



Published in final edited form as:

Cult Health Sex. 2021 May ; 23(5): 659–673. doi:10.1080/13691058.2020.1720297.

Structural and Syndemic Barriers to PrEP Adoption among Black Women at High Risk for HIV: A Qualitative Exploration

Liesl A. Nydegger^{*a}, Julia Dickson-Gomez^b, Thant Ko Ko^c

^aDepartment of Kinesiology and Health Education, The University of Texas at Austin, Austin, TX, USA

^bDepartment of Epidemiology, Medical College of Wisconsin, Milwaukee, WI, USA

^cInstitute for Health Equity, Medical College of Wisconsin, Milwaukee, WI, USA

Abstract

In the USA, Black women are at disproportionately higher risk for HIV compared to women of other races/ethnicities, which can be explained by the Substance Abuse, Violence and AIDS (SAVA) syndemic. Disparities in HIV, substance use and violence are driven by multiple influences, including structural factors (e.g. housing and poverty), which exacerbate social- and individual-level factors leading to more sex partners, engaging in unprotected sex, having sex for money, experiencing forced sex from an intimate partner or increased substance use, all of which increase HIV risk. Pre-exposure prophylaxis (PrEP), a pill that can prevent HIV, is a discreet and underutilised method that Black women experiencing syndemics can use to decrease their risk. This study explored Black women's interest in, and barriers to adopting PrEP over 6 months. Thirty Black women (age $M = 32.2$) who experienced multiple substance use, violence and HIV-related syndemic factors were interviewed four times over a 6-month period. Results demonstrated that experiencing IPV, substance use, community violence and other structural factors (poor access to social services, transport and childcare) all acted as barriers to PrEP adoption. Future research should consider multi-level interventions that include methods such as media campaigns, providing PrEP or referrals where women who experience syndemic and structural factors seek help, and implement a PrEP adherence programmes and interventions in support group settings.

Keywords

Black/African American women; pre-exposure prophylaxis adoption; SAVA syndemic; housing instability; HIV

*Corresponding Author: Liesl A. Nydegger Liesl.Nydegger@gmail.com.

¹Participants were provided the option to sign a form to waive the Health Insurance Portability and Accountability Act granting permission to the clinic to disclose their protected health information to the research team for research purposes only and only for the duration of their participation in the study. They could cancel or revoke their authorisation at any time.

Conflict of Interest

The authors have no conflict of interest to disclose.

Data access

Data is available in the Texas Data Repository: <https://doi.org/10.18738/T8/6WJIXG>

Introduction

In the USA, Black women are at disproportionately higher risk for HIV (Centers for Disease Control and Prevention 2019) and intimate partner violence (IPV) (Black et al. 2011; Catalano 2015) compared to women of other races/ethnicities. In 2017, Black women accounted for 59% of new HIV diagnoses (Centers for Disease Control and Prevention 2019) even though they only make up 6.8% of the US population (United States Census Bureau 2018). Black women are also more likely to experience sexual violence, stalking and physical violence by an intimate partner compared to Hispanic and non-Hispanic white women (Black et al. 2011).

Black women's increased risk of HIV can be explained by syndemic theory, in which mutually enhancing health and social factors interact to affect the urban poor (Singer 1994). Syndemic theory provides a socioecological perspective that considers structural, interpersonal, and behavioural factors that affect one's health (Tsai and Venkataramani 2016). The SAVA syndemic (substance abuse, violence, and AIDS) comprises a number of synergistic factors (Stockman et al. 2012), which increase women's risk for HIV. Violence may here be understood at multiple levels: structural violence (i.e. poverty, homelessness, racism and gender inequality) and IPV (Singer 2006; Meyer, Springer and Altice 2011; Gilbert et al. 2015).

Historically, structural violence is rooted in residential segregation and structural racism leading to poverty, under- and un-employment among Black communities and thus overall economic inequality. Black communities and Black women and mothers in particular, are more likely to be affected by the structural violence of homelessness, housing instability (Dickson-Gomez, McAuliffe and Quinn 2017), substandard housing (Nydegger & Dickson-Gomez, 2017), neighbourhood disorder (Beyer, Wallis and Hamberger 2015), and poverty (DeNavas-Walt, Proctor and Smith 2010). Structural violence exacerbates other syndemic factors that lead to increased risk of HIV. Racism, segregation, substandard/unstable housing and poverty lead to barriers preventing Black communities from accessing health care (Centers for Disease Control and Prevention 2015; Dunkle et al. 2010; Lane et al. 2004).

Several studies suggest an association between housing instability and HIV risk. Homelessness and housing instability are associated with women having more sex partners (Dickson-Gomez, McAuliffe and Quinn 2017; German et al. 2015), engaging in more unprotected sex (Dickson-Gomez, McAuliffe and Quinn 2017), having sex for money (Dunkle et al. 2010), and experiencing forced sex from an intimate partner (El-Bassel et al. 2000).

Substance use can be used as a means to cope with structural violence (Boyd, Phillips and Dorsey 2003; Henry et al. 2017) but may in turn lead to risky sexual behaviours while under the influence (Epperson et al. 2009; Seth et al. 2011). Women who experience IPV use alcohol and illicit substances at higher rates than those who do not (Moore et al. 2008). Those who used substances and experienced IPV were more likely to experience HIV-risk behaviours (Gilbert et al. 2000). IPV also increases women's risk for HIV from forced or coerced sex (El-Bassel et al. 2000); for women in abusive relationships, negotiating male

condom use can be difficult and even dangerous (El-Bassel et al. 2000; Rountree, Granillo and Bagwell-Gray 2016). Substance use also has a bi-directional relationship with IPV by impairing judgement leading to difficulty in detecting when an abusive situation is escalating and becoming threatening, or using substance use to cope with IPV (El-Bassel et al. 2011).

Pre-exposure prophylaxis (PrEP), a pill that if taken once daily can prevent HIV, is a discreet but underutilised method that Black women experiencing syndemic factors may use to decrease their HIV risk. Because of Black women's increased risk for violence and HIV risk, PrEP may be an important prevention tool. PrEP usually consists of a combination of the antiretroviral medications tenofovir disoproxil fumarate and emtricitabine (Centers for Disease Control and Prevention 2018) that is effective in preventing HIV as long as there is good adherence (Jiang et al. 2014). PrEP may be ideal for women experiencing IPV as it is easier to use clandestinely (Institute of Medicine 2008) and thus women do not have to rely on condom negotiation for HIV prevention.

Several studies have explored PrEP's acceptability or use among women with conflicting results. Studies among large samples of Black women report a majority expressed interest in PrEP if it were available (Sales and Sheth 2018; Sales et al. 2018). While Black women report greater medical mistrust compared to white women, they also report greater interest in and intentions to take PrEP (Tekeste et al. 2019). One study reported women who experienced IPV were more interested in PrEP than non-abused women (Rubtsova et al. 2013), but another study reported results to the contrary (Garfinkel et al. 2017). Yet another study reported low interest among women and interest continued to decrease as participants learned about possible side effects, recommended adherence, and required doctors' appointments (Carley, Siewert and Naresh 2019). While a couple of studies provided the opportunity for Black women and men to take PrEP, both were conducted in HIV or clinic-related settings. After initial interest, one clinic contacted the participants for PrEP appointments, and interest and PrEP initiation substantially decreased (Kwakwa et al. 2018). Another study conducted among clinic patients seeking an HIV test linked interested participants to PrEP; participants in serodiscordant relationships compared to seroconcordant were most likely to adopt PrEP (Flash et al. 2018). While the design of some studies was informed components of syndemic theory such as IPV, substance use, or housing instability (Willie et al. 2017; Roberts et al. 2016; Doblecki-Lewis et al. 2016), no study considered these factors together or the mutually reinforcing nature of syndemic factors that may undermine Black women's ability to adopt PrEP, regardless of their interest.

Present Study

Based on the limited research regarding facilitators and barriers to PrEP adoption among high-risk Black women, and actual rather than hypothetical adoption, this study used the SAVA syndemic framework (Meyer, Springer and Altice 2011; Gilbert et al. 2015) to qualitatively explore Black women's interest in and adoption of PrEP over time. We explored structural and syndemic factors as facilitators and barriers to adopting PrEP over a six month period. Understanding the facilitators and barriers to adopting PrEP is an essential step toward designing interventions to promote and increase PrEP uptake among high risk

Black women. Black women who experience structural and syndemic factors are at high risk for HIV and PrEP can be used as a female-controlled prevention method.

Materials and Methods

Thirty Black women (age $M=32.2$, range 18 – 57) were interviewed four times over 6 months between July 2016 and April 2017. One participant did not complete the fourth interview. Eligibility criteria included: aged 18 years or older, identifying as a Black or African American cis-gendered woman, having unprotected vaginal or anal sex with a cis-gendered man in the past 30 days, and being able to speak fluent English. In line with the SAVA syndemic framework and ensuring HIV risk, additional eligibility criteria included having at least one of the following risk factors: experiencing physical, sexual, or psychological IPV in the past three months (adapted from the Conflict Tactics Scale-2) (Straus and Douglas 2004); engaging in sex exchange in the past three months; or engaging in problematic substance use in the past 30 days. Problematic substance use was defined as any illicit substance use (except for marijuana), more than 8 drinks of alcohol per week or four or more drinks on one occasion (National Institute on Alcohol Abuse and Alcoholism 2015), or marijuana use 14 days or more per month (Konstantopoulos et al. 2014).

Procedures

The Institutional Review Board at the Medical College of Wisconsin approved all study procedures. Recruitment took place in Milwaukee, WI at community events, a clinic, and through snowball sampling. Snowball sampling occurred by providing participants, if interested, with cards containing study information and contact number, and basic eligibility criteria for participants to hand out. Recruiting others was not a requirement of the study; participants remained in the study regardless of whether they referred others, and they were not compensated for referrals. Potential participants would call the study phone number if they received a card and were interested in the study; the research team never contacted potential participants directly.

Participants were first consented and then an individual, audio-recorded structured interview determined eligibility (i.e. sociodemographic criteria and SAVA syndemic factors). Participants who were ineligible were paid \$10 for their time. Eligible participants completed an audio-recorded, in-depth semi-structured interview and were interviewed again one, three, and six months after baseline. We partnered with a local PrEP clinic and after the baseline interview each participant was asked if they were interested in setting up an appointment with the PrEP clinic to learn more about and potentially be screened for PrEP by a medical provider. Participants who expressed interest had the option of signing a HIPAA waiver so that the clinic could share their medical records with the research team for the duration of the participants' engagement with the study. Participants remained in the study regardless of signing the waiver. Clinic visits were paid for by the participants' insurance. Clinic staff were knowledgeable about PrEP assistance programmes in the event that participants did not have insurance, or their insurance would not cover PrEP. We did this so that participants could remain on PrEP if they adopted it after the study ended.

Participants were contacted every two weeks in between interviews to increase retention and to check-in in the event a participant initiated PrEP. Participants were paid increasing incentives of \$25, \$30, \$35, and \$45 for interviews. Those who travelled to LAN's office for interviews were reimbursed \$5 and participants who needed childcare during interviews were reimbursed \$15. All interviews were conducted in English and LAN conducted over 90% of the interviews. The remaining interviews were conducted by a research assistant who was trained by [first author] and had prior experience conducting qualitative interviews among young gang-involved Black men and women. Interviews lasted between 30 minutes and 2 hours, most of which (~75%) were conducted in participants' homes. The remaining interviews were conducted in an interview room at LAN's office. Care was taken when scheduling interviews to emphasise that interviews conducted at participants' homes be in a safe, quiet environment with no one around. Participants were informed about the sensitive nature of the questions ahead of time and given alternative options for interview location (e.g. LAN's office).

Interview guides explored structural and SAVA syndemic factors along with PrEP interest, attitudes, adoption, and experiences. Follow-up interviews asked the same questions and how participants' lives changed across all those factors since the last interview (see online supplemental materials for details of the interview guides). Participants were provided with a comprehensive resource list including housing and emergency shelters, crisis interventions, family violence interventions, mental health services, substance use services, OB/GYN services, HIV/STD testing sites and LGBT services.

Data Analysis

Interviews were transcribed verbatim, and coded and analysed in MAXQDA qualitative software. The first and second author developed a preliminary codebook based on syndemic theory and research questions, and an initial reading of transcripts. All three authors then used didactic and iterative coding to identify family codes and sub-codes to develop the coding tree using team coding with 3 interviews. Team coding resulted in four iterations of the codebook, which was finalised once no new codes emerged and all three authors reached consensus. Examples of preliminary family codes are: IPV, sex exchange, drug use, sex partner, and home/house. Examples of emergent codes were: cheating, alcohol, crack, marijuana and community violence. We conducted thematic content analysis to identify primary themes to explore the feasibility and acceptability of PrEP adoption and how structural and syndemic factors acted as barriers to PrEP adoption among Black women. Analysis focused on the interrelationships among different syndemic factors (e.g. housing instability and substance use) and among syndemic factors and PrEP adoption. Pseudonyms are used throughout to protect the confidentiality of participants.

Results

Syndemic Experiences Overview

At baseline, the majority of participants lived in substandard housing, doubling up in overcrowded housing with family or friends, were homeless, or lived in violent neighbourhoods. Throughout the study, most participants remained in or moved into other

substandard living conditions. Most participants lived in poverty throughout the entire study even though more than half of participants were looking for employment, second jobs, or to enrol in school. Almost all participants engaged in risky sexual behaviours such as unprotected sex, having multiple or concurrent partners, exchanging sex, mostly for money to pay bills or buy food, or sex under the influence of alcohol or other drugs. As determined from the baseline eligibility interview and the in-depth interviews, a majority of participants experienced IPV, psychological, physical and sexual coercion or rape by their main partner. Over one-third of participants engaged in problematic alcohol use, half engaged in problematic marijuana use and 20% used other substances such as crack cocaine, cocaine, pain pills, and K2 (synthetic marijuana). See Table 1 for further results of participants' structural and syndemic experiences.

PrEP Interest

Only two participants had heard of PrEP, although one was not sure what it was and the other heard about it at a recruitment site for this study; the remaining participants had never heard of PrEP. At baseline, most participants expressed initial interest in learning about or taking PrEP and wanted to schedule an appointment with the PrEP clinic. However, while many participants continued to express interest throughout the study, only three participants attended appointments at the PrEP clinic and four attended appointments at other doctors' offices.

Syndemic Barriers to PrEP Adoption

Participants experienced barriers to PrEP adoption such as IPV from unsupportive partners and substance use.

IPV

Both anticipated and actual IPV played a role in participants' interest and decision to adopt PrEP. Initially, almost all participants but two said that they would tell their main sexual partners that they were taking PrEP, which was surprising given that 21 participants experienced physical, sexual, and/or psychological IPV. Over one-third anticipated negative reactions from their partners such as thinking that the participant was HIV-positive, that the participant was accusing their partner of being promiscuous, or that the participant herself was promiscuous. Given that most participants had not heard of PrEP prior to the study, we suggest that their fears of partners' negative reactions were based on their experiences negotiating condom use. One participant had a sexual partner who slept with other women, ignored her requests to use a condom when having sex, and sometimes coerced her into having sex, and she was unsure if she would tell him if she were taking PrEP. When asked if she would hide it, she was afraid he might still find out:

I don't know, because he seems sort of nosy, so I probably would have to put it in my purse or something, 'cause I don't think he would go through my purse. Plus, there's so much stuff in there he'd have to dig down to the bottom and, like, scoop it or something. Dump out my whole purse. (Gabrielle, 34, Interview 1)

Gabrielle was afraid her partner would accuse her of lying, of having HIV and having an ulterior motive. Given his prior aggressive behaviour in the bedroom, she was unsure what he would do if he found the pills or if she told him.

Two additional participants anticipated negative reactions from their boyfriends. These were confirmed when they actually discussed PrEP with them. When they brought up the topic, their boyfriends told them that they should not take PrEP, even though they had not heard of it prior to the participants informing them of the medication. One participant had a boyfriend who had been physically abusive to her in the past and was extremely unsupportive of her taking PrEP, telling her not to take it. At one point she said she was going to take PrEP regardless of his wishes, but she never did. For the remainder of the study she contemplated taking PrEP rather than making an appointment because of his persistence:

I was interested. Then [boyfriend] made me not interested... I've been used to listening to him for a long time and taking his advice. I'm more of a let people tell me what to do [person]. Like, other people's opinions because I feel like sometimes, I might not be right. So, I need a second opinion. (Kiara, 23, Interview 3)

Other participants were experiencing IPV that impeded their lives to the point that they could not make PrEP a priority. Halfway through the study, Norshelle, 19, announced she was pregnant by her boyfriend. Earlier in her fourth interview, Norshelle stated she never made an appointment because she was "lazy". However, she also described being punched in the stomach while she was pregnant by her boyfriend:

I was so early at that point, I didn't want like something to be wrong with my baby. So, I called the ambulance and then when I told 'em I was hit and stuff, they took matters into their own hands and called the cops. (Norshelle, 19, Interview 4)

Initially, she looked for a shelter to stay in, but they were all full and she ended up having to move in with her mother. Norshelle was entirely financially dependent on her boyfriend and, therefore, had no money saved up to move out of her mother's apartment. With all this occurring, Norshelle stated that she was interested in PrEP but clearly it could not be a priority.

Substance Use

Substance use led some participants to engage in risky sexual behaviours including sex exchange. Other times it played a role in their hesitation to adopt PrEP or their missing appointments to get on PrEP. Most participants engaged in unprotected sex, often while under the influence of alcohol or drugs. Samara used condoms consistently with her boyfriend until they both were drunk one night and did not use a condom:

It was just the night we went out to the bar and got drunk and realised we did it without the condom. And then we just kinda continued. (Samara, 39, Interview 1)

Afterward, they stopped using condoms altogether regardless of their sobriety. When asked if she regretted this decision Samara stated:

Even still to this day sometimes I don't think that nobody is fine. It's such a crazy world you hate to think certain things and you just have to be careful.

Her boyfriend cheated on her during the study and contracted an STD. Fortunately, she found out prior to contracting the STD, but this was a rude awakening and increased her desire to initiate PrEP although she had not done so before the study ended.

A couple of participants who used drugs engaged in sex exchange, often without a condom, in order to get money to buy drugs thus greatly increasing their risk for HIV.

I ain't want to, I just used him for the drugs [crack]... It was with my casual partner, that's what I use him for. We'll have sex and then he'll give me the \$40 and then I just go and get my drugs [crack]. And I'm just like, "hurry up!" (Ramona, 47, Interview 1)

Several participants were concerned about taking PrEP with alcohol because of potential side effects of mixing the two. Sheylinn, 18, mentioned in her fourth interview that adherence to PrEP would be problematic as she had already forgotten to take her medication for depression. Instead, she self-medicated with marijuana:

I know I'm gone lack with that [daily pill]... because I supposed to be taking medicine for my depression. I supposed to take it every day. I be forgetting so I just be smoking [marijuana]... If it [PrEP] was a shot then yeah...because they probably won't give it to you every day. They have to give it to you every 3 months or something like that.

Sheylinn also stated that she felt like the medication for her depression did not work, so her self-described "forgetfulness" may also be a preference to self-medicate with marijuana as she stated:

I'm supposed to be taking this medication for my depression and stuff, my bipolar but I don't take it. Because I just feel like it don't do nothing. I still have my mood swings, I still be happy one minute, sad one minute, mad one minute, things like that. It don't do nothing to me so I just, I deal with that through my weed.

Another participant who was recovering from an addiction to crack cocaine expressed her strong interest in PrEP and attended her first appointment at the clinic. However, she missed her second appointment when she was supposed to receive her prescription for PrEP because she was at her drug rehabilitation outpatient centre:

I was at my drug meetin' at the time. I went to it [first PrEP appointment] and then she gave me an appointment. Then I was doin' my assessment to get into drug treatment 'cause I was on my way home from outpatient. It was all takin' place at the same time. (Ramona, 47, Interview 2)

Ramona never rescheduled in order to receive her prescription. One reason she stated was because her car broke down so she no longer had transportation.

Structural Violence as a Barrier to PrEP Adoption

Structural violence including poverty, under-employment, substandard and unstable housing, and community violence also impacted participants' lives and PrEP adoption.

Poverty, employment and housing

Several participants described poverty as both a direct and indirect barrier to adopting PrEP. Women in poverty have to go through many different processes to receive basic benefits. Aliyah had an appointment at a Women, Infants and Children (WIC) office, which was next door to the PrEP clinic in which she had an appointment. Her appointment with WIC to which she brought her children was time consuming. She missed her appointment at the PrEP clinic because her children were misbehaving after the long WIC appointment.

Not having these nagging kids around...that's how I forgot last time... I just need reminders... I got a million and one things that I got to [do]... I can get somebody to watch them [kids] real quick... I shouldn't have made the appointment when I was going to WIC. (Aliyah, 26, Interview 4)

Appointments for PrEP include HIV tests, and often STD testing and PAP smears. Attending such an appointment could have been difficult with young children to look after, especially after the long WIC appointment.

Four participants stated that it was difficult to schedule a clinic appointment for PrEP evaluation because of work schedules or applying for jobs, such as Jasmine, 27:

The only thing I have concerns about ever is scheduling. Just making sure that I don't have to, like, take a day off or take a day late or anything like that. (Interview 2)

Given their limited income, PrEP was a low priority for several woman in comparison to earning money.

The search for permanent or better-quality housing also impeded women's ability to attend clinic appointments to initiate PrEP and was an additional form of structural violence. Many participants lived in substandard housing (n=12), three lost housing during the study period due to evictions (including informal), and fourteen moved frequently, often into substandard housing. Others (n=8) could not afford their own housing and doubled-up with family, friends or sex partners. Overcrowding inevitably led to conflict creating the need to move and find new housing. Housing that women could afford was often substandard with problems such as pests, no electricity, flooding or mould.

Community Violence

Almost one third of participants experienced community violence during the study in which friends, family and/or significant others were severely injured or killed, or participants themselves were severely injured. In such situations, participants had to cope with recovering from injuries or grieving the loss of loved ones injured or killed. Jaynie, 30, was attacked by several people on one occasion and then stabbed by a woman on a separate

occasion. When discussing why she was unable to attend any of her clinic appointments she said her fourth interview:

Getting jumped, and then transportation issues. My sister, how she talkin' about she comin' to get me. And she ain't come... Transportation issues too.

Imani was interested in PrEP during her first interview. However, prior to her second interview, her ex-fiancée was murdered and prior to her third interview, a family friend died. Therefore, she was grieving for the remainder of the study.

I think it's a good thing that they came out with something like that. I mean like I said I missed an appointment that I had before, so I still have to reschedule, I'm trying to get on track with everything... I'm trying to wait a little bit, trying to wait...I think I just need a couple of weeks. The funeral was today, my fiancée's birthday is next Sunday so it's been a month of stressful weeks. (Imani, 38, Interview 3)

Discussion

This study identified numerous barriers to PrEP adoption among the Black women participating. The longitudinal design of this study aided in observing structural and syndemic barriers develop over time. While the majority of participants expressed great initial interest in PrEP, significant syndemic factors and structural violence acted as barriers to PrEP initiation among this population.

Previous research has found mixed results regarding the relationship between IPV and PrEP uptake. One study found that women with a history of IPV were significantly less likely to hypothetically accept PrEP compared to non-abused women (Garfinkel et al. 2017) while another study found that women with a history of IPV were significantly more likely to hypothetically accept PrEP (Rubtsova et al. 2013). However, this study demonstrated that hypothetical PrEP acceptance is not the same as actual PrEP initiation, and PrEP initiation was certainly influenced by women's experience with IPV.

This study confirmed results from previous research suggesting that substance use increases sexual risk (Booth, Kwiatkowski and Chitwood 2000; Cook and Clark 2005; Seth et al. 2011), but it also interfered with PrEP initiation. Several participants were uninterested in PrEP because they were concerned about the side effects of mixing alcohol with PrEP. One participant missed her second PrEP appointment for her prescription because she was at her outpatient drug meeting. Others were self-medicating with alcohol, marijuana, and crack cocaine for mental health disorders such as depression and bipolar disorder, which may have been a deterrent from accessing medication. Poverty was also a considerable barrier to PrEP initiation. When low-income women miss appointments, they are often penalised by reductions in their benefits such as food stamps.

Results from this study suggest that poor Black women suffer from multiple syndemic factors that impede their ability to initiate PrEP. Thus, interventions that address multiple syndemic factors are needed.

Future Research

Given the interaction between structural and syndemic barriers to PrEP adoption, multi-level interventions are necessary to increase PrEP adoption among Black women at risk for HIV. A majority of participants were unaware of PrEP prior to the study. Therefore, a structural intervention could include a media campaign (Bazzi et al. 2019) targeting multiple populations, including Black women who can benefit from PrEP, and which seeks to de-stigmatise PrEP.

Intervention could also focus on pairing PrEP with other prevention methods such as condoms and birth control to demonstrate it is but one prevention tool among many. Because syndemic factors are mutually reinforcing and are exacerbated by structural factors, organisations and clinics who engage with women at risk for HIV based on these factors (e.g. domestic violence shelters, homeless shelters and substance use treatment facilities, etc.) should consider becoming PrEP providers (Bazzi et al. 2019) or putting in place referral service for women to PrEP providers.

Limitations

Like all research this has its limitations. Findings are not generalisable as the study was conducted among a small sample of Black women in one city. Future research may want to consider the situation and circumstances of women in other cities with higher HIV rates. Moreover, all data were self-reported such that participants may have under-reported sensitive or traumatic events and over-reported risk-averse behaviours. In addition, the participants already knew the study was about PrEP and may have overstated their interest in PrEP in order to provide the interviewer what she wanted to hear.

Conclusions

In the USA, Black women are disproportionately at risk for HIV and PrEP is a female-controlled method that can reduce their risk. However, significant structural violence and syndemic barriers contribute to lack of PrEP initiation among this underserved population. Future research should consider multi-level interventions that include methods such as media campaigns, the provision of PrEP, and referrals where women who experience syndemic and structural factors can seek help.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

The authors acknowledge the participants who shared their stories. They also thank the project staff and students who dedicated their time to the study and specifically Heran Kidane for her insightful feedback and editing.

Funding

This work was supported by the US National Institute of Mental Health under Grant P30 MH52776; the US National Institute of Mental Health under Grant T32 0MH19985; and by the Eunice Kennedy Shriver National Institute of Child Health and Human Development under Grant P2CHD042849.

References

- Bazzi Angela R., Yotebieng Kelly, Otticha Sophie, Rota Grace, Agot Kawango, Ohaga Spala, and Syvertsen Jennifer L. 2019. "PrEP and the Syndemic of Substance Use, Violence, and HIV among Female and Male Sex Workers: A Qualitative Study in Kisumu, Kenya." *Journal of the International AIDS Society* 22 (4): e25266. doi:10.1002/jia2.25266. [PubMed: 30983147]
- Beyer Kirsten, Wallis Anne Baber, and Hamberger L. