention, as well as their overall sexual health.[151] Due to the lack of trust expressed among African American women with the health care system, an opportunity not just to recommend PrEP, but to discuss and receive routine sexual health screenings may never occur. Given African American women's perceived stigma around HIV in the health field, providers should work to improve their demeanor and discussions around HIV and HIV prevention methods to increase the amount of at-risk African American women who seek HIV prevention services.

Participants believed that PrEP had the potential to combat certain risk behaviors and influences on risk behaviors that may be out of their "control." For instance, given the prevalence and acceptance of sexual partner sharing within the African American community, [89,90] women may acquire risk unintentionally through their partner. PrEP has the potential to reduce their HIV risk, by allowing women to protect themselves and their

sexual health from an involuntary risk. Other factors such as a partner's refusal to use a condom and false disclosure of HIV status may inadvertently put African American women at risk of HIV. Similar to other studies, [18,150] PrEP was believed to provide a sense of protection, empowerment, and self-control when health risks were high; however, our study focused mainly on advantages of potential PrEP use and did not discuss potential disadvantages that may occur.

Our study has several limitations. The sample size (N=27) was small and focus groups were conducted in a single, South Carolina community; therefore, findings may not be reflective of influences on sexual risk and opportunities for PrEP among African American women in the South. Our study focused on African American women in the South. These results may not be generalizable to all African American women given the high rates of HIV in the South and the cultural influences that are specific to the South.

CONCLUSION

Our study examined social and structural influences associated with increased HIV risk among African American women in the South. Understanding the multi-level factors that may contribute to the disproportionate risk of HIV, experienced by African American women could improve our targeted HIV prevention efforts that include PrEP. PrEP interest and uptake can also be influenced by multiple individual, social, community, and structural level factors. Findings from our study provide support for expanding PrEP implementation efforts among African American women, and highlight the need to consider multi-level influences that contribute to HIV when assessing potential PrEP benefits and eligibility among African American women in the South.

MANUSCRIPT 3

African American women's current knowledge, perceptions, and willingness of PrEP use for HIV prevention in the South

Prepared for: *AIDS and Behavior*
Jamie Troutman, Lucy Annang Ingram, Bambi Gaddist, Alyssa Robillard, Shan Qiao,

ABSTRACT

Introduction: African American women accounted for approximately 60% of new HIV diagnoses among women in the United States, with the greatest burden occurring in the South. Past efforts to prevent HIV focused on behavioral interventions aimed at reducing sexual risk behavior. More recent HIV prevention methods have included oral pre-exposure prophylaxis (PrEP) with antiretroviral drugs. Although PrEP has been designated as an effective HIV prevention method since 2012, awareness and uptake of PrEP remains low among African American women. Our study explored African American women's knowledge, perceptions, and willingness of PrEP use.

Methods: Four focus groups were held in April 2019, consisting of 27 women, who identified as African American and resided in South Carolina. Focus group topics focused on participants' awareness, perceptions, and potential use of PrEP.

Results: The majority of women had heard of PrEP; however, over half of the participants were in the HIV or health field. Overall, participants believed that the "lay woman" would be unaware of PrEP. Participants' perceptions of PrEP included stigma of PrEP use, benefits to non-monogamous couples, and experiences with PrEP clients. The majority of women were willing to use PrEP, but major concerns around short and long-term side effects were expressed. Participants provided recommendations to improve PrEP uptake among African American women that included targeted campaigns and spokespersons.

Conclusion: African American women are interested and supportive of PrEP use for HIV prevention in the South, where HIV rates remain highest. Past PrEP implementation efforts have not been relatable to African American women; therefore, awareness and

uptake rates remain low. Future efforts to increase PrEP awareness and uptake among African American women should be relevant, and should provide comprehensive information on potential side effects, purpose of use, and eligibility criteria.

Key Words: PrEP, HIV prevention, African American women

INTRODUCTION

Within the United States, there are over 1.1 million people living with HIV and an average of 40,000 new HIV diagnoses annually.[1] Women represent 19% of new HIV diagnoses in the United States, with African American women accounting for 60% of new cases.[3] HIV/AIDS related illnesses continue to be among the top-leading causes of death among African American women between the ages of 20-54 years.[5] The distribution of HIV in the United States varies geographically, with the South accounting for nearly 52% of people living with HIV. [2,3] Of the new HIV diagnoses among women, 54% of diagnoses were among women residing in the Southern United States.[192] In the South, the rate of new HIV diagnoses among African American women per 100,000 (26.8) was 11 times the rate of non-Hispanic white women (5.8) and 5 times the rate of Hispanic women (2.4).[192]

Unknown HIV status, sexual risk behaviors (i.e., unprotected sex and multiple sexual partners), previous sexually transmitted infections (STIs), sexual assault, and alcohol and other drug use are influential factors that increase HIV risk among African American women.[6] In addition, the high prevalence of HIV within their sexual networks increases their risk of HIV, regardless of their relationship status.[6] Sexual partner sharing and difficulty with condom negotiation with their primary partner creates additional HIV risk for African American women. Therefore, actual risk can vary across reported risk behaviors and perceived risk, and thus HIV prevention efforts should be measured and considered across all risk groups (no-, low-, medium-, and high-risk) among African American women.

Current efforts to reduce HIV risk and transmission among African American women include tailored behavioral interventions that aim to increase safer sexual behaviors and practices (i.e., routine HIV and other STI testing, condom use, and reduced number of sexual partners), reduce HIV-related stigma, and improve treatment services and retention rates among HIV-positive individuals.[7] Due to reported barriers to HIV testing and condom access, and continued high rates of HIV among African American women, further HIV prevention efforts are needed.

Pre-exposure prophylaxis (PrEP) has been shown to be highly effective (92%-99%) at preventing HIV when taken consistently and as prescribed.[8] PrEP has been recommended for men who have sex with men (MSM), transgender individuals, injection drug users (IDU), and heterosexual men and women who report one or more of the following risk factors: inconsistent condom use, having multiple sexual partners, having an HIV-positive sex partner, having a recent STI, having an HIV-positive IDU partner, sharing of injection equipment, involvement in commercial sex work, and use of post-exposure prophylaxis (PEP) for HIV prevention in the past 12 months.[8]

Past research studies around PrEP have focused on MSM and high-risk international and heterosexual men and women.[10-18] Understanding knowledge, attitudes, perceptions, and interest in PrEP use among populations who continue to experience high rates of HIV is essential, however there are limited studies that examine African American women's knowledge, perceptions, and willingness of PrEP use in the United States. PrEP studies involving African American women in the United States have taken place in predominantly urban cities, have included mixed-race and mixed-gender participants, and were single method studies. [10,17,18,148-153] Given the consistently high

rates of HIV experienced in the Southern United States, specifically among African American women, continued research focusing on HIV prevention in the South is needed. Our study aimed to fill these gaps, using qualitative research, by exploring the awareness, knowledge, perceptions, and willingness of PrEP use among African American women in the South.

METHODS

The data for our study was derived from a mixed-methods study focusing on sexual behaviors and PrEP awareness, perceptions, and potential use among African American women. Focus group participants were recruited from the quantitative survey sample (N=413). A total of 27 women participated in the focus groups. The study will only report findings from the qualitative data collected.

Procedures

Surveys were collected between May 2018 and March 2019. Multiple channels were used to invite participants to take the online survey. This included emails and social media advertisements, as well as face-to-face recruitment. Emails and social media posts provided the link to the survey and eligibility requirements. Face-to-face recruitment for the online survey involved handing out cards with the survey link and information about the survey and eligibility criteria. In addition to the online survey, participants were also given the chance to take the survey in-person at a local non-profit organization and various community events, which included The Black Women's Expo, community health fairs, and targeted testing events in Columbia, South Carolina.

Eligibility criteria for survey participation included women who (1) self-identify as African American or Black, (2) are18 years of age or older, (3) self-report as HIV-

negative, and (4) reside in the Southeastern United States (South Carolina, North Carolina, Georgia, Alabama, or Florida). A total of 413 participants completed a quantitative survey that assessed their demographic information, sexual risk behaviors, perceived HIV risk, dynamics of their sexual relationships, and basic PrEP knowledge and perceptions.

Participants who completed the survey were entered into a drawing for the chance to win one of two $50 VISA gift cards. At the completion of the survey, participants were asked if they would be interested in participating in a focus group to discuss the survey topics further, sometime at a later date. If interested, participants were asked to provide their email and/or phone number so that they could be contacted at a later date to invite them to a focus group. Only women who completed the survey were eligible for focus group participation.

Participants who were interested in the focus group were contacted between February 2019 and March 2019 to invite them to the upcoming focus groups. A total of four focus groups were conducted in April 2019. A total of 27 women participated in the focus groups. All participants received a $25 VISA gift card upon completion of the focus group session.

