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Barriers to PrEP uptake among Black female adolescents and emerging adults

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ABSTRACT

HIV/AIDS disproportionately impacts Black cisgender female adolescents and emerging adults. Pre-Exposure Prophylaxis (PrEP) reduces the risk of HIV infection; however, structural barriers may exacerbate resistance to PrEP in this population. The purpose of this paper is to understand the characteristics of age, race, gender, history, and medical mistrust as barriers to PrEP uptake among Black female adolescents and emerging adults (N = 100 respondents) between the ages of 13–24 years in Chicago. Between January and June of 2019, participants completed the survey. We used directed content analysis to examine reported barriers to PrEP uptake. The most commonly identified barriers to PrEP uptake were side effects (N = 39), financial concerns (N = 15), and medical mistrust (N = 12). Less frequently reported barriers included lack of PrEP knowledge and misconceptions (N = 9), stigma (N = 2), privacy concerns (N = 4). We describe innovative multi-level strategies to provide culturally safe care to improve PrEP acceptability among Black female adolescents and emerging adults in Chicago. These recommendations may help mitigate the effect of medical mistrust, stigma, and misconceptions of PrEP within Black communities.

1. Introduction

Perpetuated by individual and structural barriers to health maintenance (Feb 07P, 2019; HIV and African American Gay and Bisexual Men, 2019), human immunodeficiency virus (HIV) disproportionately impacts Black communities in the United States (US), and new HIV diagnoses among young Black women aged from 13 to 24 is nearly 1.5 times that of white women (HIV Surveillance Report, 2020). Improving access to and uptake of pre-exposure prophylaxis (PrEP) among Black cisgender female adolescents and emerging adults (AEA) is essential to ending the US HIV epidemic and reducing new infections by 90 % by 2030 (Copeland and Miller, 2021; Celum et al., 2015). Racial and gender inequities in STI rates among AEA drive HIV (Ransome et al., 2016; Adimora et al., 2006; Pellowski et al., 2013). For example, chlamydia cases for those aged 15–19 years are 4.5 times higher than white girls in the same age group (Ransome et al., 2016). Similarly, STI rates among Black women aged 20–24 years are 3.7 times that of their white counterparts (Ransome et al., 2016). Despite increased condom use and other self-protective behaviors compared to non-Black peers, Black girls and women still have a higher probability of exposure to HIV due to sexual concurrency, defined as multiple, co-occurring sexual relationships (Adimora et al., 2006; Pellowski et al., 2013; Prophylaxis and (PrEP), 2019; Seidman et al., 2018; Chandler et al., 2020). Despite being disproportionally affected, Black female AEA account for the lowest level of PrEP uptake (Copeland and Miller, 2021; Goparaju et al., 2015; Davey et al., 2021). For Black female AEA who are currently HIV negative and at increased risk of acquiring HIV, PrEP (Prophylaxis and (PrEP), 2019) offers an empowering option because it is controlled by the individual

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and requires no partner negotiation (HIV Surveillance Report, 2020; Seidman et al., 2018). Additional research is needed to better understand the barriers and facilitators to PrEP uptake in this underserved population (Prophylaxis and (PrEP), 2019; Chandler et al., 2020; Copeland and Miller, 2021).

Previous research points to individual and structural barriers influencing HIV outcomes and PrEP uptake among Black communities (Prophylaxis and (PrEP), 2019; Copeland and Miller, 2021). Individual barriers include risk of side effects, fear of low efficacy, the burden of the regular medication regimen, lack of social support, and lack of intrinsic motivation (Goparaju et al., 2015; Davey et al., 2021; Celum et al., 2015). Despite evidence supporting PrEP efficacy, beliefs of those closest to Black female AEA exacerbate negative perceptions. Family, peers, and partners perpetuate misinformation and mistrust about PrEP, thereby contributing to AEA obstacles for uptake and adherence of PrEP (Celum et al., 2015; O'Rourke et al., 2021).

