ABSTRACT

Title of Dissertation:	DISPARITIES IN PRE-EXPOSURE PROPHYLAXIS AWARENESS AMONG WOMEN: A SYSTEMATIC REVIEW OF THE LITERATURE AND LATENT CLASS ANALYSIS OF SYNDEMIC RISK FACTORS
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While rates of HIV infection have declined among women in recent years, women still account for 19% of all new infections each year in the United States (US). With the debut of pre-exposure prophylaxis (PrEP), an FDA-approved once-daily pill to prevent HIV transmission, researchers believed that this user-controlled method would be an innovative method in reducing HIV in this subpopulation. While we know the clinical efficacy of PrEP, more understanding of the behavioral, social, and structural factors that impede PrEP awareness among women is important in the dissemination of PrEP-related information and subsequent use.

In this dissertation, I took an exploratory approach to a) identify awareness, knowledge, barriers, and facilitators of PrEP use among US-based women through a systematic review; b) identify factors associated with PrEP awareness among female

participants in the 2018 Community Health Survey; and c) explore how the presence of multiple deleterious factors can create distinct subgroups of women and further exacerbate disparities in PrEP awareness. In Paper 1, the systematic review identified 12 articles and primary findings included gaps in PrEP knowledge; acceptability and willingness to use once informed of PrEP; perceived disadvantages because of exclusion in clinical trials and early dissemination; and social, structural, and institutional barriers to engagement in the PrEP care continuum. Papers 2 and 3 leveraged data from the 2018 Community Health Survey, a cross-sectional telephone survey of randomly selected adults aged 18 and older living in New York City. In Paper 2, 36% of a female subsample (N=2,295) were aware of PrEP at time of survey and nine variables were significantly associated with PrEP awareness such as nativity, education level, and age. In Paper 3, latent class analysis was used to identify distinct classes of women with varied responses to behavioral and structural variables. The adjusted item-response probabilities resulted in three distinct profiles of women: high resource and low risk group (39%), low resource and moderate risk group (33%), and moderate resource and high-risk group (28%). Future studies should consider the importance of the social and structural context through which women engage with HIV prevention materials and promotional campaigns.

DISPARITIES IN PRE-EXPOSURE PROPHYLAXIS AWARENESS AMONG WOMEN: A SYSTEMATIC REVIEW OF THE LITERATURE AND LATENT CLASS ANALYSIS OF RISK FACTORS

by

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Dedication

This dissertation is dedicated to my mother, Loretta Stubbs, and my papa, James L. Stubbs, for always motivating me to be the best version of myself. This dissertation is also dedicated to the Black men and women who have come before me who had the courage to amplify the voices of the oppressed, even when their lives and liberty were at stake.

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I am forever grateful to my mom for instilling in me the importance of education from a young age. My mom and immediate family have cheered me on from day one and I am blessed to have them in my life. I would also like to thank my close friends for their support and encouragement. My best friend, Tahïri Jean-Baptiste, has been my ride or die and her support through the highs and lows of this program was unmatched. I am forever thankful to have such amazing people in my life and I am proud to share this moment with all of them.

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
aOR	Adjusted odds ratio
ART	Antiretroviral therapy
CI	Confidence interval
FDA	Food and Drug Administration
HIV	Human Immunodeficiency Syndrome
MSM	Men who have sex with men
PrEP	Pre-exposure prophylaxis
WICJ	Women involved in the criminal justice system

Chapter 1: Introduction

1.1: Problem Statement

1.1.1: History of HIV in the United States

Since 1981, over 700,000 people have died from HIV/AIDS in the United States (CDC, 2019). The release of highly active combination antiretroviral therapy in the mid-nineties led to the decline of opportunistic infections and mortality among people of living with HIV (Forrest et al., 1998; Hoggs et al., 1998). "Undetectable = Untransmittable," a byproduct of treatment as prevention, is a testimony of how adherence to antiretroviral medication can lead to undetectable viral loads and elimination of onward HIV transmission (Eisinger, Dieffenbach, & Fauci, 2019; National Institutes of Health, 2019). Although the nature of HIV has evolved from a short-term death sentence to a manageable chronic illness over the decades, it remains an epidemic that the nation hopes to end in the coming years (CDC, 2020). As of 2018, 1.2 million people in the United States were reported to be living with HIV, including approximately 14% of people unaware of their status, increasing their risk of onward transmission to a partner, whether through sexual intercourse and sharing needles (CDC, 2018).

1.1.2: The HIV Epidemic Among Women

While most new infections are among men, specifically men who have sex with men (MSM), approximately one out of five new infections occur among women (CDC, 2018). By age, adult women 25-44 years old are most vulnerable to HIV,

representing 50% of new HIV diagnoses. Racial and ethnic disparities remain with much of the burden falling on Black women. In 2017, Black women accounted for 59% of all new HIV infections among women. Lastly, most cases among all women, approximately 85%, were a result of heterosexual contact suggesting the importance of partner selection in the assessment of risk (CDC, 2018).

Despite the progress that has been made in reducing HIV acquisition among women as a whole, more needs to be done to reduce disparities in incidence rates and overall eradication in this population. There are a host of behaviors and exposures, ranging from individual to policy, that influence one another and contribute to HIV transmission among women (Amaro & Raj, 2000; Zierler & Krieger, 1997). Women report having sexual relationships with known non-monogamous partners and condomless sex with men they do not trust to be faithful, making it difficult to maintain a seronegative status (Bowleg, Lucas, and Tschann, 2004; Ferguson et al., 2006; Smith, 2015). To prevent HIV acquisition, condom use significantly reduces the likelihood of HIV transmission and has been a leading modality for use (CDC, 2013). However, for women, these protective behaviors can often be sabotaged by undesirable relationship characteristics, such as intimate partner violence (IPV) and reproductive coercion (Anderson, Grace, and Miller, 2017; Campbell et al., 2013; Mittal, Senn, and Carey, 2013). IPV has been shown to have a moderately significant association with HIV infection among women across various studies (Li et al., 2014). Coupled with financial insecurity and low educational attainment, a woman's ability to negotiate safe sex practices is further diminished in her partnership (Willie et al., 2018). Further upstream, structural and institutional factors, such as geographical

location, can further increase a woman's risk to HIV. For example, a woman's neighborhood characteristics, such as criminal activity and illicit drug use, indirectly exacerbates a woman's risk (Haley et al., 2017; Zierler & Krieger, 1997). The various combinations of interpersonal and structural factors can make it difficult to enact individual-level preventive measures.

1.1.3: Pre-exposure Prophylaxis (PrEP)

Oral pre-exposure prophylaxis, better known as PrEP, is the use of orally-administered antiretrovirals to prevent HIV acquisition prior to risk exposure (CDC, 2020). Once an effective amount of the drug is in a person's system, it blocks the virus from taking a hold of the host's immune system if exposed (Buchbinder & Liu, 2011). In 2012, Truvada©, an antiretroviral agent used for the treatment of HIV, was approved as a form of PrEP by the Food and Drug Administration to prevent HIV acquisition among HIV-negative adults. A first of its kind, PrEP entered the market as a biomedical option for men and women to protect one's self from HIV while engaging in sexual activity or injection drug use (FDA, 2012). Despite its availability in the US, there has been low uptake among vulnerable populations, especially women (Reisner et al., 2019; Eaton et al., 2015; Zhang et al., 2019). In 2015, more than 170,000 cisgender women had indications for PrEP use, however, only 2.1% were prescribed PrEP (Huang, Zhu, Smith, Harris, & Hoover, 2018). There is also an inequitable prescription rate of PrEP among racial and ethnic groups prescribed PrEP in 2016; nearly 6 times as many were for white women than were for African American women (Huang et al., 2018).

1.2: Current Perspectives on PrEP and Women

The concept of PrEP is an exciting one as the nation focuses on ending the HIV epidemic in the United States. Its biomedical innovation allows women to discreetly control their susceptibility to HIV (Grace, 2016; McCarraher, Martin, and Bailey, 2006). When exposed to situations that minimizes a woman's power to choose, such as sexual coercion, poor negotiation skills, or partner intimidation, PrEP can be a tool for women who must engage in HIV prevention without their partner's knowledge or cooperation (Willie, Kershaw, Campbell, & Alexander, 2017). Theoretically, PrEP was met with high enthusiasm because researchers believed that a female-controlled modality could empower women to protect themselves from HIV and level the playing field in high-risk partnerships (Kofman & Adashi, 2014; Opuku-Anane, Diouf, & Nour, 2012). Combined with treatment as prevention, a strategy that promotes adherence to antiretroviral therapy among people living with HIV to achieve undetectable viral loads, PrEP has the potential to greatly reduce the number of new infections and bring us closer to the goal of 75% reduction by 2025 (Fauci, Redfield, Sigounas, Weahkee, & Giroir, 2019).

While there are interventions in development to increase PrEP use and adherence among MSM, women are far behind on the PrEP care continuum and need awareness and knowledge of PrEP. Recent studies have found that PrEP awareness among women is quite low, roughly 10-30%, and work needs to be done to improve PrEP knowledge and perceived risk in this population before we can focus on initiation and retention in the PrEP care continuum (Auerbach et al., 2015; Walters et al., 2017; Patel et al., 2019). The clinical effectiveness of PrEP has been made public,

but there are gaps in the understanding of behavioral, interpersonal, and structural factors that impede PrEP awareness among women and the extent to which these barriers disproportionately affect women of different backgrounds. This study addresses the current gaps in knowledge by (a) systematically reviewing the current literature on PrEP awareness and knowledge; and (b) characterizing groups of women with varying levels of risk and PrEP awareness. Findings from this dissertation research have implications for the dissemination of PrEP-related information via women-focused, multilevel messaging to improve awareness and subsequent use.

1.3: Justification for Current Study

While we know the clinical efficacy of PrEP, more understanding of the behavioral, social, and structural factors that impede PrEP awareness among women is important to the dissemination of PrEP-related information and interventions. In the current dissertation, I propose to identify awareness, knowledge, barriers, and facilitators of PrEP use among Black women living in the US through a systematic review of the literature. To quantify these findings, the remaining study components utilized data from a cross-sectional survey to a) identify key factors related to PrEP awareness among female participants and b) explore how the presence of multiple deleterious factors can further exacerbate disparities in PrEP awareness. Findings can be used to inform multi-component interventions addressing barriers and facilitators to PrEP awareness and knowledge.

1.4: Theoretical Considerations

The following section summarizes the three theories that were used in this dissertation research. Chapter 3 utilizes the Grounded Theory to inform qualitative data analysis for the systematic review. The Minority Stress Theory was applied to secondary data in Chapter 4 to highlight the multilevel stressful exposures and their proximity to PrEP awareness. Lastly, the application of the Syndemic Theory in Chapter 5 supports analysis to examine how exposure to multiple exposures can either inhibit or promote PrEP awareness among women.

1.4.1: Grounded Theory

Qualitative research methods provide an opportunity to uncover links among concepts and behaviors and Grounded theory suggests taking an inductive approach to analyzing qualitative data and generating theory from data (Glaser & Strauss, 1967). Open coding is the act of assigning codes to segments of information and then finding commonalities and differences between codes (Padgett, 1998; Patton, 2014). Frequency and dominance of participant experiences, combined with high-level insights from the data, resulting in overall themes, or fundamental concepts (Ryan & Bernard, 2003; Strauss & Corbin, 1998). For this dissertation research, Grounded Theory informs data methods for Chapter 3 and how information from eligible articles were analyzed. Finding common themes across literature focused on PrEP awareness, knowledge, beliefs, and attitudes among Black women in the US help inform variable selection for subsequent quantitative studies.

1.4.2: Minority Stress Theory

To evaluate higher susceptibility to poor health outcomes among marginalized populations, some researchers have gravitated towards Minority Stress Theory and its constructs. Minority Stress Theory suggests that sexual and gender minorities are vulnerable to cumulative and chronic stress that can occur at interpersonal and structural levels (Meyer, 2015; Denton et al., 2014). The theory suggests that homophobic social conditions lend to stress among lesbian, gay, bisexual, and transgender (LGBT) people and further exacerbate poor mental health conditions such as anxiety, mood disorders, and substance use (Herek & Garnets, 2007). With the inclusion of race, findings suggest that racial discrimination, intersecting with sexual and gender minority stigma, resulted in increased substance use, anxiety, and depressive symptoms (English, Rendina, and Parsons, 2018).

Prior studies have found correlations between an accumulation of stressors and HIV-related health outcomes, such as poor retention in HIV treatment and prevention services (Garcia et al., 2016; Levy et al., 2014; Santos et al., 2014). Specific to PrEP, studies have found that the accumulation of minority stressors experienced by men who have sex with men (MSM) across the lifespan resulted in lack of PrEP awareness and stagnation in the PrEP care continuum (Watson et al., 2017; Meanley et al., 2020).

For this dissertation research, the Minority Stress Theory was used to inform the way in which existing data are analyzed and findings are interpreted in Chapter 3. The multinomial logistic regression model includes interpersonal and structural

stressors to evaluate how PrEP awareness is informed beyond individual level factors. Findings give insight into which characteristics and experiences are associated with the likelihood of PrEP awareness.

1.4.3: Syndemic Theory

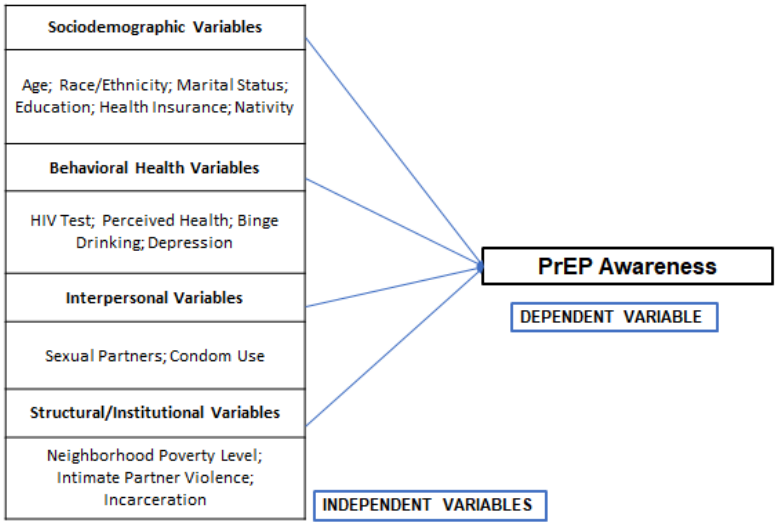
The goal of the syndemic theory is to provide a framework for the analysis of disease interactions in a social context. (Singer, 2009). A syndemic is defined as "the aggregation of two or more diseases or other health conditions in a population in which there is some level of deleterious biological or behavior interface that exacerbates the negative health effects of any or all of the diseases involved, (Singer, 2009)." In recent years, the use of the syndemics theory to inform HIV interventions has been on the rise, suggesting the implementation of multi-level and multi-component interventions addressing co-occurring conditions with the goal of reducing HIV-related risk behavior (Tsai & Burns, 2015).

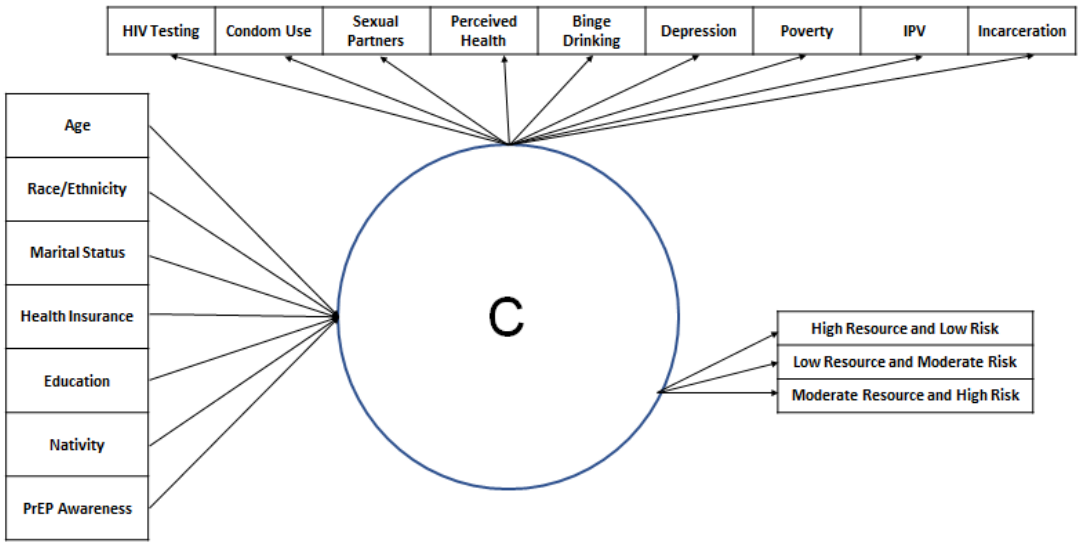
Prior studies have demonstrated the association between co-occurring psychosocial conditions and HIV risk in vulnerable populations. The substance use, violence, and HIV/AIDS (SAVA) syndemic is commonly used to understand how the entanglement of these co-occurring epidemics exacerbate a woman's risk of acquiring HIV. Although physical violence may not be a direct pathway to HIV transmission, the intimidation and coercion from an intimate partner combined with being under the influence of a substance has been shown to increase risk by 28-52% (Gilbert et al., 2015). Researchers from a handful of studies have begun to estimate syndemic effects on PrEP uptake among MSM and transgender women. Findings demonstrate the need for expanding current PrEP guidelines to capture more eligible candidates (Beymer et

al., 2017) and providing more PrEP use support for individuals with diminished perceived risk (Chandler et al., 2019). To my knowledge, there are no publications examining how syndemics play a role in the prevalence of PrEP awareness among women in the US.