A topical guide was developed to guide focus group discussions and to ensure all focus groups covered the same overall topics. The moderator and note taker used the topical guide to lead the focus group and to ensure the focus group stayed within the intended time frame. Each focus group lasted approximately 90 minutes. At the beginning of each focus group, participants signed an informed consent form, where they were provided information about potential risks or harms of participating in this study,

and completed a demographic questionnaire. Participants were asked questions about 1) knowledge, awareness and understanding of PrEP; 2) attitudes about PrEP usage for themselves and others; 3) perceptions of PrEP's impact on future sexual behaviors (i.e., condom use); 4) stigma related to PrEP use; 5) willingness to use PrEP; 6) likelihood of recommending PrEP to their sexual partners; 7) likelihood of PrEP uptake and adherence, given the behavioral requirements and financial obligations; 8) current relationship with their provider, focusing on patient-provider discussions around sexual history and behaviors, and provider recommendations of PrEP use; 9) past and recent sexual activity behaviors; and 10) experiences and composition of sexual relationships. All procedures for this study were approved by the Institutional Review Board at the University of South Carolina.

Data Analysis

Focus groups were recorded, transcribed, and analyzed using NVivo (version 12). A codebook was developed to guide data analysis and to further analyze identified themes. The transcripts were reviewed, coded, and discussed by three researchers. All four transcripts were double coded. Researchers met post coding to discuss and compare similarities and differences between themes from each focus group. Analysis indicated consistency of themes across all four focus groups.

RESULTS

A total of 27 women participated in the focus groups. All participants resided in South Carolina. The average age was 39.15 years among participants, with participants' age ranging from 20-67 years. Among the 27 participants, 59.3% reported they were

interested in PrEP prior to the focus group through the sexual behavior survey. Table 4.4 includes the demographic data for the participants.

Table 4.4. Participants' Demographic Characteristics, PrEP Focus Group Study

	n	%
Education		
9^{th}-12^{th} grade	2	7.4
Some college or university	9	33.3
Bachelor's degree	5	18.5
Higher education	11	40.7
Employment		
Employed	26	96.3
Disabled	1	3.7
Income		
Less than $5,000	4	14.8
$5,000-$20,000	4	14.8
$21,000-$40,000	9	33.3
$41,000-$60,000	7	25.9
$61,000	3	11.1
Health Insurance		
Yes	22	81.5
No	5	18.5
Relationship Status		
Single	16	59.3
Married	4	14.8
Partner	2	7.4
Divorced	4	14.8
Widowed	1	3.7
Sexual Orientation		
Heterosexual	25	92.6
Bisexual	2	7.4
Profession		
HIV field	10	37.0
Health field	6	22.2
Other	8	29.6
Student	3	11.1

Focus group discussions were categorized under the following themes: PrEP knowledge and awareness, perceptions of PrEP, willingness to use PrEP, concerns about PrEP, and recommendation to increase PrEP uptake among African American women. Major findings from each emergent theme are presented below.

PrEP Knowledge and Awareness

The majority of participants had heard of PrEP prior to the focus group. Participants reported hearing of PrEP through various channels such as commercials on television, television shows, magazines, and at their place of employment. The majority of participants reported working in the health care field and contributed their awareness of PrEP to their occupation. One woman stated, "If I wasn't working here, I know I probably would never have heard of PrEP. When I worked at [health insurance company], I knew HIV, but I didn't *know* HIV." Several women said they had heard of PrEP from relevant television shows featuring a predominantly African American cast. One participant had heard of PrEP through a family member who was a MSM and had started taking PrEP.

PrEP not targeting African American women. All groups expressed that although they had heard of PrEP, the advertisements and promotions for PrEP targeted mainly MSMs, and were therefore not relatable to African American women. Several women believed this was a reason why many African American women are still unaware of PrEP. One participant commented, "PrEP should be marketed to anyone who is having sex." Some participants mentioned that more recent advertisements for PrEP have started to include women and African American women, but they only make a small appearance, so the advertisements still do not feel targeted towards African American women. One participant said, "There has been more focus on getting PrEP and PrEP information into the MSM community. The same has not been on women and African American women who are at high risk for HIV."

Providers not promoting PrEP. No participants had heard of PrEP through their provider. Some participants felt that their provider was only concerned about birth control and preventing pregnancy. Several women mentioned that they would have been interested in PrEP if their provider would have recommended it. One participant shared, "If I would have known, and my provider would have shared this information, I probably would have known about PrEP, and probably would have at least used it before to know what it's like. But guess that's why I'm here." Some women also felt that providers target their PrEP recommendations to MSM and fail to consider women and others who may be eligible for PrEP. One woman hesitantly said, "And it seems like providers mainly, and this is, I mean it's bad, but mainly they're told to talk about PrEP with MSM. They don't really talk about promoting it with other like heterosexuals."

Poor marketing. All participants agreed that the African American community had very little awareness or knowledge of PrEP. One participant argued that PrEP hasn't infiltrated the "urban market" strong enough yet to know that there is a product than can help those who are HIV negative. Another participant commented, "I think it should be marketed more to African Americans because we are the highest risk of people becoming newly infected with HIV. So I think it's a great thing, but we are unaware of it. A lot of people don't know a lot about it."

Overall, general knowledge of PrEP was high among participants — however, the majority of participants worked in the HIV or health field. For the participants who did not work in the field and still had heard of PrEP, they still did not know about the side effects, the timeframe for the drug to go into effect, and the guidelines and criteria for taking PrEP (e.g., routine HIV screenings, routine STI screenings, and routine provider

visits to assess kidney function). Several participants questioned how long the drug had to be taken to be effective and to continue preventing HIV. The majority of participants working in the field felt that most African American women do not know about PrEP, but are aware of the HIV risk and epidemic in the African American community.

> Outside of women working in this field, and not all of them working in this field because every agency is not as thorough as ours [HIV/AIDS service organization], I don't know anybody I could walk up to now, if I'm just going to go do outreach, and I asked any woman, any black woman, how many days it takes before PrEP is it effective in your body? Nobody is gonna tell me twenty-one days. That's how inadequate the education, the rollout, and exposure of PrEP is in our community.

Perceptions of PrEP

Stigma. The majority of participants believed there was a stigma associated with PrEP. Many participants felt that taking PrEP was associated with "unfaithfulness" and "cheating." Some participants believed that research and clinical trials do not accurately represent what would happen in real life situations with couples who try to take PrEP; emphasizing that the majority of couples would have an issue with their partner taking PrEP.

> Participant: What comes out of research and clinical trials is not what happens in real life. The first thing that African American says is 'you must not only be fucking me.'
> Participant: That's right. Yeah. It's that stigma.

Several participants mentioned that they would doubt or question their partner if they started to take PrEP; however, if their partner was taking PrEP before they started dating then they would be more accepting of them taking PrEP. One woman commented:

> I would be a little bit, um, I think I would be a little bit offended because I know myself and it probably would make me start to wonder 'okay, so are you doing something that I need to know about?' It would probably bring that

> into my mind a little bit, but if it were a scenario where we just met and the person was on it, I think it would be fine.

Several participants believed that people who take PrEP are more promiscuous and tend to have more sexual partners. One participant responded, "Yeah, they love to have sex with everybody."

Sex practices on PrEP. The majority of participants believed that their sex practices on PrEP would either remain the same or become riskier than their current sex practices; reporting that they most likely would not use a condom on PrEP. One participant compared PrEP to the birth control pill, saying that it would give them more of a reason not to use a condom and that the combination of birth control and PrEP together may result in people feeling "invincible." A minority of participants said they would "try" to use a condom still if they were on PrEP, particularly if they doubted the monogamy of their relationship. One woman stated:

> I would say, if I could like absolutely, 100% trust somebody, that I probably, to be honest, probably would engage in just not using a condom. Because I'm trusting that we're in a monogamous relationship and we're not going to step out on each other. But I guess just being realistic, at least from my situation… I'd probably stay strapped up [use a condom] and use PrEP too.

Several participants questioned how PrEP was better or any different from using a condom, given that they still should use a condom consistently when on PrEP.

> Participant: And so one of my issues, my personal issue with PrEP, is that they say use PrEP in conjunction with the condom. So what is the PrEP doing that the condom is not doing?
> Participant: STDs.
> Participant: No, the condom is going to prevent that [STDs] and HIV as well. That's what I'm saying. The condom works. The condom works.

Some participants felt that PrEP could help promote regular testing among couples who decided to take PrEP either together or singularly. One participant, that routinely received HIV screenings with her partner, felt that it would make the conversation around getting tested every three months easier so that she wouldn't have to ask her partner every three months. She stated, "If I said 'hey there's a pill out, let's start taking it because we get tested every few months anyways'...I think that it can help me get him to get tested without the every 3-month discussion that we have to have about it."

