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## Using an Intersectional Framework to Understand the Challenges of Adopting Pre-exposure Prophylaxis (PrEP) Among Young Adult Black Women

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### Abstract

**Introduction**—There is limited functional knowledge and utilization of pre-exposure prophylaxis (PrEP) among young adult Black cisgender women (YBW).

**Methods**—We conducted four focus groups with YBW using an intersectional framework to explore multiple levels of factors that impede YBW awareness, interest, and utilization of PrEP in conjunction with their sexual and reproductive healthcare needs.

**Results**—Influences at the cultural-environmental level included a lack of information and resources to access to PrEP and medical mistrust in the healthcare system. At the social normative level, influences included attitudes towards the long-term effects on sexual and reproductive health and self-efficacy to follow the PrEP regimen. At the proximal intrapersonal level, influences included anticipated HIV stigma from family and peers along with the fear of rejection from their main partners.

**Conclusions**—Translation of these results indicated that interventions to increase PrEP utilization and adherence among YBW will require multi-level strategies to address barriers to integrating HIV prevention into sexual and reproductive healthcare.

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## Keywords

HIV; Sexual reproductive health; Pre-exposure prophylaxis; Cisgender women; Young adult; Black/African American; Intersectionality

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## Introduction

Black individuals are disproportionately affected by HIV/AIDS compared to their overall representation in the US population (Centers for Disease Control and Prevention [CDC], 2019). However, Black women (cisgender and transgender) appear to be at increased susceptibility to HIV infection, not only because of racial inequities but also because of gender-based inequalities in social and economic conditions that are reflected in disparities observed in incidences of HIV and other sexually transmitted diseases (Poteat et al., 2020; Centers for Disease Control and Prevention, 2019). Black cisgender women accounted for 11% of all new HIV infections in the USA and the majority (57%) of all new infections among women in 2018, which were attributed to heterosexual contact (92%) (Centers for Disease Control and Prevention, 2019). Black women have a higher probability of exposure to HIV despite engaging in more protective behaviors, such as condom use, compared to women of other racial groups (Caldwell & Mathews, 2015; Paxton, Williams, Bolden, Guzman, & Harawa, 2013). This suggests that Black cisgender women experience vulnerability to HIV infection due to social and structural factors, such as racism, living in sexual networks in high HIV prevalence areas, social stigma, poverty, lack of access to healthcare, and imbalanced relationship power dynamics (El-Bassel, Caldeira, Ruglass, & Gilbert, 2009; Frew et al., 2016; Watkins-Hayes, 2014).

Interrelated systems of racism-related oppression of Black cisgender women in the USA, including interpersonal racism, personally mediated racism, and internalized racism, all contributed to the way in which Black cisgender women of all ages experience health inequalities (Prather et al., 2018; Prather, Fuller, Marshall, & Jeffries IV, 2016). These challenges not only call for the integration of individually controlled, HIV prevention strategies, such as preexposure prophylaxis (PrEP) with sexual and reproductive health (SRH) practices, but the deviation from the “one size fit all” approach to HIV prevention. PrEP, under the brand name Truvada, is the first and only, commercially available HIV prevention method that offers Black cisgender women an alternative to strategies that rely on partners (Van Damme et al., 2012). PrEP has the potential to reduce a person’s risk of contracting HIV by more than 90% if taken correctly (Van Damme et al., 2012). However, the difference between the number of persons with PrEP indications and those prescribed PrEP is substantial, especially among Black cisgender women (Huang, Zhu, Smith, Harris, & Hoover, 2018). There is an estimated 468,000 women at significant risk of HIV acquisition and eligibility for PrEP (Huang et al., 2018), yet the uptake has been relatively limited and slow among all cisgender women in the USA with many female users being in serodiscordant relationships (one partner HIV-positive, one partner HIV-negative) for conception purposes (Blackstock, Patel, Felsen, Park, & Jain, 2017; Smith, Toledo, Smith, Adams, & Rothenberg, 2012; Weinstein, Yang, & Cohen, 2017). Cisgender women accounted for 3,678 (4.7%) of the 78,360 PrEP users, which is only 2.1% of the estimated

176,670 heterosexual women for whom PrEP is indicated (Huang et al., 2018). Among the estimated 1.1 million adults for whom PrEP is indicated, 43.7% were Black; however, among current PrEP users, only 11.2% were Black, indicating the need to focus on efforts to increase the impact of PrEP among underserved populations (Huang et al., 2018).

Systematic exclusion of women, and particularly Black cisgender women, in the initial dissemination of PrEP is associated with this large discrepancy between the numbers of persons with indications for PrEP and those who were prescribed PrEP (Aaron et al., 2018; Flash, Dale, & Krakower, 2017; Lambert, Marrazzo, Amico, Mugavero, & Elopre, 2018). Literature on the acceptability and adoption of PrEP among HIV-negative, ethnoracial minorities and heterosexual female community members in the USA is scarce (Bond & Gunn, 2016; Flash, Stone, Mitty, Mimiaga, Hall, Krakower, & Mayer, 2014). Despite Black cisgender women viewing PrEP as an empowering, individually controlled method that could be considered an option for women with risky sex partners, many are still unaware of its potential (Bond & Gunn, 2016). Among the few studies that have examined PrEP acceptability among young Black cisgender women (YBW) in the USA, YBW seem to be highly interested in PrEP compared to their white counterparts, but this interest is not reflected in number of active PrEP prescriptions among YBW (Garfinkel, Alexander, McDonald-Mosley, Willie, & Decker, 2017; Smith et al., 2012). Implications from the negative PrEP trials among cisgender women (Schuster, Reisner, & Onorato, 2016) in several countries in Africa highlight the need to explore implementation strategies that address the individual and systemic barriers for the uptake of PrEP among women in the U.S. (Marrazzo et al., 2015; Van Damme et al., 2012; Van der Straten, Van Damme, Haberer, & Bangsberg, 2012). The lack of engagement in the PrEP care continuum and the given the number of complex barriers related to HIV prevention among Black cisgender women in this new era of combination prevention options is a reflection of their intersectional invisibility in the healthcare system (Purdie-Vaughns & Eibach, 2008). More precisely, intersectional invisibility (Purdie-Vaughns & Eibach, 2008) indicates that Black women can be affected when broader health strategies fail to understand their particular experiences of both racism and sexism (Prather et al., 2018). Intersectionality theory provides an approach for examining how a group such as Black women experiences unique consequences as a function of their race and gender identities which is essential to identifying the kind of information and support that could assist YBW in making sexual health decisions (Bond & Gunn, 2016; Chapman Lambert, Marrazzo, Amico, Mugavero, & Elopre, 2018; Flash et al., 2017). In light of these complex vulnerabilities, an intersectional approach was used to explore the intrapersonal, interpersonal, and sociocultural-environmental factors that influence young Black women's HIV sexual risk behavior and factors that would influence their utilization of oral PrEP.