For this dissertation research, the Syndemic Theory was used to inform the way in which existing data are analyzed and findings are interpreted. The identification of subgroups provides a perspective on how multilevel factors interact to either be protective or inhibitory to PrEP awareness. Aim #4 takes things a step further by quantifying the association of sociodemographic variables to class membership identified in Aim #3. This allows us to see if there are disparities in class membership based on age, race, and other variables.

1.4.4: Conceptual Models




HIV Testing
Condom Use
Sexual Partners
Perceived Health
Binge Drinking
Depression
Poverty
IPV
Incarceration
Age
Race/Ethnicity
Marital Status
Health Insurance
Education
Nativity
PrEP Awareness
C
High Resource and Low Risk
Low Resource and Moderate Risk
Moderate Resource and High Risk

1.5: Research Overview

This dissertation research investigates the complex relationship between sociodemographic, interpersonal, and structural factors as they relate to PrEP awareness among women. In the first component of the study, a qualitative systematic review of the literature identified key themes related to barriers and facilitators to PrEP uptake among US-based Black women. Findings, coupled with constructs from the Minority Stress Theory, informed the variable selection for the secondary data analysis. The quantitative component of this study, informed by the Syndemic Theory and broken up into three distinct aims, incorporated data from the Community Health Survey to a) examine the simple and multivariable associations between explanatory variables and PrEP awareness; b) identify and characterize subgroups of women who vary in in responses to survey questions related to behavioral, interpersonal, and structural factors; and c) describe how the prevalence of PrEP awareness and significant sociodemographic variables vary across classes. Findings provide insight on how multilevel exposures impact PrEP awareness and identify priority subgroups of women in need of multi-component interventions to improve PrEP awareness and subsequent use.

Research Question #1: What are the perceptions of PrEP among Black women in existing literature?

Aim I: Identify patterns of knowledge, attitudes, and perceived barriers and facilitators of PrEP use among Black/African American women in the United States.

Research Question #2: Which predictors are significantly associated with the report of PrEP knowledge?

Aim II: Determine which predictors most likely explain the report of PrEP awareness among female Community Health Survey (CHS) participants.

Research Question #3: What are the number of distinct classes of female participants based on health-related questions in the 2018 CHS?

Aim III: Utilize latent class analysis (LCA) to identify distinctive classes of women that vary in responses to survey questions related to behavioral, interpersonal, and structural factors.

Aim IV: Describe how the prevalence of PrEP awareness and significant sociodemographic variables vary across classes identified in Aim III.

Chapter 2: Literature Review

The purpose of this chapter is to provide an in-depth understanding of the various study components and summarize the current literature. The first section describes the evolution of PrEP and the clinical trial outcomes that have effects on PrEP is utilized today. The second section highlights the PrEP care continuum and the importance of awareness in improving linkage to health information, specifically PrEP. Lastly, the third, fourth, and fifth sections of this chapter outline the factors that are relevant to HIV prevention and PrEP awareness among women.

2.1: PrEP History

2.1.1: Overview of PrEP Efficacy Trials

Prior to its approval by the Food and Drug Administration in 2012, several studies took place around the globe to establish the effectiveness of PrEP (Food and Drug Administration, 2012). Seven major clinical trials took place across sub-Saharan African and European countries and participants included cisgender women, transgender women, and men who have sex with men (MSM). The Pre-Exposure Initiative (iPrEx) study, consisting of 2,499 MSM and transgender women from multiple countries, occurred from 2007 to 2010 and demonstrated a 92% reduction in HIV transmission among adherent users (Grant et al., 2010). The Partners PrEP Study enrolled in 4,747 heterosexual, serodiscordant couples in Kenya and Uganda from 2008 to 2010. Like iPrEx, researchers found a 90% reduction in transmission rates when participants followed prescription guidelines (Baeten et al., 2012). However, the tide began to turn when women-only trials were initiated in 2009. The Vaginal

and Oral Interventions to Control the Epidemic (VOICE) trial and the FEM-PrEP trial were multinational studies in Sub-Saharan Africa with 5,029 and 2,120 HIV-negative women enrolled, respectively (Marrazzo et al., 2013; Van Damme et al., 2012). Unfortunately, both studies were discontinued in 2011 due to lack of efficacy and equivalent infection rates between both study arms. In the FEM-PrEP trial, the incidence rate was 4.7 per 100 person-years and 5.0 per 100 persons for the PrEP group and placebo group, respectively, and less than 40% of PrEP participants demonstrated recent pill use (Van Damme et al., 2012).

Although there are findings that elucidate the difference in drug concentration levels between rectal tissue and vaginal tissue, the efficacy of PrEP remains stable among both men and women under ideal prescription conditions (Hanscom et al., 2016; Patterson et al., 2011). Models show that if women in the VOICE and FEM-PrEP trials had been adherent to taking PrEP once-a-day, then the effectiveness outcomes would have mirrored iPrEx, Partners PrEP, and other studies (Hanscom et al., 2016). Although there is understanding of how PrEP works biologically, findings from the women-focused clinical trials exposed gaps in the understanding of behavioral, social, and structural factors that impact PrEP use among women; all of which are important for the implementation and scale-up of PrEP in real-world settings (Pinto et al., 2018).

2.1.2: Gender-based Differences in PrEP Uptake

Since PrEP has been made available to the public, there has been slow uptake among vulnerable populations that are at high risk of seroconversion. A PrEP

indication refers to the number of people who report sexual risk-taking and could benefit from PrEP to prevent HIV acquisition (Wu et al., 2017). As of 2015, the Centers for Disease Control and Prevention suggest that approximately 1.2 million people have an indication for PrEP; specifically, 1 in 200, or 280,000 HIV-negative heterosexual adults (CDC, 2015; Smith, Van Handel, & Grey, 2018). It is estimated that 15.4%, or 176,670, of all people with PrEP indications are women despite only 3,229 women having been prescribed PrEP (Smith et al., 2018). As of 2017, 70,395 individuals used PrEP which is equivalent to 1.8 PrEP users for each one new HIV diagnosis (Siegler et al., 2018). By gender, there are disparities in the PrEP-to-need ratio (PnR) which compares the number of PrEP users to the number of new HIV diagnoses (Siegler et al., 2018). Nationally, in 2017, 2.3 per 100,000 women were on PrEP while 5.5 per 100,000 women were diagnosed with HIV, resulting in a PnR of 0.4. Conversely, 50.3 per 100,000 men were on PrEP while 24.4 per 100,000 men were diagnosed with HIV, resulting in a PnR of 2.1; a five-fold difference between genders (Siegler et al., 2018).

2.2: PrEP Awareness

2.2.1: PrEP Continuum of Care

With the scale-up of oral PrEP, the need for benchmarks of success became apparent and the logic mirrored that of the HIV care continuum (Kelley et al., 2015; Gardner et al., 2011). The PrEP care continuum consists of nine key steps: (1) identifying HIV vulnerability among key populations; (2) improving perceived risk among individuals; (3) raise PrEP awareness; (4) facilitating PrEP access; (5) linking

to PrEP care; (6) prescribing PrEP; (7) initiating PrEP; (8) PrEP adherence; and (9) retention in PrEP care (Nunn et al., 2017). While the first three steps are bucketed in the awareness category, the third step directly addresses the need for PrEP awareness to be heightened so that subsequent steps may commence (Nunn et al., 2017; Kelley et al., 2015). Low PrEP awareness inhibits self-referral to PrEP services, preventing participation in the PrEP care continuum (Aaron et al., 2018).

2.2.2: Health Communication Theory

Historically, various health and communication theories have identified awareness as an important first step in seeking a desired outcome or behavioral change. The Health Belief Model recognizes the importance of awareness in evaluating perceived susceptibility and perceived benefits for potential behavior change (Becker, 1974; Rosenstock, 1974). The Theory of Planned Behavior also depends on the presence of awareness for people to form an attitude about the behavior of interest (Ajzen, 1991). In the field of communications research, the notion of marginalized communities experiencing unequal access to and utility of health information is supported by the knowledge gap hypothesis (Tichenor, Donohue, & Olien, 1970). This hypothesis has been tested and supported in literature looking at differential awareness by socioeconomic status and access by race/ethnicity (Viswanath et al., 2006; Beacom and Newman, 2010). In a study evaluating disparities in awareness of the linkage between physical activity and cancer risk, researchers found that non-Hispanic Blacks had 30% reduced odds compared to White, non-Hispanic participants (Oh et al., 2010).

2.2.3: Risk and Protective Factors for HIV Prevention and PrEP Awareness

For women, there are numerous factors, operating at multiple levels of influence, that inform heightened susceptibility to HIV acquisition (Brawner, 2014; Lambert et al., 2018). This dissertation research examines whether these factors are correlated with PrEP awareness and, if so, how they can manifest in distinct classes of women experiencing multiple exposures at once. The following section provides a comprehensive review of the existing HIV and PrEP awareness literature that delineates disparities in exposure to factors that fall within the following categories: individual; behavioral health and interpersonal; and structural and institutional. It provides justification for the variable selection and methodology for the three studies.

2.3: Individual Factors

2.3.1: Racial and Ethnic Disparities across the Lifespan

Despite declining HIV incidence rates for all women in the US, there remains disparities in new cases based on a variety of sociodemographic factors. For instance, Black women are disproportionately impacted by HIV compared to non-Hispanic White women. In 2017, Black women accounted for almost 60% of new cases among women (CDC, 2018). By age, women 25 to 34 years old accounted for the highest number of new cases across all age groups (CDC, 2018). In 2017, all age classes experienced drops in HIV infections except for women 55 and older, which remained stable (CDC, 2018). Age can be correlated with perceived HIV risk as women of reproductive age may perceive themselves to be more susceptible to HIV than older women (Lindau, Leitsch, Lundberg, & Jerome, 2006). Lastly, immigration status also

plays a role in explaining disparities of HIV infection among women in the US. Prior studies show disproportionate rates between African-born women in the US and White female counterparts as large as 360% (CDC, 2008). In the Latinx community, both male and female immigrants are severely impacted by the HIV crisis. In 2018, Hispanics/Latinos accounted for 27% of new HIV diagnoses and it is estimated that half of new cases are among Latinx immigrants, of which 44% are women (CDC, 2020). For immigrants across racial groups, fear of stigma, both social and medical, and encounters with immigration authorities act as barriers to preventive care (CDC, 2020; Okoro & Whitson, 2017).

2.3.2: Socioeconomic Status

HIV risk has been shown to be significantly associated with education and socioeconomic status with the burden placed on those who report less than high school education, unemployment, and living below the poverty level (CDC, 2011). Poverty and income inequality, among other indicators, have surfaced as key drivers in the spread of HIV among America's most vulnerable populations (Buot et al., 2014). For women, financial insecurity can exacerbate the risk of acquiring HIV as the reliance on a male partner for economic stability can lead to power imbalance and bleed into sexual intimidation (Wingood & DiClemente, 2000). A recent qualitative study on seronegative women in the US found that 80% of participants stated that some form of financial insecurity (i.e., lack of housing, food insecurity) was the primary reason for engaging in sexual risk-taking with male partners (Frew et al., 2016).

Prior studies have shown a positive relationship between education status and PrEP awareness, with those reporting higher education being more aware of HIV prevention modalities (Garnett et al., 2017; Garofalo et al., 2015). In comparison, participants who had lower levels of education are more likely to report engaging in high-risk sexual behaviors (Justman et al., 2015) compared to those with higher educational levels, suggesting that PrEP information is not reaching those who need it most. Lack of knowledge and awareness of preventive services has been associated with reproductive issues such as pap smear testing, abortion services, contraceptive use (Breitkopf, Pearson & Breitkopf, 2005; Lara et al., 2015; Haider et al., 2013), indicating that awareness is a critical step in preventive efforts to curb disease-related outcomes.

2.4: Behavioral Health and Interpersonal Factors

2.4.1: Mental Health and Substance Use

Common mental disorders (CMDs), such as depression, have been shown to act as barriers to adherence to antiretroviral therapy among people living with HIV (Uthman, Magidson, Safren, & Nachega, 2014). Depression is also associated with HIV risk, with positive associations between the presence of depression and risky sexual behavior (Defechereux et al., 2016; Reisner et al., 2009; Stall et al., 2003). There is evidence to support that PrEP is effective among people living with depression and has no negative interactions with depression medication (Defechereux et al., 2016). Preliminary studies have found lower PrEP adherence among people with depressive symptoms and with adherence being such a critical factor for PrEP

effectiveness among women, it is important to identify and treat depressive symptoms in a parallel fashion (Velloza et al., 2018).

Binge drinking, operationalized as four or more drinks in a two-hour span for women, has been shown to reduce inhibitions during sexual contact and oftentimes leads to condomless intercourse (CDC, 2019a). Misuse of alcohol among people living with HIV heightens the risk of condomless sex with multiple partners and onward transmission (Shuper, Joharchi, Irving, & Rehm, 2009). In terms of HIV prevention, exposure to multiple psychosocial health problems (e.g., depression, substance use, etc.) has been associated with increased sexual risk-taking (Oganbujo et al., 2019; Simbayi et al., 2004) and excessive alcohol use alone has been linked to greater intentions to engage in unprotected sex (Scott-Sheldon et al., 2016). Although alcohol screening is included in CDC's PrEP guidelines for clinicians, hazardous alcohol and drug use has been shown to be associated with low PrEP awareness (Garnett et al., 2017). Also, beliefs around alcohol use diminishing the efficacy of ART among people living with HIV has also been adapted to PrEP in some groups (Kalichman and Eaton, 2017).

2.4.2: HIV Prevention

In the United States, a little over half of US adults have ever received an HIV test in their lives; roughly 8% of whom received a test in the past year. By race, Black and Latino people were more likely to have had an HIV test in the past 12 months than Whites with rates of 19%, 10%, and 6%, respectively (Kaiser Family Foundation, 2019). The national averages mirror HIV testing behavior among women; half of all women have had an HIV test at least once in their lives but only

18% of women have had a test in the past 12 months (Kaiser Family Foundation, 2020). Black women are more likely to have had a test in the past 12 months compared to White women, 21% and 6%, respectively (Kaiser Family Foundation, 2020). Prior research on correlates of PrEP awareness found HIV testing in the past year to be associated with increased PrEP awareness in the adjusted model. Those who received a negative test were more likely to know about PrEP than those who tested positive, 63% and 47%, respectively (Hoagland et al., 2016). It is suggested that HIV testing serves as an ideal medium for PrEP information because testing clients already have a perceived risk for HIV and pick up on PrEP information during clinic visits (Hoagland et al., 2016; Lee et al., 2017).

Most new HIV cases among women in the US derive from heterosexual intercourse, accounting for 85% of cases, suggesting the importance of partner dynamics in reducing HIV incidence among women (CDC, 2018). Research shows that Black women are more likely to report concurrent partnerships, sexual relationships that overlap in a period of time (Adimora et al., 2011; Manhart, Aral, Holmes, & Foxman, 2002). From an economic standpoint, women who report having high incomes or home ownership were less likely to report concurrent partnerships (Adimora et al., 2011). However, the literature suggests that a female's monogamous status is not automatically a protective factor for HIV risk. Indirect concurrency refers to the number of female partners involved with a man who is in a partnership with a woman (Adimora et al., 2004; Adimora et al., 2011; Frew et al., 2016). Whether known or unknown, indirect concurrency widens a woman's sexual network further elevating risk for HIV acquisition (Frew et al., 2016).

2.5: Structural and Institutional Factors

2.5.1: Neighborhood Characteristics

Social and environmental epidemiologic studies have demonstrated the importance of a person's neighborhood in determining the likelihood of HIV acquisition (Burke-Miller et al., 2016; Wiewel et al., 2016). HIV incidence among MSM was associated with poverty and racial/ethnic segregation (Buot et al., 2014) and a positive relationship between HIV incidence and percentage of non-Hispanic Black people, mediated by household income, in Atlanta, GA (Sullivan et al., 2015). Research suggests that an area of high HIV burden in which Black women reside and meet sexual partners can be indicative of HIV risk (Aral, Adimora & Fenton, 2008).

A recent study found participants residing in highly educated neighborhoods and areas with greater primary care density were 2-38% more likely to be aware of PrEP (Chen et al., 2018). Other studies have found neighborhood disorder to be a facilitator to PrEP awareness because of coping with sexual activity and increased perceived risk (Lachowsky et al., 2016; Frye et al., 2017).