Beneficial for women in non-monogamous relationships. All participants felt PrEP would be an effective HIV prevention strategy for African American women who are in relationships with a partner that has other sexual partners. Several participants mentioned that PrEP is for any woman who feels like they may be at risk, with one woman commenting, "Even if you're not high risk, you still want her to take it [PrEP] because you may be monogamous, but your partner may not be; because you got a lot of men that like to do that…undercover." The majority of participants expressed that they believe most relationships are no longer monogamous and PrEP could be used to "protect" women who may have "concerns" about their partner, or who may be aware of their partner's additional sexual partners —especially when they decide to stay with this partner. One woman said:

> Some women know they partners cheating, but they still want that person. So they go along with it when they should be using PrEP or using condoms, but they want to keep that person and they know that they're not sleeping with just them. Maybe they're a good provider, so they gonna over look."

Several participants acknowledged the physical benefit PrEP could provide to women who are experiencing a partner who is sexually active with others, but

participants also mentioned the potential emotional and psychological impact PrEP may have on these women. Participants discussed how PrEP could provide a positive sense of empowerment and protection to women. One woman shared, "I would see it like, as me like, taking my power back. Like you going to sleep with such-and-such, well I'm going to take this pill, and I'm not going to tell you I'm taking it, but I know that I'm protecting myself." Some participants mentioned the potential negative effects PrEP may have by serving as a daily reminder that their partner is "unfaithful" and were concerned about the toll it may take on them mentally; however, participants agreed that the benefits outweighed the potential negative effect. One participant explained:

> I think physically it's great for her for the obvious reason. I just think that there's an emotional or psychological component that comes with that. Like, every day that she puts that pill in her mouth, she's kind of being reminded of why she's doing it. Because I think, for any of us that have had that suspicion or concern, it can kind of nag at you. And just to put that pill in your mouth every day because of that concern, I think that would be something different. Especially if it wasn't something that I communicated to my partner, like 'oh I'm going to start taking this just because I want to protect myself;' but if I'm doing it and not having that conversation because I know or I think you're doing something…it would eat me up.

All participants agreed that PrEP gives women who may be in an abusive relationship or forced to have sex with their partner who is "stepping out" a chance to be "proactive" and to protect themselves. One woman said, "You gotta protect yourself. If you're not worried about the other person, at least be worried about yourself." These participants also felt that PrEP was a good option for women who are at high risk of HIV or in a relationship with someone who is HIV positive. One participant commented, "If I was dating somebody or having sex with somebody that

I know is HIV positive, then I'd want to protect myself of course with condoms; but if PrEP is going to help, I'd remember to take that pill everyday then."

Disclosure of PrEP use. The majority of participants felt that PrEP would protect their sexual health and would allow them to take their health into their "own hands," given the epidemic in the area. The majority of participants reported that they wouldn't let their partner know that they are taking PrEP because it might make their partner think that they are trying to cheat or might make their partner think they can go engage in riskier behaviors. Participants felt that the decision to take PrEP, was a personal choice and strategy to take care of themselves, and also could be taken discreetly without their husband or partner knowing. Two of the participants commented:

> Participant: And that's like personal health. That's not…well it is sexual related, but it's not like pregnancy where if you know you're expecting to have a child and then you withdrew from birth control, or you added yourself on birth control, and you didn't talk to your husband about it… maybe that could be an issue. But this is, I think it's more of like, just personal for you. It's strictly just taking care of yourself.
> Participant: Yeah, a choice you're making.
> Participant: It's like a vitamin for HIV prevention.
> Participant: Mmhmm, that's right. I agree with that. Nine out of ten, if he already in another relationship, he's not paying that much attention to what you taking anyway. Like you said, it can be a vitamin. That's right.

However, several participants reported that they would feel comfortable bringing up PrEP to their partners, with several participants saying that they were comfortable telling their partner that they need to get tested before they have sex, so bringing up PrEP would not be an issue.

Experiences with PrEP clients. Several participants actively counsel and test individuals who are currently taking PrEP. Their experiences with PrEP clients have been mixed; however, most mentioned negative experiences and perceptions of the PrEP clients. Several participants believed that clients on PrEP are not provided with a thorough education of PrEP prior to being prescribed the medication. These participants also reported that the majority of PrEP clients do not follow-up every three months for their required testing. Moreover, participants reported that many PrEP clients continue to come back in testing positive for other STIs. Participants believed that their PrEP clients were getting a false since of protection against more than HIV, or they were no longer worried about getting other STIs because they were curable, unlike HIV. One participant shared "Some people that come in, and they on PrEP, we tell them make sure they use the condoms. And one guy told me 'Well, I'm young.' I said, 'But you leaving here with syphilis.' You know, he say 'Well I don't have HIV. I'm taking my PrEP,' I'm like, 'but you still got syphilis.'" Several participants commented:

Participant: But I think PrEP messes up people really bad, because I have a lot of clients that take PrEP, but they still coming in having gonorrhea, chlamydia, and syphilis.
Participant: Because it's just stopping that [other STDs].
Participant: It's only preventing HIV. It's not preventing the other STDs.
Participant: So you still gotta use condoms. I mean, you gotta be smart.
Participant: But they don't worry about that because you can get treated for chlamydia. You can get treated for gonorrhea. You can get treated for syphilis. So they don't worry about it. They like, 'I'm good.'
Participant: They're just worried about HIV.

Willingness to Use PrEP

Willing to use PrEP. Participant's willingness to use PrEP had mixed responses. Roughly 59% of the participants said they would be interested in using

PrEP. Several of these participants said that they would consider using PrEP if it were recommended to them by a provider. One woman said, “I think if I was in a high risk situation, you know, if my doctor would talk to me about PrEP, maybe I would consider it more; but I do worry about the long term effects of everything”. Those who were interested in taking PrEP thought it was a good method to prevent HIV, as long as they used a condom and were not “promiscuous.” Most women said they would start PrEP immediately if it was available and covered by insurance. One participant said, “I’m gonna call my doctor and tell him give me this shit [PrEP]. Gimme my PrEP.”

Willing participants also said that they would want to know more about the research that has been conducted on PrEP before they start taking it. Participants were interested in knowing who the research participants included, the number of participants that contracted HIV while on PrEP, and the percentage of participants that were taking the medication correctly. One participant commented, “I feel like I learned something. I think that it's very useful because I hadn't heard about it before, um, and I do want to tell more people about it. And I’m hesitant, but I'm willing and I'm open, you know? So I will be looking more into it when I get home.”

Among the participants willing to use PrEP, there were still concerns around the potential long-term side effects and about how long they would have to take PrEP. One woman commented:

> My worry would just be the consistent part. Like when can I stop? Like I shouldn’t have to take this for the rest of my life; I'm even considering like being married, and still having to protect myself. I still have to take PrEP? I don't want to have to do that. I’d still have to take PrEP, so I'm literally going to have to take PrEP until I die. That's just my opinion.

Not willing to use PrEP. Of the participants that were not willing to use PrEP, several mentioned that they would not take PrEP because they felt it was associated with distrust in the relationship. Some participants were still hesitant to take PrEP because of the "newness" of the drug, the potential side effects, and risk to their kidneys. All of the non-interested participants said that they would still recommend PrEP to women who may be high-risk or eligible, but believed that women in relationships may not be receptive to PrEP.

Participants that considered themselves not very sexually active said they would not be interested in PrEP at the moment, but they would promote PrEP to other women. However, these women stated that if they became more sexually active in the future then they would be very interested in starting PrEP.

Concerns about PrEP

Several concerns about PrEP were discussed among participants. Potential health issues and side effects caused by PrEP were two main concerns among participants. Many participants were concerned about the harshness of the medicine and the potential long-term effects. One participant commented, "We know how harsh HIV medications are. Why take this medication, that has to go through my kidneys, and may potentially affect me 15 to 20 years down the road, versus using the damn condom?" Some participants were particularly concerned with the potential effects PrEP could have on their reproductive system; especially, if they wanted to have children in the future.

The mistrust of the health care system that still exists in the African American community was also a concern. Some participants discussed how one "bad" incident that someone may experience on PrEP in the Black community may cause complete distrust

of the medicine. One woman commented, “It only has to happen to one Black person and all Black people will start saying that PrEP caused kidney disease.” Participants also stated that it is difficult for the African American community to trust new innovations due to the substandard health care they received for over 100 years. One participant mentioned how most African Americans do not participate, “as a rule,” in clinical trials and so new medications were “not made to work on us from the beginning.” Another woman agreed and responded saying, “So new innovations are always harder too. We are not, in public health terms, ‘early adapters’. We’re more laggards. It takes us a little longer.”

Additional concerns about PrEP included potential effects on women’s sex drive, being able to meet the criteria to stay on PrEP, worries that the medication may show up on a drug test for work, and affordability and access among African American women. One woman said, “You can’t pay for the medicine or the doctor. So if you want to start and pick a target population, start where people have jobs, with insurance, that can afford PrEP, without a barrier — or just make PrEP affordable.”

Recommendations to Increase PrEP Uptake among African American Women

Participants were asked for their suggestions and recommendations to improve PrEP awareness and use among African American women in the South. Several key strategies were proposed and discussed, which included targeted campaigns, use of a relatable PrEP spokesperson, increasing support from the African American community, and targeting younger generations. Regardless of what tactic was used to promote and advertise PrEP moving forward, all participants agreed that they need to come together within the African American community to show a concerted effort and support for PrEP.