Structural barriers, such as discrimination, contribute to Black communities' lack of engagement in the HIV continuum of care, including participating in routine testing, attending appointments, adhering to medications, and PrEP uptake (Nydegger and Hill, 2020). Medical mistrust stems from historic and current mistreatment and results in a reduced likelihood to receive HIV-related treatments, diagnostics procedures, and prescribed medications (Wells and Gowda, 2020). Further structural barriers such as poor access to social services, transportation, and childcare have been documented as barriers to PrEP uptake among Black adult women (Nydegger et al., 2021). Additionally, the systematic exclusion of women, particularly Black cisgender women, in the initial dissemination of PrEP has been associated with a lack of PrEP delivery and uptake (Aaron et al., 2018; Lambert et al., 2018).

A pervasive consequence of historical oppression is medical mistrust, as it is twice as likely to be reported by Black individuals than by their white counterparts (Wells and Gowda, 2020). Mistrust in the medical system has been passed down from generation to generation through cautionary storytelling. Rooted in the mistreatment, neglect, and exploitation of Black people by healthcare providers, medical mistrust is not only a concept, but a coping mechanism often learned during childhood to facilitate personal and community safety. (Ash et al., 2021). In addition to medical racism perpetuated by the 1932 Tuskegee Syphilis study (Brandon et al., 2005) or cervical cells being taken for study purposes from Henrietta Lacks without consent, examples spanning over 400 years illustrate why Black people would doubt the altruistic motives of a medical system that has repeatedly caused them harm (Stump, 2014). Dr. Kimberly Manning describes the multigenerational impact of maltreatment as the "tip of a 400-year-old iceberg" and states, "We are not simply untrusting—we remember" (Manning, 2020). Such historical trauma lends itself to the underutilization of preventative health care services, such as PrEP (Wells and Gowda, 2020; Crooks et al., 2021; Ojikutu et al., 2020).

Literature on the acceptability and adoption of PrEP among HIV-negative Black female AEA in the US is scarce (Bond and Gunn, 2016; Flash et al., 2014). Despite major advances in HIV prevention, racial and gender inequities in HIV incidence continue. Of the 36,801 new HIV cases in the U.S. in 2019, nearly 16 % of infections occurred among heterosexual women (June 02, 2021).In particular, Black women in the U.S. are disproportionately affected by HIV and although annual infections remained stable overall from 2015 to 2019 among this population, the rate of new HIV infections among Black women is 11 times that of white women and four times that of Latina women (Impact on Racial and Ethnic Minorities, 2022). Given that Black girls and women in Chicago account for 59 % of new HIV diagnoses (4,397/23,800) (Health, 2018), a survey was conducted to document and better understand PrEP hesitation and barriers among Black girls and women in Chicago. Quantitative results are presented elsewhere (Haider et al., 2022). Using qualitative results from an open-ended survey question, this paper explores barriers to PrEP uptake experienced by Black female AEA.

2. Methods

2.1. Respondents

Self-identifying African American or Black, cisgender females between ages 13–24 years were eligible to participate in this study if they spoke English, lived in Chicago, and reported being sexually active in the last six months. Between January-June of 2019, 100 Black female AEA completed the survey and 74 % completed the open-ended question.

2.2. Data collection

An observational cross-sectional survey was conducted with Black female AEA attending a women's health clinic in a midwestern urban city. Black female AEA 18 years and older provided verbal consent. Permission was obtained for respondents under 18 years, and parental consent was waived to protect participant privacy and confidentiality. Respondents received $50 compensation and local resources to initiate PrEP after survey completion. Survey data were collected and managed using REDCap, an electronic data capture tool. The Institutional Review Boards from [blinded per review] reviewed and approved the study.

The survey was completed in a private clinic location. Survey responses were self-reported and entered into REDCap using a handheld device. Descriptive statistical methods were used to summarize quantitative survey data using SPSS. The 91-item survey included items designed to capture sexual health and behavior, PrEP awareness, acceptability, barriers, and facilitators to uptake. One close-ended question ("which of the following are barriers for you to PrEP uptake?") assessed multiple barriers and asked respondents to select all that apply from a list which included: lack of communication among community members, mistrust of the medical community, cost, side effects, the drug is too new, lack of housing, fear of using parental insurance. If respondents indicated barriers on the multiple-choice question, they were asked, "Given your answer(s) to the question above, can you explain further? Perhaps tell me more about your thoughts on these barriers?" This secondary data analysis analyzed the verbatim responses to this single open-ended question about PrEP barriers.