2.5.2: Engagement with the Justice System

Compared to males, female inmates are twice as likely to be living with HIV and past or current incarceration plays a significant factor in a woman's vulnerability to HIV (Fogel & Belyea, 1999; Hutton et al., 2001; Wise et al., 2017). Women involved in the criminal justice system (WICJ) experience more severe multilevel stressors such as unstable housing, illicit drug use, and transactional sex which increases HIV risk (Hearn et al., 2015). Regarding sexual partnership, it has been

shown that incarceration is a significant factor in the availability of men and contributes to complex sexual networks, primarily in the Black community (Grieb, Davey-Rothwell, & Latkin, 2012; Lichtenstein, 2009). While HIV prevention services have been made available to WICJ, most of the programming focuses on condom negotiation and safe syringe usage--both of which can be sabotaged by intimate partners (El-Bassel, Terlikbaeva, & Pinkham, 2010). For this specific population, PrEP is ideal since it is effective and user-controlled (Rutledge et al., 2018). However, rates of PrEP awareness among WICJ are low, around 25%, and similar to women who have no experience with the criminal justice system (Rutledge et al., 2018).

2.5.3: Intimate Partner Violence

Intimate partner violence (IPV) is defined as "physical, sexual, and emotional abuse and controlling behaviors by a current, or former, intimate partner (World Health Organization, 2012)." Manifestations of IPV include physical violence, sexual violence, emotional abuse, and controlling behaviors. IPV is highly correlated with HIV risk and recent studies have forayed into reproductive coercion (Willie, Kershaw, Campbell, & Alexander, 2017). Sexual intimidation can result in forced and unwanted sex and/or the inability to perform condom negotiation (O'Malley, Hawk, Egan, Krier, & Burke, 2019). PrEP grants the opportunity for women in violent relationships to have a covert, user-controlled option for HIV prevention (Grace, 2016; McCarraher, Martin, and Bailey, 2006). As it pertains to PrEP awareness, prior studies have not found significant differences in rates between women who have

experienced IPV and those who have not, despite having higher rates of HIV worry (Willie et al., 2019).

Chapter 3: STUDY 1 - A SYSTEMATIC REVIEW OF PRE-EXPOSURE PROPHYLAXIS (PrEP) KNOWLEDGE, ATTITUDES, AND BELIEFS AMONG HIV-NEGATIVE BLACK WOMEN

3.0: Abstract

A Systematic Review of Pre-Exposure Prophylaxis (PrEP) Knowledge, Attitudes and Beliefs among HIV-Negative Black Women

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Objective: To scientifically evaluate research articles and identify key themes that pertain to pre-exposure prophylaxis (PrEP) uptake among African American women in the United States (US).

Methods: This two-phase systematic review process consisted of a preliminary search to identify keywords and terms; followed by a systematic review and evaluation of articles from six databases. The inclusion criteria were a) studies that had samples of 60-100% women; b) greater than 50% of female participants identified as Black/African American; and c) the study was conducted in the United States.

Results: A total of 1,362 articles were identified through database searches. Articles were removed because of duplication (n=203) and not meeting eligibility criteria (n=1,147). The final number of records eligible for analysis was 12. Findings were grouped into four key themes: Knowledge of PrEP; Perceived Advantages and Disadvantages of PrEP; and Perceived Barriers and Facilitators to PrEP Uptake. Primary findings include gaps in PrEP knowledge; acceptability and willingness to use once informed of PrEP; perceived disadvantages because of exclusion in clinical trials and early dissemination; and social, structural, and institutional barriers to engagement in the PrEP care continuum.

Conclusions: Identifying key factors related to PrEP uptake among Black women in the US help inform tailored prevention interventions to meet the unique needs of the Black women, achieving equitable health outcomes for at-risk individuals.

3.1: Introduction

In 2018, approximately 1.1 million people were living with HIV in the United States (US) and 37,832 new cases were reported. Black people are disproportionately affected by HIV compared to other racial and ethnic groups. While only comprising 13% of the US population, Black people accounted for 42% of incident HIV cases in 2018 (CDC, 2018). Black women, who occupy an intersectional social position based on both race and gender, are at increased risk for HIV acquisition compared to women of other races/ethnicities in the US, despite an overall decline in incidence among all women in the US. As of 2018 in the US, Black women accounted for 57% of all HIV infections and were 15 times more likely than white women to receive an HIV diagnosis (CDC, 2018). Racial disparities in mortality outcomes also reflect the burden of HIV in the lives of Black women. While HIV is not included in the top 10 leading causes of death for all women, it is the 6th leading cause of death for Black women aged 20 to 44 years old (CDC, 2018).

There are myriad behavioral and structural factors, ranging from the individual to the policy level that exacerbate HIV vulnerability among Black women.

With heterosexual contact accounting for 92% of new cases among Black women, condom use has been the primary mode of HIV prevention for this population (CDC, 2018; CDC, 2013). Despite White women engaging in risky sexual behavior more frequently, Black women acquire HIV at a higher rate; almost 15 times higher than the rate of new HIV cases among White women (CDC, 2020). At the partner level, prior studies suggest loss of autonomy, poor condom negotiation skills, and gender power imbalance in relationships may be associated with an increased risk of HIV acquisition (Nehl, 2016; Salazar, 2004). At a structural level, research suggests that at the neighborhood/community level, Black women who reside in areas where there is also a high burden of HIV among potential sexual partners can also be at increased risk for HIV acquisition (Aral, Adimora & Fenton, 2008).

Oral pre-exposure prophylaxis, better known as PrEP, is the once-daily use of orally administered antiretrovirals to prevent HIV acquisition prior to risk exposure (Buchbinder & Liu, 2011). PrEP demonstrated clinical efficacy in reducing the risk of HIV acquisition, if taken as prescribed, and in 2012, Truvada© was approved as a form of oral PrEP by the Food and Drug Administration (Food and Drug Administration, 2012; Grant et al., 2010). An unforeseen outcome of the PrEP clinical trials were the gender differences in PrEP effectiveness. Two PrEP studies that enrolled heterosexual cisgender women in Sub-Saharan Africa (Corneli et al., 2016; Montgomery et al., 2017) were unable to establish PrEP efficacy due to low adherence among young women (Marrazzo et al., 2015). Study participants encountered barriers such as family and partner stigma due to unfamiliarity with the

drug and perceived side effects (Corneli at al., 2016), disrupting full adherence to the regimen and thus resulting in mixed findings.

Since its release, PrEP uptake among those at most risk of acquiring HIV, specifically heterosexual cisgender women, has been low (Auerbach, Kinsky, Brown, & Charles, 2015). As of 2015, the Centers for Disease Control and Prevention suggest that approximately 1.2 million people have an indication for PrEP; specifically, 1 in 200, or 280,000, HIV-negative heterosexual adults (CDC, 2015; Smith, Van Handel, & Grey, 2018). For women, it is estimated that 15.4%, or 176,670, of all people with PrEP indications are women despite only 3,229 women having been prescribed PrEP (Smith et al., 2018). There is a substantial amount of research examining the perceptions, beliefs, and attitudes of PrEP among sexually active men who have sex with men (MSM) and findings from these studies have identified facilitators such as older age, risk perception, and higher educational attainment (Golub, Gamarel, Rendina, Surace, & Lelutiu-Weinberger, 2013; Khawcharoenporn, Kendrick, & Smith, 2012; Krakower et al., 2012; Young & McDaid, 2014).

The purpose of this systematic review is to identify existing literature prioritizing PrEP outcomes among Black women in the US and assess key factors related to the uptake of PrEP in this priority population. Improved understanding of the psychological, social, and behavioral barriers and facilitators to PrEP that are unique to Black women can inform tailored PrEP interventions.

3.2: Methods

3.2.1: Article Selection Process

The systematic review process was conducted in three phases: a) a preliminary search to identify additional keywords and terms; and b) a systematic search of six databases; and c) the evaluation of eligible articles. In the first phase, a general search of the literature was conducted to identify relevant keywords and phrases to be included in the structured systematic search. An initial search string was entered into a subset of phase two databases: “African American OR Black AND woman OR women OR girl* OR female AND United States AND preexposure prophylaxis OR PrEP OR pre-exposure prophylaxis AND HIV OR AIDS.” Keywords, titles, abstracts, and MeSH terms associated with each article were noted and relevant phrases were tested in the second phase for each database.

The second phase involved a systematic review of six electronic databases: PubMed, EMBASE, POPLINE, PsycINFO, Web of Science, and MEDLINE. These six databases were chosen for this study based on their relevance to the research objective and the inclusion of public health literature. Initially, each word or phrase was individually searched to identify the number of corresponding results. Grouped into categories, population (e.g., “African American” AND “women” [MeSH Term]), condition (e.g., “HIV” [Text Word]), prevention (e.g., “PrEP” [Abstract]), and setting/location (e.g., “United States” [Abstract]) terms were entered into each database and the terms with the highest number of results were used in the database’s final search string. For example, the search string used for PubMed: ("African Americans" [MeSH Terms] and "women" [Text word]) OR "African American

women" [Title/Abstract] OR "African-American women" [Title/Abstract] OR "Black women" [Title/Abstract] OR ("African Americans" [MeSH Terms] and "female" [MeSH Terms]) AND ("HIV" [Text word] OR "HIV" [MeSH term] OR "human immunodeficiency virus" [Text word]) AND ("PrEP" [Text word] OR "pre-exposure prophylaxis" [Text word] OR "preexposure prophylaxis" [Text word]) AND ("United States" [MeSH term] OR "United States" [Text word] OR "urban" [Text word] OR "US" [Text word]).

After merging the six result lists together, all duplications were removed. For the final set of articles, the inclusion criteria were a) studies that had samples of 60-100% women; b) greater than 50% of female participants identified as Black/African American; and c) the study was conducted in the United States. Articles were excluded if they lacked primary data collection; contained studies that were conducted outside of the United States; and/or the majority of participants identified as MSM or transgender women. Titles and abstracts were individually reviewed by two of the authors and disagreements in coding were discussed with senior colleagues.

Both studies relying on quantitative and qualitative methods and approaches were included in this review. Articles that met inclusion criteria were uploaded into Nvivo 12, a qualitative research software package, for thematic analysis. Qualitative methods, rooted in grounded theory, were used to identify PrEP-related themes within each article. Grounded theory suggests generating theory from data (Glaser and Strauss, 1967). Open coding is the act of assigning codes, such as ‘medical mistrust’ or ‘side effect concerns,’ to segments of information and then finding commonalities

and differences between codes (Padgett, 1998; Patton, 2002). Once patterns become more visible in the data, these codes can inform overarching themes, such as barriers and facilitators to PrEP. In some cases, codes had applicability with two or more themes due to the code's complexity and the context in which the data presented itself. For example, a code could be perceived as an advantage of PrEP while also serving as a barrier to its use. As with the title/abstract review, all the coding was done independently by two of the authors and discrepancies were discussed and reconciled. NVivo 12 (QSR, 2018) was used for organizing and coding the data.

3.3: Results

As summarized in **Figure 1**, a total of 1,362 articles were identified through database searches. After duplicative results were removed, the total number of articles reduced to 1,159. A total of 990 records were removed for reasons including studies conducted in global settings, samples of people living with HIV, and exclusively MSM populations. The full text of remaining articles (n=169) was reviewed and the final number of records eligible for analysis was 12. The primary reason for the exclusion of 157 articles was the lack of intersectional findings that spoke to the Black female experience, exclusively. A summary of characteristics for each article can be found in **Table 1**.

3.3.1: Overview of Studies

There were a few notable sample characteristics from the collection of articles. Majority of studies enrolled adult participants except for one that enrolled mother/daughter dyads. Eligibility for study participation ranged from engagement

with community-based organizations to prenatal care at a local medical facility. Study location varied with the majority having at least one site in the Northeast, one in the Midwest, and a couple with sites scattered across the South. Three studies were conducted completely online. As for methods, five of the studies were qualitative focus groups while the remaining studies were composed of online surveys, a retrospective cohort, and observation of social media behavior. The following paragraphs summarize key findings from the four main themes of the systematic review: Knowledge of PrEP; PrEP Acceptability and Willingness; Perceived Advantages and Disadvantages of PrEP; and Perceived Barriers and Facilitators to PrEP Uptake.

3.3.2: Knowledge of PrEP

Many of the studies highlighted the lack of PrEP knowledge among Black women across regions of the US. Auerbach (2015) found that less than 10% of the sample (N=144) knew of PrEP. Once informed of the drug's purpose and effectiveness, participants expressed anger and frustration about being left out of the conversation (Auerbach, 2015). In addition to low levels of PrEP knowledge among clients, there are also gaps in HIV prevention knowledge among physicians and medical staff. In a series of focus groups conducted with clients and clinic staff in the Bronx, most participants, 74% and 57%, respectively, stated they had not heard about PrEP before participating in the focus groups (Collier, 2017). Although knowledge of PrEP among study participants was low, desire to know more was high and indicative of interest (Collier, 2017).

3.3.3: PrEP Acceptability and Willingness

Majority of articles (N=7) touched on various facets of PrEP acceptability and willingness among Black women in the US. Wingood (2013) used data from a nationwide telephone survey entitled "Social Health of African-American and White Women (SHAWL)" and found that Black women were more likely to express interest in using PrEP compared to White women. Secondly, Black women reported the importance of a supportive partner, peer group, and healthcare provider in deciding whether they would use PrEP. Flash (2014) conducted focus groups with 25 Black women in Boston and found that most participants expressed interest in PrEP, preferably the pill form because it provides better privacy than the gel form (Flash, 2014). Majority of participants (60%) in the study by Garfinkel and colleagues (2017) also reported they would consider taking PrEP in a pill form daily to prevent HIV. Additionally, participants who were not interested in using condoms due the belief that it decreases sexual pleasure or those who was afraid of condom failure were more open to using PrEP in the pill form (Flash, 2014). In comparison to other preventive methods, participants found PrEP to be an adequate alternative to condom use in preventing HIV acquisition.

In a few studies, participants also indicated lack of interest in using PrEP in any form due to mistrust of the medical system (Flash et al., 2014; Hill et al., 2018; Fletcher et al., 2018). In the study by Hill and colleagues (2018), participants who expressed unwillingness to use PrEP mentioned concerns about PrEP safety, mistrust of government and the pharmaceutical industry, and support of other HIV prevention methods (Hill, 2018). Fletcher and colleagues (2018) also found that fear of medical

and scientific exploitation of communities of color and stigmatization of clinical trial participation makes Black women unwilling to use PrEP. Alternatively, young Black women who had experiences with controlling partners who prevented them from using contraceptives were more willing to use PrEP (Willie, 2017). However, in the study by Garfinkel and colleagues (2017), PrEP acceptability was significantly lower (57% vs. 62%, AOR .71, CI: .59–.85) among women with a history of intimate partner violence, relative to their non-abused counterparts.

3.3.4: Perceived Advantages and Disadvantages of PrEP

PrEP has been described as 'empowering' and a female-controlled prevention method that can be highly effective for women experiencing power imbalance in their relationship (Bond et al., 2016). Women experiencing sexual coercion and/or birth control sabotage expressed higher willingness to use PrEP than women who were not, (Willie, 2017). Participants believe that PrEP provides an option for women involved with partners of unknown HIV status and serodiscordant couples (Bond, 2016). Fletcher (2018) conducted focus groups among Black mothers of young adult women and many of them suggested that PrEP should be used as a “back-up” method to condoms for optimal protection. Some of the mothers expressed skepticism regarding adolescents’ ability to adhere to PrEP. Other disadvantages of PrEP use were reported to be the burden of taking a daily pill, newness of the drug, burden of HIV testing, increased visits to the clinic, potential side effects, and its potential to promote unsafe sex.

3.3.5: Perceived Barriers and Facilitators to PrEP Uptake

Despite interest in PrEP, there are numerous social and structural barriers that may delay or prevent Black women from engaging in the PrEP care continuum. Black women experience various forms of intersectional stigma and discrimination based on race, gender, and sexual preferences (Bond, 2016). Participants expressed anticipated stigma from friends, peers, and physicians if they were to discuss their interest in PrEP, especially among women in relationships (Fletcher, 2018; Rubtsova, 2013). Participants also mentioned that the stigma associated with medical visits and the burden of taking pills for multiple health concerns would prevent them from using PrEP (Collier 2017). One group of participants suggested the importance of PrEP testimonies from other Black women in reaching and linking Black women to PrEP care (Wingood, 2013). Women suggested that the newness of the drug further exacerbated their skepticism regarding the efficacy of PrEP (Fletcher, 2018; Hill, 2018). Other barriers to PrEP uptake that were discussed included side effects of the drug, medication cost, concerns about the effectiveness of the drug and susceptibility to contracting HIV, burden of taking a daily medication and being judged by others to be taking an HIV medication (Smith 2012).

Although quite a few barriers to PrEP use were identified, there were discussions of facilitators to PrEP use that included insurance coverage; PrEP as a contingency plan for failed condoms; and recognizing that PrEP could reduce HIV incidence in their communities (Collier, 2017). Other factors that facilitated PrEP use included having supportive social environments and healthcare provider recommendations (Wingood, 2013). Some Black women reported that doctors and

community agencies are the best sources of information for PrEP, while others reported that peers are the best sources of information (Auerbach, 2015). Additionally, having convenient locations that dispense PrEP was reported as a facilitator to potential PrEP uptake (Smith, 2012).