## Methods

### LOVE Study

The primary study, the LOVE (Learning Options through Video Education) study, is a mixed-method study focused on exploring the factors that facilitate and impede YBW's interest in oral PrEP and investigate the feasibility of using a brief eHealth intervention to

increase awareness and motivation for PrEP (Bond, 2018). The LOVE study utilized focus groups to identify key barriers and facilitators to PrEP utilization among YBW to develop and evaluate the acceptability of a brief eHealth intervention for increasing awareness and motivation for PrEP among YBW.

### Study Sample

Women were recruited (July 2016–October 2017) from two community-based organizations (CBOs) located in New York City that provided services to young adults and through social networking websites (e.g., Craigslist and Facebook) in New York City. A member of the research team (KTB or PW) screened women for the following criteria: (1) 18 to 25 years old; (2) self-identified as heterosexual; (3) self-identify as African American, Black, Caribbean Black, or multiethnic Black; (4) self-reported negative or unknown HIV status; (5) reported oral, vaginal or anal sex with a man in the past 12 months, (6) current or past problematic substance use; (7) and reside in New York City. We screened 78 women, of whom 37 (47%) were eligible to participate. The final sample included 26 women who engaged in research activities.

### Procedures

Study visits were conducted in English by trained research staff in a private space at one of the CBO recruitment sites. After screening for eligibility, participants underwent a detailed verbal informed consent process before data collection commenced. Eligible women were invited to complete a brief assessment survey administered by tablet or paper and participate in a focus group discussion. The survey included validated measures to assess women's initial knowledge of PrEP, HIV knowledge, sexual behaviors, relationship dynamics, self-efficacy, and HIV stigma. Four focus groups that consisted of six to seven women ( $N=26$ ) were conducted in English, took approximately 2 h to complete, audio-recorded, and facilitated by the first author and a trained research assistant. Participants who completed focus groups were compensated \$45 and a round-trip public transportation for the completion of the study. To preserve confidentiality, data was de-identified, stored in a secured location, and securely transferred to investigators involved in the analysis. The study was reviewed and approved by the Institutional Review Boards of the National Drug and Research Institute, Inc. and New York University (IRB-FY2017-408).

### Focus Group Discussion: Theoretical Basis and Content

The frameworks of the intersectionality and the theory of triadic influence (TTI) guided the development of the focus group guide and analysis. TTI includes a focus on three streams of influence, which includes (1) sociocultural-environmental influences on knowledge and values; (2) social situation contextual influences on social bonding and social learning; and (3) intrapersonal influences on self-determination/control and social skills (Flay & Petraitis, 1994; Flay, Snyder, & Petraitis, 2009). TTI explains behavior as being the result of three streams of causes of behavior (*intrapersonal*, *interpersonal*, and *sociocultural-environmental*) that flow through several levels of causation (ultimate→distal →proximal) (Flay & Petraitis, 1994; Flay et al., 2009). Factors in each of the three streams interact with factors in each of the other streams. All three streams converge on decisions/intentions as the final predictor of behavior (Flay & Petraitis, 1994; Flay et al., 2009). The purpose of the study was to explore

the intrapersonal, interpersonal, and sociocultural environmental factors that influence Black women's utilization of PrEP, therefore, it is important to identify a framework, such as intersectionality, that reflects how co-existing identities (e.g., Black, woman) and connected systems of oppression (e.g., patriarchy, white supremacy) interact to maintain a structural power imbalance (Collins, 2000; Crenshaw, 1989). The concept of intersectionality created by Kimberlé Crenshaw argues that these multiple oppressions are a synthesized experience (Crenshaw, 1989). Using a Black feminist intersectional approach further acknowledges that Black women have a shared history embedded in how multiple oppressions (race, class, and gender discrimination) have impacted on their lives and how black women have resisted structural intersectionality (Collins, 2000; Crenshaw, 1989; Isoke, 2013). The application of an intersectional lens in qualitative research allows us to examine beyond the limitations of quantitative and qualitative health science studies (Abrams, Tabaac, Jung, & Else-Quest, 2020; Stephens & Phillips, 2005). The use of both intersectionality and TTI supports an analysis which considers how multilevel influences shape Black women's PrEP utilization and how they define and navigate their realities as it pertains to the biomedical HIV prevention strategies they employ.

The primary goals of the focus groups were to elicit detailed descriptions and reflections of the intrapersonal, interpersonal, and sociocultural-environmental factors that impact attitudes toward PrEP and issues related to PrEP (e.g., sexual risk and protective behaviors, sexual partners, attitudes toward HIV medications, stigma) through the unique experiences created by YBW's interconnected identities. Focus group discussions were divided into three parts. Part One, the women's perceptions of normative sexual behaviors, intimate relationships, and sexual risk, including approaches to risk reduction and the personal, behavioral, and socio-structural factors that influence risk and riskreduction attitudes and behaviors. At the beginning of Part Two, participants watched a 5-min video that provided a detailed explanation of oral PrEP (e.g., dosing schedule, cost, potential side-effects, how to access PrEP). This was intended to ensure that all respondents had accurate information about this medication. Additionally, participants were given a written summary of this information they could refer back to if necessary during the subsequent discussions. Participants were asked what they liked and disliked about oral PrEP; respondents were encouraged to focus on specific likes and dislikes that could be unique to Black women. Table 1 illustrates sample questions from parts 1 and 2 of the focus group guide. In part 3 (which is not addressed in this paper), participants elicited feedback on preliminary thinking regarding eHealth intervention characteristics for increasing knowledge and utilization of PrEP among young Black women.