Targeted campaigns and PrEP spokesperson(s). All participants mentioned and agreed that campaigns moving forward need to target African American women, and not only MSM and transsexuals. Future commercials and marketing tactics should have advertisements that only focus on African American women to ensure women feel relatable to the situation and to increase their interest in PrEP. Participants believed that any campaign moving forward should recruit or hire on a "PrEP spokesperson" that is both relatable and inspirational to African American women. Several women recommended a celebrity that is open about taking PrEP and promotes taking PrEP, to be used as a spokesperson. Through these updated and targeted campaign strategies, participants believed that PrEP could become "normalized" in the African American community.

> I also think that part of the rollout, and the uptake of PrEP, is going to have to be to come up with some type of massive campaign that normalizes it. Like they did with birth control; the birth control pill eventually became normal. It became that you didn't hide that round thing in everybody's pocketbook. They be having lunch and pop it out. And you know you would no longer hide your pills and don't want nobody to know. And until we get there with PrEP, then we're still gonna have an uphill roll. We're not there yet. You know, in the African American community, with African American women across age groups, we have not gotten there yet. And so that's part of the rollout, the normalization of PrEP, a spokesperson, a face — recognizable, famous, what have you.

Frequented and targeted areas. Participants discussed target areas in the South where advertisements and campaigns for PrEP need to targeted such as clubs, churches, and doctor's offices in the African American community. One participant commented, "I mean in the South, what do people do most of the time? They either go to the club or they go to church. And so, if it's being discussed in either of those places, they may be more receptive to it." Another participant mentioned that future efforts may have difficulty

getting into churches to promote PrEP given the sensitivity of the topic, and would have to be strategic about who the information comes from in the church. This participant compared her story of trying to teach safe sex practices in the church by sharing:

> It depends on the connection within the church, I think. Because for my church, if you, for example went to my pastor's wife and she received it well, then everyone would really get on board with it. Um, if you asked me, like they were upset that I was promoting safe sex to the youth, so like it just depends on who it's coming from. When it was me it was wrong, but when she said it, it was okay. So I think for you to do that, you would have to be very strategic about who you went to and how you presented it.

Promote PrEP earlier. The majority of participants felt that future tactics needed to start promoting PrEP sooner among younger generations and sooner in the relationship cycle. Participants highly recommended using social media platforms to promote PrEP to the youth using sponsored advertisements. One participant commented, "They're always on social media, for everything." Participants also recommended that PrEP be promoted and targeted at high schools, universities and colleges, in order to reach the younger generations. Most participants mentioned how sexual activity comes sooner than it used to in relationships; now people are having sex before they "really get to know one another or before courting one another." One participant shared:

> You had to sit in that living room, you had to talk to them, and now we are using the sex and intimacy to decide whether or not you go court and get to know each other. The sex comes first to decide if you're going to court. So the risk now comes first. So now PrEP has to come first before as a health issue and not as a sexual issue. Because now, getting to know somebody is judged on whether you go out with him again. So because of the shift, we will have to shift our messages about protection, prevention, and PrEP, and things of that nature. We're gonna have to start sooner.

DISCUSSION

The participants expressed and emphasized their concerns about the "newness" of PrEP and possible side effects. Although they were informed of the drug's 2012 release date and supportive research demonstrating no-low side effects, women were questionable of the short timeframe and accuracy of the research findings. Evidence of PrEP safeness and effectiveness were not relatable due to the lack of research targeting specifically African American women and PrEP. Continued research involving African American women and PrEP should focus on the clinical outcomes of PrEP for this population to improve acceptance and uptake of PrEP among African American women.

Findings related to PrEP awareness and knowledge were similar to previous studies,[188] demonstrating there is still a lack of information and promotion targeting potential PrEP user groups, specifically African American women. Although overall knowledge and awareness was high among participants, the majority of African American women are still unaware of PrEP as method of HIV prevention. Additionally, PrEP promotion and advertisement efforts have focused mainly on targeting MSM, which has made PrEP advertisements not relatable to African American women, resulting in no-to-low interest in PrEP use.

Participants were supportive of PrEP when sexual partner sharing and lack of monogamy were of concern. Similar to other studies, women believed PrEP to provide a sense of protection and empowerment.[18,150] Our participants highlighted this advantage by conveying that PrEP provided an opportunity to "take their sexual health into their own hands" and to "take back control." Other than the female condom, PrEP is the only female-controlled HIV prevention method. For women who may experience concurrent

sexual partnerships or abusive situations where they are forced to have sex without consent, PrEP may serve as a practical and discrete option for HIV prevention.

There were no significant differences among focus group participants in regards to awareness, concerns, and recommendations of PrEP. There were several differences around willingness to use PrEP and perceptions of PrEP among participants. Eleven participants were not willing to start using PrEP for HIV prevention; however, the remaining 16 participants were willing to use PrEP, with many stating that they were eager to start taking PrEP immediately if it was available and covered by insurance. Participants who described themselves as low-risk individuals and reported low-risk behavior, had a high willingness to use PrEP. The high willingness to use PrEP could be reflective of their need to engage in continued safer sexual practices (e.g., consistent condom use) or engaging in very little sexual activity. However, not reflective of their current approach to sexual activity, these participants, along with the other participants reported they would be less likely to use a condom if on PrEP — demonstrating that even women who practice safe and responsible sex can feel a sense of invincibility on PrEP. It is imperative that potential PrEP users receive a proper and thorough education of PrEP and how it works most effectively with condom use prior to uptake.

Our study was unique in that several participants provided testimonies about experiences they have had with their PrEP clients. The majority of these participants only provided negative experiences involving their PrEP clients. For example, many of their PrEP clients do not follow the drug criteria for regular testing and follow-up visits, and many test positive for STIs and become “repeat offenders.” It was believed that PrEP created a false since of protection against more than HIV and concern about other STIs

was lessened given their curable nature. Continuing to witness PrEP clients incorrectly using and abusing the medication could negatively impact both health care professionals' and African American women's perception of and promotion of PrEP. Providers must work to improve knowledge of PrEP, requirements for PrEP, and enforcement of PrEP requirements for those who are interested and begin taking PrEP. However, research has found that providers do not envision themselves to be primarily responsible for prescribing PrEP.[208] Future efforts to increase PrEP uptake may focus on PrEP promotion, counseling, and prescription recommendations mainly through counselors and other health care workers.

Recommendations to improve PrEP awareness and use among African American women in the South were provided. Similar to previous research, participants identified venues such as doctor's offices, billboards, social media, schools and peers.[151] Other areas recommended included places that participants considered to be most frequented and prominent in the African American community in the South, which included churches and clubs. Participants felt strongly that future PrEP efforts should involve a targeted campaign for African American women and should include a PrEP spokesperson who is both relatable and a user of PrEP. Future PrEP efforts should focus on reaching the youth population and should take into account that sexual activity is occurring sooner in the relationship cycle compared to older generations. These efforts will aid in the normalization of PrEP awareness and use among African American women, and within the African American community.

To our knowledge, our study was one of the first to conduct qualitative focus groups to explore knowledge, perceptions, and willingness of PrEP use among African

American women in the rural South. However, there were several limitations to our study. First, the sample size of 27 focus group participants was small and took place in a single community in Columbia, South Carolina. Second, the sample may have been biased due to the majority of participants being health care professionals or directly working in the field of HIV. Conversely, this also allowed us to gather unique insight related to health care workers' perceptions, support, and potential willingness of PrEP use, that were not specifically medical providers' opinions as examined in previous research.

CONCLUSION

Our study provides findings that are encouraging of potential PrEP interest and use for HIV prevention among African American women in the South. Future PrEP research focused on African American women should examine 1) determinants that influence actual PrEP use and adherence, 2) sexual risk behaviors and STI incidence while using PrEP, 3) outcomes of PrEP use disclosure, 4) stigma and/or acceptability of PrEP use, and 5) short-term and long-term side effects of PrEP use. The findings from our study provide targeted avenues for future research and PrEP implementation efforts for African American women in the South. Data from our study can inform the development of targeted campaigns aimed to increase PrEP awareness, knowledge, and uptake among African American women residing in areas experiencing the greatest burden of HIV.

CHAPTER 5

DISCUSSION

This chapter will present an overview of the findings in Chapter 4, guided by the specific aims of our study. This chapter will also provide a discussion on the limitations and future directions for HIV prevention research efforts focused on PrEP use among African American women.

5a. Major Findings and Implications

The *first aim* of our study was to assess perceived risk of HIV infection and sexual behaviors of African American women that put them at risk of HIV and eligible for PrEP use.