3.4: Discussion

PrEP use among women is an emerging area of interest and research across the country is being conducted to identify the psychosocial factors linked to PrEP knowledge, use, and adherence. This systematic review identifies synergy in findings from a variety of studies focused on Black women across the United States. Primary findings include gaps in PrEP knowledge; acceptability and willingness to use once informed of PrEP; and social, structural, and institutional barriers to engagement in the PrEP care continuum. In a recent systematic review of 14 women's studies and 3 provider studies, PrEP awareness ranged from 0-33% and willingness to use PrEP ranged from 51-97% (Bradley et al., 2019). Among women who use drugs, 20.6% of participants were aware of PrEP and 60.2% of them are willing to use PrEP (Bazzi et al., 2019). Both systematic reviews identified similar barriers, such as access and medical mistrust, and enablers to PrEP engagement, such as intimate partner violence. Despite their similarities, neither study disaggregated their findings for Black women, specifically.

There are several ongoing challenges to addressing the needs of Black women for HIV prevention. The "Ending the HIV Epidemic" (EHE) initiative was introduced

by the US Department of Health and Human Services in 2019 and it proposes to reduce new HIV infections by 75% in five years and by 90% in 10 years. "Prevention" serves as one of the four key strategies of the initiative and it emphasizes the scale-up of PrEP in states and counties across the US experiencing a high burden of HIV (Fauci et al., 2019). However, the plan contains no language specific to Black women in the US and tailored approaches to identify, engage and retain Black women in the PrEP care continuum. In tandem with the erasure of Black women in the EHE initiative, recent clinical trials testing the effectiveness of Descovy (emtricitabine 200 mg and tenofovir alafenamide 25 mg) as a second PrEP option were composed of male participants only; thus, there are no data to support the drug's effectiveness among women (FDA, 2019). Despite the dissemination of gender-based differences in findings from the Truvada clinical trials, lessons were not applied to the Descovy trials and much is left to question how this new form of PrEP applies to vulnerable women. As the majority of new HIV infections among women fall on Black women, it is imperative that Black women are included in the PrEP discussion from bench to bedside as we aim to make HIV infection a thing of the past in the United States.

Limitations. Survey and interview questions were not the same across articles and findings may be interpreted differently. As we build more literature around PrEP-uptake among women, harmonization in measures can help compare findings across studies. In addition to differences in instrumentation, most of the PrEP-related articles were excluded due to lack of intersectionality. While many of the publications distinguished between categories of race and gender separately, very few focused on

the intersectionality of these two demographic criteria and did not produce results that specifically spoke to Black women. Future studies that can leverage high cell counts for this level of categorization should investigate the subgroup differences.

Conclusions. This systematic review focused solely on PrEP and cisgender Black women, an underserved and understudied population, living in the United States. The findings demonstrate the lack of awareness and education on PrEP to inform one's own perceived risk and willingness to use PrEP as an HIV prevention tool. Furthermore, future studies should consider the importance of enrolling Black women in US-based PrEP studies that are sufficiently powered to identify differences in subgroups at the intersection of race and gender.

Figure 3.1: Placement of articles through the search and screening process.

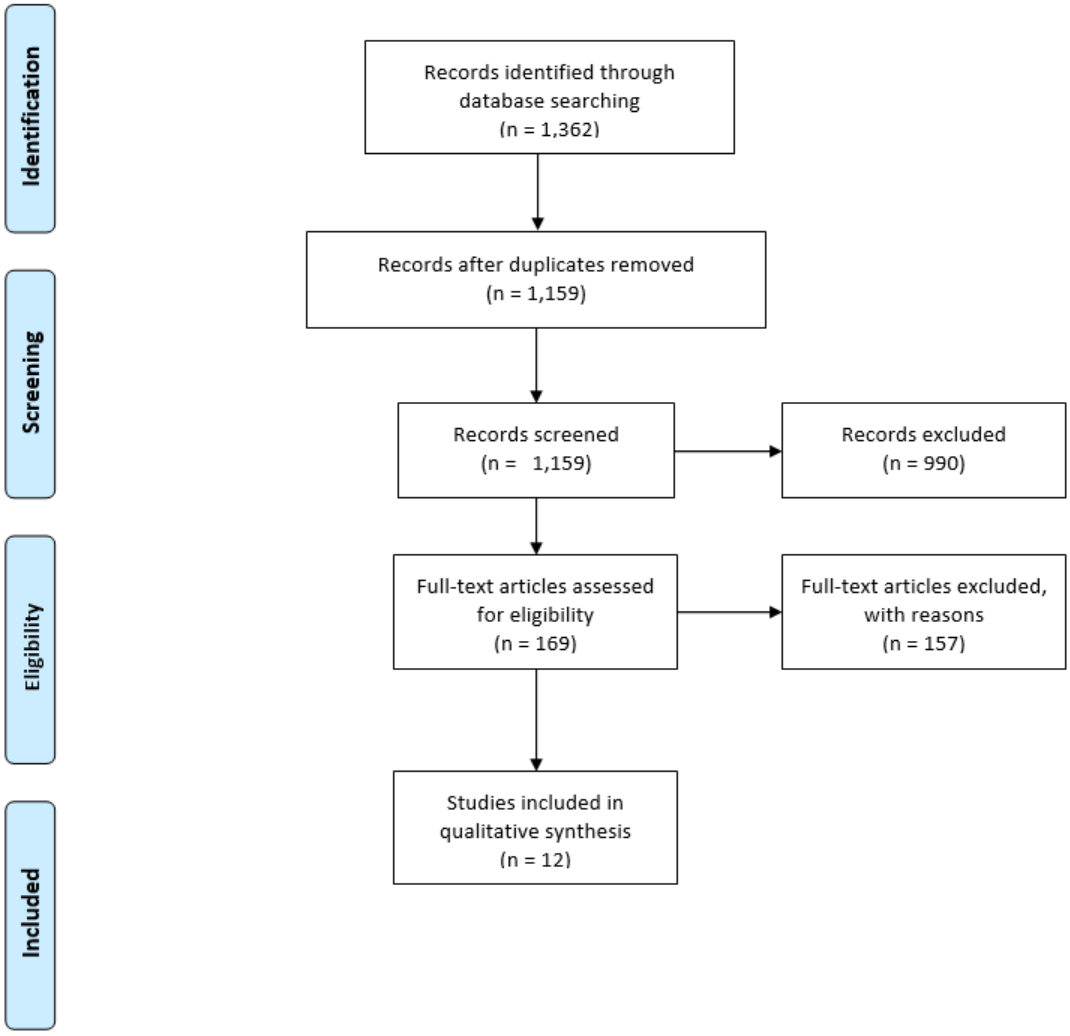

Table 3.1: Summary of Peer-Reviewed Articles' Characteristics

First Author, Year	Study Location	Objective	Study Design	Sample Size
Auerbach, 2015	New York, NY; Dallas, TX; Atlanta, GA; Newark, NJ; Chicago, IL; and New Orleans, LA	To investigate PrEP's acceptability and feasibility among women at risk for HIV in the US	Qualitative focus group	144
Bond, 2016	Online	To identify the perceived advantages and disadvantages to using PEP and PrEP	Online survey	119
Collier, 2017	Bronx, NY	To explore PrEP knowledge and attitudes, perceived facilitators and barriers to adoption, and message preferences	Qualitative focus groups	44
Flash, 2014	Boston, MA	To explore the factors that influence PrEP acceptability and preferences for oral or vaginal administration of PrEP	Qualitative focus groups	25
Fletcher, 2018	Chicago, IL	To assess perceptions of adolescent PrEP use and clinical trial participation among African American women and their adolescent daughters	Qualitative focus groups	30

Fruhauf, 2017	Baltimore, MD	To estimate the proportion of women at increased risk of sexual HIV acquisition during pregnancy in a high HIV incidence urban setting to identify those who may be eligible for pre-exposure prophylaxis	Retrospective cohort study	1637
Garfinkel, 2017	Baltimore, MD	To explore individual, behavioral, and structural factors associated with (1) HIV risk perception and (2) PrEP acceptability, among young adult female family planning patients	Cross-sectional, clinic-based survey	146
Hill, 2018	Online	To gain further insight into novel factors that may influence PrEP uptake among Black women	Observation of social media behavior	76
Rubtsova, 2013	Nationwide	To examine potential use of pre-exposure prophylaxis (PrEP) among young adult women	Telephone-based survey	1453
Smith, 2012	Atlanta, GA	To elicit attitudes about, and service access preferences for, daily oral antiretroviral pre-exposure prophylaxis (PrEP) from urban, African American young men and women	Qualitative focus groups	77
Willie, 2017	Baltimore, MD	To: (1) describe the prevalence and associations of IPV, reproductive coercion experiences, and PrEP acceptability among urban-dwelling low-income young Black women, and (2) examine birth control sabotage and pregnancy	Cross-sectional survey	147

		coercion as mediators of the association between IPV and PrEP acceptability		
Wingood, 2013	Nationwide	To examine the association between sociodemographic factors, sexual behaviors, and social factors on potential uptake of PrEP among African American and White adult women in the United States	Telephone-based survey	1509

Chapter 4: STUDY 2 - PREDICTORS OF PrEP AWARENESS AMONG FEMALE COMMUNITY HEALTH SURVEY (CHS) PARTICIPANTS, 2018

4.0: Abstract

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Objective: To enumerate the rate of pre-exposure prophylaxis (PrEP) awareness and identify multi-level factors associated with PrEP awareness among women participating in the 2018 Community Health Survey.

Methods: Cisgender female participants with complete entries for all variables of interest were included in this study. Individual, interpersonal, and structural variables were analyzed to understand how multi-level exposures can influence the likelihood of PrEP awareness. The analysis plan consisted of: (1) descriptive frequencies, (2) simple logistic regression, and (3) multinomial logistic regression.

Results: Among 2,295 women, only 36% of them were aware of PrEP at time of survey. Black, non-Hispanic race (aOR 1.471; 95% CI 1.134-1.907), US birth (aOR 2.259; 95% CI 1.830-2.790), multiple sex partners (aOR range 1.667-2.135; 95% CI 1.144-3.230) and a recent HIV test (aOR 1.492; 95% CI 1.211-1.840) were a few of the factors significantly associated with the outcome of PrEP awareness.

Conclusions: PrEP awareness is low among women participating in this survey and there are a variety of factors that serve as barriers and facilitators to PrEP information. Future studies and interventions should prioritize women across the lifespan and social and structural considerations should be made in the development of PrEP materials and promotional campaigns.

4.1: Introduction

As of 2018, women accounted for 19% of new HIV infections in the United States with Black women representing 57% of all HIV infections (CDC, 2018). Pre-exposure prophylaxis, better known as PrEP, is the use of orally administered antiretrovirals to prevent HIV acquisition prior to risk exposure (Buchbinder & Liu, 2011). Since its FDA approval in 2012, there has been slow uptake of PrEP among vulnerable populations, specifically women in the United States. Nationally, in 2017, 2.3 per 100,000 women were on PrEP while 5.5 per 100,000 women were diagnosed with HIV, resulting in a PrEP-to-need ratio (PnR) of 0.4. Conversely, 50.3 per 100,000 men were on PrEP while 24.4 per 100,000 men were diagnosed with HIV, resulting in a PnR of 2.1; a five-fold difference between genders (Siegler et al., 2018). The disparity in PrEP use between women and men suggests that there are gaps in engaging women into the PrEP care continuum and supports the need for women-focused research on factors that impede engagement, particularly PrEP awareness.

With the availability of oral PrEP, care and engagement for people seeking preventive treatment significantly mirrors that of the HIV care continuum. The PrEP care continuum consists of nine key steps with the first three bucketed in the awareness category: (1) identifying high-risk individuals; (2) increasing HIV risk awareness; (3) enhancing PrEP awareness; (4) facilitating PrEP access; (5) linking to PrEP care; (6) prescribing PrEP; (7) initiating PrEP; (8) adhering to PrEP; and (9) retaining individuals in PrEP care. For the subsequent steps (e.g., prescription, initiation, and adherence) to commence, the client must be aware of PrEP and informed of its

purpose (Nunn et al., 2017). While the literature is scant on the behavioral mechanisms associated with women and the use of PrEP in the US, previous observational studies have found very little awareness of PrEP among women, especially those belonging to vulnerable populations (Doblecki-Lewis et al., 2016; Auerbach, Kinsky, Brown, & Charles, 2015).

To evaluate higher susceptibility to poor health outcomes among marginalized populations, some researchers have gravitated towards Minority Stress Theory and its constructs. Minority Stress Theory suggests that sexual and gender minorities are vulnerable to cumulative and chronic stress that can occur at interpersonal and structural levels (Meyer, 2015; Denton et al., 2014). The theory suggests that homophobic social conditions lend to stress among lesbian, gay, bisexual, and transgender (LGBT) people and further exacerbate poor mental health conditions such as anxiety, mood disorders, and substance use (Herek & Garnets, 2007). With the inclusion of race, findings suggest that racial discrimination, intersecting with sexual and gender minority stigma, resulted in increased substance use, anxiety, and depressive symptoms (English, Rendina, and Parsons, 2018).

Prior studies have found correlations between an accumulation of stressors and HIV-related health outcomes, such as poor retention in HIV treatment and prevention services (Garcia et al., 2016; Levy et al., 2014; Santos et al., 2014). Specific to PrEP, studies have found that the accumulation of minority stressors experienced by men who have sex with men (MSM) across the lifespan resulted in lack of PrEP awareness and stagnation in the PrEP care continuum (Watson, Fish,

Allen, and Eaton, 2017; Meanley et al., 2020). This study investigated correlations among sociodemographic, interpersonal, and structural factors as they relate to PrEP awareness among cisgender women. The analysis incorporates data from the 2018 Community Health Survey to: a) measure the prevalence of PrEP awareness and associated factors among female participants; and b) examine the simple and multivariable correlations between explanatory variables and PrEP awareness. Informed by Minority Stress Theory, intimate partner violence (IPV), an interpersonal action, was evaluated at the structural level to better understand how its occurrence interacts with criminal justice involvement and neighborhood poverty. Findings can be used to understand how factors exacerbate, or minimize, disparities in PrEP awareness among women in New York City and provide insight on how consideration of multi-level exposures can improve PrEP promotional strategies.

4.2: Methods

4.2.1: Overview of the Community Health Survey

The 2018 version of the Community Health Survey (CHS) dataset, developed by the New York City Department of Health and Mental Hygiene (NYC DOHMH), is a cross-sectional telephone-based survey administered to New York City (NYC) residents via landline and cellphone carriers. The survey was administered to adults aged 18 or older across all five NYC boroughs using a computer-assisted telephone interviewing system. The CHS questionnaire was adapted and translated into a variety of languages and it collected information on numerous chronic diseases and behavioral risk factors.

In 2018, the CHS sampled a total of 10,076 individuals with 56% of them identifying as cisgender women (n=5,677). The PrEP awareness question was only asked of women who reported sexual activity in the past 12 months (n=2,818). For this analysis, we included women who answered the PrEP awareness question as well as all other variables of interest (n=2,295). All quantitative analyses were performed using SAS 9.4, (SAS Institute, Cary, NC).

4.2.2: Variable Selection

The variables are grouped based on how they were used in the aforementioned statistical analysis: a) Outcome variable; b) Explanatory variables (behavioral health, intrapersonal, and structural/institutional); and c) control variables.

Outcome Variable

PrEP Awareness. Prior to asking the question, the interviewer shared some background on PrEP with the following statement: "Sometimes people who do not have HIV take a daily HIV medication, known as Truvada, to keep from getting HIV. This is called PrEP, or Pre-Exposure Prophylaxis." To assess PrEP awareness the interviewer asked, "Have you heard of PrEP (Pre-Exposure Prophylaxis)?" and the response options were: (1) Yes and (2) No.

Explanatory Variables

Interpersonal Factors

Sexual Partnerships. This variable derives from the respondent's "number of male and female sex partners in the past 12 months." Responses were categorized into four levels: (1) One; (2) Two; and (3) Three or more.

Condom Use. The following question was asked among all participants who identified as being sexually active: "The last time you had sex; did you use a condom?" Response options were either (1) Yes or (2) No.

Behavioral Health

Perceived Health. Participants were asked, "Would you say that in general your health is excellent, very good, good, fair or poor?" The response options were: (1) Excellent; (2) Very Good; (3) Good; (4) Fair; and (5) Poor.

Binge Drinking. Female participants were asked, "Considering all types of alcoholic beverages, during the past 30 days did you have 4 or more drinks on one occasion?" Response options were (1) Yes and (2) No.