## Data Analysis

Descriptive statistics were calculated for the focus group participants using IBM SPSS Statistics 26(IBM Corp and Released, 2019). Digital recordings of focus group discussions were transcribed and imported into Dedoose software (Dedoose Version 8.0.35, 2018) for coding and analysis. Codes were identified by the two lead analysts (KTB & AG) and a research assistant (PW) trained in qualitative methods, using a multilayered strategy was generated based on topics addressed by the focus group guide. We used a thematic analysis driven by grounded theory to inform this research (Braun & Clarke, 2006).

Analysis occurred in two stages, corresponding to the inductive approaches of open coding and axial coding used in grounded theory (Patton, 1990; Strauss & Corbin, 1997). The coding process entailed all three analysts reading through the transcripts twice to familiarize themselves with the data before coding began (Bogdan & Biklen, 1997). This was done to achieve a clearer overall perspective of the context as well as participants' expectations and experiences in order to minimize the possibility of the analysts' own subjective opinions during analysis of the data. The team analyzed the first focus transcript jointly to ensure that the meaning, interpretation, and analytic approach were uniform across coders. The initial open coding phase was conducted by the research team and consisted of an iterative process; wherein codes were re-organized, redefined, divided, and grouped into larger themes or experiences described by participants that characterized their perceptions of oral PrEP. The codebook was refined through comparison, categorization, and discussion of the interpretation of codes.

Finally, all rater themes and lists were independently reviewed response codes that did not fit within the deductive themes and identify new, inductively derived themes. The team constructed new themes that are not described by previous literature, with corresponding definitions to capture the prevalent characteristics described by the participants. This coding process allowed for the extraction and sorting of the text by themes, which helped elucidate the range of participant experiences and perceptions and allowed for the exploration of new and unanticipated relationships, interactions, and patterns. Both theory-driven (deductive) and data-driven (inductive) stages of analysis were used to generate themes from the response codes. The codebook was refined through comparison, categorization, and discussion of the interpretation of codes. As our goal was to understand the perspective of factors that facilitate and impede YBW's interest in PrEP. Here, we present accounts of the major, representative themes related to barriers and challenges to PrEP uptake among YBW. To ensure that themes represented data in a consistent way, all analysts worked separately to identify codes.

## Results

### Sample Description

Among the 26 focus group participants, all identified as Black or African American, with a mean age of 22 years (range 18–25 years), and all but two (92%) were born in the USA. Prior to participating in this study, 65% and 73%, respectively, reported that they heard of post-exposure prophylaxis (PEP) and PrEP. None of the participants reported taking PEP or PrEP in their lifetime. Table 2 describes the demographic characteristics and sexual risk behaviors of the study participants, including condom use, HIV testing practices, STI history, and PrEP knowledge.

### Qualitative Analysis Results

The aim of this study was to address the gaps in knowledge about barriers that are unique to YBW's PrEP utilization, our findings focus on the issues that were raised that are relevant to the sociocultural context of young Black women's lives. Some of the barriers to PrEP utilization identified by the participants are common among many populations susceptible

to HIV infection, such as concerns about cost, general side effects (e.g., kidney issues) and sexual risk disinhibition (e.g., decrease condom use) (Bond & Gunn, 2016; Flash et al., 2014; Namey et al., 2016), yet the unique experiences of YBW have rarely been centered in most literature on PrEP. Narratives about barriers to PrEP utilization and acceptability centered around six key themes: lack of information and knowledge and medical mistrust in the sociocultural environment stream; HIV stigma and fear of main partner rejection in the social normative stream; and maintenance and long-term effects on reproductive health in the intrapersonal stream (Fig. 1).

### Cultural-Environmental Stream

**Lack of Information and Resources.**—Across the focus groups, participants reported very little knowledge of PrEP (only one participant had extensive knowledge of PrEP because she worked in HIV prevention). As noted by one woman:

“I was just going to say if there’s more of an awareness that it’s [PrEP] out there, then there would probably be some people that would consider taking it and then there’s going to be some people that would just be like no it’s not that serious. It’s not a clear cut yes or no answer. I just feel there’s just more of a whether or not people know about it.”

Among those who have heard about PrEP, there was some misinformation and confusion about the PrEP regimen and guidelines about who should be prescribed PrEP. Women perceived PrEP to be primarily for men, particularly in same sex relationships, as described here:

“I heard about PrEP but when I heard about it, it was for men. I don’t know if I’m right this is what I’m remembering. It was for gay men and you take it every day to prevent yourself and um yeah, but now I heard they have it for women too now. I don’t know much about it.”

Some participants expressed their anger towards the lack of marketing and promotion of PrEP to women, particularly Black women, as one participant expressed:

“Society is trying to keep us in this bubble of uneducation or miseducation because if ... I believe HIV rates in Black women are the highest. If that’s the case, then that’s the group that should be targeted and most educated about this because if it’s preventable then that should be on the forefront of every [clinic], just like condoms are right there, of every clinic. That’s horrible that we’re not being told about this.

The women also discussed how a lack of insurance coverage or high-out-of-pocket prices for PrEP would deter them for initiating PrEP. Since the participants were at an age where they continued to receive medical insurance coverage from their parents’ insurance, they preferred for PrEP to be a modestly priced prescription or no cost. As noted by one participant:

“So I would ask the doctor to make sure that insurance covers it because I know my parents wouldn’t be willing to spend x amount of money on something that costs thousands of dollars. So if it was reasonably priced or no payment, then I would probably consider taking it.”