2.3. Data analysis

This study aimed to address the gaps in knowledge about barriers to PrEP utilization by focusing on the unique experiences of Black female AEA. We conducted a directed content analysis to identify themes associated with the previously identified quantitative PrEP barriers among Black female AEA (Blackstock et al., 2017) Content analysis is used to interpret the meaning from the qualitative data, with a directed approach starting from prior research findings as guidance for the initial codes (previously identified PrEP barriers) (Hsieh and Shannon, 2005). The coding team included two researchers (NC, RS) with experience in qualitative methods and community-based research with underrepresented populations. The coding process consisted of each team member reading the qualitative responses individually and applying specific codes to indicate common responses. After the codes were finalized, team members separately created themes that best represented the codes (Blackstock et al., 2017). Preliminary themes, discrepancies, and themes apparent in the data were discussed.

3. Results

Respondents were 100 % (N = 100) Black AEA ranging in age from 13 to 24 years. The median age was 22 years, with 13 participants under 18 years of age. Respondents 97 % (n = 97) identified as Black and non-Hispanic. Respondents, 99 % (n = 99) identified as only female, while one respondent identified as both female and gender non-conforming. A majority 63 % (n = 63) of participants lived in the Southside of Chicago. Almost half of the respondents 53 % (n = 53) had above high school

education or GED and the other half 47 % (n = 47) had a high school diploma or GED. All respondents were recruited while sitting in the clinic waiting rooms: 32 % (n = 32) were there for a women's healthcare visit, 15 % (n = 15) had accompanied a friend or family member, 12 % (n = 12) were waiting to have an abortion, ten were currently pregnant, and at the clinic for a prenatal care visit, five were present for STI testing or treatment, and 26 % (n = 26) did not disclose a reason. More than 37 % (n = 37) AEA had been pregnant, and 20 % had had one or more abortions in the past year. The low perceived risk of HIV infection is incongruous with descriptive statistics which highlight how nearly all AEA were sexually active, but inconsistently using condoms. Inconsistent condom usage during vaginal sex was reported by 92 % (n = 92) of participants, and inconsistent condom usage during anal sex was reported by 94 % (n = 94) of participants. Among AEA, over half 53 % (n = 53) were aware of PrEP 8 % (n = 8) and reported probable likelihood of contracting or transmitting HIV.

3.1. Lack of PrEP knowledge and misconceptions

Lack of knowledge and misconceptions related to PrEP were made apparent through 9 % (n = 9) of Black AEA responses. For example, one respondent (age 22) wrote - "*like I said, I didn't even know that women could take this*." Participants were unaware that PrEP was available to women. Other respondents related their hesitation to taking PrEP to their overall hesitation in preventive medicine, including vaccine hesitancy. One respondent (age 23) wrote, "*I am taking PrEP to prevent one disease, and it could cause another disease*." A 21-year-old respondent equated PrEP to the flu shot: *"Vaccinations put you at risk for contracting what you were vaccinated for. Like the flu shot… I never get the flu shot, ever."* Statements reflected confusion about whether PrEP is a medication preventing HIV or a live vaccination containing HIV.

Furthermore, lack of PrEP knowledge intersected with reports of inadequate communication by health care providers. One AEA noted this lack of communication (age 15): *"me not knowing about it and actually communication to me about the medicine, so it's like yeah…I am not going to take it."* This example expresses how ineffective communication by care providers perpetuated barriers to PrEP and exacerbated misconceptions about HIV prevention.