Depression. All eight items from the Patient Health Questionnaire (PHQ-8) were administered to the participants. Items included "Over the last 2 weeks, how often have you been bothered by feeling bad about yourself – or that you are a failure or have let yourself or your family down?" and "Over the last 2 weeks, how often have you been bothered by trouble falling or staying asleep, or sleeping too much?" Response options for each item were: (1) Not at all = 0; (2) Several days = 1; (3) More than half the days = 2; and (4) Nearly every day =3. Responses were summed and the cutoff score for current depression was 10. Participants who scored a 10 or

higher out of the possibility of 32 were indicated as (1) Yes for current depression and those who scored below 10 were indicated as (2) No.

HIV Test (12 Months). Participants were asked, "Have you had an HIV test in the last 12 months?" Response options were (1) Yes and (2) No.

Structural and Institutional Determinants of Health

Neighborhood Poverty Group. Based on the participant's zip code, this variable is the percent of the zip code population living below 100% federal poverty level (FPL) per the American Community Survey, 2013-2017. The response options range from low to high poverty: (1) 0 - <10%; (2) 10 - <20%; (3) 20 - <30%; and (4) 30 - <100%.

Intimate Partner Violence (IPV). Prior to the initiation of the question, the interviewer provided the following statement: "The next questions are about your personal safety. Remember that all your answers are kept private and if a question upsets you, you don't have to answer it." To measure verbal abuse, participants were asked, "Has a current or former intimate partner ever insulted you, or called you names repeatedly, or controlled your behavior?" To measure physical violence, participants were asked, "Has a current or former intimate partner ever hit, slapped, shoved, choked, kicked, shaken, or otherwise physically hurt you?" Response options for both questions were (1) Yes and (2) No. In this study, responses were combined to reflect (1) any exposure to IPV and (2) no exposure to IPV.

Justice Involvement. For self, Participants were asked, "Have you ever in your life, spent any amount of time in a juvenile or adult correctional facility, jail, prison, or

detention center OR have you ever been under probation or parole supervision?" For family, participants were asked, "Has an immediate family member such as a spouse or partner, child, sibling, or parent ever spent any amount of time in a juvenile or adult correctional facility, jail, prison, or detention center OR ever been under probation or parole supervision?" Response options for both questions were (1) Yes and (2) No. In this study, responses were combined to reflect (1) any exposure to incarceration and (2) no exposure to incarceration.

Control Variables

Age. Participants were asked, "what is your age?" and participants provide their numerical age. For analysis, age was transformed into a four-level categorical response: (1) 18-24 yrs.; (2) 25-44 yrs.; (3) 45-64 yrs.; and (4) 65+ yrs.

Marital Status: Participants were asked to provide details about their marital status. Response options were: (1) Married; (2) Divorced; (3) Widowed; (4) Separated; (5) Never married; and (6) Member of unmarried couple living together or partnered. For analysis, 'Married' and 'Member of unmarried couple living together or partnered' were combined into a partnered category and all other responses were combined into a single category.

Race/Ethnicity. Prior to giving a response, participants are asked if they identify as Hispanic or Latino. Because race and ethnicity are not mutually exclusive, participants were asked to choose which race/ethnicity combination they most identify with. Response options were: (1) White Non-Hispanic; (2) Black Non-Hispanic; (3) Hispanic; and (4) Asian/PI/Other Non-Hispanic.

Education. Participants were asked, "What is the highest grade or year of school you completed?" Response options were: (1) Less than high school; (2) High school graduate; (3) Some college; and (4) College graduate.

Insurance. This variable is a combination of responses to prior questions regarding insurance types (e.g., Medicare, Medicaid, private insurance, etc.). Participants who reported some form of insurance or medical coverage were grouped into responding 'Yes' to insurance and all others were 'No.'

Nativity. Participants were asked to identify their country of birth. People who responded with the United States or any of the US territories were categorized as 'Yes' to being US born. Participants born in a foreign country were marked 'No.'

4.2.3: Analysis Plan

Secondary data analysis for this paper were implemented in three major steps: (1) descriptive frequencies, (2) simple logistic regression, and (3) multivariable logistic regression. Because the outcome of interest, PrEP awareness, is a binary variable, regression analysis was conducted in the form of logistic models. For this study, both simple and multivariable regression models were estimated using logistic regression. First, frequencies and percentages were calculated for each individual risk factor associated with PrEP awareness. For situations in which individual cell counts were too low, less than five percent of the sample, categories were combined. Second, simple logistic regression was used to estimate the odds ratio for each risk factor and the report of PrEP awareness. Based on the results, only significant correlations (p-value less than 0.05) were loaded into the multivariable logistic

regression model. Lastly, multivariable logistic regression was utilized to determine which predictor variables are significantly associated with the outcome of interest, PrEP awareness. Performed with the stepwise method, variables with a p-value of 0.10 or lesser could enter and variables with a p-value of 0.05 or lesser could remain in the model until a threshold is reached. Significant variables from the different factor groups, along with confounders, were used to calculate adjusted odds ratios for PrEP awareness.

4.3: Results

4.3.1: Descriptive Statistics

A subsample of sexually active female participants with complete entries (N=2295) was used for this study. As summarized in **Table 1**, most women were aged 30-44 years (37%), married (55%), college educated (48%), and had health insurance (92%). There was significant representation from minority communities with Black, non-Hispanic and Hispanic women accounting for 25% and 32% of the sample, respectively. Most women were in monogamous relationships (88%), did not use a condom during last sex (75%), and had not received an HIV test in the past twelve months (56%). A small proportion of women reported recent binge drinking and depressive symptoms (17% and 9%, respectively). At the structural level, participants were evenly spread out among the four poverty groups with 43% of women living in high or very high impoverished neighborhoods. Twenty-four percent of women experienced intimate partner violence (verbal and/or physical) in their

lifetime and nineteen percent experienced some form of interaction with the incarceration system (self and/or family) in their lifetime.

The majority of women (n=1464; 64%) did not know about PrEP at the time of survey (**Table 1**). Black, non-Hispanic, single, and young adult women had the highest proportions of PrEP awareness, 45%, 42%, and 44%, respectively. As education level increased, the proportion of PrEP awareness also increased with 15% of participants with less than high school and 45% of college graduates knowing about PrEP. Behaviorally, participants with two or more sexual partners in the past year, condom use at last sex, and an HIV test in the past year had higher PrEP awareness than contrasting participants, respectively. Participants who expressed having good, very good, or excellent health had high proportions of PrEP awareness. Significant differences in PrEP awareness were found with binge drinking, intimate partner violence, and incarceration; participants who engaged in binge drinking, ever experienced some form of IPV, and ever engaged with the incarceration system, whether directly or indirectly, had higher rates of PrEP knowledge than participants who did not.

4.3.2: Simple and Multinomial Logistic Regression

Each variable was individually compared to PrEP to identify which variables contributed to the outcome's likelihood. Based on the findings summarized in **Table 2**, all the variables except Depression (p=0.9067) and Neighborhood Poverty Level (p=0.2571) were significantly associated with PrEP awareness. In the multinomial regression model (summarized in **Table 3**), nine variables were found to be

significantly correlated with the likelihood of knowing about PrEP: nativity, education level, recent HIV test, number of sex partners, IPV, age, race/ethnicity, general health, and prior incarceration.

Women aged 65 years or older were 55% less likely than women aged 18-24 years of age to know about PrEP (AOR=0.448, 0.274-0.731). As for race/ethnicity, Black, non-Hispanic women were 47% more likely to know about PrEP compared to White, non-Hispanic women (AOR=1.471, 1.134-1.907) suggesting more PrEP information being disseminated in this population. Aside from Black, non-Hispanic women, there were no significant differences in PrEP awareness among White, non-Hispanic women compared to women of all other races and ethnicities. Participants without some college education or less were 42-74% less likely to be aware of PrEP compared to college graduates with those less than high school education the least likely to know about PrEP (AOR=0.261, 0.172-0.395). As for nativity, being born in the United States was associated with higher PrEP awareness (AOR=2.259, 1.830-2.790). Lastly, there was a marginally significant correlation between PrEP awareness and perceived health; participants who deemed themselves to be in very good health were 33% more likely to be aware of PrEP than participants who deemed themselves to be in excellent health (AOR=1.328, 1.021-1.727).

Regarding sexual health, an increase in the number of sex partners reflected an increase in the likelihood of PrEP awareness among women with two sex partners (AOR=1.657, 1.144-2.399) or three or more sex partners (AOR=2.135, 1.411-3.230) in the past twelve months compared to women with only one sex partner, 66% and

134%, respectively. Women who had an HIV test were also 49% more likely to know about PrEP compared to women who did not receive an HIV test in the past 12 months. As for structural factors, both IPV and incarceration were significantly associated with PrEP awareness. Participants who experienced IPV (AOR=0.691, 0.555-0.859) or the incarceration system (AOR=0.724, 0.570-0.918) were more likely to know about PrEP than those who did not.

4.4: Discussion

Compared to other studies, the proportion of women aware of PrEP (36%) in this cohort is slightly higher than the average 10-20% that has been observed in other cohorts of female participants (Auerbach et al., 2015; Edelstein et al., 2014) but still much lower than PrEP awareness among MSM, approximately 90% (Finlayson et al., 2019). While only making up 25% of the total sample, 45% of Black, non-Hispanic women were aware of PrEP; the highest proportion out of all race/ethnicity categories. This finding contrasts findings from similar studies that have observed lower rates of PrEP awareness among both Black male and female participants compared to White participants (Edelstein et al., 2014; Misra & Udeagu, 2017).

Women of an older age and lower education level were not as informed about PrEP as their counterparts. Educational attainment has been shown to have an inverse relationship with HIV risk (Hargreaves et al., 2008; Paasche-Orlow, Clarke, Hebert, Ray, & Stein, 2005) as it is a strong indicator of current socioeconomic status and access (Brawner, 2014). In this study, education level has an almost dose-response relationship with PrEP awareness; increases in educational attainment were correlated

with higher PrEP awareness. Some studies suggest that age and education are associated with a person's level of health literacy, defined as "the degree to which individuals have the capacity to obtain, process and understand basic information and services needed to make appropriate decisions regarding their health," (Kindig, Panzer, & Nielsan-Bohlman, 2004). A systematic review of health literacy among people 65 years of age or older found that the prevalence of inadequate health literacy was perceived to increase with age (Zamora & Clingerman, 2011). Findings highlight the importance of using language that is understandable for people across varying education levels and age ranges.

Another notable finding was the role in which IPV and incarceration served in explaining the outcome of PrEP awareness. Participants who did not experience IPV, whether verbal or physical, ever in life were 30% less likely to know about PrEP than women who reported ever experiencing a violent interaction with a partner. Additionally, women who have ever experienced a form of IPV whether sexual or psychological, would be in fear of a current partner preventing PrEP use (Willie, Stockman, Overstreet, & Kershaw, 2018). The same phenomenon occurred among women who experienced the incarceration system; the absence of these interactions, whether self or family, was associated with not knowing about PrEP. While there is little evidence of PrEP services being scaled up for those affected by the criminal justice system, prior studies have evaluated efficacious strategies that leverage the system to provide women access to HIV prevention services (Rutledge et al., 2019; Meyer et al., 2017; Underhill et al., 2014). Both scenarios underscore the importance

of providing PrEP-related information in service and outreach settings that address bleak relationship characteristics and home situations.

Findings demonstrate the need for PrEP campaigns and interventions to have multiple targets that expand above and beyond individual-level behavior. Prior studies have called for the incorporation of socioeconomic and environmental factors that create risk environments and increase susceptibility to HIV (Brawner, 2014; Biello et al., 2012). The Minority Stress theory was hypothesized to be an ideal framework for the identification of PrEP awareness predictors because it aims to understand how interpersonal and social stressors impact individual-level outcomes (Meyer, 2015; Denton et al., 2014). The study sample was composed of diverse women who had varying levels of exposures that would be considered negative stressors and risk factors for HIV acquisition. Although the foundation of this theory was built on the sexual minority experience, findings have implications for how stress impacts health outcomes among racial/ethnic minorities and gender minorities Herek & Garnets, 2007; English, Rendina, and Parsons, 2018). Findings also suggest that PrEP materials be tailored to older populations and individuals of varying levels of health literacy. Lastly, the source of information may be the missing key; meeting women where they are and providing PrEP-related information in settings that fit the context of their current situation may improve subsequent knowledge of and linkage to this HIV prevention method.

4.4.1: Strengths and Limitations

This is one of the first studies to identify multilevel factors associated with PrEP awareness among diverse women living in the United States. Exploratory in nature, this study identified intrapersonal, interpersonal, and structural factors that may be associated with the likelihood of exposure to and saturation of PrEP information. There are a few limitations that must be considered. First, data derives from a cross-sectional questionnaire, which negates any determination of causality. However, the correlations can inform longitudinal designs that capture the timing of exposures to the PrEP care continuum stage, specifically PrEP awareness. Secondly, the PrEP question was only asked of women who reported having sex in the past 12 months. While it makes sense to focus on sexually active participants, PrEP awareness should be known amongst all women despite their current status. Since sexual activity is a dynamic state, it is important that PrEP information is made available and tailored to women of various relationship statuses. Lastly, the data were collected in New York City only which reduces the generalizability of findings. There was representation across age and racial groups and findings may be generalizable to metropolitan cities that have a demographic makeup similar to New York City.

4.5: Conclusions

We conclude that PrEP awareness is low among women living in New York City and there are a variety of factors that serve as barriers and facilitators to PrEP information. More focus should be placed on women across the lifespan and social

and structural considerations should be made in the development of PrEP materials and promotional campaigns.

Figure 4.1: Conceptual Framework for Factors associated with PrEP Awareness.

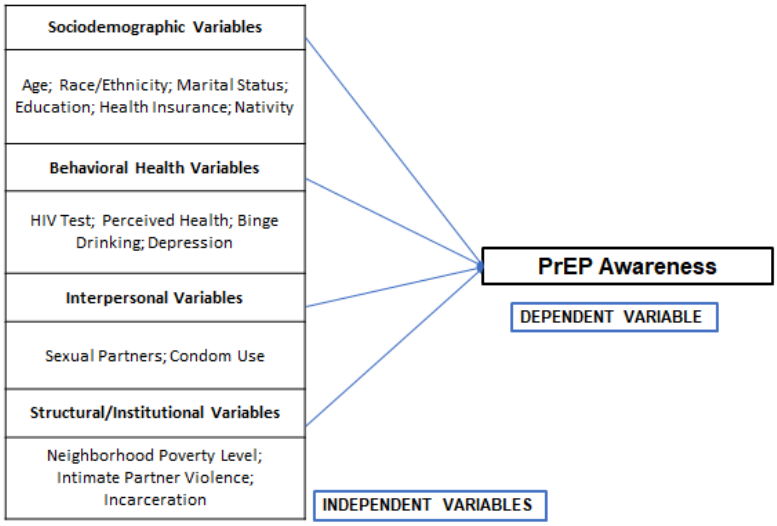

Table 4.1: Frequency of risk factors and bivariate effects on PrEP awareness among women. (N=2295)

Risk Factor	Aware of PrEP (n=831) n (row %)	Not Aware of PrEP (n=1464) n (row %)	Total (n=2295) n (col %)	χ^2 P-value
Age				
18-24	77 (44)	99 (56)	176 (8)	REFERENCE
25-29	103 (42)	143 (58)	246 (11)	0.70
30-44	325 (38)	530 (62)	855 (37)	0.15
45-64	272 (34)	527 (66)	799 (35)	0.01
65+	54 (25)	165 (75)	219 (9)	<.0001
Marital Status				
Married	329 (30)	760 (70)	1089 (47)	REFERENCE
Divorced	84 (37)	141 (63)	225 (10)	0.04
Widowed	12 (23)	41 (77)	53 (2)	0.24
Separated	31 (32)	66 (68)	97 (4)	0.72
Never Married	316 (47)	353 (53)	669 (29)	<.0001
Living together or partnered	59 (36)	103 (64)	162 (7)	0.11
Race/Ethnicity				
Non-Hispanic White	277 (39)	438 (61)	715 (31)	REFERENCE
Non-Hispanic Black	254 (45)	313 (55)	567 (25)	0.03
Hispanic	216 (29)	529 (71)	745 (32)	<.0001
Non-Hispanic Asian/PI	48 (24)	149 (76)	197 (8)	<.001
Non-Hispanic Other	36 (51)	35 (49)	71 (3)	0.05
Education				
Less than high school	36 (15)	199 (85)	235 (10)	REFERENCE
High school graduate	100 (23)	340 (77)	440 (19)	0.02
Some college/technical school	189 (37)	316 (63)	505 (22)	<.0001
College graduate	506 (45)	609 (55)	1115 (48)	<.0001
Health Insurance				
Yes	785 (37)	1322 (63)	2107 (92)	REFERENCE
No	46 (24)	142 (76)	188 (8)	<.001
Nativity				
US born	620 (45)	752 (55)	1372 (60)	REFERENCE
Foreign born	211 (23)	712 (77)	923 (40)	<.0001
Imputed Number of Sex Partners				
One	676 (33)	1351 (67)	2027 (88)	REFERENCE
Two	78 (53)	69 (47)	147 (6)	<.0001
Three or More	77 (64)	44 (36)	121 (5)	<.0001
Condom Use				
Yes	235 (40)	350 (60)	585 (25)	REFERENCE
No	596 (35)	1114 (65)	1710 (75)	0.02
HIV Test (Ever)				
Yes	734 (40)	1100 (60)	1834 (80)	REFERENCE
No	97 (21)	364 (79)	461 (20)	<.0001
HIV Test (Past 12 Months)				
Yes	417 (42)	584 (58)	1001 (44)	REFERENCE
No	414 (32)	880 (68)	1294 (56)	<.0001