**Medical Mistrust.**—Participants reported concerns about taking an optional medication to prevent HIV infection due to the side effects. One participant compared her hesitation to taking PrEP to the same hesitation that people have to taking vaccines:

“There are a whole bunch of things that they [doctors] give you, and it is like, why should I take it then? I’m trying to prevent something and you’re adding on more. I don’t get it.”

They expressed distrust in HIV research and believed that if they have a medicine that could prevent HIV infection; they also have a cure available that is not being distributed.

“If you can find ways to combat the HIV virus then that means that there’s a cure. Those medicines, they’re just – They keep the industry going for medicine. They keep getting paid on the backs of the Black community.”

Some were not interested in using PrEP at all, due to mistrust of medicine and belief that pharmaceutical companies had access to a cure for HIV, but prioritize money over people’s lives. Moreover, women had concerns about the effectiveness of taking vaccines to build up immunity, and compared that same concern about PrEP’s effectiveness.

“It’s not that I’m stubborn. It’s because they say that the vaccines “make you immune” to certain things but a lot of people, when they get these vaccines, they get it. So how can PrEP be different?”.

### **Social Normative (Interpersonal) Stream**

**Fear of Rejection.**—The findings revealed that respondents were also concerned about being rejected by their sex partners or being accused of infidelity. There was a collective response among the participants that it would be difficult to introduce PrEP within an established relationship.

“It may cause friction because he might be on team petty and like I’m like, “So what are you trying to say?”

They identified men’s suspicion about infidelity as a barrier to safer sex communication and subsequently a barrier to initiating PrEP. One woman provided an example of how disclosing PrEP usage to a partner would be difficult:

“Let’s say you’re on PrEP and you tell your significant other that you’re on PrEP and you give them details about what it’s actually about, I feel like if they don’t have HIV, they’re going to look at you like, “So are you trying to say I have it?”.

Women reported that men would become defensive about their sexual practice and HIV status if they were to incorporate PrEP in their relationship. Throughout many of the women’s narratives the fear of rejection and an assumption of being associated with having HIV as a result of utilizing PrEP permeated conversations about the potential usefulness of PrEP.

That’s what I was about to say... you’re in a relationship with somebody and you be like, “Hey. Here take this. This is PrEP. I want to start taking this because it might prevent us from HIV,” they’re going to start questioning things like why?



Why would you want to take this? Are you cheating? So even if it just prevents HIV, they're still going to question it because they're going to be like why do you want to take this? Unless you go to a doctor and then you bring it up before him.

As further evidenced, the participants reported that introducing PrEP in a romantic relationship may signal infidelity to male partners unless it is coupled by the reassurance and legitimacy of a doctor's word. This is interesting to consider in light of evidence that the focus group participants reported medical mistrust as being a barrier to PrEP utilization. Nevertheless, the quote provides evidence that women feared that they could not assuage the concerns of male partners who carried assumptions of female infidelity. These stigmatizing views are also displayed on the interpersonal level and may hinder women from engaging in safer sex practices.

"I think they'll [Black women] hide it because if they do mention it, they'll probably look like, Oh what are you doing? You out here hoing around or you got something? Should I be worried?" and stuff like that. I think that's the reason why they'll hide it because then they'll be like, "Oh if you don't get it why are you taking it? You should just stop taking it," and in all actuality they're just trying to protect themselves. I swear guys will try to knock out any way you try to protect yourself and anyhow."

While some women expressed that men's negative response would be justified in established relationships, others expressed that the introduction of PrEP in a relationship should not cause any conflicts within the relationship. PrEP should be acceptable in any relationship because it is a safer sex strategy that would reassure both partners' lower risk of HIV infection. Another response to the accusation of infidelity was that PrEP only prevented HIV infection.

"But how [could PrEP cause conflict] if we can still get other stuff, you know? We could still be cheating or not because we can still get other stuff so if we're just preventing ourselves from catching HIV which is the most – What most people don't want to get, HIV or AIDS, then it shouldn't be a problem to guys. They should know that they can still get chlamydia."

The women acknowledged that infidelity could increase your risk of other sexually transmitted infections, making PrEP a viable option for only one risk (HIV infection) associated with unprotected sex.

**HIV Stigma.**—Anticipated HIV stigma associated with the use of PrEP was a common theme among the focus group participants. The women described the perceived consequences of other people knowing about them utilizing PrEP, including their family, friends, and sex partners. Participants felt that the pills could be misidentified as antiretroviral medications, which are more commonly known for HIV treatment. This misidentification would result in women perceiving stigma associated with having HIV as their informal networks would assume they are taking medication to treat their illness. As noted by one participant:

“Some ignorant people do say, ‘I’m not taking it because then somebody’s probably going to think that I have it [HIV] because I’m taking that pill.’”

Participants report that some women may be concerned about the public attitudes towards HIV and being identified as HIV positive.

“There’s a negative connotation behind people who catch HIV that weren’t born with it. I watched this movie one time and the guy was just like, “People that were born with AIDS, that’s sad. People that contracted it in their adult life or however, that’s just irresponsible.” And it’s like it has nothing to do with irresponsibility because you can have one boyfriend, have sex with that one boyfriend, get pregnant, get gonorrhea, get syphilis, get everything that this man has just from being with that one person. So, people are so stupid sometimes.”

Despite viewing PrEP as being beneficial to individuals who may feel that it would lower their vulnerability to HIV infection, respondents indicated a direct relationship between taking PrEP and assuming all the negative beliefs that are held about women living with HIV, particularly around irresponsibility, deservingness of the illness, and moral character. As evident in the above quote, assumptions that a woman who contract HIV/AIDS have engaged in sex with multiple partners and displayed a level of cavalier sexual risk taking that holds them culpable for acquiring HIV infection.

### Intrapersonal Stream

**Maintenance.**—Many of the women expressed the required PrEP regimen was not realistic for someone to adhere to strictly. Women have multiple priorities in their life that may not allow them to adhere to taking PrEP daily or increasing their number of routine HIV and STIs screenings.

