Distribution Agreement

In presenting this thesis or dissertation as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis or dissertation in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis or dissertation. I retain all ownership rights to the copyright of the thesis or dissertation. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

Signature:

______________________________ __________________

Ndidi Enyinnia Date

Recommendations to Increase PrEP Uptake and Adherence: A Review of the Barriers and Challenges to PrEP Uptake and Adherence Among Black Women in The Southeastern United States

Ndidi Enyinnia

Master of Public Health

Hubert Department of Global Health

____

Miriam Kiser, DMin, MPH, RN
Committee Chair

____

Igho Ofotokun, MD, MSc
Committee Chair

Recommendations to Increase PrEP Uptake and Adherence: A Review of the Barriers and Challenges to PrEP Uptake and Adherence Among Black Women in The Southeastern United States

By

Ndidi Enyinnia

Bachelor of Arts, Human Health
Emory College of Arts and Sciences
2012

Thesis Committee Chair: Miriam Kiser, DMin, MPH, RN

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Hubert Department of Global Health
2018

Abstract

Recommendations to Increase PrEP Uptake and Adherence: A Review of the Barriers and Challenges to PrEP Uptake and Adherence Among Black Women in The Southeastern United States

By Ndidi Enyinnia

Background: Black women are disproportionately affected by HIV within the United States, especially within the Southeastern region. Despite the introduction of PrEP as an effective prevention method, HIV rates among Black women remain high. A review of the literature was undertaken to examine the barriers and challenges to PrEP uptake and adherence, in addition to techniques addressing the barriers.

Objectives: The purpose of this review is to summarize the literature on PrEP uptake and adherence among Black women in the Southeastern region of the United States. Additionally, this review seeks to increase the understanding of the barriers and challenges that may inhibit PrEP uptake and adherence. This review also analyzes and presents effective HIV prevention techniques and recommendations that address the challenges and barriers to PrEP adherence.

Methods: A review of the literature was conducted in Medline as well as Google Scholar for peer-reviewed articles from 2008-2018 addressing PrEP use among Black women.

Results: The search for articles in Medline and Google Scholar yielded 11 articles. The results of these articles revealed that Black women face a multitude of behavioral, social, and structural barriers toward PrEP uptake and adherence. The main findings showed the cost of PrEP, stigma associated with PrEP, and inconsistent use were major barriers to PrEP uptake and adherence. Based on the findings, techniques were recommended to address the challenges to uptake and adherence.

Conclusions: Understanding the behavioral, social, and structural barriers Black women face, especially within the Southeast, is essential to PrEP research and prevention initiatives. Using techniques that address the multiple barriers is key to reducing the HIV incidence and prevalence among Black women. Addressing the unequal power dynamics between Black men and women is essential to increasing PrEP uptake. Additionally, implementing community-wide education and incorporating culturally competent care are practical techniques to addressing the barriers.

Recommendations to Increase PrEP Uptake and Adherence: A Review of the Barriers and Challenges to PrEP Uptake and Adherence Among Black Women in The Southeastern United States

By

Ndidi Enyinnia

Bachelor of Arts, Human Health
Emory College of Arts and Sciences
2012

Thesis Committee Chair: Miriam Kiser, DMin, MPH, RN

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Hubert Department of Global Health
2018

Table of Contents

Introduction & Rationale 1
Problem Statement 1
Purpose Statement 2
Significance Statement: 3
Definition of Terms 3
Chapter II: Methods 5
Literature Search Methodology 5
Data Extraction and Management 6
Quality Assessment 7
Analysis Plan 7
Chapter III: Literature Review on PrEP as Prevention 9
PrEP as Prevention 9
Chapter IV: Literature Review on Barriers 12
Behavioral Barriers 12
Social Barriers 14
Structural Barriers 16
Specific Population Barriers 18
Review of Literature Summary and Study Relevance 20
Chapter V: Effective Approaches 21
Addressing Behavioral Barrier 21
Addressing Social Barriers 22
Addressing Structural Barriers 23
Addressing Transgender-Specific Barriers 24
Chapter VI: Results 26
PrEP as Prevention 26
Behavioral Barriers 26
Social Barriers 27
Structural Barriers 28
Special Population Barriers 28

Chapter VII: Discussion, Recommendations, and Conclusion 30
Introduction & Summary 30
Discussion and Recommendations 30
Implications and Recommendations 32
Strengths & Weaknesses 33
Conclusion 34
Figures & Tables 36
Appendix 39
References 44

Chapter I: Introduction

Introduction & Rationale

In 2015, approximately 1.1 million individuals in the United States were living with HIV (CDC, 2017), of which Black Americans are the majority (Sangaramoorthy et al., 2017). In particular, the incidence is higher among Black women when compared to other races and ethnicities, such as White, Latina and Asian women. In 2015, Black women, who make up 13% percent of the U.S. female population, accounted for an estimated 61% (4,524) of women diagnosed with HIV, while 19% and 15% were White and Latina women respectively (McCree, 2017).

As HIV continues to disproportionately affect Black women in the Southeastern United States, it is essential to understand and implement effective HIV prevention methods. As of 2012, the FDA approved Truvada for PrEP as an effective method to prevent HIV infection, especially among high-risk groups. Current and more commonly promoted HIV prevention methods include condom usage and post-exposure prophylaxis (PEP).

While these methods are effective when used properly, an HIV epidemic persists among Black women despite the availability of condoms and PEP. Hence, this epidemic calls for a further exploration of other prevention methods such as PrEP. Shifting the focus to PrEP as a more common prevention method would require an understanding of barriers and challenges affecting Black women's uptake and adherence to PrEP.

Problem Statement

The burden of HIV/AIDS significantly impacts government resources (Schackman et al., 2015). For example, the cost of new diagnoses of HIV/AIDS was $16.6 billion in 2009. Southern states, such as Florida, Texas, and Georgia, carried the largest financial burden of $2,120,

$1,575, and $761 million respectively (CDC, 2017). The high incidence and prevalence of HIV also lead to increased societal cost. The burden of HIV/AIDS greatly impacts Black women in the United States, especially in the Southeastern region. Among Black women, HIV/AIDS has led to an increase in lost productivity, cost of social services, and physical and emotional stress to HIV-positive individuals and their families (CDC, 2017). Moreover, the high HIV incidence and prevalence rates among Black women leads to an increase in the disability-adjusted life years (DALYs) and inversely a decrease in the quality-adjusted life years (QALYs) among Black women (CDC, 2016).

A gap remains in understanding the barriers to HIV prevention, such as PrEP use and adherence, as well as effective techniques to address the barriers. This review will fill the gap in knowledge regarding the barriers to PrEP use among Black women and inform potential interventions. By filling the knowledge gap, the burden of HIV/AIDS on government resources and individual well-being will likely decrease.

Purpose Statement

Without an adequate understanding of the barriers and challenges Black women face in relation to PrEP uptake and acceptability, the incidence rates and prevalence of HIV will likely remain disproportionate in this population. This literature review contributes to knowledge of the barriers and challenges Black women face towards HIV prevention, specifically towards the use of PrEP. Additionally, this review informs public health initiatives and research by assessing and exploring methods to address the barriers and challenges to PrEP.

The following objectives address how this literature review will increase knowledge and understanding of the barriers and challenges Black women face in relation to PrEP usage and adherence:

Objective I: Review and summarize the literature on PrEP uptake and adherence among Black women in the Southeastern region of the United States.

Objective II: Increase understanding of the barriers and challenges that may inhibit PrEP uptake and adherence.

Objective III: Identify effective techniques in the literature and make recommendations that address the challenges and barriers to PrEP adherence.

Significance Statement:

Understanding the multifaceted barriers and challenges that decrease the use of HIV prevention methods, specifically PrEP, provides insight on how to reduce the HIV incidence among Black women. For example, public health researchers and professionals who use the findings and recommendations from this systematic review will be equipped to better serve this unique population. Moreover, the findings will inform future interventions as well as support existing interventions targeting this specific population and public health issue. Additionally, this review addresses the knowledge gap regarding effective methods or approaches to support PrEP usage among Black women.

Definition of Terms

Intersectional stigma: A theory describing how characteristics, such as race, class, sexual orientation, and gender, are interwoven and contribute to the systematic oppression of an individual (Sangaramoorthy et al., 2017)

Post-exposure prophylaxis: The use of antiretroviral medication after possible exposure to HIV (Bond & Gunn, 2016).

Pre-exposure prophylaxis (PrEP): A pill containing tenofovir and emtricitabine (also known as Truvada) taken by individuals who are at risk of contracting HIV, but not yet HIV positive (Bond & Gunn, 2016).

Disability-adjusted life years: Calculated from the sum of years of life lost and years lost due to disability which calculates the burden of disease from mortality and morbidity (WHO, 2018).

Quality-adjusted life years: Measures the burden of disease by factoring in the quality and the quantity of life lived (CDC, 2016).