A total of 413 surveys were used to assess the risk behaviors and perceived HIV risk of African American women in the South. The majority of participants believed they had no risk of HIV infection (53.7%). The remaining participants believed they had a small (37.4%), moderate (6.9%), and great risk (2.0%) of contracting HIV. Fifty-eight women (14.0%) were unsure if they had ever engaged in sex with an HIV positive person, with 40 women not knowing within the past 12 months. Over one-fourth of women (27.3%) reported having multiple vaginal sexual partners within the past 12 months. Frequency of multiple sexual partners ranged from 2-20, with the majority having 2-3 vaginal partners. Only 56 women reported engaging in anal sex over the past 12 months, with the majority only having one anal sex partner (89.2%). Consistent condom use was low among participants for vaginal sex, with the majority of participants

(55%) reporting inconsistent condom use within the past 12 months. Perceived HIV risk was not reflective of the reported risk behaviors. Participants reporting medium-high risk behaviors reported lower perceived risk of HIV infection. Future efforts to promote and recommend PrEP for HIV prevention, among African American women, should address disconnects between actual HIV risk and perceived HIV risk.

HIV risk perception was low among participants in both phases of the study; however, the majority of participants reported engaging in behaviors that can be objectively categorized as low risk to high risk. Given the incongruence between perceived risk and the sexual risk behaviors participants reported, we believe our population demonstrated a state of cognitive dissonance. As originally proposed by Festinger,[209] and supported by Annang et al.,[210] cognitive dissonance occurs when an individual's belief is incongruent with their actions. Our observation of cognitive dissonance was two-fold: 1) dissonance between perceived risk and actual reported risk behaviors and 2) hypocrisy [211] of promoting behaviors that participants did not practice themselves. First, when discussing topics around sexual risk behaviors and practices, focus group participants more often referred to other women as opposed to discussing their personal behaviors and practices. Participants demonstrated a disconnect between the behaviors they engage in and the behaviors that other women engage in — many women finding it easier to discuss and generalize risk behaviors of African American women as a whole. Second, the majority of the focus group participants worked in the HIV or health field; however, they reported engaging in risk behaviors that they discouraged to others or clients. For example, the majority of participants reported that they did not use a condom when they engaged in sexual activity — yet, given their

professions (e.g., Medical Case Manager, HIV Tester and Counselor, Prevention Coordinator, etc.) they did promote consistent condom use to others as a way to prevent HIV and other negative sexual health outcomes. In addition, approximately 41% of focus group participants said that they would not be willing to use PrEP at that point in time; though, all focus group participants said that they would promote PrEP use to other women who were eligible or at risk of HIV infection. Specifically, participants who worked in the HIV field, and interacted with both HIV-negative and HIV-positive clients on a regular basis, stated that they would promote PrEP to their clients as an HIV prevention method along with condom use. Efforts to reduce cognitive dissonance may affect 1) the probability that an individual will engage in sexual risk behaviors that increase HIV risk and 2) the likelihood that individuals would be willing to use an HIV prevention method like PrEP. These findings have important implications for promoting HIV risk reduction strategies such as PrEP, particularly among groups who don't see themselves as eligible.

The second aim of our study was to explore knowledge, perceptions, and willingness of PrEP use, sexual activity, and provider relationships among African American women in the Southeastern United States.

Research Question (RQ) 2a: What are African American women's current knowledge, perceptions, and willingness of PrEP use in the Southeast?

Awareness and knowledge of PrEP among African American women was low, consistent with previous research where knowledge among women ranged from 0%-33%.[188] Roughly 41% of survey respondents had heard of PrEP, but the majority of focus group participants had high awareness and knowledge of PrEP. Focus group participants

gained awareness and knowledge of PrEP primarily through their current or past work experience in the health and/or HIV field. Most focus group participants believed that the lay woman, particularly African American women, would not be aware or knowledgeable of PrEP as an HIV prevention tool. Participants believed this was due to poor marketing and advertisements that were not relatable to African American women. Future efforts aimed at increasing PrEP awareness and knowledge among African American women should implement targeted campaign and marketing strategies that are relevant to African American women.

Overall, we found women to have a supportive and positive attitude about PrEP. We also explored women's perceptions about PrEP and potential PrEP use. Participants believed PrEP could serve as an effective HIV prevention method for other African American women and within the African American community. The majority of participants believed PrEP would be beneficial for women who may be in a non-monogamous relationship, either willingly or unwillingly. PrEP was considered to be an HIV prevention option that provided protection and empowerment, and a means to regain control over their sexual health. Similar to other studies, participants would recommend PrEP to other women for HIV prevention.[212] However, participants did not believe their female friends would be interested in using PrEP, particularly if they were currently in a relationship or married. Largely, participants were supportive of PrEP as an HIV prevention method for African American women who were at substantial risk of HIV infection.

Approximately 45% of overall survey participants reported an interest in PrEP use; equally, 45% of PrEP eligible participants reported an interest in PrEP use.

Participants who reported inconsistent condom use, multiple sex partners, previous STIs, and receiving or exchanging money for sex were more likely to be interested in PrEP. Predictors of PrEP interest among participants included age, perceived HIV risk, receiving or exchanging money for sex, experiences of sexual assault, and condom negotiation skills. Age and HIV risk were found to be predictors among African American men and women; [153] however, sexual assault, exchanging or receiving money for sex, and issues with condom negotiation are reported more frequently among women compared to men. A previous study found women who had ever traded sex to be significantly more accepting of PrEP use compared to those who have not; conversely, PrEP acceptability was significantly lower for women who had experienced intimate partner violence.[189] Research has shown that providers believe PrEP could empower women who may have trouble negotiating condom use with their partner.[213,214] Providers are beginning to understand potential predictors of PrEP; however, more research is needed to determine the accuracy of our proposed predictors. Moving forward, gender specific predictors could be essential to discovering potential PrEP users among women and should be considered when assessing interested candidates.

Overall, the majority of focus group participants (59.3%) reported they were willing to use PrEP for HIV prevention. Our findings were similar to previous studies examining women's willingness to use PrEP, which ranged from 51%-97%.[188] Regardless of willingness to use PrEP, women were still concerned with potential side effects and health care intentions found in previous research.[17,151,212] Therefore, addressing concerns about PrEP, not just considering willingness, might serve as a controlling factor for successful PrEP uptake.

Women between the ages of 18-24 years and 25-34 years reported high rates of risk behaviors and were more likely to be interested in PrEP compared to older women. Unlike a previous study that found younger women reporting lower potential PrEP uptake and adherence despite their increased HIV risk,[215] we found women in younger age groups to report higher rates of PrEP interest corresponding to their HIV risk behavior. However, although potential PrEP use was high among younger groups, perceived HIV risk remained low among women 18-24 years of age. Although PrEP is available to both younger and older women, public health professionals should target women between the ages of 18-35 years who have shown a significant interest in PrEP use. Furthermore, in order to increase the effectiveness of PrEP for HIV prevention, additional efforts are needed to increase young women's awareness of HIV risk.

RQ 2b: What impact could African American women's sexual relationships have on sexual risk taking and potential PrEP use in the Southeast?

African American women face multi-level factors that contribute to their engagement in sexual risk behaviors that put them at risk of HIV infection. Participants reported consistent risk behaviors that included no condom use, sexual partner sharing, and lack of HIV status disclosure and HIV testing. Although participants were aware of the risk that came with the reported behaviors, the majority reported that they still engaged in these behaviors due to influential factors. These risk behaviors were influenced by factors such as cultural and southern influences, perceived societal worth, and health care system and provider experiences impacting health care seeking. The severity of the risk behaviors was mitigated by the reported influential factors that were considered to be "out of their control." PrEP was discussed as a potential method that

could combat HIV risk and protect women from the influential factors that may increase their risk behavior. Our study also highlighted influential factors specific to the South and southern culture among African American women. Influential factors such as conservative outlooks on sex, church and religious affiliations, sexist repercussions, and gender roles significantly impact African American women's communication about and engagement in sexual risk behaviors. For example, gender roles remain prevalent in the South, within in the African American community, which can lead to involuntary engagement in riskier behaviors and a lack of control over what happens to their bodies. Participants believed PrEP provided an opportunity to intervene on circumstances that increase their risk of HIV infection. Similar to previous research, participants appreciated that PrEP was a woman-controlled method[216] and believed PrEP provided a sense of protection and self-control, when risk was high or unavoidable. [18,150] African American women have shown interest in female-initiated HIV prevention methods in previous research.[217] Our findings suggest that PrEP has the opportunity to protect women at risk of HIV from not only risk behaviors, but other influential factors that inadvertently increase their HIV risk. Additionally, we have provided influential factors specific to the South that can be considered in future efforts to reduce HIV risk and increase likelihood of PrEP uptake among African American women in the South.

RQ 2c: What is the relationship dynamic between African American women and their health care providers, and how could this relationship effect the recommendation of PrEP?