“So yeah, it’s going to be a problem because everybody is doing something else every single day in their everyday life, running around and stuff like that. If they’re taking it at night or in the morning or in the afternoon, they might be outside so they might not remember to take it at that time and that’s messing up the whole cycle all over again.”

Some of the priorities discussed were recreational (e.g. clubbing, engaging in alcohol use), while others were considered crucial priorities such as employment and child care which could be hindered by routine testing. One woman described a scenario of her work schedule conflicting with having to make regular HIV and STI screening appointments:

“But if I have a shift and you’re telling me to come here about a screening and I already think I know what’s going to happen, I’m not coming because I got to make money. It’s just reality.”

In addition, they address that taking PrEP may be complicated and become an additional burden for women who are already taking hormonal contraceptives including birth control pills, skin patches, vaginal rings, or injections to prevent pregnancy.

**Long-Term Effects on Sexual and Reproductive Health.**—The participants were concerned with the possible side effects and safety of PrEP, including the long-term use of

PrEP. The women made comparisons between PrEP and common causes of infertility or high-risk pregnancies such as STDs and substance use.

“It [PrEP] could be like hookah. You know how you smoke hookah and you read the little ingredients? It is like you’re going to have difficulty getting pregnant. ... I’m like, ‘Oh hell no.’ I don’t want that”.

Many of the participants questioned the long-term use of PrEP on their reproductive health. As noted by one participant:

“It’s also the mixtures because you know how they say, ‘Oh you can’t take this medication if you’re taking this and you can’t take that.’ And I don’t know. For me, I’ll just be scared for the baby’s sake. I don’t know. My baby got kidney problems now because of the side effects that are on them.”

They were not only concerned with how it would impact their or ability to become pregnant in the future but also its effect on the baby.

“You know when you take too many different types of medication it brings difficulties with babies.”

In addition, participants were concerned that PrEP would make them more susceptible to HIV infection by reducing their body’s resistance to infection.

## Discussion

The current study examined knowledge, attitude, and experience with PrEP among YBW and their perspectives toward PrEP usage shows that there are multiple levels of influences that may impede YBW’s utilization of PrEP, including racism, sexism, and economic inequities. The barriers described in this study reinforced those found in previous studies, such as lack of information, access to resources, HIV-related stigma, fear of rejection from partners, medical mistrust, maintenance requirements of the PrEP regimen, and long-term effects (Auerbach, Kinsky, Brown, & Charles, 2015; Flash et al., 2017; Sevelius, Keatley, Calma, & Arnold, 2016). However, this study expands upon those factors by addressing the unique challenges that YBW face by incorporating PrEP as part of their sexual and reproductive health routine of care while dealing with stigma associated with gender racism (Prather et al., 2018). These findings suggest that existing prevention messages focused on PrEP utilization and current prescription protocols have not been reached or successful with cisgender women, specifically YBW, who are considered highly vulnerable to HIV infection because of disproportionate amount of reproductive and sexual health disparities (Aaron et al., 2018). This study focused on identifying whether YBW will be interested in using PrEP and able to sustain adherence in the context of the multilevel of influences that shape young Black women’s agency.

On the socio-cultural level, findings suggest that low knowledge, lack of resources, and medical mistrust have a strong influence on YBW uptake of PrEP. Among the participants in the study, there was low and inconsistent knowledge beyond general awareness of PrEP, especially as it relates to cisgender women. These findings are consistent with other studies with women, both cis- and transgender women, which identified low awareness

as a potential barrier to PrEP uptake (Bond & Gunn, 2016; Flash et al., 2017), but it expands on the current literature by assessing how low awareness further contributes to low perception of risk, minimizing the utilization of PrEP among this population. The participants did not see themselves as the target of the current messaging for PrEP, since most campaigns targeted gay men (Hirschhorn, Brown, Friedman, Greene, Bender, et al., 2020) and as a result did not fully understand the functionality of PrEP as part of their SRH care routine. Participants expressed that if women saw themselves as PrEP users they would be more willing to consider it as an option for HIV prevention. The lack of culturally responsive and attuned educational messages targeting cisgender women who have sex with men, specifically Black women, may cause women to have a low perception of HIV risk (Blackstock et al., 2015) and hinder acceptance of PrEP as an HIV prevention method (Hirschhorn et al., 2020). Previous research has shown that willingness to use PrEP has been associated with a higher perceived risk of HIV acquisition (Draper et al., 2017) and misunderstandings about PrEP can compound distrust of PrEP efficacy (Patel et al., 2018). This suggests that education and promotion strategies must be tailored to highlight the value of PrEP with Black women as PrEP users (Bond & Ramos, 2019) along with tailoring PrEP delivery to their needs in their daily lives to improve adherence (Haberer et al., 2019). Using community engagement approaches, such as engaging Black women directly throughout the research process and building partnerships with schools, faith-based organizations, and social services could provide an opportunity to develop strategies to address the immediate needs and concerns (Painter et al., 2014; Prado, Lightfoot, & Brown, 2013). Incorporating technology resources with community engagement strategies as an alternative to conventional health education approaches could increase awareness and ultimately influence the uptake of PrEP (Bond & Ramos, 2019) at the individual, interpersonal, and community-level for women.