3.2. Stigma

One of the barriers identified was the stigma associated with PrEP. A 22-year-old respondent expressed social perceptions of PrEP:

> "*There is so much stigma associated with HIV just in general … people might say 'oh you are over there having sex with HIV people' even though you are protecting yourself, people might think you are out there being wild or whatever*."

Highlighted in the above quote, 2 % (n = 2) respondents described including PrEP in their daily routine as a challenge because they felt PrEP would only amplify them as being labeled as promiscuous due to the sexual stereotyping they endure. Another respondent (age 19) described that PrEP was not "*socially accepted*," and people would be looked down on and "*frowned*" upon by the Black community for taking it. These findings underscore how stigma related to sexuality creates more stigma around PrEP. Reaffirming a public health imperative to dispel perpetuated and stigmatizing myths is required to address these issues.

4. Side effects

Respondents 39 % (n = 39) were concerned about the possible side effects and safety of PrEP, citing fevers, vomiting, and pregnancy complications as most concerning. Many AEA were exposed to regular information about medication side effects via social media and television. One 22-year-old stated: "*When you watch those commercials and say they might cause dizzy, nausea and things like that…if it's something that I will have to take every day, it will be frustrating*." One 14-year-old respondent shared: "*It's like I am starting to get used to my body and by taking this and the side effects and messing with it*," suggesting that PrEP may interfere with natural adolescent development. Fueling fear, some believed PrEP would lead to other health problems or worsening pre-existing conditions. A 23-year-old AEA wrote: "*I feel like everything has side effects. Anytime you take something, for one thing, I feel like it ends up affecting something else and making situations worse as far as your body*."

Because fear of potential risks may play a role in PrEP uptake, AEA requested evidence-based information about possible side effects and PrEP's long-term implications for fertility. Among participants, misconception and insufficient knowledge about PrEP side effects intersected with, and in some cases, was further fueled by medical mistrust. For example, one respondent, age 20, wrote, "*I don't know, I just feel like they [doctors] force these drugs on you knowing that it has very damaging side effects. And, I just don't trust it*." Others questioned the sufficiency of PrEP research related to potential long-term side effects on reproductive health. A concerned 19-year-old stated: "I might want more kids, and I don't want that affecting me having kids. I have an active body; I don't want to bring me down".

4.1. Medical mistrust

Respondents 12 % (n = 12) described mistrust contributing to PrEP uptake. One respondent (age 19) wrote, "*I feel like a lot of the drugs people don't hear about, and people are starting to hear about its like: should I trust it or not? Because I feel like my doctor would have been told me about it*". Other respondents considered PrEP to be understudied among Black female AEA as a 17-year-old stated: *"some people might not use it cause they feel like it's too new and not studied."* Another respondent (age 21) acknowledges many such intersecting themes leading to medical mistrust, including the usage of PrEP in Black and Latinx communities:

> *"Well, honestly, I don't know what's going on in the medical field. But, the fact that you just introduced this pill that prevents you from getting HIV…I didn't know about it. So, now that I know, it's kind of like, oh, what's this about? You know, like, I kind of want to learn more about it. More so, the back, you know, the background of it. Like, how long it took, who all worked on it, and, you know, what was the…and how did it come about… cause there's a lot of us, especially in the Latino and the Black community, that's, you know, not as fortunate and not as… financially stable…And the mistrust of the medical community that kind of follows with the drug is too new. It's really new, and I didn't think that could even be possible. If that's the case, they need to be finding the cure."*

Medical mistrust as a theme informing barriers to care among those within the Black community is not new. Medical mistrust predates PrEP. Generations of strong Black women pass down cautionary tales detailing evidence of medical racism.