Recommendations of PrEP from a provider were low overall, ranging from 0%-3% among participants. Of the 166 survey participants who had heard of PrEP, only 5

participants had been recommended PrEP by a provider. None of the focus group participants had ever been recommended PrEP by a provider. However, our participants reported that they would be open and more likely to use PrEP if their provider recommended PrEP. Similarly, women have reported that recommendations from providers, gynecologists, obstetricians, and trusted health care workers from community-based organizations would encourage them to use PrEP.[151,218] Recent studies found 60%-92% of providers reported willingness to prescribe PrEP to women, as well as positive attitudes towards PrEP.[219-223] These findings suggest that willingness to prescribe PrEP and attitudes towards PrEP among providers may not accurately represent PrEP implementation practices. Additionally, providers are continuing to miss opportunities to prescribe PrEP to both eligible and willing female candidates.

RQ 2d: What types of sexual behaviors are African American women engaging in that may put them at risk for HIV infection in the Southeast and that may make them eligible candidates to take PrEP?

In a 2015 CDC report, an estimated 468,000 women were at substantial risk of HIV infection and had indications for PrEP use.[224] Of the 9,375 commercially insured PrEP users in 2014, only approximately 2.5% were women.[225] As of 2017, the CDC has issued revised clinical guidelines for PrEP recommendations.[177] Currently, PrEP is recommended for heterosexual women who have an HIV-positive sexual partner and women in communities with a high prevalence of HIV and one or more of the following risk factors: recent STI, multiple sexual partners, inconsistent or no condom use, or commercial sex work.[177]

The majority of our participants were engaging in sexual risk behaviors, with 31.5% qualifying as medium-high risk women and 47.0% qualifying as low risk women. Given the risk factor criteria for PrEP, we determined approximately 78.5% of our participants were eligible for PrEP. The majority of PrEP eligible participants reported inconsistent condom use (89.5%), followed by multiple sex partners (41.4%), exchanging or receiving money for sex (9.3%), previous STI (9.3%), sex with in HIV-positive person (1.9%), and sex with a MSM (0.6%) within the last 12 months. Of the PrEP eligible participants, approximately 45% were interested in taking PrEP. Our study found the majority of African American women to be at some risk of HIV infection and nearly half of at-risk women to be interested in PrEP use for HIV prevention. Despite the updated guidelines, and high eligibility and interest among African American women, PrEP use rates remain low. Future efforts to increase PrEP uptake among African American women should consider both low risk and medium-high risk individuals as ideal candidates for PrEP use.

5b. Strengths

Our study was one of the first to conduct a mixed-methods approach examining 1) PrEP eligibility and interest and 2) exploring knowledge, perceptions, and willingness of PrEP use among African American women in the South. Unlike previous research our study sample consisted exclusively of African American women who resided in a predominantly rural area in the South. In addition, the sample of participants were drawn from geographic areas, with significantly high HIV incidence and prevalence rates, that should be a primary target to implement innovative HIV prevention methods and interventions.

5c. Limitations

Several factors may make the results of our study ungeneralizable to other African American women. First, all focus group and the majority of survey participants were from South Carolina, which could make our results inapplicable to African American women residing in other Southern states. Second, our sample may not be representative of the population which we aimed to research given the small sample size of 27 focus group participants. Though, participants were representative of an area with a high HIV prevalence and incidence rate, which allowed us to understand a high-risk area and population's perceptions and interest in a new HIV prevention method like PrEP. Third, the majority of focus group participants had experience or were currently working in the health or HIV field. This may have biased themes related to PrEP awareness and knowledge; however, this was acknowledged and discussed in the results. Future research should be conducted with a larger sample and with "lay persons" who are not involved in the field of HIV or health care. Lastly, survey data could be biased due to the sensitivity of the topics (e.g., sexual behaviors, STI history, sexual assault, etc.) and social desirability of participants. Attempts to reduce social desirability were made by ensuring that all surveys and data collected were confidential.

5d. Positionality and Reflexivity

This section serves as an opportunity for me to examine and reflect upon my positionality as a researcher for this specific study. Below I have briefly discussed how my interest in this study topic came about, how my positionality could have impacted my study and interaction with my participants, and how it was necessary to continuously reflect on my positionality as I conducted and completed my research project.

I am a white, heterosexual, female, and I have lived in the Southeastern United States for my entire life. Prior to this research study, I have worked as a Graduate Research Assistant at the University of South Carolina. Although my research interest has always been focused around sexual health and STI prevention, my interest in HIV prevention among African American women began while working with Dr. Robillard. Her research focused on understanding the experiences from HIV-positive African American women, before, during, and after they were diagnosed; using their stories as a component of an HIV prevention intervention for African American females. Working directly with several of the HIV positive women through the Community Advisory Board, my interest in developing and promoting novel HIV prevention tools grew. From there, I acquired a position in 2016 working for what was then called South Carolina HIV/AIDS Council; since starting, the name has changed to the Wright Wellness Center dba South Carolina HIV Council. My position has allowed me to work with individuals dedicated to ending the HIV epidemic in South Carolina; however, we know there is much more work ahead in order to accomplish this goal. Not only are efforts needed on the frontline, providing testing, treatment, and care, but research is needed to increase our understanding of the populations most affected by this epidemic, so that we may develop strategies that are both relevant and effective. Knowing this, my study aimed to increase our understanding of African American women's sexual behaviors and their awareness, knowledge, perceptions, and willingness of PrEP use, so that we could inform future HIV prevention efforts specifically for African American women living in the South.

I acknowledge that our backgrounds, social status, and environment have the potential to impact our research. Specifically, the identity of the researcher in qualitative

research has the potential to impact the research process in regards to the study and study participants. I worked with a population that is different from me and who have experiences different from my own. It was important that I recognized this so that I could approach this research objectively, and so that my participants felt comfortable to discuss subject matter openly and without fear of judgment from the researcher.

Prior to the start of our study, I worked with Dr. Bambi Gaddist, my current boss and committee member, to discuss important and relevant topics that should be included in the sexual behavior survey and focus group topical guide. We would hold brainstorming sessions to determine topics that should be covered and to discuss *why* they were important to include. We also discussed *how* each question should be asked or presented for both the survey and topical guide. Working with Dr. Gaddist, an African American female, allowed me to gain perspective and insight, which I may have not gained otherwise, into how future study participants may interpret and react to some of the survey and focus group questions. In addition, in an effort to prevent less robust discussions among participants during focus groups due to my presence, I recruited two individuals, both African American females, who served as note-takers during the focus groups. I believe this allowed participants to observe researchers that may be relatable to them and may have improved participants' perceptions about researcher intentions.

5e. Conclusions and Future Directions

Our study suggests that African American women, residing in the South, are engaging in HIV risk behaviors that make them eligible for PrEP use. Although PrEP awareness was low among women, interest in PrEP and willingness to use PrEP was relatively high among both survey and focus group participants. Given the high eligibility

rates and interest in PrEP, future public health efforts to reduce HIV infection using PrEP among high prevalence groups should also target African American women, and not solely MSM and African American men. It is important for efforts to increase PrEP uptake to be relatable to African American women so that opportunities are not missed.

Future HIV prevention and intervention efforts, such as PrEP, focusing on African American women must consider the multi-level factors that contribute to their HIV risk. Individual-level, interpersonal-level, community-level, institutional-level, and structural-level factors interact and create unique experiences related to sexual risk behaviors and HIV vulnerability among African American women. Therefore, these experiences warrant targeted and innovative HIV prevention strategies, equally as unique, like PrEP.

Although distrust still exists with the health care system among African American women, providers can still play an important role in HIV prevention and PrEP uptake with this population. Providers were considered to be a trusted and valued source for PrEP information and recommendations among African American women. Moving forward, providers should be prepared to provide PrEP information and recommendations to African American women who report any risk behavior or who inquire about getting screened for HIV. Contrary to provider beliefs and practices, women would be receptive and accepting of PrEP recommendations if coming from a trained health care professional.

Overwhelmingly, African American women expressed support for PrEP as an HIV prevention method. Although concerns were expressed around side effects, stigma, and disclosure of PrEP use, African American women still demonstrated a strong interest

and willingness to use PrEP. Future research should examine African American women's actual experiences with PrEP use, focusing on experiences with side effects, stigma, disclosure of use, acceptance among partners, family, and friends, and adherence.

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APPENDIX A

STUDY IRB APPROVAL LETTER

UNIVERSITY OF
SOUTH CAROLINA

OFFICE OF RESEARCH COMPLIANCE

INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH
APPROVAL LETTER for EXEMPT REVIEW

Jamie Troutman
Arnold School of Public Health
Health Promotion, Education & Behavior
915 Greene Street, Rm 531
Columbia, SC 29208

Re: **Pro00074508**

Dear Mr. JTroutman:

This is to certify that the research study ***Pre-Exposure Prophylaxis (PrEP) for HIV Prevention: A Mixed-Methods Study of Sexual Risks and Knowledge, Attitudes, and Willingness of PrEP Use Among African American Women*** was reviewed in accordance with 45 CFR 46.101(b)(**2**), the study received an exemption from Human Research Subject Regulations on **2/16/2018**. No further action or Institutional Review Board (IRB) oversight is required, as long as the study remains the same. However, the Principal Investigator must inform the Office of Research Compliance of any changes in procedures involving human subjects. Changes to the current research study could result in a reclassification of the study and further review by the IRB.