The participants also expressed distrust in the medical system as it related to available HIV treatment as a barrier to PrEP uptake. Most medical mistrust research has focused on patient-provider interactions, but few have focused on the mistrust of the pharmaceutical industry and its influence on HIV treatment (Goparaju et al., 2017). The USA has a long history of reproductive oppression which included sterilization and administration of contraceptives without women's consent—particularly low-income women, Black, Indigenous women of color (Hodge, 2012), immigrant women, uninsured women, women with disabilities, women in prison (Mazza, 2011), and women whose sexual expression was not respected (Killien et al., 2000; Roberts, 1997; Sistersong: National Women of Color Reproductive Justice Collection, 2016). Previous research has reported that the Black individuals viewed drugs and devices related to sexual and reproductive healthcare with suspicion and distrust of medical science and government-sponsored healthcare because of historical reproductive oppression by both healthcare providers and politicians (Our Own Voices: National Black Women's Reproductive Justice Agenda, 2017). The participants describe their concern with taking an optional medication, such as PrEP, that could potentially increase health complications for someone who is HIV-negative (Jaiswal, Singer, Siegel, & Lekas, 2018). Participants in the current study also reported that the pharmaceutical industry had a cure for HIV that was not being distributed to the general public, especially among the Black population, which emphasizes that HIV conspiracy

theories (i.e., a cure for HIV exists and is being withheld from the public) and core AIDS denialism ideologies continue to exist despite medical advancements in HIV treatment (PrEP, postexposure prophylaxis, and treatment as prevention for viral suppression)(Brooks et al., 2018; Kalichman, 2018). Beliefs about the role and intentions of the government and pharmaceutical industry in the HIV epidemic have been reported in previous work examining conspiracy beliefs among HIVpositive individuals, but most studies are among Black men, specifically Black sexual minority men (Sauermilch, 2020). Future research should address both HIV conspiracy theory belief and institutional mistrust concurrently among Black women and other historically disenfranchised and maltreated populations to tailor HIV/AIDS interventions to the communities' needs without reinforcing the social stigma that impedes HIV care (Sauermilch, 2020).

Two primary normative social influences that impacted whether the participants would utilize PrEP included the PrEP-related HIV stigma that women would face if they started to take PrEP and the fear of rejection from their partners. The few studies that have examined PrEP-related HIV stigma only focused on interpersonal factors such as possible rejection by partners, peers, and family (Goparaju et al., 2017), but the participants in this study also described stigma on the socio-cultural level and how their co-existing identity as being both Black and women, limits their HIV prevention efforts. Previous research has addressed how HIV stigma critically hinders prevention efforts, which included routine testing and engagement treatment among HIV-positive individuals (Young & Bendavid, 2010). Gender, race, and class are usually treated as static identities, but when it comes to HIV prevention among Black women they are interconnected to their self-efficacy to engage in preventive behaviors (Hall & Pichon, 2014; Stephens & Phillips, 2005). Participants described including PrEP in their SRH routine as a challenge because of the stereotypes they may face because of their intersecting experiences of HIV-related stigma, racism, and sexism and gender discrimination.

Utilization of PrEP among YBW is impeded by the historical and present-day discrimination that Black women face within society, including inequities in the healthcare system (Castro & Farmer, 2005; Prather et al., 2018). The complexity of HIV-related stigma is more persistent among individuals marked by other forms of discrimination and social inequities compared to societies not affected by racism, sexism and poverty (Castro & Farmer, 2005; Prather et al., 2018; Rice et al., 2018). These social inequities, such as racism, sexism, and poverty that contribute to the risk of both HIV infection and HIV-related stigma may discourage young Black women to utilize PrEP (Mayer, Agwu, & Malebranche, 2020). Examining the stigma associated with HIV and the intersecting identities of Black women is essential to addressing how risk is framed for this population at the micro- and macro-level. Interventions centering Black women's health should explicitly address the contributing factors to community-level stigma that create barriers to engagement in the HIV neutral status care continuum which includes PrEP. Community-wide interventions to reduce stigma between individuals have been shown to have an impact on HIV stigma, preconceptions, stereotyping, and "othering" of people living with HIV (Beer, McCree, Jeffries IV, Lemons, & Sionean, 2019; Frye et al., 2017). These initiatives have been shown to increase awareness around HIV stigma and its effect on certain groups and communities, as well as to stop discriminatory behaviors (Beer, McCree, Jeffries IV, Lemons, & Sionean, 2019; Frye et al.,

2017). Explicit bias, implicit bias, microaggression, stereotype, and prejudice contribute to HIV stigma (Marcelin, Siraj, Victor, Kotadia, & Maldonado, 2019), but currently there are no structural interventions focused on women in the USA. Purposefully utilizing intersectional frameworks, such as critical race theory (West, 1995) and Black feminist thought (Collins, 2000) in the development of interventions and addressing stigma at the micro- and macro-level (Gwadz, Leonard, Honig, Freeman, Kutnick, & Ritchie, 2018) could have a positive influence on PrEP acceptance and adherence for YBW.

The PrEP-related HIV stigma described by the participants further increased the potential for sexual risk-taking including through the engagement in condomless sex (Bond & Gunn, 2016). Participants generally viewed PrEP as inducing tension in interpersonal relationships because they feared negative reactions from their sex partners. Some participants felt that PrEP would add a further layer of mistrust to their relationship, while others feared that others might mistake PrEP for ART which reflected the stigma around HIV, which would hinder their utilization of PrEP. Past and current literature provides evidence that relational challenges to promoting commitment, trust, and barrier-free intimacy have undermined Black women's negotiation of condom use and perpetuates their concerns regarding HIV risk (Kalichman, 2018). PrEP has been promoted as an individually controlled option for women, but it does not diminish the dyadic interdependence-related unprotected sex heterosexual relationships (Umberson, Donnelly, & Pollitt, 2018). The need for emotional closeness in heterosexual relationships is one of the most important challenges in reducing HIV risk (Gamarel & Golub, 2015, 2019; Hotton et al., 2015), and it still has an influence on PrEP uptake for women (van der Straten et al., 2014). A recent study in with mutually disclosed HIV-serodiscordant couples in Kenya and Uganda demonstrated success with HIV-uninfected partners using PrEP as a bridge until the partner living with HIV takes antiretroviral therapy to achieve viral suppression (Musinguzi et al., 2020; Pyra et al., 2018). Couple-centered HIV prevention and treatment interventions, specifically targeting Black heterosexual couples in the USA are limited, and primarily involve HIV serodiscordant heterosexual couples (Jiwatram-Negrón & El-Bassel, 2014). Future research should explore PrEP uptake among seroconcordant and unshared status heterosexual couples to improve communication and sexual decision-making skills among women who are vulnerable to HIV infection.