General Health				
Excellent	158 (38)	257 (62)	415 (18)	REFERENCE
Very Good	322 (44)	409 (56)	731 (32)	0.05
Good	240 (32)	508 (68)	748 (32)	0.04
Fair	96 (28)	249 (72)	345 (15)	0.003
Poor	15 (27)	41 (73)	56 (2)	0.10
Binge Drinking				
Yes	173 (44)	217 (56)	390 (17)	REFERENCE
No	658 (35)	1247 (65)	1905 (83)	0.0002
Depression				
Yes	79 (37)	137 (63)	216 (9)	REFERENCE
No	752 (36)	1327 (64)	2079 (91)	0.91
Imputed Neighborhood Poverty Group				
0 - <10% (low poverty)	159 (38)	257 (62)	416 (18)	REFERENCE
10 - <20%	329 (37)	567 (63)	896 (39)	0.60
20 - <30%	188 (35)	354 (65)	542 (24)	0.26
30 - <100% (very high poverty)	155 (35)	286 (65)	441 (19)	0.35
IPV (Verbal)				
Yes	225 (47)	254 (53)	479 (21)	REFERENCE
No	606 (33)	1210 (67)	1816 (79)	<.0001
IPV (Physical)				
Yes	152 (48)	164 (52)	316 (14)	REFERENCE
No	679 (34)	1300 (66)	1979 (86)	<.0001
Incarceration (Self)				
Yes	64 (57)	49 (43)	113 (5)	REFERENCE
No	767 (35)	1415 (65)	2182 (95)	<.0001
Incarceration (Family)				
Yes	181 (47)	207 (53)	388 (17)	REFERENCE
No	650 (34)	1257 (66)	1907 (83)	<.0001

Table 4.2: Simple logistic regression of risk factors on PrEP awareness. (N=2295)

Variable	OR Point Estimate	95% CI	P-Value
Age	0.826	0.761-0.897	<.0001
Marital Status	1.639	1.381-1.946	<.0001
Race/Ethnicity	0.836	0.769-0.910	.0004
Education	1.649	1.504-1.809	<.0001
Health Insurance	0.546	0.387-0.770	.0006
Nativity	0.359	0.298-0.433	<.0001
Sex Partners	1.953	1.644-2.320	<.0001
Condom Use	0.797	0.657-0.966	.0215
HIV Test (Past 12 Months)	0.659	0.555-0.782	<.0001
General Health	0.816	0.750-0.888	<.0001
Binge Drinking	0.662	0.531-0.826	.0003
Depression	0.983	0.735-1.315	.9067
Neighborhood Poverty	0.952	0.874-1.037	.2571
IPV	0.580	0.477-0.705	<.0001
Incarceration (Family)	0.541	0.438-0.667	<.0001

Table 4.3: Multinomial logistic regression of risk factors on PrEP awareness. (N=2295)

Variable	Adjusted Odds Ratio (aOR) (95% CI)
Age Group	
18-24	1.0 (ref)
25-29	0.952 (0.620-1.463)
30-44	0.839 (0.579-1.215)
45-64	0.708 (0.484-1.035)
65+	**0.448 (0.274-0.731)**
Race/Ethnicity	
White, non-Hispanic	1.0 (ref)
Black, non-Hispanic	**1.471 (1.134-1.907)**
Hispanic	0.951 (0.727-1.243)
Asian/Other, non-Hispanic	1.027 (0.732-1.441)
Education	
College Graduate	1.0 (ref)
Less than High School	**0.261 (0.172-0.395)**
High School Graduate	**0.344 (0.260-0.455)**
Some College	**0.585 (0.459-0.745)**
Nativity	
Foreign Born	1.0 (ref)
US Born	**2.259 (1.830-2.790)**
Sex Partners	
One	1.0 (ref)
Two	**1.657 (1.144-2.399)**
Three or more	**2.135 (1.411-3.230)**
HIV Test	
No	1.0 (ref)
Yes	**1.492 (1.211-1.840)**
General Health	
Excellent	1.0 (ref)
Very Good	**1.328 (1.021-1.727)**
Good	0.902 (0.686-1.187)
Fair	0.848 (0.599-1.200)
Poor	0.889 (0.440-1.796)
Intimate Partner Violence	
Yes	1.0 (ref)
No	**0.691 (0.555-0.859)**
Incarceration	
Yes	1.0 (ref)
No	**0.724 (0.570-0.918)**

Chapter 5: STUDY 3 - A LATENT CLASS ANALYSIS APPROACH TO IDENTIFY SUBGROUPS OF WOMEN WITH VARYING PREP AWARENESS, COMMUNITY HEALTH SURVEY 2018

5.0: Abstract

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Objective: To identify latent classes of women of varying exposure to behavioral health and structural factors and the odds of pre-exposure prophylaxis (PrEP) awareness based on class assignment.

Methods: Cisgender women participating in the 2018 Community Health Survey (CHS) with complete entries for all variables of interest were included in this study. Latent class analysis (LCA) of nine multi-level variables were used to identify distinct subgroups of women: number of sexual partners in the past 12 months; condom use at last sex; an HIV test in the past 12 months; current depression; binge drinking; general health; neighborhood poverty; intimate partner violence; and criminal justice involvement. Adjusted odds ratios identified significant differences between classes based on PrEP awareness and key sociodemographic variables such as age, race/ethnicity, and nativity.

Results: The sample consisted of 2,295 women and the best fit LCA model consisted of three distinct profiles of women: high resource and low risk group (Class 1), low resource and moderate risk group (Class 2), and moderate resource and high-risk group (Class 3). Class 1 was more likely to be married or partnered with higher education. Although Class 2 did not engage in sexual risk-taking, they were most likely to live in impoverished neighborhoods and be in poor or average health. Lastly

Class 3 reported high sexual risk-taking behavior but was most likely to know about PrEP and engage in HIV testing.

Conclusions: Findings reinforce the notion that women encounter barriers and facilitators to preventive information on varying levels and timepoints. PrEP information should be tailored to women of diverse experiences, especially when exposures are occurring simultaneously.

5.1: Introduction

As of 2018, women accounted for 19% of all new HIV infections in the United States (CDC, 2018). Despite advancements in reducing HIV rates for women overall, stark racial and ethnic disparities remain with Black women representing 57% of all new HIV infections among women (CDC, 2018). There are a host of individual, interpersonal, and structural factors that can exacerbate a woman's risk to HIV acquisition. For example, depression is associated with increased risky sexual behavior (Defechereux et al., 2016; Reisner et al., 2009; Stall et al., 2003) while binge drinking has been linked to condomless intercourse because of reduced inhibitions (CDC, 2019a). At the structural level, poverty is a key influence in the spread of HIV within vulnerable populations (Buot et al., 2014) and partner selection in HIV-burdened neighborhoods and communities directly impacts the likelihood of onward transmission (Bowleg et al., 2014).

Pre-exposure prophylaxis, better known as PrEP, is the use of orally administered antiretrovirals to prevent HIV acquisition prior to risk exposure (Buchbinder & Liu, 2011). Since its FDA approval in 2012, there has been slow uptake of PrEP among vulnerable populations, specifically women in the United States. While there are interventions in development to increase PrEP use and adherence among MSM, the knowledge base around PrEP and women is severely

lacking. While the literature is scant on the behavioral mechanisms associated with women and the use of PrEP in the US, recent studies have found that PrEP awareness among women, especially those belonging to vulnerable populations, is quite low, roughly 10-20% (Doblecki-Lewis et al., 2016; Auerbach, Kinsky, Brown, & Charles, 2015; Patel et al., 2019).

The goal of the Syndemic Theory is to provide a framework for the analysis of disease interactions in a social context (Singer, 2009). A syndemic is defined as "the aggregation of two or more diseases or other health conditions in a population in which there is some level of deleterious biological or behavior interface that exacerbates the negative health effects of any or all of the diseases involved, (Singer, 2009)." In recent years, the use of the Syndemic Theory to inform HIV interventions has been on the rise, suggesting the implementation of multi-level and multi-component interventions addressing co-occurring conditions with the goal of reducing HIV-related risk behavior (Tsai & Burns, 2015).

Prior studies have demonstrated the association between co-occurring psychosocial conditions and HIV risk in vulnerable populations. The substance use, violence, and HIV/AIDS (SAVA) syndemic is commonly used to understand how the entanglement of these co-occurring epidemics exacerbate a woman's risk of acquiring HIV (Gilbert et al., 2015). Although physical violence may not be a direct pathway to HIV transmission, the intimidation and coercion from an intimate partner combined with being under the influence of a substance has been shown to increase risk by 28-52% (Gilbert et al., 2015). Findings from a handful of studies estimating syndemic effects on PrEP uptake demonstrate the need for expanding current PrEP guidelines to

capture more eligible candidates (Beymer et al., 2017) and providing more PrEP use support for individuals with diminished perceived risk (Chandler et al., 2019). While there is emerging literature on the association between attitudes about PrEP and syndemics (Willie et al., 2020), there is little research on how syndemics play a role in the prevalence of PrEP awareness among cisgender women in a major US city.

For this study, the Syndemic Theory informs statistical analysis to identify subgroups of women in New York City and provide a perspective on how multilevel factors interact, either be protective or inhibitory, with PrEP awareness. Furthermore, the association between sociodemographic variables and class membership uncover disparities based on age, race, and other characteristics.

5.2: Methods

5.2.1: Overview of the Community Health Survey

The 2018 version of the Community Health Survey (CHS) dataset, developed by the New York City Department of Health and Mental Hygiene (NYC DOHMH), is a cross-sectional telephone-based survey administered to New York City (NYC) residents via landline and cellphone carriers. The survey was administered to adults aged 18 or older across all five NYC boroughs using a computer-assisted telephone interviewing system. The CHS questionnaire was adapted and translated into a variety of languages and it collected information on numerous chronic diseases and behavioral risk factors.

In 2018, the CHS sampled a total of 10,076 individuals with 56% of them identifying as cisgender women (n=5,677). The PrEP awareness question was only

asked of women who reported sexual activity in the past 12 months (n=2,818). For this analysis, we included women who answered the PrEP awareness question as well as all other variables of interest (n=2,295). All quantitative analyses were performed using SAS 9.4, (SAS Institute, Cary, NC).

5.2.2: Analysis Plan

Latent class analysis (LCA) is a person-centered approach that groups individuals into distinct classes. Paired with cross-sectional data, LCA identifies unmeasured heterogeneity in a sample of participants, creates mutually exclusive groups separated by the levels of a latent variable, and is quite useful for disease subtypes. Findings from this type of analysis assisted with the identification priority subgroups of women with varying rates of risk factors for targeted intervention development. In this study, LCA was carried out to identify classes of women who vary in responses to survey questions related to behavioral (e.g., HIV test, binge drinking), interpersonal (e.g., number of sexual partners), and structural factors (e.g., incarceration, neighborhood poverty). The goal was to empirically define the underlying latent variable(s) as it relates to the outcome of PrEP awareness and key sociodemographic variables.

Explanatory Variables

Interpersonal Factors

Sexual Partnerships. This variable derives from the respondent's "number of male and female sex partners in the past 12 months." Responses were categorized into two levels: (1) One or (2) Two or more.

Condom Use. The following question was asked among all participants who identified as being sexually active: "The last time you had sex; did you use a condom?" Response options were either (1) Yes or (2) No.

Behavioral Health

Perceived Health. Participants were asked, "Would you say that in general your health is excellent, very good, good, fair or poor?" For statistical purposes, responses were grouped into two categories: (1) excellent/very good; and (2) good/fair/poor.

Binge Drinking. Female participants were asked, "Considering all types of alcoholic beverages, during the past 30 days did you have 4 or more drinks on one occasion?" Response options were (1) Yes and (2) No.

Depression. All eight items from the Patient Health Questionnaire (PHQ-8) were administered to the participants. Items included "Over the last 2 weeks, how often have you been bothered by feeling bad about yourself – or that you are a failure or have let yourself or your family down?" and "Over the last 2 weeks, how often have you been bothered by trouble falling or staying asleep, or sleeping too much?" Response options for each item were: (1) Not at all = 0; (2) Several days = 1; (3) More than half the days = 2; and (4) Nearly every day =3. Responses were summed and the cutoff score for current depression was 10. Participants who scored a 10 or higher out of the possibility of 32 were indicated as (1) Yes for current depression and those who scored below 10 were indicated as (2) No.

HIV Test (Past 12 Months). Participants were asked, "Have you had an HIV test in the last 12 months?" Response options were (1) Yes and (2) No.

Structural and Institutional Determinants of Health

Neighborhood Poverty Group. Based on the participant's zip code, this variable is the percent of the zip code population living below 100% federal poverty level (FPL) per the American Community Survey, 2013-2017. The response options range from low (0-10%) to high poverty (30-100%). For analytical purposes, levels were grouped into two categories: (1) low-medium poverty (0-20%); and (2) high-very high poverty (20-100%).

Intimate Partner Violence (IPV). Prior to the initiation of the question, the interviewer provided the following statement: "The next questions are about your personal safety. Remember that all your answers are kept private and if a question upsets you, you don't have to answer it." To measure verbal abuse, participants were asked, "Has a current or former intimate partner ever insulted you, or called you names repeatedly, or controlled your behavior?" To measure physical violence, participants were asked, "Has a current or former intimate partner ever hit, slapped, shoved, choked, kicked, shaken, or otherwise physically hurt you?" Response options for both questions were (1) Yes and (2) No. In this study, responses were combined to reflect (1) any exposure to IPV and (2) no exposure to IPV.

Justice Involvement. For self, Participants were asked, "Have you ever in your life, spent any amount of time in a juvenile or adult correctional facility, jail, prison, or detention center OR have you ever been under probation or parole supervision?" For family, participants were asked, "Has an immediate family member such as a spouse or partner, child, sibling, or parent ever spent any amount of time in a juvenile or

adult correctional facility, jail, prison, or detention center OR ever been under probation or parole supervision?" Response options for both questions were (1) Yes and (2) No. In this study, responses were combined to reflect (1) any exposure to incarceration and (2) no exposure to incarceration.

Control Variables

Age. Participants were asked, "what is your age?" and participants provide their numerical age. For analysis, age was recategorized into two groups: (1) 18-44 years old and (2) 45+ years old.

Marital Status: Participants were asked to provide details about their marital status. Response options were: (1) Married; (2) Divorced; (3) Widowed; (4) Separated; (5) Never married; and (6) Member of unmarried couple living together or partnered. For analysis, 'Married' and 'Member of unmarried couple living together or partnered' were combined into a partnered category and all other responses were combined into a single/unpartnered category.

Race/Ethnicity. Prior to giving a response, participants are asked if they identify as Hispanic or Latino. Because race and ethnicity are not mutually exclusive, participants were asked to choose which race/ethnicity combination they most identify with. Response options were: White Non-Hispanic; Black Non-Hispanic; Hispanic; Asian/PI Non-Hispanic; and Other Non-Hispanic. For analytical purposes, the variable was recoded into two levels: (1) White Non-Hispanic and (2) All other (minority status).

Education. Participants were asked, "What is the highest grade or year of school you completed?" Response options were: Less than high school; High school graduate; Some college; and College graduate. This variable was transformed to have two levels: (1) Not a College Graduate and (2) College Graduate.

Insurance. This variable is a combination of responses to prior questions regarding insurance types (e.g., Medicare, Medicaid, private insurance, etc.). Participants who reported some form of insurance or medical coverage were grouped into responding (1) Yes to insurance and all others were (2) No.

Nativity. Participants were asked to identify their country of birth. People who responded with the United States or any of the US territories were categorized as (1) Yes to being US born. Participants born in a foreign country were marked (2) No.

Behavioral, interpersonal, and structural factors were recoded into dichotomous variables with an established at-risk cutoff point. Nine multilevel variables were entered into the LCA model: number of sexual partners in the past 12 months; condom use at last sex; an HIV test in the past 12 months; current depression; binge drinking; general health; neighborhood poverty; intimate partner violence; and criminal justice involvement.

Once the set of models with varying class sizes was produced, the model with the most appropriate fit was chosen. Goodness of fit was determined by the Akaike's Information Criterion (AIC), the Bayesian Information Criterion (BIC), the consistent AIC (CAIC), and the sample-size-adjusted BIC (aBIC) (Dziak et al., 2020). It is suggested that the model with the lowest values across criteria is the most

parsimonious model with an accurate number of classes (Lanza & Rhoades, 2013). Once the final model was chosen, classes were labeled based on logical reasoning and grouping of exposures. Item-response probabilities were plotted to demonstrate the likelihood of reporting an adverse behavior or exposure given the participant's class membership. Lastly, the probability of PrEP awareness and other sociodemographic factors across classes were calculated to see if the groups differed. All quantitative analyses were performed using SAS 9.4, (SAS Institute, Cary, NC).