Community-Based Organization (CBO): A public or private nonprofit group that represents a community and provides services to individuals within the community (NIH, 2018)

Social barrier: Conditions in which individuals are born, live, and learn; also related to the social determinants of health (CDC, 2016).

Structural barrier: The policies, practices, environment that affects, directly or indirectly, an individual behavior and access directly or indirectly (Riley et al., 2012).

Concurrent relationships or partnerships: When an individual is involved with more than one sexual partner at the same time (Pouget et al., 2010).

Gray literature: Non-scholarly literature produced by researchers, practitioners, and those considered experts in a certain field (Cornell, 2017).

Chapter II: Methods

Introduction

The goals of this systematic review were to (1) identify and analyze the literature on PrEP uptake and adherence among Black women in the Southeastern region of the United States; (2) identify the barriers and challenges inhibiting PrEP uptake and adherence; and (3) research literature for effective techniques and recommendations that address the challenges and barriers to PrEP adherence. To address these primary goals, a comprehensive review of the literature was conducted to identify peer-reviewed articles and gray literature from 2008-2018 relating to HIV prevention, primarily PrEP, and barriers among Black women in the United States.

Literature Search Methodology

Inclusion criteria were created and applied to the literature selection. To be included, a study had to (1) focus on PrEP; (2) focus primarily on Black women or Black transgender women; (3) focus on the barriers to PrEP usage or access, and/or the promotion of PrEP usage; (4) be conducted within the United States; (5) be published in English between January 2008 to February 2018 in a peer-reviewed journal. Articles were excluded if they did not relate to HIV or PrEP among Black women. This researcher initially conducted a broad search of the literature, screened relevant titles and abstracts using the inclusion criteria, and reviewed full texts in order to confirm eligibility.

Details of the selection process are found in Figure 1. The search strategy used both keywords and medical subject heading (MeSH) terms (Figure 2). Terms pertaining to the Southern region of the United States were not used in every combination of MeSH terms in order to produce a greater body of literature and avoid narrowing background knowledge. Any article

that did not relate to the population of interest or topic of interest (such as HIV/AIDS or PrEP) was excluded.

The following MeSH terms were used to search for articles relevant to the population, intervention, and disease of interest: “pre-exposure prophylaxis or PrEP”, “Black women or African American women”, “HIV or AIDS”, “Southeast United States or United States”. Initially, terms such as “PrEP and African-American women”, “PrEP and Black women”, “PrEP and barriers”, “PrEP and transgender women” yielded 2,163 articles in Medline. Upon further review of titles and abstracts, the number of articles was reduced to 34 based on the inclusion criteria. The abstracts of interest were examined in order to check for relevance; nine abstracts were excluded based on the inclusion criteria (Figure 2). After the researcher reviewed the remaining 25 articles, 23 additional articles were excluded due to the focus on the risk of HIV infection for the general female population rather than specifically for Black women.

In order to examine the barriers and challenges to PrEP uptake and adherence as well as effective techniques addressing these barriers among Black women, an open search was also conducted in Google Scholar. Keywords such as “barriers”, “stigma”, “black women”, “PrEP” and “challenges” were used in various combinations to find peer-reviewed literature (Table 1). Based on the inclusion criteria, 8 articles were selected from Google Scholar.

Data Extraction and Management

The researcher extracted data from ten eligible studies. The following data was obtained from each study: research aim, data collection method, analysis method, study type, and findings. Each of the studies was categorized according to the following characteristics: researcher or author name, year of publication, sample characteristics.

A Microsoft Word document was created in order to manage the selected studies. All references were stored in a word document and duplicate citations were removed. Data extraction forms were made in Microsoft Word to store relevant information from each study meeting the inclusion criteria (Table 2).

Quality Assessment

Since none of the included articles were randomized controlled trials, the Cochrane Method was not used in the quality assessment. For example, criteria such as the risk of bias (e.g. lack of blinding), inconsistency (e.g. methodological heterogeneity), indirectness, magnitude of effect (e.g. risk ratio) and confounding factors were not used to screen each article. In place of the Cochrane criteria, the quality assessment was based on characteristics considered most relevant to PrEP usage and uptake among Black women. Each qualitative study used in this review to identify effective techniques addressing challenges and barriers to PrEP use was assessed for the following criteria: Clearly specified research question or objective, clearly identified and defined population of interest, participation rate of eligible persons (at least 50%), consistent inclusion and exclusion criteria, well-defined intervention, sufficient timeframe, well-described results, well-described limitations, and limited publication bias.

One point was assigned for each of the criteria. Scores ranged from zero to nine; and, studies meeting at least seven of the criteria were categorized as suitable quality. Studies scoring below seven were considered inadequate quality and not included in the literature review. The final two studies accessed from Medline met the quality assessment criteria, along with the additional eight peer-reviewed articles identified through an open search in Google Scholar.

Analysis Plan

By using inductive reasoning, the researcher extracted relevant data, such as barriers and challenges, then noted important concepts and patterns. The researcher read all relevant studies and gray literature sources. Upon reading each selected source, codes were created to identify important data that answered the research question and meet the outlined objectives. The codes were then examined to identify broad patterns and potential themes. In order to create higher order themes, the researcher refined each code and explored the relationship between themes by comparing them across all articles and gray literature sources. Additionally, the higher order themes and the relationship between each theme were consistently checked against the research objectives (Figure 3).

Upon completion of the thematic analysis, objectives I and II were addressed by summarizing the literature related to the outlined themes. Objective III was addressed by analyzing qualitative research studies to identify effective techniques addressing the barriers and challenges to PrEP use reported directly from the target population.

Methods Summary

The researcher used Medline and Google Scholar to conduct a literature search. After titles and abstracts were reviewed, 34 articles were selected to undergo rigorous assessment. The remaining 34 articles from Medline were assessed based on the inclusion criteria, which resulted in two articles remaining. These two articles met the criteria for the quality assessment and thus were included in the review. Eight articles were selected from Google Scholar after undergoing the same rigorous assessment as the articles selected from Medline. The final ten articles all scored a seven or above on the quality assessment scale. Major themes of the review were also created from inductive reasoning and used to organize this review.

Chapter III: Literature Review on PrEP as Prevention

Introduction

Black women infected through heterosexual sexual contact are the 4th largest group in the United States to be diagnosed with HIV. Although the high incidence of HIV among Black women has led to an increased promotion of condom use, incidence rates remain high. Moreover, Black women face many barriers to condom use, such as a lack of control. To lay a foundation for knowledge that could reduce HIV in Black women, this chapter addresses objective I by examining the use of PrEP as a prevention method and a way to address the challenges of condom use.

PrEP as Prevention

Among Black women, condom use has been the center of HIV prevention research and interventions since about 87% of new HIV infections are attributed to heterosexual contact (Caldwell & Matthews, 2015). Despite the focus on condom use, the incidence of HIV among Black women remains a public health epidemic. Although consistent and correct condom use is highly effective at protecting against HIV, there are various reasons as to why their protective effects are not significantly decreasing HIV incidence among Black women (Caldwell & Matthews, 2015).

Aside from condoms slipping and breaking during sexual acts, people may find using a new condom during each different sex act or with each partner inconvenient. Moreover, individuals may only use condoms occasionally or lack a choice in condom usage (Fonner et al., 2014). Studies conducted on condom usage among Black women revealed that inconsistent condom use may be due to perceptions of less autonomy and control during condom negotiation. More specifically, using condoms in situations where Black women do not feel in control may

create feelings of tension and powerlessness. For example, in a focus group conducted by Caldwell & Matthews, one participant stated: “If the guy says, ‘I want to do this without the condom,’ I think there are women who would go ahead and do it because they don’t want to lose him with the shortage of single, available Black men. They’re like, ‘Oh, what’s one time,’ or something stupid like that. In my opinion, it is stupid because you’re putting yourself at risk. You’re trying to be happy but you could eventually get pregnant or die so you really got to take that seriously and a lot of women will put the option of having a relationship or a committed relationship above their own safety as far as sex is concerned.” This comment addressed the feeling that may affect perceptions of control and confidence when enforcing condom use (Crosby et al., 2018).

In order to counteract the complexity of condom use, other HIV prevention methods have been explored. In particular, PrEP is an HIV prevention method that is not only highly efficacious but addresses the barriers, such as self-control and power, of condom usage among Black women.

PrEP, also known as Truvada, is a daily medication taken by individuals at high risk for HIV (CDC, 2017). PrEP prevents HIV from spreading, which in turn reduces the risk of infection. Data from U.S. retail pharmacies reported that 500,000 heterosexual women are eligible for PrEP, but only about 19,000 women have received the medication (CDC, 2017). More specifically, Black women have a significantly low PrEP initiation rates when compared to the general and female population. While randomized clinical trials demonstrated that PrEP is an effective HIV prevention method among at-risk populations, PrEP initiation remains low. Research also showed that correct daily use of PrEP reduced the risk of contracting HIV from sex by more than 90% (Underhill et al., 2016)

Aside from the reduced risk of HIV, there are multiple advantages of PrEP uptake that address condom usage barriers. In a mixed-methods study conducted on the perceived advantages and disadvantages of PrEP, Black women reported female-control and empowerment as advantages. A female-controlled method for HIV prevention, in particular PrEP, has the advantage of allowing women to protect themselves without depending on a male partner. Additionally, PrEP has the potential to be helpful for Black women, who experience higher rates of power imbalanced relationships than other races, in relationships in which condom negotiation is not realistic. PrEP also has the potential to empower women through self-efficacy. For example, the use of PrEP has shown to increase feelings of self-control, especially among women at high risk for HIV (Bond & Gunn, 2016).

Analysis

PrEP's potential to reduce certain barriers, such as power and autonomy, associated with condoms warrants more focus in HIV interventions and research. While condoms should not be eliminated as a method of HIV prevention, PrEP provides the advantage of having self-control whereas condoms may not. Therefore, PrEP may be highly efficacious at preventing HIV among Black women in power-imbalanced relationships as well as women experiencing difficulty with condom negotiation.

Chapter IV: Literature Review on Barriers

Introduction

This chapter addresses objective II by increasing the understanding of the various barriers and challenges that hinder PrEP uptake and adherence among Black women. First, behavioral barriers, such as condom use, are reviewed in order to provide an understanding of the personal choices that may affect PrEP use. Then, social barriers, such as sexual networks, are highlighted to provide increased awareness of the conditions reducing PrEP uptake and adherence. Structural barriers are also discussed in this chapter, in addition to historical inequities preventing PrEP use. Lastly, unique barriers within special populations, specifically transgender black women, are explored.

Behavioral Barriers

The health belief model is a psychological model used to explain and predict health behaviors by focusing on individual attitudes and beliefs. According to the model, individuals decide if the benefits of changing a behavior outweigh the costs or problems associated with the behavior change. The model also emphasizes four parts of the internal assessment: risk perception, perceived severity of ill-health, perceived benefits of behavior change, and perceived barriers to taking action (Green & Murphy, 2014). In the case of HIV among Black women, the health belief model can be used to understand perceived barriers to PrEP and how these barriers pose a threat to uptake and adherence.

Consistent barriers arose in various qualitative focus groups conducted on the knowledge, attitudes, and acceptability of PrEP use among Black women. For example, study participants in most of the selected studies noted that PrEP may impact sexual behavior by increasing the frequency of sex without the use of condoms and participation in riskier sexual acts. In

qualitative focus groups conducted by Bond and Gunn, a participant stated: “I think it’s [PrEP] a great idea. I just hope people don’t decide not to use condoms just because they can get this.” Another participant in the same focus group commented: “My thoughts are some women might stop using condoms because they feel that there is PrEP and they are not at risk for HIV as long as they have the medication.” These perceptions of PrEP as a facilitator to risky sexual behavior among Black women not only inhibit uptake but also lead to a reduction in the desire to pursue PrEP despite potential benefits. Ultimately, the perception that PrEP increases risky sexual behavior outweighed the benefits of daily PrEP use for potential consumers in the focus group (Bond & Gunn, 2016).

Daily adherence to PrEP is essential for optimal effectiveness. However, in various reports and focus groups regarding adherence, many Black women reported taking PrEP consistently as a challenge. In a study conducted by Smith et al, one participant stated: “I barely take my birth control every day, so I don’t know if I could take a pill every day. I’ll try but it’s hard to take a pill constantly every day. Medicine for the rest of your life? I don’t know about that.” Another participant stated: “What this pill can do is amazing but it is hard for me to imagine taking a pill for the rest of my life, maybe a shot every couple of weeks but not a pill. But you do have to do what you have to stay healthy and live as long a life as possible,” (Smith et al., 2012). Various literature sources also reported that being in a violent or unstable relationship is more common among Black women and a challenge to PrEP uptake and adherence (El-Bassel et al., 2009). Black women in these unstable relationships were observed to have low uptake PrEP rates and inconsistent use due to fear of negative effects PrEP uptake may have on their existing and future relationships. Furthermore, reports showed that women at high

risk for HIV and those in violent relationships experience higher rates of depression and low self-esteem, which lowers adherence (Auerbach et al., 2015).

Social Barriers

In addition to behavioral barriers, numerous social barriers exist that contributed to the HIV epidemic among Black women and affect PrEP uptake and adherence. For example, the U.S. census showed that Black Americans' gender ratios are imbalanced in comparison to other racial groups. For example, Black Americans gender ratio is characterized by 90 males per 100 females, while other gender ratios are as follows: Hispanics at 105.1 males per 100 females, Native Americans at 98.7 males per 100 females, Whites at 96.3 males per 100 females, and Asians at 92.8 males per 100 females (U.S. Census, 2010). While Asians experience comparable gender ratios, this racial group does not have the same level of incarceration rates and mortality rates and risk that affects the Black community. Overall, these imbalanced gender ratios in the Black community also contributed to the high rates of concurrent sexual relationships (El-Bassel et al., 2009).

Research has shown that Black men have more concurrent relationships and sexual partnerships due to the low male-to-female sex ratio within the Black community. A study conducted by Morris et al found that rates of concurrent relationships in Black males were 3.5 times higher than White males and 1.9 times higher than men of other racial and ethnic backgrounds. Additionally, Morris et al reported that the rates of having sex with a male partner in concurrent relationships among Black women were 2.1 times higher than White women and 4.1 times higher than women from other racial backgrounds (Newsome et al., 2013).

While the imbalanced ratio of male to females within the Black community increases the rate of concurrent relationships, especially ones in which the male has multiple partners, the

combination of these unequal ratios increases dense sexual networks. These dense and high-risk sexual networks, due to the increased risk behaviors of a few, increase the level of risk for all within the network. Moreover, the smaller sexual network results in more numerous interactions between high and low-risk individuals (Pouget et al., 2010).

Another unique result of the imbalanced ratios and limited sexual networks is the power inequality between Black men and women, which limits prevention methods such as PrEP. A study conducted by Newsome et al demonstrated that Black men in high demand may have increased decision making power and authority in relationships due to their limited availability (Newsome et al., 2013). Moreover, a study by El-Bassel et al argued that the limited availability of Black men may decrease Black women's self-protective behaviors, due to the fear of losing a partner. The fear of losing a partner not only reduced condom negotiation or PrEP use, which both influence risk for an HIV infection, but this fear also may make Black women more sexually passive and more vulnerable to intimate partner violence (El-Bassel et al., 2009).

Aside from limited sexual networks, unbalanced gender ratios, and unequal power dynamics, societal stigma towards HIV is a significant barrier towards PrEP use. Within the Black community, HIV is often stigmatized and leads to discrimination and limited social support (Galvan et al., 2008). The stigmatization of HIV within the Black community limits the circulation of accurate HIV related information and often prevents Black women from seeking HIV-related care due to negative stereotypes and internalized stigma or shame. In a focus group conducted on knowledge of PrEP and perceived stigma within the Black community, many women reported fearing that family or friends would discover and question their use of PrEP, which generated feelings of fear and shame that reduced the likelihood of PrEP use. When asked about perceived peer reactions in a focus group conducted by Smith et al, one participant stated

that: “[People will say,] ‘Oh, that girl got AIDS.’” In another focus group conducted by Auerbach et al, a participant from Atlanta stated: “So if you’re around a community of people who don’t understand or they don’t get it, then you may get the negative look or shunned. So that would kind of stop people from doing it or that would stop people from being open to doing it. But I think if people are widely educated and they understand the complications or the scenarios of what could possibly happen if not, then more people would be open to do it.” These statements are consistent with literature reporting that perceived community-level stigma is a barrier to PrEP uptake among Black women (Smith et al., 2012).

Additionally, the perceived attitudes and reactions of male partners factored into the decision to use PrEP. In various qualitative literature sources, Black women frequently expressed how fears of their partner assuming infidelity or showing a lack of support if PrEP use was disclosed led to a resistance to use PrEP. Interactions and perceived attitudes of healthcare providers also limited the use of PrEP. Multiple bodies of research also demonstrated that Black women face many barriers communicating with healthcare providers and experience discrimination or judgment when inquiring about PrEP or discussing sexual health. For example, a participant from the Bond and Gunn focus group stated that: “The stigma related to having the drug show up on my insurance and at the pharmacy level is enough to not make me want to take it”.

Structural Barriers

As of 2015, approximately 23.1% of Black women in the United States lived in poverty. Among Black women, poverty is associated with an increased risk of HIV. Furthermore, Black women experience report higher rates of homelessness and Medicaid-use, which are both associated with an increased vulnerability to HIV. Research showed that individuals facing

homelessness have less access to health care and experience more instability, which can hinder PrEP use. Similarly, individuals with low incomes or limited insurance coverage often face financial barriers to accessing PrEP (Ivy et al., 2014). In a focus group conducted by Smith et al, participants were asked if they would purchase PrEP at a $25, $50, and $75 price point. Overall, most participants stated that $25 was the most reasonable and feasible price point for PrEP. Additionally, one participant stated: "If I don't got it [the money], then no, I wouldn't buy it every month. I'd probably skip a month. If I had them, I'd take them, but if I don't have the money to get them, then I can't get them, but if it's free, of course. I'd be the first one in line to get them. But if I have to pay for them, I have to think about that." Another participant said: "And I be looking at my last $25 like, 'Do I go get my nails done? Or do I need to go get these pills? Up, I'm about to get my nails done.'" Another participant shared similar thoughts and stated: "Now, I can probably scrape up the 25, but I probably couldn't scrape up no 50 a month because the struggle is just a little too much right now." These comments further demonstrated there are numerous financial barriers to PrEP and these barriers often severely inhibit access.

Research also demonstrated that subtle and persistent forms of discrimination serve as underlying causes of health disparities among Black women, such as the disproportionate rates of HIV and PrEP access (Hausmann et al., 2008). Historically, Black women are more likely to experience lesser quality healthcare, which may reduce the opportunity to use PrEP. Common fears, stemming from medical mistrust, such as fears of sterilization, the use of unnatural medicine, and adverse side effects also deterred Black women from using PrEP (Auerbach et al., 2015). In an article by Hill et al., researchers conducted a qualitative study of Facebook comments on an article promoting PrEP in order to analyze factors that influence PrEP use among Black women. One participant on the Facebook page commented: "Why not across the

board marketing? Yes, we are at higher risk. However, pharmaceutical companies and the government track records are questionable." While another Facebook commenter stated: "Not buying this [PrEP]. [It's] another experiment from the government." These comments from the Hill et al study are consistent with the Auberbach et al study, in which researchers asked Black women about the barriers to PrEP. In the Auerbach et al study a participant stated: "Like with this Tuskegee syphilis thing issue, we think we're getting one thing, right? Well, really they're injecting our brothers, our fathers, and husbands with syphilis. And then down the line, 25–30 years, I just don't trust the whole [thing]." An analysis of the comments showed that many participants displayed mistrust towards the medicine and intentions of healthcare providers.

Specific Population Barriers

In research on Black women and HIV, transgender women (male to female) are often excluded. Transgender women are typically categorized under men who have sex with men (MSM). However, categorizing transgender women into the same high-risk MSM group demonstrated a lack of understanding regarding gender identity and the unique experiences of transgender women. Moreover, the lack of research focused on Black transgender women's unique HIV risk factors and barriers to PrEP worsens the HIV epidemic. Similar to Black women who were assigned female at birth and identify as a woman, transgender women face limited sexual networks, unequal power distributions within intimate relationships, stigma, and poverty. Transgender women also face a multitude of trans-specific barriers, such as non-inclusive marketing of PrEP, concerns about hormone interactions, and transphobia (Sevelius et al., 2016).

The HIV epidemic within the MSM population has received a great amount of medical and public health attention within the past few years. While other prevention methods, such as condom use are encouraged within the MSM community, PrEP is heavily promoted and many

interventions and research focus exclusively on PrEP use in the MSM community. Due to the lack of PrEP promotion in the transgender community, many perceive PrEP as a prevention method for homosexual men (Escudero et al., 2015).

Many transgender women undergo hormone replacement therapy, which is used to change masculine sexual characteristics to feminine characteristics. Although there have been no reported adverse interactions between PrEP and hormone therapy, concerns among many transgender individuals serve as a barrier to PrEP use. For example, in a focus group about PrEP use among transgender women, many questioned PrEP's interactions with hormone therapy. Additionally, studies on PrEP use in transgender communities noted that transgender women may avoid healthcare settings due to fear of interactions in which providers or clinical staff may display transphobia or provide culturally insensitive care (Sevelius et al., 2016).

Analysis Summary

All reviewed sources identified frequent behavioral, social, and structural barriers to Black women's use and adherence to PrEP. For example, Black women face behavioral barriers to PrEP use such as inconsistent use due to unstable environments or relationships. Moreover, the idea that PrEP increases promiscuity outweighs the benefits and thus deters many black women from using PrEP.

Black women also faced numerous and overlapping unique social barriers. For example, Black women's limited sexual networks and low male-to-female ratios are exacerbated by Black male's incarceration rates, higher HIV risks, and engagement in concurrent relationships further exposes Black women to HIV, in addition to negatively impacted perceived power in relationships and reduced preventive behaviors. Black women consistently also expressed fear of assumed infidelity from Black male partners or a lack of support for using PrEP in sexual

relationships. Outside of intimate relationships, the stigmatization of HIV and PrEP use within the Black community further limited Black women's desirability to use PrEP. Additionally, the potential for negative interactions due to racially-targeted discrimination or judgment from healthcare providers lessened the likelihood of Black women using PrEP. The addition of structural barriers to PrEP use, such as poverty, discrimination, racism, and historical medical mistrust, further decreased the possibility of using PrEP among Black women.

Although Black transgender women face the same behavioral, social, and structural barriers discussed in this review, they also face unique barriers related to their sexual and gender identity. Black transgender women's fears of PrEP's interaction with hormone replacement therapy, transphobic medical interactions, and being categorized as men decrease the interest in and use of PrEP.

Review of Literature Summary and Study Relevance

After reviewing the literature regarding factors associated with PrEP use and adherence, it is clear that significant challenges to PrEP use remain and continue to limit Black women's use. More specifically, behavioral, social and structural barriers negatively affect the interest, acceptability, and use of PrEP. However, as demonstrated in this literature review, promotion of PrEP has not addressed the unique barriers Black women face. Thus, HIV incidence and prevalence remains high among Black women. The next chapter of this review seeks to address the challenges and barriers of PrEP use by presenting effective approaches to promote PrEP. In doing so, this review will fill a gap in research and contribute to a deeper understanding of how to effectively address the barriers to PrEP use and adherence. By presenting effective techniques to address the barriers and challenges of PrEP use, the incidence and prevalence of HIV among Black women may be reduced.

Chapter V: Effective Approaches

Introduction

Although there has been a lack of PrEP clinical trials targeting Black women, especially in the South, existing literature provides information on effective techniques to address the reported barriers and challenges. The majority of PrEP research studies addressing ways to counter the challenges and barriers of PrEP use qualitative methods. Using these sources, this chapter presents information on effective techniques and suggestions for PrEP facilitation derived from a variety of qualitative research and gray literature sources focused on PrEP uptake in the Southeastern region of the United States.

Addressing Behavioral Barrier

While a variety of behavioral barriers hinder PrEP uptake, prevention strategies centered on empowerment may increase use and desirability. One facilitator of PrEP use is that it can be female-controlled. In Bond & Gunn's focus group, one participant mentioned PrEP as an "alternative for women to protect themselves if they may be in an abusive relationship." Another participant stated: "It's a great way to help women; particularly Black women take more control of their sexual health." These two comments demonstrate that PrEP could be used to both empower women to take control of their own health and have an option in cases when their partner may be high-risk or refuses to use condoms. In order to promote PrEP use among Black women, it may be effective to market PrEP as a method of taking control of one's health. Moreover, researchers and scholars promoting PrEP use should also address the interpersonal factors that create power differences between Black women and men.

In order to address the adherence barrier among Black women, studies have shown that consistent reminders increase adherence. For example, during an intervention aimed at

improving treatment compliance in hyperlipidemias participants received three phone calls over a four-month period. These phone calls were used to discuss adherence and remind participants about upcoming visits. The consistent reminders resulted in a 20% increase in patients with hyperlipidemia. Although all strategies used in Contreras et al may not be generalizable to PrEP adherence, this study provides an insight into potential PrEP adherence interventions. Moreover, the Contreras et al study, reviewed by Marcus et al, demonstrated that multi-modal interventions are useful in increasing adherence. In terms of PrEP among black women, a multi-modal approach may be highly effective if education, counseling, and adherence feedback are provided by healthcare providers or community outreach workers (Marcus et al., 2014).

Addressing Social Barriers

Although many Black women could benefit from PrEP within the Southeast, HIV-related stigma continually hinders uptake. However, there are potential strategies to reduce the societal and community-based stigma towards HIV and PrEP. In Smith et al, focus group participants were asked about the reactions of peers to taking PrEP. While most participants expressed potential stigmatization, two participant responses differed. One participant stated: “I want to say this. If I was taking the pill…I wouldn’t be ashamed to take one. I give [it to] my friend, ‘Hey man, like, take this,’ because I want to help everybody out around me. Especially if they ain’t got it and it going protect them. I’m fixing to give my friend, ‘Hey, y’all better take this!’” Similarly, the other participant stated: “You know what? I’d probably sit [my PrEP pills] on the dresser, so those who come can see… ‘This is what I’m taking so I can make sure that I don’t get…something bad’ …Those who come in…should know. This is what I’m doing to make sure I don’t get those kinds of germs.” These responses demonstrate the potential for PrEP users to reduce stigma within their own communities by promoting their own use. Additionally,

mobilizing Black women to promote PrEP within their own communities may increase PrEP uptake.

Addressing Structural Barriers

In this review, several structural barriers were highlighted, such as cost and historical mistrust. Although PrEP cost about $1,300 per month, many health insurance plans provide coverage. For individuals who do not have private insurance, companies like Gilead offer a prescription assistance program in order to cover the cost of PrEP. For example, with Gilead's co-pay assistance program, co-pay for PrEP is covered for qualified individuals whose private insurance may not meet their needs (Gilead, 2016). Gilead and similar assistance programs are available, but potential and current PrEP users may be unaware of these programs. Therefore, healthcare providers and community-based organizations working to reduce HIV need to increase knowledge and awareness of assistance programs through continued outreach and promotion.

In order to address issues of historical mistrust or provider discrimination, the use of community-based organizations or clinics catering to Black women may be effective in reducing the PrEP and HIV disparity. In Auerbach et al, one participant stated: "We need more [name of community-based organization (CBO)] centers in place. We need the funding to have more [name of CBO] centers because if you go to any cities, you don't have a lot of women-centered prevention organizations." Another participant shared a similar stance by stating: ‘‘I like that [CBOs]. Because we are talking about women, the best place to get information and to make a decision would be going to a woman-centered environment, so I like that." Both participants expressed the desire to have women-centered providers, which may decrease feelings of shame or discomfort when discussing sexual health.

Another unique solution to address healthcare access and quality is the use of safety net clinics. Safety net clinics typically deliver wide-ranging health services to the medically underserved and uninsured populations. For example, safety net clinics may offer primary health care, HIV testing and treatment, chronic disease management, and non-emergency care services at no cost to clients. The role of safety net clinics not only benefits those without access to healthcare but also benefits underserved communities of color, which are often historically disadvantaged and face higher rates of ill-health outcomes. Specifically, availability of safety net clinics has improved access to healthcare services and improved gaps in health insurance coverage and care among low-income populations. The potential of safety net clinics to reduce health disparities among underserved groups, such as Black women, has been identified as a possible solution. However, culturally competent care is also necessary to improve the quality of care in safety net clinics. Although further research is necessary to determine the impact of safety net clinics in combination with cultural competency on Black women's health, previous studies indicate that there is potential for these clinics to increase PrEP uptake and adherence. (Eisert et al., 2008).

Addressing Transgender-Specific Barriers

Transgender women face unique barriers to healthcare, such as transphobia, which affects PrEP use. In a study conducted by Sevelius et al, a participant stated: "Sometimes just to find a doctor that's trans-friendly and make sure that we're on our right hormones is hard enough. I think there would be trans-women who would be scared [to take PrEP] because it's all about finding that right doctor. Having a good relationship with your doctor, I think, is a very good help – a very good healthy thing." In order to address the trans-specific barriers of potential discrimination and concerns regarding hormone interactions, medical personnel serving this population need to provide trans-competent care, which involves an understanding of gender

identity. Additionally, programs and services regarding PrEP need to cater to the trans-population as well by providing trans-specific messaging, risk assessments, and support.

Analysis Summary

The unique experiences of Black women and Black transgender women deserve a targeted approach to PrEP interventions and prevention efforts. Study results and recommendations show that PrEP prevention and education in the form of a culturally-based approach may be the most effective way to increase PrEP uptake and usage. PrEP initiatives focused on Black women should also consider investing in community-wide education and participation in order to spread PrEP awareness. Additionally, CBOs may benefit from using representative peer educators or navigators to increase PrEP awareness and acceptability within the Black community. Overall, future PrEP interventions need to include provider and community-centered education addressing beliefs regarding mistrust, power-dynamics, stigma, and access.

Chapter VI: Results

Introduction

Of the ten studies that met the criteria for inclusion in this review, eight were qualitative studies, one was a systematic review, and one was a cross-sectional study. The features of the studies and their primary findings are presented below. The chapter begins by discussing the studies that highlighted PrEP as an HIV prevention method. Then studies are reviewed that discussed the behavioral, social, and structural barriers respectively. The summary of the studies concludes by addressing the barriers of Black transgender women (Table 2).

PrEP as Prevention

This section summarizes the results of two qualitative studies (Caldwell & Matthews, 2015) (Underhill et al., 2016) about HIV risk perception and HIV message framing. The selected papers presented the results of multiple focus groups (n=23) centered around HIV prevention strategies. The Caldwell and Matthews article presented the results of four focus groups and 15 semi-structured interviews examining sexual behavior, use of HIV prevention methods, and perceptions of HIV risk. The Caldwell and Matthews study reported gender power dynamics and SES greatly affect HIV prevention among Black women. In the Underhill et al, study researchers conducted 8 focus groups and 56 individual in-depth interviews in order to collect data on preferences regarding PrEP messaging. The main findings of the Underhill et al study suggested that potential PrEP users prefer numerical information about PrEP efficacy and success-framed messaging.

Behavioral Barriers

This section presents the findings of two studies (Smith et al., 2012) and (Bond & Gunn, 2016). Smith et al addresses the attitudes and program preferences regarding PrEP among young

Black Americans. This study used semi-structured guides to collect data from focus groups. The main findings presented in this paper suggest that interest in PrEP was associated with cost, access, and effectiveness.

In the Bond and Gunn article, 119 women completed survey data to provide an accurate portrait of participants and answered open-ended questions focusing on the advantages and disadvantages of PrEP. Researchers in this study reported concerns regarding PrEP use due to side effects, challenges to adherence, and testing burdens.

Social Barriers

This section presents the results of three studies (Smith et al., 2012), (Pouget et al., 2010), and (Auerbach et al., 2015). In Smith et al, the researchers analyzed the attitudes of participants which included various social barriers such as perceived stigma from peers and their communities.

In Pouget et al, researchers analyzed the association of sex ratios and male incarceration rates. This cross-sectional study revealed that sex ratios and incarceration rates variedly by race and ethnicity. Findings also showed there is a greater shortage of Black males (adjusted odds ratio [AOR] = 1.9; 95% confidence interval [CI] 1.1, 3.5) and a greater number of incarcerated Black males (AOR=1.6; 95% CI 1.1, 2.3). These results are consistent with the literature on limited partner availability among Black women and provide support for the higher rates of concurrent relationships among Black women.

Auerbach et al reviewed the likelihood of PrEP use among Black women based on current attitudes and knowledge. In this study, researchers partnered with community-based organizations to conducted focus groups with HIV negative Black women. The findings from this study suggested that there is a lack of PrEP knowledge among Black women. Findings are

also consistent with the literature on medical mistrust, stigma, and cost. However, in this study, participants also shared facilitators to PrEP use and supported a range of PrEP options such as pills and injections.

Structural Barriers

This section presents three articles focused on barriers and perspectives of PrEP (Hill et al., 2018) (Smith et al., 2012) (Auerbach et al., 2015). Auerbach et al and Smith et al conducted focus groups on the attitudes and knowledge of PrEP among Black women and Black youth respectively. The findings both of the studies demonstrated that government and medical mistrust, financial barriers, and healthcare access were significant barriers to PrEP use among Black women.

Hill et al conducted a qualitative study on Facebook comments posted to an article about PrEP. In this article, Hill et al found mistrust of the government and pharmaceutical companies to be the most prominent barriers to PrEP use and adherence among Black women due to the history of health abuses by the government and healthcare providers in the Black community.

Special Population Barriers

Two studies (Sevelius et al., 2016) (Escudero et al., 2015) addressed the unique barriers affecting Black transgender women's PrEP use and adherence. Sevelius et al focused on the trans-specific barriers and facilitators to PrEP use by conducting three focus groups and nine individual qualitative interviews (n= 30 unique participants). The main findings presented by Sevelius et al include the necessity to incorporate the unique sociocultural context of trans women's lives and experiences in PrEP marketing.

Escudero et al reviewed published results from randomized clinical trials that analyzed the use of oral PrEP among transgender women. Similar to the findings from Sevelius et al,

Escudero et al found that the inclusion of trans women is minimal in PrEP clinical trials. For example, the findings of this study showed that out of the seven reviewed trials analyzing PrEP efficacy, that transgender women comprised only 1.2% of one trial and 0.2% of total trial enrollments.

Summary of Results

A majority of the reviewed studies were qualitative articles. Researchers in each of these studies analyzed focus groups, semi-structured interviews, or Facebook comments. The findings from each study informed the researcher about the various barriers to PrEP use and adherence Black women face. The findings were also categorized by barriers they addressed.

Chapter VII: Discussion, Recommendations, and Conclusion

Introduction & Summary

Black women within the Southeastern United States face the highest rates of HIV in comparison to other races as well other regions, despite the availability of PrEP. Although PrEP is available for HIV prevention and is highly efficacious, Black women face significant barriers to uptake and adherence. This review summarizes articles and gray literature exploring these barriers and challenges, in addition to providing recommendations based on effective prevention techniques. This chapter contains a discussion of key results, recommendations, strengths, and weakness of the review. Major findings and the application to the field of public health are also discussed in this section.