4.2. Privacy

Respondents 4 % (n = 4) worried their parents would discover they were taking PrEP. Those covered by parental insurance were afraid they would not be assured provider-patient confidentiality. A 24-year-old AEA described:

> *"Since I am on my parent's insurance, they do have the capability of seeing exactly what prescription I get…but it's like privacy for me. You have these HIPAA laws, but if you are in your parents' insurance, they have a capability of (seeing) exactly what you got prescribed."*

4.3. Financial concerns

Other AEA 15 % (n = 15) expressed financial concerns related to PrEP. One 16-year-old stated: "If *it's too high, I probably won't be able to*

afford it because those types of drugs are too much money." Those uninsured had questions about the out-of-pocket costs. One respondent (age 23) would agree to take PrEP if it was covered by insurance: "*I don't have the extra money to spend right now. I do have Medicaid. If it was $10, then I will get it*". For others, lack of insurance often intersects with unemployment. A 23– year-old described this intersecting, double whammy barrier to PrEP uptake; *"Right now, I just got out of the military, so I don't have any insurance. I am also unemployed, so I wouldn't be able to come up with the money for anything."*

5. Discussion

This study provided insight into how experiences of Black cisgender female AEA impede PrEP uptake (Prophylaxis and (PrEP), 2019; Chandler et al., 2020; Copeland and Miller, 2021). In addition to limited PrEP knowledge, concerns about side effects, and medical mistrust (Bond et al., 2021; Nydegger et al., 2021; Flash et al., 2017), Black female AEA reported barriers to PrEP, including the stigma associated with PrEP, fears around privacy, and financial concerns (Celum et al., 2015).

To address barriers for Black female AEA, we must seek to understand and incorporate their intersecting identities within PrEP care. For example, the process of sexual development for Black girls begins at as early as 9 years old (Crooks et al., 2019). The adultification of Black girls, resulting from negative historical stereotypes (i.e., Jezebel-hypersexualized promiscuous slave) often in the media, impact their interpersonal relationships and the quality of care received in a health care setting (Epstein et al., 2017; Cheeseborough et al., 2020). Studies demonstrate that Black girls are perceived as less innocent, needing less protection, and more knowledgeable of adult topics than their white peers (Crooks et al., 2019; Raifman et al., 2019). Developmentally, AEA are struggling to develop a sense of identity as a peer, and romantic relationships become more important and remain heavily influenced by their social networks. The intersection of age, race, gender, history, and the sociocultural context of Black female AEA should be considered in PrEP implementation (Crooks et al., 2020). This combination of factors may contribute to knowledge disparities regarding the utility and effectiveness of PrEP for HIV treatment among Black female AEA.

Although Black girls are particularly vulnerable to HIV/STI, sexualization, and sexual trauma, Black female AEA are severely underrepresented in the PrEP care literature in the US, which may contribute to uptake and acceptability (Prophylaxis and (PrEP), 2019; Chandler et al., 2020; Copeland and Miller, 2021). A lack of tailored PrEP messaging specific to the lived experience of cisgender heterosexual Black females may contribute to their low self-perception of HIV risk (Blackstock et al., 2017; Patel et al., 2019) and uptake of PrEP (Hirschhorn et al., 2020). Lack of social support, concerns regarding male partners' responses, long-term side effects related to pregnancy, and underestimating one's risk for HIV served as barriers to acceptance and adherence to PrEP among reproductive-age women (Brandon et al., 2005). Our findings suggest educational and delivery strategies need to be age-appropriate and tailored to the needs of Black AEA that explain the value of PrEP. Additionally, the influence of sexual partners, reproductive coercion, and intimate partner violence should be further explored as barriers to PrEP uptake. These factors intersect with HIV vulnerability among Black girls and women (Bond et al., 2021; Patel et al., 2019).

Medical mistrust was identified as a barrier to PrEP uptake among Black female AEA. Researchers have indicated that the rise in medical mistrust and societal norms feeding misinformation has increased HIV and COVID-19 rates among Black communities (Nydegger and Hill, 2020). Respondents also stated concerns about the long-term effects of PrEP on their sexual and reproductive health. The US has a legacy of medical mistrust related to reproductive abuse resulting in the forced sterilization and administration of contraceptives without the consent of Black, Latinx, and Indigenous women of color (Hodge, 2012). It has been noted that health care providers have limited knowledge related to PrEP (Walsh and Petroll, 2017; Petroll et al., 2017) which may lead to misinformation, lack of trust and may perpetuate negative attitudes about PrEP use among AEA. Our findings suggest if participants trust physicians this creates an area of opportunity for increasing PrEP information and uptake. Additionally, stigma enhances structural racism and discrimination; therefore, culturally safe interventions are necessary to improve PrEP uptake among Black female AEA.