5.3: Results

5.3.1: Sample Characteristics

A subsection of sexually active female participants with complete entries (N=2295) was used for this study. Univariate findings are summarized in **Table 1**. Most participants were not aware of PrEP at the time of survey (64%). Demographically, most women were aged 30-44 years (37%), married or partnered (55%), college educated (48%), of racial/ethnic minority status, US born, and had health insurance (92%). Forty-four percent of the women had an HIV test in the past 12 months and 75% reported not using a condom at last sex. It was an even split for perceived general health; 50% of participants felt that they were in 'very good' or 'excellent health and the other half perceived themselves to be in 'good,' 'fair,' or 'poor' health. A subset of participants reported recent binge drinking and current depression, 17% and 9%, respectively. As for structural factors, 57% of women lived in neighborhoods with low to medium poverty levels, 24% of women experienced

intimate partner violence, whether verbal or physical, ever in life, and 19% of women experienced some form of incarceration, whether self or close loved one.

5.3.2: Classes of Women

Based on fit statistics, the three-class model had slightly higher AIC, BIC, CAIC, and adjusted AIC values than the four-class model, but it had the highest entropy out of all three models (see **Table 2**). As summarized in **Table 3**, the adjusted item-response probabilities resulted in distinct differences between groups: high resource and low risk group (39%), low resource and moderate risk group (33%), and moderate resource and high-risk group (28%). **Figure 1** visually depicts the variance in responses between the three classes.

5.3.3: PrEP Awareness, Sociodemographic Factors, and Class Membership

Compared to those in the high resource and low risk group (Class 1), participants in the moderate resource and high-risk group (Class 3) were more likely to know about PrEP (aOR=29, 0.17-0.48) (**Table 4** and **Figure 2**). PrEP awareness among participants in the low resource and moderate risk group (Class 3) was not significantly different from Class 1. By age, women in Class 2 (aOR=0.51, 0.29-0.90) and Class 3 (aOR=0.10, 0.06-0.17) were significantly younger than women in Class 1. Women in Class 2 and Class 3 were also more likely to be not in a current relationship, of racial/ethnic minority status, and less educated than women in Class 1. In addition to racial/ethnic identity, women in Class 2 were over 2 times more likely to be foreign born than women in Class 1 (aOR=2.62, 1.39-4.95) with no differences in Class 3.

5.4: Discussion

Overall, the proportion of women aware of PrEP at time of survey was 36%, higher than the 10-20% that has been found in similar studies (Auerbach et al., 2015; Edelstein et al., 2014). The combination of sexual health, behavioral outcomes, and structural determinants resulted in three distinct groups of women: high resource and low risk; low resource and moderate risk; and moderate resource and high risk. Participants in the high resource and low risk group were more likely to be married, highly educated, older White, non-Hispanic women. Compared to Classes 2 and 3, there was a lower probability of a recent HIV test and condom use in this group which aligns with findings from studies looking at rates of HIV testing among pregnant women in the United States (Koumans et al., 2018). However, prior literature has shown that women in perceived monogamous relationships still run the risk of HIV acquisition if unaware of their partner's concurrent sexual activities and/or HIV status (Tims-Cook, 2019).

Like Class 1, women in the low resource and moderate risk group were highly likely to report having only one partner in the past 12 months. Although they may have not been partnered at the time of survey, these women may have short-term monogamous partnerships. Class 2 women engage in preventive health behavior (condom use and HIV testing) but were subjected to poor health and community outcomes, unlike Class 1 women. Living in medium-high poverty neighborhoods has profound effects on partner selection and HIV risk (Gindi et al., 2011). Higher prevalence of HIV tends to reside in low socioeconomic areas and said residents are more likely to choose a sexual partner from the surrounding area (Haley et al., 2018;

Hixson et al., 2011; Cooper et al., 2016). Class 2 participants perceived themselves to be in less-than-optimal health; this may suggest that these women experience poor access to services. Secondly, the Class 2 participants had similar rates of PrEP awareness as Class 1 participants which is an issue; women in Class 2 are more likely to be single and of lower socioeconomic status so PrEP may be more beneficial to this group.

Class 3, the moderate resource and high-risk group, has a unique profile that stands apart from Class 1 and 2. This group had the highest probability of multiple sex partners, binge drinking, depression, intimate partner violence, and justice involvement. Despite these high-risk characteristics, Class 3 participants also had the highest probability of HIV prevention behavior (condom use and a recent HIV test) out of all three classes and were significantly more likely to know about PrEP than Class 1.

In summary, study findings, guided by the Syndemic Theory, exemplify the symbiotic nature of individual, interpersonal, and structural factors, and their bearing on PrEP awareness. The accumulation of deleterious attributes among Class 3 participants was associated with high PrEP awareness and supports the effectiveness of PrEP promotion in New York City (Myers et al., 2018). Despite being a very important step in the PrEP care continuum, awareness does not equate to linkage and retention so more needs to be done to meet these women where they are and propose PrEP strategies that fit the context of their situation. Prior literature shows that men and women who face syndemic conditions have more approving attitudes towards PrEP than those without (Willie et al., 2020; Martinez et al., 2017; Koblin et al.,

2015) so it is important to leverage opportunities for intervention and information dissemination.

5.4.1: Strengths and Limitations

This is one of the first studies to identify subgroups of women that have varying levels of risk behavior and access to resources that can inform targeted PrEP information delivery. Exploratory in nature, this study evaluated the co-occurrence of intrapersonal, interpersonal, and structural factors and their association with PrEP awareness. The nature of the study does come with its own set of limitations. First, data derives from a cross-sectional questionnaire, which negates any determination of causality. Secondly, the PrEP question was only asked of women who reported having sex in the past 12 months, which significantly reduced the study sample from its original size. Lastly, the data were collected in New York City only which reduces the generalizability of findings. There was representation across age and racial groups and findings may be generalizable to other US metropolitan cities. Despite these limitations, findings from this study have implications for PrEP promotional strategies and the prioritization of heterogeneous female subgroups that have their own unique barriers and facilitators.

5.5: Conclusions

This study sought to identify subgroups of women with varying life circumstances that could inform tailored PrEP information dissemination. Three distinct classes of women emerged from the syndemic nature of individual, interpersonal, and structural conditions. Findings suggest that women who are

perceived as low or moderate risk for HIV acquisition may still benefit from PrEP information. High risk women are experiencing co-occurring conditions, such as intimate partner violence and justice involvement, that may be leveraged to improve outreach efforts and linkage to PrEP services.

Figure 5.1: Conceptual Framework for Latent Class Analysis of Risk Factors associated with PrEP Awareness.

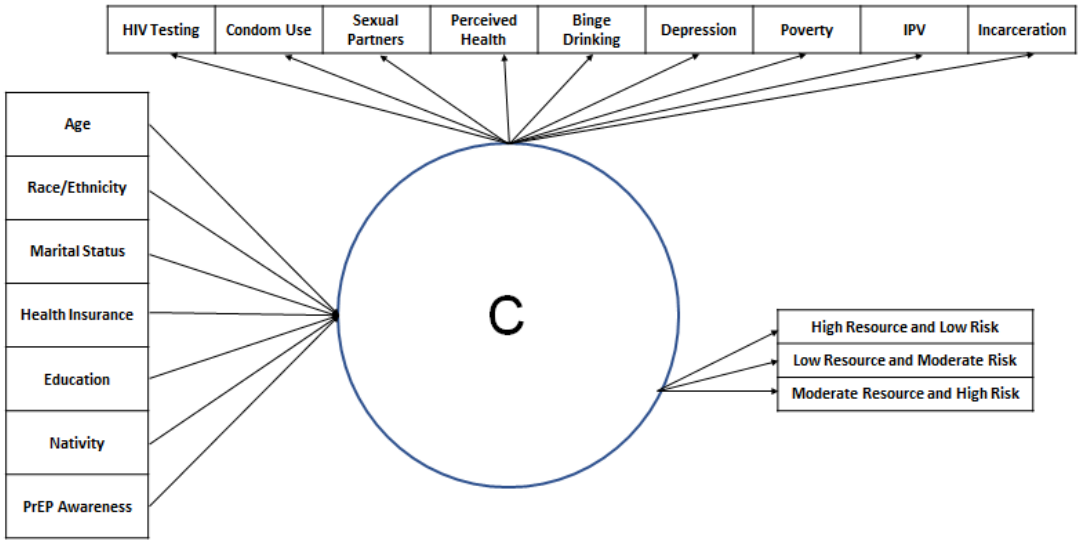


Table 5.1: Univariate analysis of LCA variables and covariates (N=2295)

Variable	N (%)
PrEP Awareness	
Yes	831 (36)
No	1464 (64)
Age	
18-44 years old	1277 (56)
45+ years old	1018 (44)
Marital Status	
Married/Living with Partner	1251 (55)
Single/No Partner	1044 (45)
Race/Ethnicity	
White, non-Hispanic	715 (31)
Other	1580 (69)
Education Level	
Less than College	1180 (51)
College Graduate	1115 (49)
Health Insurance	
Yes	2107 (92)
No	188 (8)
Nativity	
US Born	1372 (60)
Foreign Born	923 (40)
Sex Partners	
One	2027 (88)
Two or more	268 (12)
Condom Use	
Yes	585 (25)
No	1710 (75)
HIV Test (Past 12 Months)	
Yes	1001 (44)
No	1294 (56)
General Health	
Very Good/Excellent	1146 (50)
Poor/Fair/Good	1149 (50)
Binge Drinking	
Yes	390 (17)
No	1905 (83)

Depression Yes No	 216 (9) 2079 (91)
Neighborhood Poverty Level Low-Medium (0-20%) Medium-High (20-100%)	 1312 (57) 983 (43)
Intimate Partner Violence Yes No	 547 (24) 1748 (76)
Justice Involvement Yes No	 443 (19) 1852 (81)

Table 5.2: Fit statistics across three LCA models using 9 indicators (N=2295)

Goodness of fit Indicator	2-Class Model	3-Class Model	4-Class Model
Log-likelihood	-10751.79	-10693.02	-10630.95
G-squared	829.28	712.44	588.3
AIC	867.98	770.44	666.3
BIC	977.01	936.86	890.1
CAIC	996.01	965.86	929.1
Adjusted BIC	916.65	844.72	766.19
Entropy	0.46	0.58	0.51
Degrees of Freedom	492	482	472

Table 5.3: Probability of class assignment and item-response probabilities for 3-class model (unadjusted and adjusted for covariates; N=2295)

Variable (Response = 1)	Class 1 63%	Class 2 14%	Class 3 23%	Class 1[a] 39%	Class 2[a] 33%	Class 3[a] 28%
Number of Sex Partners (One)	**100%**	49%	**80%**	**99%**	**100%**	**60%**
Condom Use (Yes)	19%	46%	31%	12%	25%	44%
HIV Testing (Yes)	28%	**69%**	**69%**	12%	**54%**	**74%**
General Health (Very Good/Excellent)	**57%**	**73%**	16%	**69%**	27%	**50%**
Binge Drinking (Yes)	11%	44%	18%	14%	7%	33%
Depression (Yes)	2%	1%	33%	4%	9%	17%
Neighborhood Poverty (Low-Medium)	**67%**	48%	36%	**80%**	41%	45%
Intimate Partner Violence (Yes)	15%	31%	43%	22%	15%	38%
Justice Involvement (Yes)	10%	26%	39%	12%	14%	35%

Figure 5.2: Plot of item-response probabilities for behavioral and structural factors related to PrEP awareness, adjusted for covariates.

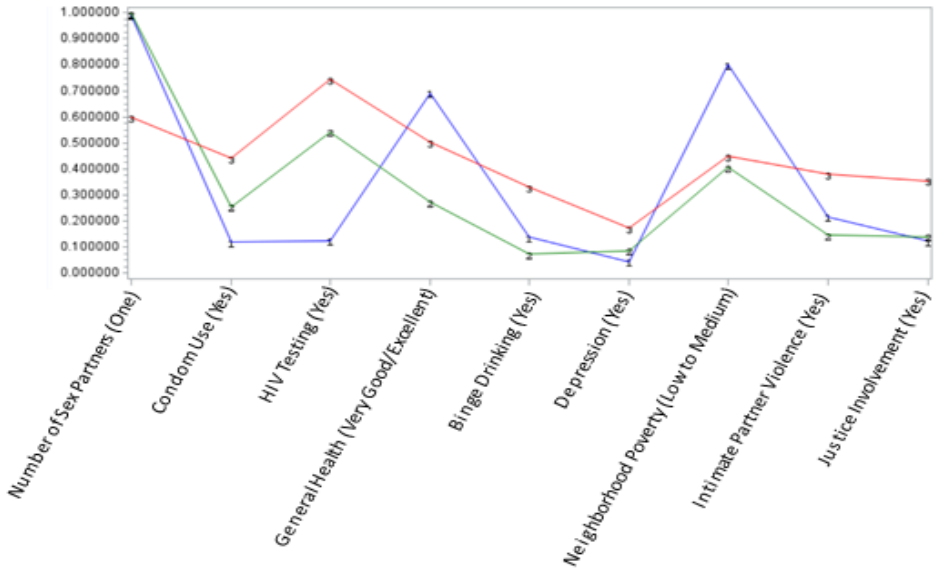
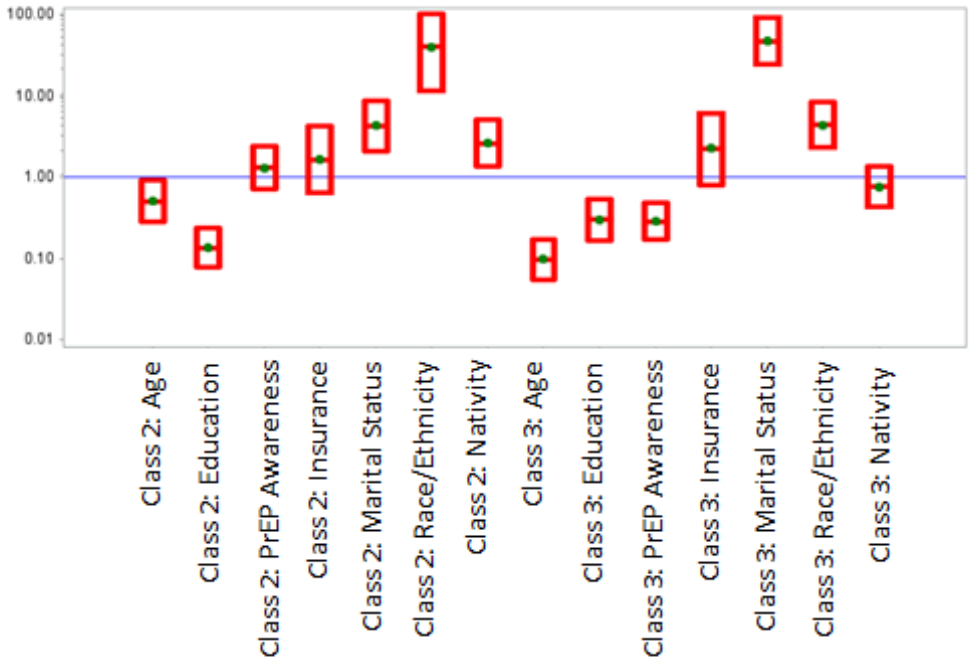


Table 5.4: Adjusted associations between sociodemographic factors and class membership (N=2295; Reference = Class 1)

Variable	Class 2 aOR (95% CI)	Class 3 aOR (95% CI)
PrEP Awareness		
Yes	Ref.	Ref.
No	1.3135 (0.7260-2.3764)	**0.2879 (0.1730-0.4791)**
Age		
18-44 years old	Ref.	Ref.
45+ years old	**0.5116 (0.2916-0.8974)**	**0.0975 (0.0559-0.1701)**
Marital Status		
Married/Living with Partner	Ref.	Ref.
Single/No Partner	**4.2965 (2.1125-8.7383)**	**47.5795 (24.446-92.604)**
Race/Ethnicity		
White, non-Hispanic	Ref.	Ref.
Other	**39.9549 (11.513-138.65)**	**4.4024 (2.3341-8.3036)**
Education Level		
Less than College	Ref.	Ref.
College Graduate	**0.1361 (0.0794-0.2332)**	**0.3012 (0.1722-0.5270)**
Health Insurance		
Yes	Ref.	Ref.
No	1.6340 (0.6335-4.2142)	2.2581 (0.8211-6.2099)
Nativity		
US Born	Ref.	Ref.
Foreign Born	**2.6199 (1.3861-4.9519)**	0.7634 (0.4327-1.3468)

Figure 5.3: Adjusted odds ratio plot of associations between sociodemographic variables and class membership. (N=2295; Reference = Class 1)



Chapter 6: SUMMARY

6.1: Study Overview

Biomedical innovations, such as antiretroviral therapy, in the fight against HIV has greatly changed the face of the epidemic, both global and domestic, since the virus's inception in the 1980s (Fauci, 2003). While the rate of new HIV infections among all women in the United States has decreased 23% from 2010 to 2017, they still account for 19% of new infections (CDC, 2018). Significant racial/ethnic disparities persist with 65% of new female infections occurring among Black/African American women (CDC, 2018). By age, women 25 to 34 years old accounted for the highest number of new cases across all age groups (CDC, 2018). With ongoing acquisition and stark disparities, it is evident that gaps in HIV prevention among women in the US exist and must be addressed.