When the participants were informed about the PrEP regimen, they expressed additional concerns about how PrEP would realistically fit within women's lives as it relates to gendered social and economic burdens. The participants expressed their concerns about the structural impact of gender as it relates to challenges of adhering to a daily PrEP regimen while dealing with multiple responsibilities and potential long-term effects of the drug on their reproductive health and future children. These findings highlight the importance of a contextualized and integrated approach to sexual and reproductive health care for women (Seidman & Weber, 2016). It is necessary for women to adhere more consistently to oral PrEP than men to achieve equivalent protection due to differences in drug concentrations in the vagina compared with the rectum (Kelesidis & Landovitz, 2011). While previous research has suggested that new vehicles for PrEP may be the solution for adherence barriers for women (Krakower & Mayer, 2015), it does not address the social forces that complicate women's ability to sustain the regimen. Black women are influenced by socio-

cultural attitudes and practices that shape their individual opportunities, quality of life, and health risk and outcomes (Our Own Voices: National Black Women's Reproductive Justice Agenda, 2017). Healthcare providers integrating reproductive goals into HIV prevention would not only facilitate discussion of contraception, but also prompt conversations about the intersection of pregnancy and HIV susceptibility (Seidman & Weber, 2016).

### Limitations

It is important to point out that this study has several potential limitations. First, this is small sample of a selected group of heterosexual, young adult, low-income Black/African American, cisgender women living in high HIV prevalence urban neighborhood in New York City. We are aware that the small sample size limited our capacity of generalizing to what point these dynamics are representative of other Black American women who have sex with men. Second, this study took place in New York City, and some findings may not be applicable to other regions of the USA (e.g., US Southern region) where there is high prevalence of HIV infection among Black women. For example, access to PrEP, health insurance coverage, access to healthcare providers who prescribe PrEP in this context is likely higher in New York City compared to other parts of the country because of their regional PrEP expansion efforts. However, given the low uptake of HIV prevention medication among cisgender Black women in the US, the issues raised by participants may be representative and thus warrant further exploration. Third, we cannot assume that all Black American women are monolithic, it is important to recognize that the experiences of Black American women may vary depending on ethnicity, age, socioeconomic status, sexuality and environment. Future research should address unique needs of different subpopulations of Black women.

Lastly, focus group peer discussions about PrEP could have influenced other attitudes towards the utilization of this biomedical prevention strategy. Specifically, it is possible that those who had a favorable or unfavorable opinion of PrEP could have swayed the attitudes of other respondents on this topic within the focus group context. While the focus group method is well-understood as an effective strategy that allows the researcher to observe individuals' exchange of ideas, there is still the potential for the group influencing individual views expressed (Krueger & Casey, 2010). However, the first author took significant time in creating a space that promoted honesty and safety to mitigate the potential for perceived peer group judgment. Moreover, the focus group process can also be a context for creating community and support allowing respondents to more freely express their individual viewpoints (Barbour, 2007). Despite these limitations, the results of this study have important implications for addressing PrEP utilization among young Black American cisgender women.

### Conclusion

To ensure that PrEP will be an acceptable option for cisgender women, particularly YBW who are at risk for HIV infection, several suggestions are derived from this study. Effective interventions focused on the PrEP uptake and adherence for women will require a combination of behavioral, biomedical, and structural strategies that extend to policy

changes in how HIV care is treated in primary healthcare (Prevention Research Synthesis (PRS), 2020; Rotheram-Borus, Swendeman, & Chovnick, 2009). There is a need for PrEP outreach and education that is focused on women. This education should address the concerns and misconceptions that the focus group participants expressed such the lack of awareness of women as PrEP users and the fear of longterm side effects on their reproductive health. Community-level interventions that are culturally tailored are needed to reduce discrimination and raise awareness about PrEP and other components of the HIV continuum of care for women, both cis- and transgender women. This study identifies the needs to broaden the basic readiness requirements of drug adherence and risk compensation when implementing PrEP by addressing multiple levels of factors that could be fixed through policy and clinical practice. The standardization of integrated reproductive and HIV prevention services could support healthcare providers in communicating to potential female PrEP candidates and implementation of PrEP in women health services. In conclusion, despite the benefits of PrEP, it is important to acknowledge that new HIV prevention will not be readily embraced just because they are needed. To address the needs of women vulnerable to HIV infection and increase the utilization of PrEP among this population, we need to better understand the social and structural contexts in which biomedical innovations are introduced to facilitate the adoption of these HIV prevention approaches along with existing risk management strategies. It is important to note that most of the studies addressing PrEP usage among cisgender women in the USA are not focused on emerging adults, exclusively, and may miss an opportunity to identify engagement strategies for intervention. Addressing economic, gender, race inequities and reducing the HIV-related stigma that fuels the control of gender and sexuality expression is essential to alleviating the restrictions that YBW access to effective biomedical prevention options and ensuring access to comprehensive sexual and reproductive health information care.