Culturally safe interventions are needed to combat these barriers. However, cultural safety involves understanding the historical context, safety needs, and power imbalances that the health care system represents and how that influences service delivery values and beliefs to underrepresented populations (Ronica Mukerjee et al., 2021). Cultural safety also needs to be embedded in policies related to protecting confidentially of PrEP use among AEA. In this context, practicing culturally safe care would require that health care providers aim to not only understand the lived experiences of Black female AEA but to self-reflect about potential biases and incorporate newfound understanding into their PrEP education and care (Ronica Mukerjee et al., 2021). Examples of this may include creating or delivering PrEP information at the correct literacy level for AEA, acknowledging they may mistrust the medical system, and addressing misinformation about side effects seen in the media and their communities.

6. Next steps

Interventions that directly address historical oppression and medical mistrust must guide future engagement around PrEP education and care for Black female AEA—creating interventions in partnership with the community. Community-engaged HIV/STI interventions have demonstrated increased PrEP uptake and acceptability (Singer et al., 2021). Other options for participatory engagement include training AEA to be peer leaders or co-facilitators of PrEP education sessions. Another innovative way to build trust and reach the population is to align with community leaders (i.e., Black-led churches and organizations) and matriarchs (i.e., mother-daughter family-based HIV/STI interventions) (Crooks et al., 2019; Singer et al., 2021). Utilizing technology and social media platforms to address barriers is critical when engaging younger populations in PrEP uptake (Kudrati et al., 2021). To foster culturally safe care around PrEP, health care providers must take the time to minimize potential fears at the onset of health care delivery. By offering direct, comprehensive, and comprehendible evidence-based information about side effects, stigma, confidentiality, and costs with or without insurance, care providers simultaneously honor intersecting Black female AEA experiences while addressing potential knowledge gaps and medical mistrust.

Our findings have several limitations. Our small sample was recruited from only two women's health clinics and exclusively among respondents of one racial group within a limited age range. The sample size may have limited variability within responses and the ability to detect subgroup differences. Data were self-reported and may be subject to social desirability bias. Although these sample limitations reduce the generalizability of findings to all Black female AEA, the strength of the qualitative analysis is to characterize a specific population's experience. As data was derived from a primarily quantitative survey, delving more deeply into presented qualitative themes will require additional research to probe further about experiences of barriers to PrEP uptake. Future studies should have larger samples, with participatory multisite and mixed-method data collection approaches.

7. Conclusion

Overcoming barriers to PrEP uptake among Black female AEA requires multi-level strategies to provide culturally safe care. Our findings demonstrate that respondents desired more specific foundational, evidence-based information about using PrEP. Therefore, health care systems and providers that engage Black female AEA should consider introducing PrEP and discussions about drug safety and efficacy

evidenced by clinical trials. Medication cost, insurance coverage, and policies supporting free PrEP access should also be discussed when providing sex education and prevention sessions. Also, engaging AEA in discussions around how they and their communities perceive PrEP is critical in gaining acceptability and trust. These recommendations can help mitigate the effect of medical mistrust, stigma, and misconceptions of PrEP.

8. Declarations

Funding: This study was funded by the University of Chicago Women's Board.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (Institutional Review Boards at the University of Illinois Chicago protocol# 2021-0093 and the University of Chicago protocol #18-0901) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to participate: Informed consent was obtained from all participants included in the study.

Consent to publish: The authors affirm that human research participants provided informed consent for publication.

Author contributions: All authors contributed to the study's conception and design. Sadia Haider, Amy Johnson, Emily Ott, Natasha Crooks, and Randi Singer performed material preparation, data collection, and analysis. Natasha Crooks wrote the first draft of the manuscript, and all authors commented on subsequent versions. All authors read and approved the final manuscript.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The authors do not have permission to share data.

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