Women encounter multilevel barriers to HIV prevention, from individual to policy, that dramatically increase HIV risk. Intimate partner violence, poor condom negotiation, and reproductive coercion are just a few of the interpersonal dynamics that can have deleterious effects on a woman's ability to protect herself from acquiring HIV. Gender inequality in health systems and compensation further drive gender-based disparities and force groups of women to rely on male partners for financial support. Lack of power in a relationship can feed into sexual dominance and thus lend to HIV worry among women.

Oral pre-exposure prophylaxis, commonly known as PrEP, is a once-daily treatment that prevents HIV acquisition prior to exposure if taken as prescribed

(Buchbinder & Liu, 2011). Several clinical trials found the drug to be effective in reducing HIV incidence despite differential outcomes based on gender. With its approval by the Food and Drug Administration in 2012, researchers expected the drug to be a gamechanger; eventually bringing us closer to ending the HIV epidemic (Food and Drug Administration, 2012; Willie et al., 2017). For women, PrEP was thought to be an option that could be implemented discreetly and less likely to be subjected to partner sabotage, unlike condom use (Willie et al., 2018).

Despite its optimistic beginnings, PrEP use has been slow to uptake among women who have been identified to be ideal PrEP candidates based on CDC guidelines (CDC, 2015; Smith, Van Handel, & Grey, 2018). Recent findings show high PrEP to need ratios among women in the US (Wu et al., 2017). A handful of observational studies have identified factors that illustrate women's hesitancy to use PrEP such as medical mistrust, unknown side effects, social stigma, and pill burden. One of the most glaring issues is that women simply do not know about PrEP; compared to other HIV vulnerable populations, such as MSM, roughly ten to twenty percent of women know about PrEP (Doblecki-Lewis et al., 2016; Auerbach, Kinsky, Brown, & Charles, 2015; Patel et al., 2019). As illustrated by the PrEP care continuum, awareness is the first and most critical step to knowledge, linkage, and sustained use of PrEP (Nunn et al., 2017). Therefore, it is important to know where disparities in PrEP awareness lie and identify subgroups of women who can benefit from targeted information dissemination.

The purpose of this dissertation was to leverage existing literature and elucidate themes around barriers and facilitators to PrEP that would then inform the secondary data analysis. The research question for Paper 1 was "what are the perceptions of PrEP among Black female participants in the literature?" Paper 1 was a systematic review of the literature on awareness, knowledge, beliefs, and perceptions of PrEP among cisgender Black women in the US. The research question for Paper 2 was "which predictors are significantly associated with the report of PrEP awareness?" and Paper 3 sought to answer, "what are the distinct latent profiles of women pertaining to PrEP awareness?" Utilizing data from the 2018 Community Health Survey, the two additional studies a) identified key factors related to PrEP awareness among female participants with multinomial logistic regression and b) explored how the presence of multiple deleterious factors can further exacerbate disparities in PrEP awareness with latent class analysis.

6.2: Key Findings

The combined three studies identified many key factors and issues related to PrEP awareness among women in the US. Low PrEP awareness was found in both the systematic literature review and the secondary data analysis and related themes spanned multiple levels of influence. All the articles in Paper 1 had low rates of PrEP awareness and 36% of the sample (N=2295) in Papers 2 and 3 were aware of PrEP. Demographics, such as race, age, and education level, were commonly highlighted in all three papers as being significantly associated with the presence or absence of PrEP awareness. In Paper 2, we saw higher PrEP awareness among Black, non-Hispanic

participants and minority status was associated with being in moderate- or high-risk groups in Paper 3. Lastly, structural factors that have severe implications for controlling one's own HIV status (neighborhood poverty, intimate partner violence (IPV), and criminal justice involvement) surfaced to the top as key themes and correlates to PrEP awareness in all three studies. Specifically, IPV was a recurring theme in Paper 1 and was significantly associated with PrEP awareness in Paper 2. The following sections provide more detail about each paper's findings.

The systematic review of PrEP knowledge among Black/African American women identified 12 articles with findings disaggregated by both race and gender. Primary findings included gaps in PrEP knowledge; acceptability and willingness to use once informed of PrEP; perceived disadvantages because of exclusion in clinical trials and early dissemination; and social, structural, and institutional barriers to engagement in the PrEP care continuum. Findings, such as intimate partner violence, informed variable selection for the subsequent studies.

A subsample of women from the 2018 Community Health Survey (CHS) who completed all survey items of interest were included for analysis in Papers 2 and 3 of this dissertation (N=2295). Only 36% of women were aware of PrEP at time of survey. Majority of women were aged 30-44 years (37%), married (55%), college educated (48%), and had health insurance (92%). There was significant representation from minority communities with Black, non-Hispanic and Hispanic women accounting for 25% and 32% of the sample, respectively. Most women were in monogamous relationships (88%), did not use a condom during last sex (75%), and

had not received an HIV test in the past twelve months (56%). A small proportion of women reported recent binge drinking and depressive symptoms (17% and 9%, respectively). At the structural level, participants were evenly spread out among the four poverty groups with 43% of women living in high or very high impoverished neighborhoods. Twenty-four percent of women experienced intimate partner violence (verbal and/or physical) in their lifetime and 19% experienced some form of interaction with the incarceration system (self and/or family) in their lifetime.

Nine variables were associated with the outcome of PrEP awareness: nativity, education level, recent HIV test, number of sex partners, IPV, age, race/ethnicity, general health, and prior incarceration. Women aged 65 years or older were 55% less likely than women aged 18-24 years of age to know about PrEP and Black, non-Hispanic women were 47% more likely to know about PrEP compared to White, non-Hispanic women. Participants with some college education or less were 42-74% less likely to be aware of PrEP compared to college graduates with those less than high school education the least likely to know about PrEP. As for nativity, being born in the United States was associated with higher PrEP awareness (AOR=2.259, 1.830-2.790). Lastly, there was a marginally significant correlation between PrEP awareness and perceived health; participants who deemed themselves to be in very good health were 33% more likely to be aware of PrEP than participants who deemed themselves to be in excellent health.

Regarding sexual health, an increase in the number of sex partners reflected an increase in the likelihood of PrEP awareness among women with two sex partners

or three or more sex partners in the past twelve months compared to women with only one sex partner, 66% and 134%, respectively. Women who had an HIV test in the past 12 months were also 49% more likely to know about PrEP compared to women who did not. As for structural factors, both IPV and incarceration were significantly associated with PrEP awareness. Participants who had experienced IPV (AOR=0.691, 0.555-0.859) and the incarceration system (AOR=0.724, 0.570-0.918) were more likely to know about PrEP.

Paper 3 took it a step further by utilizing latent class analysis to identify classes of women with varying rates of exposure to behavioral health and structural factors. Three subgroups of women were identified based on their responses to the following items: number of sex partners, condom use, HIV testing, general health, binge drinking, depression, neighborhood poverty, intimate partner violence, and justice involvement. The adjusted item-response probabilities resulted in distinct differences between groups: high resource and low risk group (39%), low resource and moderate risk group (33%), and moderate resource and high-risk group (28%). The high resource and low risk group (Class 1) was more likely to be composed of married White, non-Hispanic women of older age and higher education. Class 1 participants are the least likely to use condoms or have a recent HIV test but are most likely to be in very good health with no depressive symptoms. While the moderate resource and high-risk group (Class 3) had higher probabilities of multiple sex partners in the past year, intimate partner violence, binge drinking, and depression, these participants also had a higher probability of HIV testing, condom use, and higher likelihood of PrEP awareness than women in Classes 1 and 2. Class 3

participants were considered to be moderately resourced because they do not live in the most impoverished areas and higher education levels than Class 2 participants. Class 2, the low resource and moderate risk group, are behaviorally safe but are exposed to co-occurring conditions, such as poor/average health and neighborhood poverty. More likely to be single, foreign born, and less educated than Class 1, Class 3 participants have the same rate of PrEP awareness despite being more vulnerable to HIV acquisition.

6.3: Theoretical Considerations

The premise of this study was to evaluate how multilevel factors inform PrEP awareness and how the interaction between exposures exacerbate disparities in PrEP awareness. Literature demonstrates that women experience unique barriers to HIV prevention strategies that derive from gender-based inequalities. Oftentimes, experiences and occurrences beyond an individual's control can have ramifications for that person's health outcomes. In this dissertation, it was hypothesized that suboptimal circumstances were highly correlated with the lack of PrEP awareness, an indication of HIV prevention information not reaching priority populations.

For the two quantitative studies, the Minority Stress Theory and the Syndemic Theory were used to the relationships between multilevel factors and the outcome of PrEP awareness. The Minority Stress theory was hypothesized to be an ideal framework for the identification of PrEP awareness predictors because it aims to understand how interpersonal and social stressors impact individual-level outcomes (Meyer, 2015; Denton et al., 2014). The study sample was composed of diverse

women who had varying levels of exposures that would be considered negative stressors and risk factors for HIV acquisition. Although the foundation of this theory was built on the sexual minority experience, findings have implications for how stress impacts health outcomes among racial/ethnic minorities and gender minorities Herek & Garnets, 2007; English, Rendina, and Parsons, 2018).

While the Minority Stress Theory has relevance to the research question, results from the multinomial logistic regression suggest that the Theory of Gender and Power may be more applicable to the context of PrEP awareness among cisgender women. The Theory of Gender and Power, developed by Raewyn Connell, is a theory that conceptualizes the imbalance in power between men and women and its effects on a variety of outcomes (Connell, 1987). Over the years, researchers have used this integrative theory to understand the risk factors and exposures that heighten a woman's vulnerability to HIV (Broaddus, Owczarzak, Pacella, Pinkerton, & Wright, 2016; McMahon et al., 2015; Woolf-King & Maisto, 2015). It is divided into three major structures: the structure of labor, the structure of power, and the structure of cathexis. The structure of labor refers to the economic inequality between men and women that favors the male race (Connell, 1987). Financial insecurity among women has been shown to be a driver of increased HIV because of sex work in times of urgency or coerced sex with a partner to maintain financial support (Aidala et al., 2005; Baral et al., 2012; Gupta, Ogden, & Warner, 2011). The structure of power refers to the patriarchal society under which relationships exist and favor men (Connell, 1987). Imbalance in power between men and women in heterosexual relationships can lead to increased sexual risk behavior such as poor condom

negotiation (Nehl, Elifson, DePadilla, & Sterk, 2016), involuntary intercourse (Salazar et al., 2004), and insufficient communication about sexually transmitted infections and/or diseases with partners. Lastly, the structure of cathexis pertains to the social norms and affective relationships (Connell, 1987).

Among the nine predictors of PrEP awareness, older age, married status, and lower education were associated with being unaware of PrEP at time of survey. The Theory of Gender and Power may help to explain how these characteristics act as barriers to PrEP knowledge from the female vantage point. Specifically, the structure of labor may help inform how education and socioeconomic status play a role in the access to PrEP information and other HIV prevention modalities. In the opposite direction, women who have ever experienced intimate partner violence or some form of incarceration were more likely to know about PrEP than women who did not have these experiences. While the presence of these factors seems to be beneficial in accessing PrEP information, it is unsure whether they will become barriers once PrEP linkage and retention occurs.

6.4: Strengths and Limitations

This dissertation addressed a major gap in our understanding of PrEP awareness among women in the United States. While there is literature on the dearth of PrEP use and low rates of PrEP awareness among cisgender women, there is little information on the unique profiles of women whose experience lend to HIV risk and, therefore, should be taken into consideration when reaching ideal PrEP candidates. The quantitative component of this dissertation leveraged data from over 2,000

women who responded to a PrEP awareness survey item. The large sample size helped to produce robust data analysis and findings with higher accuracy. In addition to sample size, the sample was very diverse across age, race/ethnicity, education level, and marital status. The inclusion of women from all walks of life allows us to see how findings converge and differentiate based on a combination of attributes. Lastly, a primary strength of the study is the inclusion of multilevel factors to help elucidate how individual, interpersonal, and structural factors inform PrEP awareness. Creating a more nuanced picture of women's daily life and recognizing the interplay of these factors improves understanding of how PrEP information is disseminated and vulnerable populations can be better reached.

The nature of the study does come with its own set of limitations. Firstly, the data derives from a cross-sectional questionnaire, which negates any determination of causality. For future studies, the correlations identified in this study can inform longitudinal designs that capture the timing of exposures to the PrEP care continuum stage, specifically PrEP awareness. Time as an independent variable allows us to understand how proximity of exposures to PrEP awareness informs PrEP knowledge and subsequent use. Secondly, the PrEP question was only asked of women who reported having sex in the past 12 months which significantly reduced the study sample from its original size. While it is understandable for study staff to delegate sex-related questions to sexually active participants only, the PrEP awareness item is unique in the sense that PrEP should be known amongst all women despite their behavioral status. Since sexual activity is a dynamic state, meaning that women go in and out of varying volumes of sexual activity, it is important that PrEP information is

made available and tailored to women no matter their relationship status. Lastly, the data were collected in New York City only which reduces the generalizability of findings. There was diverse representation across age and racial groups and findings may be generalizable to other US metropolitan cities. Despite these limitations, findings from this study have implications for PrEP promotional strategies and the prioritization of heterogeneous female subgroups that have their own unique barriers and facilitators.

6.5: Implications for Future Research and Clinical Practice

Each of the three sub studies provided findings that have key implications for the way in which PrEP is marketed to vulnerable female clients in the US The systematic review investigated published findings on attitudes towards PrEP among cisgender Black women, an underserved and understudied population. The findings demonstrate the lack of awareness and education on PrEP to inform one's own perceived risk and willingness to use PrEP as an HIV prevention tool. Co-occurring conditions, such as intimate partner violence, and structural factors, such as medical mistrust, were some of the key themes that appeared across many of the sources. Furthermore, the article describes the difficulty in identifying data results that disaggregated by both sex and race/ethnicity. Future studies should consider the importance of enrolling Black women in US-based PrEP studies that are sufficiently powered to identify differences in subgroups at the intersection of race and gender. Without the consideration of intersectionality, it is quite difficult to suggest that

findings are applicable to women of a particular race if the findings are not representative of their unique identity.

The prevalence of PrEP awareness among female Community Health Survey participants (36%) was in the minority in this sample of women but higher than the average 10-20% among women across other observational PrEP studies (Doblecki-Lewis et al., 2016; Auerbach, Kinsky, Brown, & Charles, 2015; Patel et al., 2019). Future research should continue to monitor PrEP awareness among women in the US and develop information-based interventions that prioritize subclasses of women who would benefit from tailored PrEP materials. Paper 2 identified a variety of factors that serve as barriers and facilitators to PrEP information such as age, education level, relationship status, and intimate partner violence. More focus should be placed on women across the lifespan and of varying education levels and future PrEP programming should ensure that women of all ages and relationship statuses are represented in materials. Social and structural considerations should be made in the development of PrEP materials and promotional campaigns. For example, high risk women experiencing co-occurring conditions, such as intimate partner violence and justice involvement, that may be leveraged to improve outreach efforts and linkage to PrEP services.

6.6: Summary and Conclusion

This study investigated the complex relationship between sociodemographic, interpersonal, and structural factors as they relate to PrEP awareness among women in the US. In Paper 1, a qualitative systematic review of the literature identified key themes related to PrEP awareness among US-based Black women including IPV,

affordability, and medical mistrust. Findings, coupled with constructs from the Minority Stress Theory, informed variable selection for the secondary data analysis of female participants in the 2018 Community Health Survey. Paper 1 and 2 were broken up into three distinct aims: a) examine the single and multinomial associations between explanatory variables and PrEP awareness; b) identify and characterize subgroups of women who vary in in responses to survey questions related to behavioral, interpersonal, and structural factors; and c) describe how the prevalence of PrEP awareness and significant sociodemographic variables vary across classes. In Paper 2, low PrEP awareness among participants occurred and several factors, such as age, education, race/ethnicity, and history of IPV, were associated with the outcome of PrEP awareness. In Paper 3, three distinct classes of women were identified with varying levels of resource access and risky behavior. The three classes differed by PrEP awareness, age, race/ethnicity, and other related demographic variables. In conclusion, findings provide insight on how multilevel exposures impact PrEP awareness and identified priority subgroups of women in need of multi-component interventions to improve PrEP awareness and subsequent use.

Appendices

Appendix A: IRB Form

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INSTITUTIONAL REVIEW BOARD

UNIVERSITY OF MARYLAND

DATE:	July 6, 2020
TO:	Leandra Stubbs, MS
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1549670-1] Disparities in PrEP Awareness among Women: A Systematic Review of the Literature and Latent Class Analysis of Risk Factors
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
DECISION DATE:	July 6, 2020
REVIEW CATEGORY:	Exemption category # *4*

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

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