Discussion and Recommendations

This systematic review summarizes the barriers to uptake and adherence among Black women, particularly in the Southeastern region of the United States. Although there has been progress towards reducing the HIV epidemic among the Black community, there are still widespread disparities. For example, Black women face a unique set of barriers affecting their use of HIV prevention methods such as PrEP. The findings presented in this review supports the view that Black women face significant disadvantages to PrEP adherence and uptake rooted in behavioral, social, and structural barriers that disproportionately affect the Black community. Moreover, the combination of these barriers decreases Black women's access to information, access to care, and acceptability of PrEP.

Most studies addressing Black women's behavioral barriers affecting PrEP use reported unequal power dynamics, unstable relationships, and concerns about increased risk compensation as major factors decreasing adherence and uptake. In order to address these behavioral barriers,

healthcare workers, organizations, and researchers encouraging PrEP use need to use a multi-faceted approach to increase uptake and adherence. Studies also reported social barriers, such as stigma, as another factor affecting PrEP use. Black women in the Southeast are already at a disadvantage as a result of a social policy which criminalizes and stigmatizes HIV that limits sexual health knowledge and outreach through various laws and policies. In addition, Southern culture further fosters stigma and discrimination in the Black community, which is a significant barrier to HIV prevention and treatment. Additionally, Black women's limited sexual networks contribute to HIV epidemic. While improving sexual networks may be difficult due to the unequal ratios of Black men, decreasing stigma is possible through community-led promotion of PrEP and education to increase supportive networks.

The structural barriers affecting PrEP use and adherence are difficult and often out of an individual's control. However, research has shown that there are ways to address these structural barriers, such as cost and access to PrEP through cost-assistance programs, such as Gilead's, and clinics catering to Black women. Moreover, culturally competent care is another important factor to increasing PrEP knowledge and use. In order to increase culturally competent care, healthcare providers need to be better equipped and educated on the unique factors affecting Black women's susceptibility to HIV.

Similarly, providers also need to deliver trans-specific care. Studies on transgender women's use of PrEP demonstrated limited use, despite their categorization as a high-risk population. The limited use of PrEP among transgender Black women is often due to fears of transphobia and hormone interactions with PrEP. However, research has shown that PrEP does not have a negative effect on hormone therapy. Qualitative research also demonstrated that providers and healthcare organizations perceived as trans-friendly and trans-competent have a

higher chance of serving transgender clients. Increasing the number of providers and healthcare organizations delivering trans-specific care is also associated with higher PrEP uptake and acceptability.

Implications and Recommendations

The results of this review could improve how healthcare providers understand and address the barriers to PrEP uptake and adherence among Black women. This review presents findings that when applied will enhance the effectiveness of interventions used to increase adherence in Black women. This section presents recommendations that may be used by providers, medical or healthcare staff, and public health researchers to address uptake and adherence to PrEP.

In the reviewed focus groups, participants noted the fear of increased sexual behavior and difficulty taking PrEP daily as major barriers. There are common concerns regarding PrEP and the idea that use will increase risky sexual behavior due to reduced vulnerability to HIV infection is a misconception. Therefore, educational or informational materials and messages about PrEP need to address this misconception by incorporating scientific and factual findings that moderate the misconception within Black community. Additionally, many literature sources showed that daily adherence is threatened by unstable environments and relationships. While changing the unstable environments and relationships that exacerbate inconsistent use is a challenge, increasing daily adherence through adequate education, counseling and adherence feedback for women about PrEP is a necessary and potentially useful approach to reducing the behavioral barriers.

In order to address the concurrent relationships, imbalanced gender ratios, and power imbalanced relationships that impact PrEP use requires an approach that engages both the Black

women and men. For example, having initiatives that target Black heterosexual couples and focus on educating partners or couples on how to protect themselves from HIV infection may be useful. Bringing Black men and women together may increase trust, reduce gender power imbalances, increase interpersonal communication and negotiation skills, allow partners to express their needs to each other, and provide a safe space that might for partners to discuss PrEP use. Ultimately, interventions engaging both sexes may positively impact a Black woman's ability and perceived capability to protect herself from HIV as well as addresses the established social barriers. One unique approach to addressing social barriers, such as stigma towards PrEP, is to increase information on PrEP through community-wide and community-led programs. This information needs to not only address the stigma towards PrEP but also incorporate strategies to empower Black women to use PrEP despite the stigma. Additionally, having members of targeted communities participate in disseminating the information within community programs is essential.

Addressing the structural barriers include providing financial options upon a recommendation of PrEP, promoting and recommending the use of safety net clinics or women-centered clinics, and incorporating trans-competent care to providers and organizations centered on sexual health. Moreover, restoring trust in medical providers by providing culturally competent care is essential to increase the quality of care for Black women and reduce the medical mistrust that prevents many Black women from using PrEP.

Strengths & Weaknesses

A strength of this review is the use of qualitative research data. This qualitative data provided insight into the issues related to PrEP adherence and barriers directly from the target population. Another strength of this study is that the researcher used focus groups responses to

inform the recommendations and effective approaches. Using focus group responses incorporates the voice of the target population and ensures that the recommendations are specific to Black women. Limitations of this review include: limited data from PrEP clinical trials, limited research centered on the target population (i.e. Black women in the South), limited availability of rigorous studies around testing PrEP interventions, and limited generalizability to all Black women at risk for HIV. Nonetheless, this review still provides valuable insight into the barriers to uptake and adherence among Black women. Moreover, this review provides recommendations for effective techniques which may address the outlined barriers and challenges.

Conclusion

This systematic review found that there are a variety of behavioral, social, and structural barriers affecting Black women's uptake and adherence to PrEP. Additionally, many of these barriers were unique to Black women and often intersected. The intersection of these barriers is an additional challenge to the uptake of PrEP and requires a multi-faceted approach. Approaches aimed at increasing PrEP uptake in the Southeast need to be culturally sensitive and informed by the intersectional barriers that Black women face. Lastly, this systematic review revealed that there is a lack of PrEP research and promotion focused on Black women. Future research targeting PrEP use among Black women needs to incorporate both qualitative and quantitative methods to better understand the ways in which behavioral, social, and structural barriers affect Black women's sexual risk, PrEP use and what approach best addresses these barriers. Additionally, research centered PrEP use among Black women needs to incorporate the socio-economic and cultural and context-specific factors influencing PrEP use when making recommendations or informing future interventions. Overall, greater efforts need to be made to

decrease the gap in research and increase the application of PrEP in order to reduce the incidence and prevalence of HIV among Black women in the Southeast.