Because this study was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date.

All research related records are to be retained for at least three (3) years after termination of the study.

The Office of Research Compliance is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). If you have questions, contact Arlene McWhorter at arlenem@sc.edu or (803) 777-7095.

Sincerely,

Lisa M. Johnson
ORC Assistant Director
and IRB Manager

APPENDIX B

SEXUAL BEHAVIOR SURVEY

Sexual Behavior Survey

The purpose of the research is to learn more about human immunodeficiency virus (HIV) risk and common sexual behaviors among African American women. We are also interested in African American women's knowledge, attitudes, and willingness to use new HIV prevention methods. We will ask about sexual behaviors, relationship dynamics, and HIV prevention methods. The results of this survey will help us to educate and reduce HIV risk among African American women in the Southeastern United States.

Here are a few things you need to know about this research survey:

- The survey is completely confidential. No identifying information will be shared.
- There are no to very minimal risks involved in taking this survey.
- Participation is completely voluntary. In exchange for your participation, you are entitled to enter a drawing to win a $50 gift card.
- In order to participate in this research survey, you must be female, African American, 18 years or older, and residing in one of the following states: South Carolina, North Carolina, Georgia, Alabama, or Florida.
- The survey takes approximately 5-10 minutes.
- Participants will be asked if they are interested in participating in a focus group to discuss similar topics, following the completion of the survey. If so, they will be contacted with scheduling information. All focus group participants will receive a $25 gift card upon completion.
- **Completion of the questionnaire will be considered consent to participate in this study.**

THANK YOU!

Remember: Your responses to these questions are confidential. Your participation in this study is voluntary. You have the right to withdraw from the study at any time without consequence. Please try to provide an answer for each question; however, you do not have to answer a question if it makes you uncomfortable. Completion of the questionnaire will be considered consent to participate in this study.

Eligibility Questions

1. Are you female and at least 18 years of age?
    a. Yes
    b. No

2. Do you identify as African American or Black?
    a. Yes
    b. No

3. Do reside in one of the following states: South Carolina, North Carolina, Georgia, Alabama, or Florida?
    a. Yes
    b. No

Sexual Behavior Assessment

4. At what age did you have:

Age	Oral Sex	Vaginal Sex	Anal Sex
Never participate in the behavior			
<12 years old			
13-16 years old			
17-20 years old			
21-24 years old			
25+ years old			

5. Have you participated in any of the following behaviors within the past 30 days?

a. Oral Sex – received or given (mouth to penis, mouth to vagina, mouth to anus) yes no
b. Vaginal Sex yes no
c. Anal Sex yes no

6. Within the last 12 months, how many times did you participate in:

• Oral sex– received or given (mouth to penis, mouth to vagina, mouth to anus)?_____ times
• Vaginal sex? _____ times
• Anal sex? _____ times

7. Within the last 12 months, how many different sexual partners have you had for each of the following behaviors?

• Oral sex– received or given (mouth to penis, mouth to vagina, mouth to anus)? _____ partners
• Vaginal sex? _____ partners
• Anal sex? _____ partners

8. In the past 12 months, how often do you use a condom during **oral sex– received or given (mouth to penis, mouth to vagina, mouth to anus)**?

a. Never
b. Sometimes
c. Most of the time
d. Always
e. Not applicable (do not participate)

9. In the past 12 months, how often do you use a condom during **vaginal sex**?

a. Never
b. Sometimes
c. Most of the time
d. Always
e. Not applicable (do not participate)

10. In the past 12 months, how often do you use a condom during **anal sex**?

a. Never
b. Sometimes
c. Most of the time
d. Always
e. Not applicable (do not participate)

11. Did you use a condom or other barrier method the last time you participated in any of the following behaviors?

a. Oral Sex (mouth to penis, mouth to vagina, mouth to anus)	yes	no	not applicable (did not participate)
b. Vaginal Sex	yes	no	not applicable (did not participate)
c. Anal Sex	yes	no	not applicable (did not participate)

12. Have you been tested for a sexually transmitted infection within the past 12 months?

c. Yes
d. No

13. Have you ever been told by a doctor or nurse that you had:

a.	Chlamydia	yes	no
b.	Syphilis	yes	no
c.	Gonorrhea	yes	no
d.	HIV or AIDS	yes	no
e.	Genital Herpes	yes	no
f.	Genital Warts	yes	no
g.	Human Papilloma Virus (HPV)	yes	no
h.	Trichomoniasis	yes	no

14. Have you been told in the past 12 months by a doctor or nurse that you had:

i.	Chlamydia	yes	no
j.	Syphilis	yes	no
k.	Gonorrhea	yes	no
l.	HIV or AIDS	yes	no
m.	Genital Herpes	yes	no
n.	Genital Warts	yes	no
o.	Human Papilloma Virus (HPV)	yes	no
p.	Trichomoniasis	yes	no

15. How would you rate your risk of getting HIV?

a. no risk
b. a small risk
c. a moderate risk
d. great risk

16. Have you ever had sex with an individual who was HIV positive?

a. Yes
b. No
c. Don’t Know

17. Have you had sex with an individual who was HIV positive in the past 12 months?

a. Yes
b. No
c. Don’t Know

18. Have you ever had sex with a male who also has sex with men (MSM)?

a. Yes
b. No
c. Don't Know

19. Have you had sex with an MSM within the past 12 months?

a. Yes
b. No
c. Don't Know

20. Have you ever given money for sex?

a. Yes
b. No

21. Have you given money for sex in the past 12 months?

a. Yes
b. No

22. Have you ever received money for sex?

a. Yes
b. No

23. Have you received money for sex in the past 12 months?

a. Yes
b. No

24. Have you ever exchanged sex for the following:

a. Food	yes	no
b. Housing	yes	no
c. Drugs	yes	no
d. Fear of violence	yes	no

25. Have you ever injected drugs?

a. Yes
b. No

26. Have you injected drugs in the past 12 months?

a. Yes
b. No

27. Have any of your sexual partners ever injected drugs?

a. Yes
b. No
c. Don't Know

28. Have any of your sexual partners injected drugs in the last 12 months?

a. Yes
b. No
c. Don't Know

29. Do you feel comfortable discussing condom use with your partner?

a. Yes
b. No

30. Do you feel comfortable discussing HIV testing with your partner?

a. Yes
b. No

31. How would you describe your relationship status within the last 30 days?

a. I am in an exclusive/committed relationship
b. I am in an open relationship where we are free to see other people
c. I am casually dating, but not in a relationship
d. I am NOT dating or in a relationship

32. Have you ever been in a relationship where your partner openly has other sexual partners?

a. Yes
b. No (if no skip to question 35)

33. If yes, were you accepting of your partners having other sexual partners?

a. Yes
b. No

34. Were your partner's other sexual partners:

a. Female
b. Male
c. Both
d. Don't Know

35. Do you feel the power in your current relationship/s is:

a. Equal between each partner
b. You have more power
c. Your partner has more power
d. Does not apply

36. Do you feel the power in your past relationship/s is:

a. Equal between each partner
b. You have more power
c. Your partner has more power
d. Does not apply

37. Have you ever been sexually assaulted in your lifetime?

c. Yes
d. No (if no, skip to question 39)

38. If yes, were you sexually assaulted by (pick all that apply):

a. A partner
b. Someone you knew
c. A stranger

39. How comfortable do you feel discussing topics around sexual activity with your primary care provider?

a. Very Comfortable
b. Somewhat Comfortable
c. Not very comfortable
d. Not at all comfortable
e. I do not have a primary care provider

40. When you visit your provider for routine visits, does your provider ask about your sexual history (e.g., number of sexual partners, history of STIs, use of prevention methods, etc.)?

a. Yes
b. No (if not skip to question 42)

41. If yes, please select all topics that are discussed:

a. Number of sexual partners
b. Frequency of sexual activity
c. Type of sexual activity
d. History of STIs
e. HIV risk behaviors
f. HIV prevention practices
g. Other:_____
_____

PrEP

42. Have you ever heard of a pill that can prevent HIV, called PrEP?

a. Yes
b. No (if no, skip to question 46)

43. Have you ever been recommended PrEP by a provider?

a. Yes
b. No

44. Have you ever taken PrEP?

a. Yes
b. No

45. Do you know of anyone that has taken PrEP?

a. Yes
b. No

46. Would you be interested in taking PrEP once a day if it had no-to-few side effects, to prevent HIV?

a. Yes
b. No
c. Not sure

47. Would you be interested in taking PrEP if it were free of charge or only a small charge, to prevent HIV?

a. Yes
b. No
c. Not sure

Sociodemographic Questions

48. What is your current age? _____

49. What is the highest level of education you received?

☐ 1^{st} – 5^{th} grade
☐ 6^{th}-8^{th} grade
☐ 9^{th}-12^{th} grade
☐Some college or university
☐ Bachelor's Degree
☐ Higher Education

50. What is your employment status?

☐ Employed
☐ Unemployed
☐ Retired
☐ Disabled

51. What is your current income?

☐ Less than $5000
☐ $5,000 - $20,000
☐ $21,000 - $40,000
☐ $41,000 - $60,000
☐ $61,000 +

52. Which state do you currently reside in?

☐ South Carolina
☐ North Carolina
☐ Georgia
☐ Alabama
☐ Florida

53. Do you currently have health insurance?

a. Yes
b. No

54. What is your current marital status?

- ☐ Single
- ☐ Married
- ☐ Partner
- ☐ Divorced
- ☐ Widowed

55. How do you identify?

- ☐ Heterosexual (straight)
- ☐ Homosexual (gay/lesbian)
- ☐ Bisexual (both)
- ☐ Other: _____

56. Do you consider yourself a religious or spiritual person?

a. Yes
b. No

57. If yes, what religion do you practice?

_____

58. Is there a specific denomination? If yes, please specify below.

_____

59. To be entered in the $50 VISA gift card drawing, please provide your email so that we may contact you if you win. Your information will remain completely confidential.