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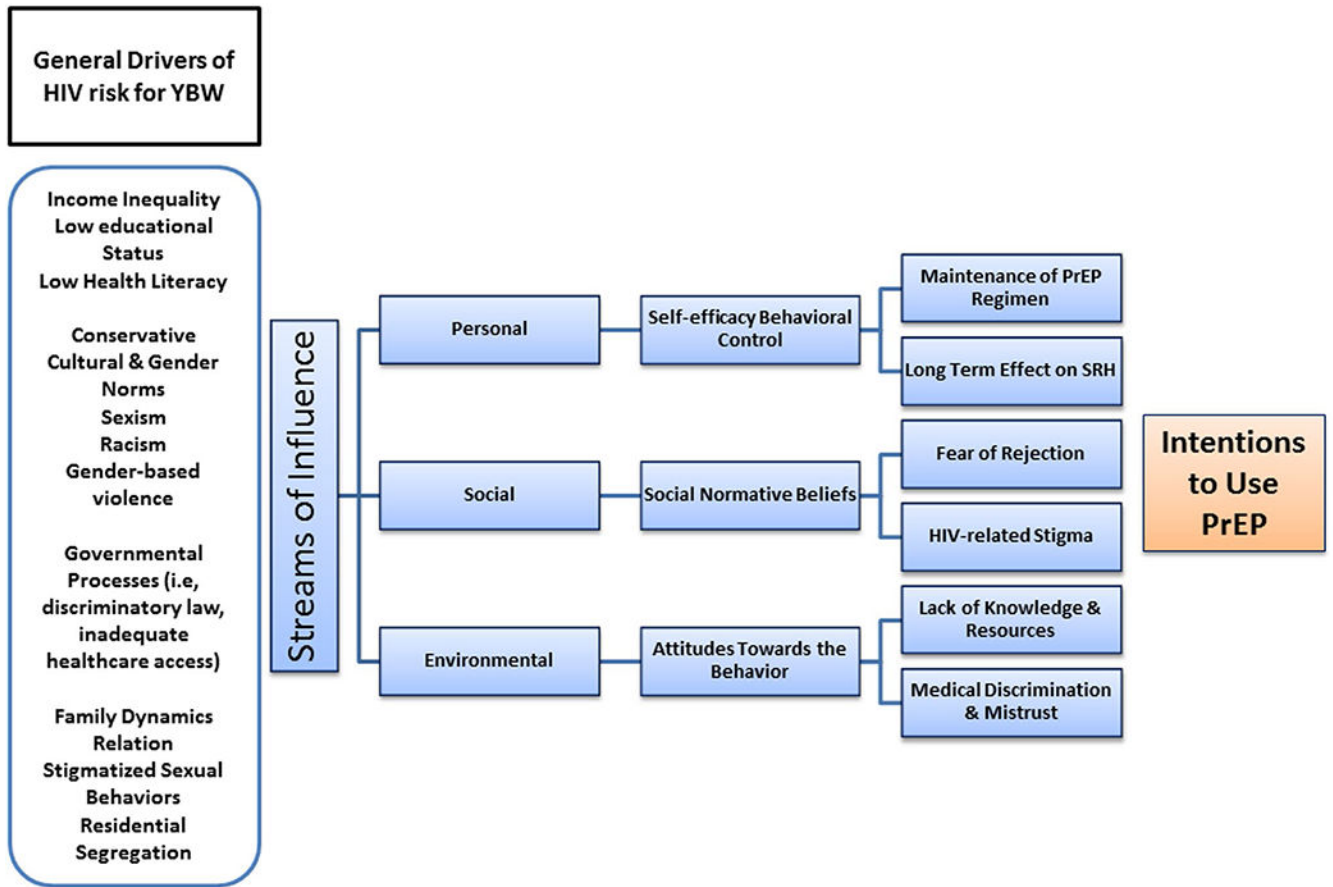
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**Fig. 1.** Factors influencing intentions to use PrEP among young adult Black women overlaid on the triadic theory of influence

**Table 1**

LOVE study focus group guide sample questions (parts 1 and 2)

Topic	Representative questions
Cultural and social factors	
Identity	What does it mean to you to be an African-American or Black woman?
Relationship dynamics	What experiences, both positive and negative, do you think that African-American or Black women have that <i>most</i> affect their sexual relationships?
Sexual behavior	In what ways do you think these experiences affect how African-American or Black women have sex? How do African-American or Black women protect themselves from HIV? What strategies do they use? What things encourage or motivate Black women to protect themselves from HIV? What encourages safer sex practices? What are the things that make it most difficult for African American/Black women and men—to protect themselves from HIV? More specifically, what are some of the things that encourage unsafe sex among African-American women?
Perspectives of safer sex practices	What are the things that motivate people to protect themselves from HIV? Are there some parts of the African-American community, who are at higher risk of getting HIV? Men or women? Young or old? If so, why do you think that is? What different things you do with your current partner to prevent HIV infection?
Pre-exposure prophylaxis	
Knowledge	Tell me what you think of PrEP for preventing HIV infection? What are some reasons why a woman would or would not want to use [have their partner use] this PrEP pill as a way of preventing HIV infection?
Adherence	What might be some reasons that women may not take the pill each day? What do you think can be done to help women on PrEP to take the pill as prescribed?
Relationship dynamic	What are some concerns that women might have about taking this PrEP pill? What are some concerns that women might have about their partner taking this PrEP pill? How likely is it that a woman would hide from her partner that she was taking PrEP?
Reproductive health	What if you were thinking about getting pregnant? Would you consider taking PrEP?

**Table 2**Characteristics of focus group participants ( $N = 26$ )

Characteristics	% (N)
Age (mean, SD)	22 (2.6)
US born	92 (24)
Education	
Less than high school	4 (1)
High school or GED	40 (10)
Some college/trade school	54 (14)
College degree	4 (1)
Current student	42 (11)
Employment	
Full-time	15 (4)
Part-time	39 (10)
Unemployed	46 (12)
Annual Income	
Less than \$19,999	73 (19)
\$20,000–\$39,000	8 (2)
More than \$40,000	19 (5)
Health insurance	100 (26)
Primary care provider	77 (20)
Has children	23 (6)
Sexual behaviors	
Relationship status	
Committed	62 (16)
Steady partner (past year)	
Sex with steady partner	82 (24)
Steady partner has other sex partner(s)	39 (10)
Inconsistent condom use with steady partner	81 (21)
Non-main partner(s) (past year)	
Sex with non-main partner(s)	39 (10)
Non-main partner(s) has other sex partner(s) $n = 10$	50 (5)
Inconsistent condom use with non-main partner(s) $n = 10$	50 (5)
HIV test (past year)	65 (17)
STI (lifetime)	39 (10)
Use of drugs/alcohol during sex (past 3 months)	77 (20)
Condom use while using drugs/alcohol (past 3 months)	15 (4)
Prior knowledge of biomedical prevention strategies	
PEP	35 (9)
PrEP	27 (7)