Figures & Tables

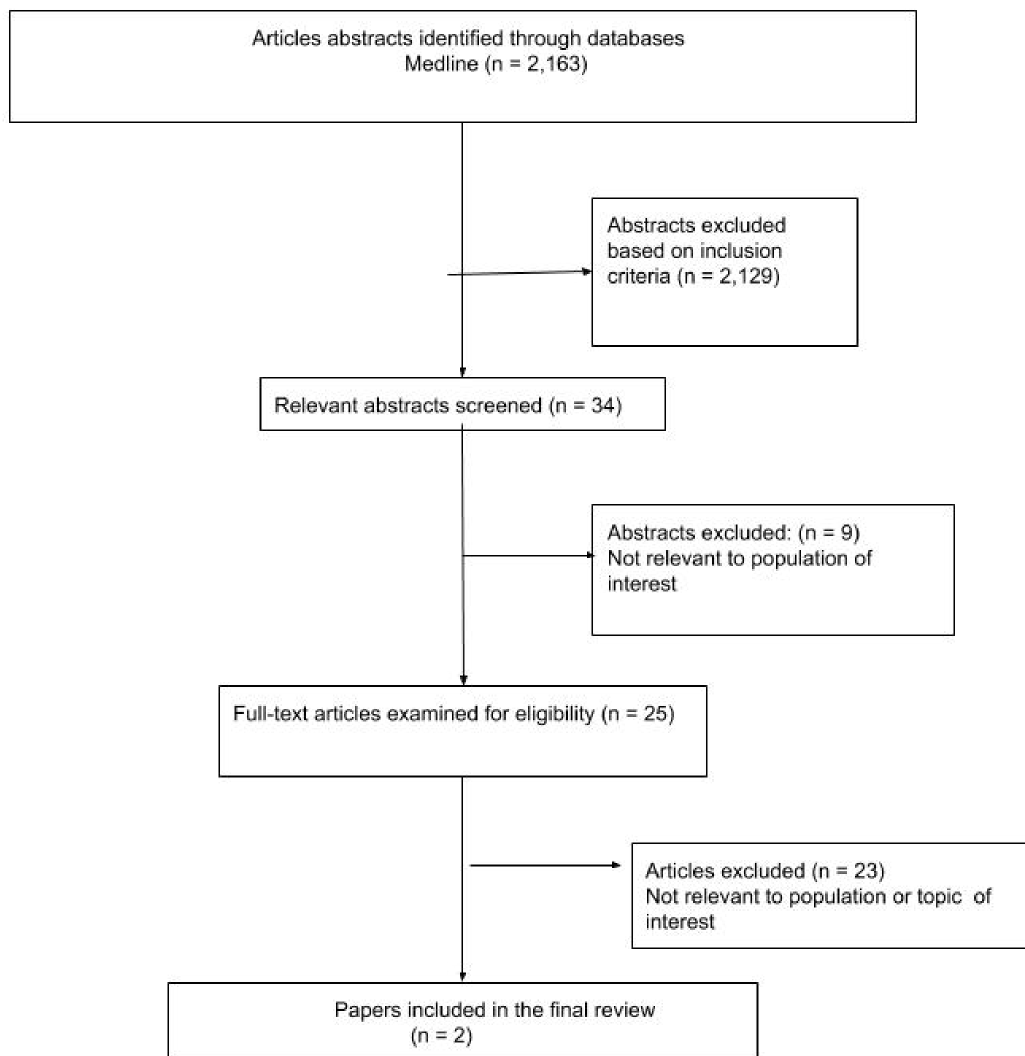

Figure 1: Inclusion and Exclusion Process

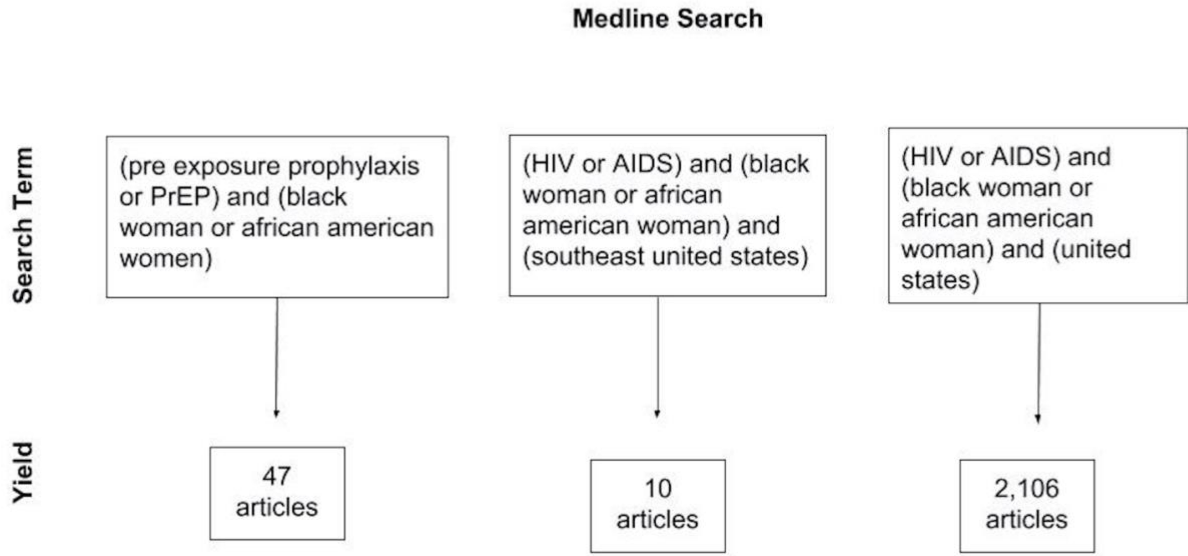

Figure 2: Medline Search

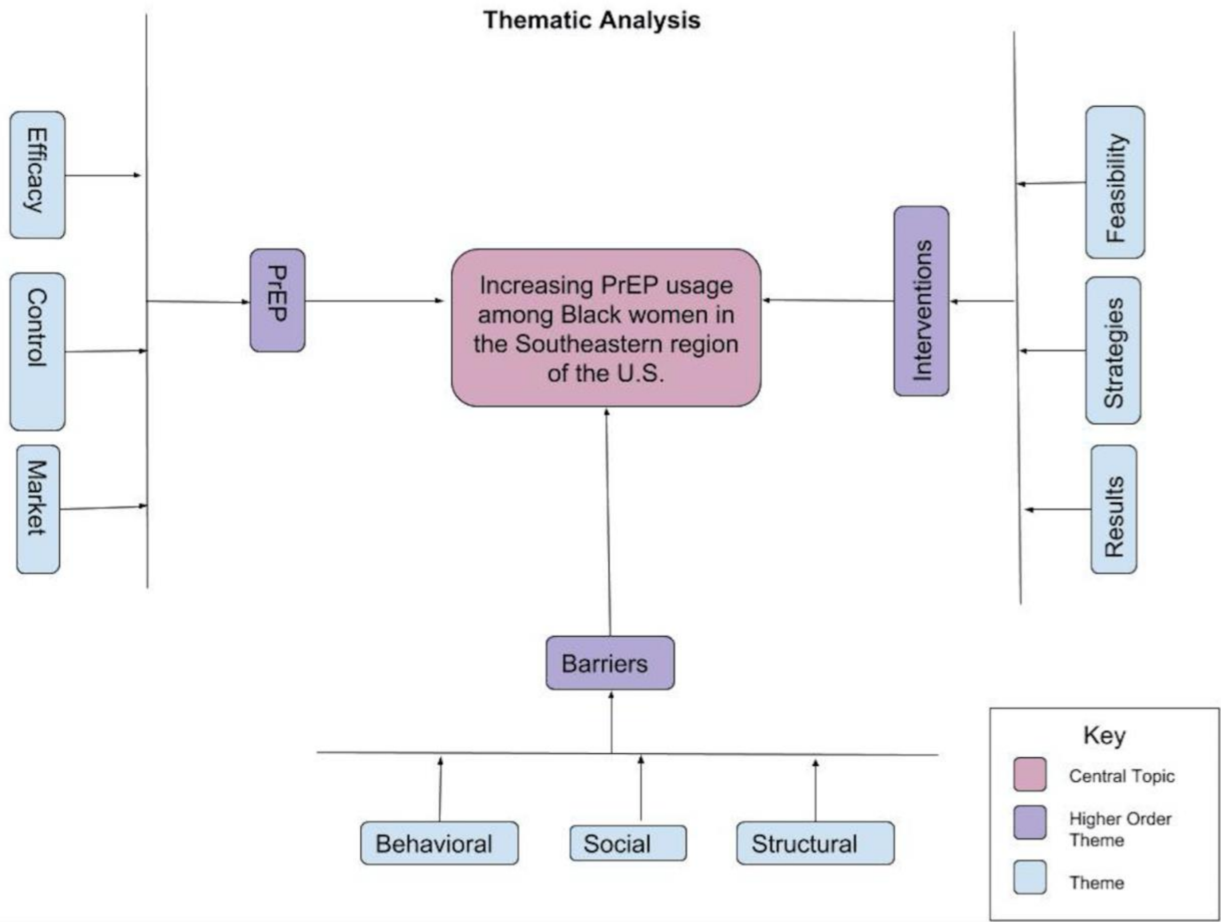

Figure 3: Thematic Map

MESH terms used	Free text search terms used (combined in multiple ways)
(pre exposure prophylaxis OR PrEP) AND (black woman OR african american women) (HIV OR AIDS) AND (black woman OR african american woman) AND (southeast united states) (HIV OR AIDS) AND (black woman OR african american woman) AND (united states	PrEP HIV prevention HIV Pre-exposure prophylaxis Black women Stigma Transgender Black Transgender Southeastern United States Barriers PrEP adherence Pre-exposure prophylaxis adherence PrEP interventions Safety Clinics

Table 1: MESH & Free Search Terms

Appendix

Studies Reviewed					
Article Title	First Author and Year	Research Type	Method of Data Collection	Analysis Method	Main Findings
The Role of Relationship Type, Risk Perception, and Condom Use in Middle Socioeconomic Status Black Women's HIV-prevention Strategies	Caldwell & Matthews, 2015	Qualitative	Focus groups & semi-structured interviews (n=23)	NVivo 9.0	Gendered power dynamics in sexual partnerships can reduce some middle SES Black women's likelihood to prioritize HIV risk prevention. from HIV risk.
Explaining the Efficacy of Pre-Exposure	Underhill et al., 2016	Qualitative	8 focus groups & 56	NVivo 9.0	preference for numerical information

Prophylaxis (PrEP) for HIV Prevention: A Qualitative Study of Message Framing and Messaging Preferences among US Men Who Have Sex with Men			individual in-depth interviews		about drug efficacy, Participants generally preferred success-framed and two-sided messages compared to failure-framed messages about efficacy, citing the need for optimism in order to motivate initial PrEP uptake.
Attitudes and program preferences of African American urban young adults about pre-exposure prophylaxis (PrEP)	Smith et al., 2012	Qualitative	Focus groups	NVivo	Interest in PrEP was associated with its cost, effectiveness, and ease of accessing services and medication near to their homes or by public transportation.
Perceived Advantages and Disadvantages of Using Pre-Exposure Prophylaxis (PrEP) among Sexually Active Black Women	Bond & Gunn, 2016	Qualitative	Open-ended questions	NVivo 9.0	PrEP can empower Black women to take control of their health and their sex lives.