Email: _____

Focus Group Interest

60. Incentive:

If you are interested in participating in a focus group and receiving a $25 Visa gift card, please select YES and provide your contact information. You will be contacted about future dates and times.

a. Yes
b. No

61. Please provide your phone number and/or email below to be contacted about participating in a focus group. Your information will remain completely confidential.

Email Address: _____
Phone Number: _____

Thank you for taking the time to complete this survey! Your response is greatly appreciated!

If you are interested in learning more about or getting on PrEP, please contact Joseph H. Neal Wellness Center at **(803) 254-6644 or** Nikki Harp, PrEP Coordinator at **(803)726-3237 and mention this survey!**

APPENDIX C

FOCUS GROUP TOPICAL GUIDE

Welcome, my name is Jamie Troutman, and I'll be your focus group moderator this afternoon/evening. Thank you for participating in our research. There is no right or wrong answer, only your opinions and thoughts.

Today we will be discussing several topics related to sexual health and HIV prevention. This focus group is part of a study to learn more about Black female's knowledge, attitudes, and willingness to use pre-exposure prophylaxis (PrEP) as an HIV prevention strategy. In addition, we will also have discussion about sexual behaviors you engage, your sexual relationships, and your experiences with your health care provider related to HIV prevention. I am not here to give you information; rather, I am here to listen to your ideas and thoughts on this important issue.

We are recording the focus group because everything you say is important to us and we want to make sure we don't miss any comments. Later, we will have the recording transcribed. We will then read through all of your comments, which will be used to prepare a report on our discussion. I want to assure you that all of your comments are confidential and will be used only for research purposes. Once the report is complete, the recordings will be destroyed.

If there are any questions you would prefer not to answer, please feel free not to respond to them. Also, if you state something and would prefer to have it stricken from the transcription and the subsequent data analyses please let us know at any time before, during or after the interview and we will make a note to remove the comment.

Finally, upon completion of this interview, you will receive a $25 Visa gift card as gratitude for your participation. I will have you sign out for your incentive before you leave.

OK great- let's start with the first question.

1. Pretend I am from another country and I am interested in knowing about sexual behaviors of Black women in the Southeastern United States. More importantly, I am interested in finding out more about sexual behaviors that may put women at risk of acquiring HIV. **What types of sexual behaviors are Black women engaging in these days?**

- Who does it involve?
- Which behaviors do you think could increase HIV infection?

2. You mentioned the types of sexual behaviors that women are engaging in, now we want to get a better understanding of the types of sexual behaviors you engage in. When we are talking about sexual behavior, we don't just mean vaginal sex. We are talking about any kind of sexual activity such as oral, anal, and vaginal. **What types of sexual behaviors have you engaged in in the past 12 months?**

- Who has it involved?

- Do you use protection against HIV or STIs while engaging in sexual activity? Why or why not?
- Which behaviors do you think could increase your risk of HIV infection?

3. Now I want to focus specifically on an HIV prevention tool called PrEP. PrEP, is a way for people who do not have HIV, but who are at risk of getting it to prevent HIV infection by taking a pill every day. This is similar to how birth control pills are taken to prevent pregnancy. **Can you tell me if you have ever heard of PrEP?**

- If yes, what have you heard about PrEP?
- Who and/or where did you get the information about PrEP from?

4. For those who have not heard of PrEP, let me provide a brief overview of PrEP and how it works. [Brief PrEP informational session]

- **4.1. After hearing this brief description of PrEP, what are your initial thoughts on PrEP?**

- **4.2. What are some reasons on why you would or would not want to use PrEP as a way of preventing HIV?**
  Probe examples [only if they are not coming up with some on their own]: Concerns about side effects, concerns about cost, less condom use, adherence issues, partner may question why they want them to use it, decreased risk of HIV infection, accessing PrEP, etc.

- **4.3. What are some reasons why you would or would not want your partner to use PrEP as a way to prevent HIV?**
  Probe examples [only if they are not coming up with some on their own]: Concerns about side effects, concerns about cost, less condom use, adherence issues, partner may question why they want them to use it, decreased risk of HIV infection, accessing PrEP, etc.

- **4.4. Are there any concerns you might have about taking this pill?**
  Probe examples [only if they are not coming up with some on their own]: Stigma, lack of social support, concern about effectiveness, trouble adhering to regimen, having access to PrEP. side effects, etc..

- **4.5. Are there any concerns you might have about your partner taking this pill?**
  Probe examples [only if they are not coming up with some on their own]: Stigma, lack of social support, concern about effectiveness, trouble adhering to regimen, having access to PrEP. side effects, etc.

- **4.6. If you and/or your partner were to take PrEP, how would you feel about your risk of contracting or transmitting HIV?**
  Probe examples [only if they are not coming up with some on their own]: Very concerned, slightly concerned, not that concerned, etc.
    - **Would your level of concern increase or decrease from what it is currently, with not taking PrEP?**

- **4.7. If you and/or your partner were to take PrEP, do you feel your need to practice safer sex would change or remain the same?**
  Probe examples [only if they are not coming up with some on their own]: Increased or decreased condom use, engage in riskier behavior, increased awareness of potential HIV infection, multiple and/or concurrent sexual partners, etc.

- **4.8. If you were able to get a prescription for PrEP today, would you start taking it?**
    - **Is there additional information you would like/need to know about PrEP before you and/or your partner start taking it?**

      Probe examples [only if they are not coming up with some on their own]: Possible side effects, price of the pill, long term effects of PrEP, etc.

5. Now we want to dive a little deeper into the potential use of PrEP. Research has shown us that Black women report high rates of being in a relationship with males partners who openly have other sexual partners. Having additional sexual partners not only increases the risk of HIV infection among these men, but puts their female partner at an increased risk of HIV infection even when the female is only having sex with their main partner. Because of the risk that can be acquired through their male partners, women can take the opportunity to control their sexual health and decrease their risk of HIV infection by taking PrEP. **Has anyone here ever experienced a similar situation with sexual partner sharing or their main sexual partner having concurrent sexual partners?**

- **5.1. If yes, can you elaborate on the relationship dynamic?**
  Probe examples [only if they are not coming up with some on their own]: Were you always aware of the additionally sexual partners, were you accepting of the other sexual partners, did you ask about the behaviors they engaged in, did you insist on condom use because of this or was that not impacted?
- **5.2. If no, do you know of anyone that has experienced this and can you elaborate on the dynamics of the relationship?**
- **5.3. Do you think PrEP could serve as a protective behavior for women in these types of relationships to decrease their risk of HIV infection?**

- **5.4. Would there be any reasons that these women would or would not use PrEP?**
  Probe examples [only if they are not coming up with some on their own]: Partner may have an issue or disapprove, their partner might accuse them of having other sexual partners, negative stigma, etc.

6. Lastly, we would like to briefly discuss your experience you have with your health care provider as it relates to your sexual health. Specifically, we would like to ask what your doctor may or may not ask about your sexual history and if you have ever been told you are at risk of HIV infection from your provider**. When visiting your health care provider, for a regular check-up, have they ever asked you about your previous sexual behaviors within the past year?**

- **6.1. If yes, what have they asked you about?**
  - **What information did you provide them with?**

- **6.2. Did you ever want to tell your health care provider more or have them ask more about your sexual history?**
  - **If yes, what about?**

- **6.3. Has your health care provider ever told you that you are at risk of HIV infection?**
  - **If yes, what did they recommend to decrease your risk of infection?**

- **6.4. Has anyone been told about PrEP from their provider during a visit?**

- **6.5. Given the both your personal experiences and African American women's experiences with the health care system in the past, would you have any hesitation moving forward using PrEP?**
  Probe examples [only if they are not coming up with some on their own]: Possible mistrust with health care providers and/or the health care system.

7. Now I would like to hear more from you about this focus group and focus group topic. **What questions or topics you were expecting to discuss in this focus group? What additional information, perspective, experiences, etc. could you add?**

Thank you so much for coming today. Your time is very much appreciated and your insights have been very helpful!