Associations of Sex Ratios and Male Incarceration Rates with Multiple	Pouget et al., 2010	Cross-sectional	in-home survey and mobile examination centers for biological assessments and surveys of data considered sensitive, such as sexual behavior	SUDAAN®	Sex ratios and incarceration rates varied greatly by race/ethnicity; however, we observed significant associations within each racial/ethnic group. Non-Hispanic black men in counties with a greater shortage of males (adjusted odds ratio [AOR] = 1.9; 95% confidence interval [CI] 1.1, 3.5) and a greater number of incarcerated males (AOR=1.6; 95% CI 1.1, 2.3) in the non-Hispanic black population had significantly greater odds of having two or more partners.
Knowledge, Attitudes, and Likelihood of Pre-Exposure Prophylaxis (PrEP) Use Among US Women at	Auerbach et al., 2015	Qualitative	Focus groups	N/A	(1) were dismayed—in fact many were angry—that they had not heard about PrEP prior to the

Risk of Acquiring HIV					focus group discussion; (3) had distinct ideas about how PrEP might affect their sex life, including the use of condoms; and (4) supported a range of PrEP delivery options, including pills, gels, injectables, and vaginal rings.
Leveraging Social Media to Explore Black Women's Perspectives on HIV Pre-exposure Prophylaxis	Hill et al., 2018	Qualitative	Facebook comments	Grounded theory	Mistrust of government and the pharmaceutical industry as a prominent theme.
'I am not a man': Trans-specific barriers and facilitators to PrEP acceptability among transgender women	Sevelius et al., 2016	Qualitative	3 Focus groups & 9 individual qualitative interviews (n=30)	Concept analysis	Unique sociocultural context of trans women's lives when considering how PrEP might best be marketed to them as a tool Furthermore, trans women do not benefit from programming and services

					that are designed for MSM or offered through clinics that primarily serve MSM.
Inclusion of Trans Women in Pre-Exposure Phrophylaxis (PrEP): A Review	Escudero et al., 2015	Systematic review	Published randomized clinical trials	N/A	Inclusion of trans women in PrEP trials has been minimal.
Intersectional stigma among midlife and older Black women living with HIV	Sangaramoorthy et al., 2017	Qualitative	Semi-structured interviews (n=35)	NVivo 11	Understanding of HIV requires considering complex manifestations of intersectional stigma among Black women

Table 2: Reviewed Studies

References

Auerbach, J. D., Kinsky, S., Brown, G., & Charles, V. (2015). Knowledge, attitudes, and likelihood of pre-exposure prophylaxis (PrEP) use among US women at risk of acquiring HIV. *AIDS patient care and STDs*, *29*(2), 102-110.

Bond, K. T., & Gunn, A. J. (2016). Perceived Advantages and Disadvantages of Using Pre-Exposure Prophylaxis (PrEP) among Sexually Active Black Women: An Exploratory Study. *Journal of black sexuality and relationships*, *3*(1), 1.

Caldwell, K., & Mathews, A. (2015). The role of relationship type, risk perception, and condom use in middle socioeconomic status black women's HIV-prevention strategies. *Journal of black sexuality and relationships*, *2*(2), 91.

CDC (2016). Common Barriers to Participation Experienced by People with Disabilities. Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html

CDC (2017). HIV/AIDS. Retrieved from https://www.cdc.gov/hiv/programresources/guidance/costeffectiveness/index.html

Cornell (2017). Gray Literature. Retrieved from http://guides.library.cornell.edu/graylit

Crosby, R. A., Salazar, L. F., Hill, B., & Mena, L. (2018). A comparison of HIV-risk behaviors between young black cisgender men who have sex with men and young black transgender women who have sex with men. *International journal of STD & AIDS*, 0956462417751811.

Eisert, S. L., Mehler, P. S., & Gabow, P. A. (2008). Can America's Urban Safety net systems be a solution to unequal treatment?. *Journal of Urban Health*, *85*(5), 766-778.

El-Bassel, N., Caldeira, N. A., Ruglass, L. M., & Gilbert, L. (2009). Addressing the unique needs of African American women in HIV prevention. *American journal of public health*, *99*(6), 996-1001.

Escudero, D. J., Kerr, T., Operario, D., Socías, M. E., Sued, O., & Marshall, B. D. (2015). Inclusion of trans women in pre-exposure prophylaxis trials: a review. *AIDS Care*, *27*(5), 637-641.

Fonner, V. A., Kennedy, C. E., O'Reilly, K. R., & Sweat, M. D. (2014). Systematic assessment of condom use measurement in evaluation of HIV prevention interventions: need for standardization of measures. *AIDS and Behavior*, *18*(12), 2374-2386.

Galvan, F. H., Davis, E. M., Banks, D., & Bing, E. G. (2008). HIV stigma and social support among African Americans. *AIDS patient care and STDs*, *22*(5), 423-436.

Gilead (2016). Gilead Patient Assistance. Retrieved from http://www.gilead.com/responsibility/us-patient-access

Green, E. C., & Murphy, E. (2014). Health belief model. *The Wiley Blackwell encyclopedia of health, illness, behavior, and society*.

Hausmann, L. R., Jeong, K., Bost, J. E., & Ibrahim, S. A. (2008). Perceived discrimination in health care and health status in a racially diverse sample. *Medical care*, *46*(9), 905.

Hill, B. S., Patel, V. V., Haughton, L. J., & Blackstock, O. J. (2018). Leveraging Social Media to Explore Black Women's Perspectives on HIV Pre-exposure Prophylaxis. *Journal of the Association of Nurses in AIDS Care*, *29*(1), 107-114.

Ivy, W., Miles, I., Le, B., & Paz-Bailey, G. (2014). Correlates of HIV infection among African American women from 20 cities in the United States. *AIDS and Behavior*, *18*(3), 266-275.

Marcus, J. L., Buisker, T., Horvath, T., Amico, K. R., Fuchs, J. D., Buchbinder, S. P., ... & Liu, A. Y. (2014). Helping our patients take HIV pre-exposure prophylaxis (PrEP): a systematic review of adherence interventions. *HIV medicine*, *15*(7), 385-395.

McCree, D. H., Oster, A. M., Jeffries IV, W. L., Denson, D. J., Lima, A. C., Whitman, H., ... & Henny, K. D. (2017). HIV acquisition and transmission among men who have sex with men and women: what we know and how to prevent it. *Preventive medicine*, *100*, 132-134.

Newsome, V., & Airhihenbuwa, C. O. (2013). Gender ratio imbalance effects on HIV risk behaviors in African American women. *Health promotion practice*, *14*(3), 459-463.

NIH (2018). HIV/AIDS Glossary. Retrieved from https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/158/community-based-organization

Pouget, E. R., Kershaw, T. S., Niccolai, L. M., Ickovics, J. R., & Blankenship, K. M. (2010). Associations of sex ratios and male incarceration rates with multiple opposite-sex partners: potential social determinants of HIV/STI transmission. *Public health reports*, *125*(4_suppl), 70-80.

WHO (2018). Metrics: Disability-Adjusted Life Year (DALY). Retrieved from http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/

Riley, E. D., Neilands, T. B., Moore, K., Cohen, J., Bangsberg, D. R., & Havlir, D. (2012). Social, structural and behavioral determinants of overall health status in a cohort of homeless and unstably housed HIV-infected men. *PloS one*, *7*(4), e35207.

Sangaramoorthy, T., Jamison, A., & Dyer, T. (2017). Intersectional stigma among midlife and older Black women living with HIV. *Culture, health & sexuality*, *19*(12), 1329-1343.

Schackman, B. R., Fleishman, J. A., Su, A. E., Berkowitz, B. K., Moore, R. D., Walensky, R. P., ... & Freedberg, K. A. (2015). The lifetime medical cost savings from preventing HIV in the United States. *Medical care*, *53*(4), 293.

Sevelius, J. M., Keatley, J., Calma, N., & Arnold, E. (2016). 'I am not a man': Trans-specific barriers and facilitators to PrEP acceptability among transgender women. *Global Public Health*, *11*(7-8), 1060-1075.

Smith, D. K., Toledo, L., Smith, D. J., Adams, M. A., & Rothenberg, R. (2012). Attitudes and program preferences of African-American urban young adults about pre-exposure prophylaxis (PrEP). *AIDS Education and Prevention*, *24*(5), 408-421.

Underhill, K., Morrow, K. M., Colleran, C., Calabrese, S. K., Operario, D., Salovey, P., & Mayer, K. H. (2016). Explaining the efficacy of pre-exposure prophylaxis (PrEP) for HIV prevention: A qualitative study of message framing and messaging preferences among US men who have sex with men. *AIDS and Behavior*, *20*(7), 1514-1526.

U.S. Census (2010). 2010 Census Data Retrieved from https://www.census.gov/2010census/data/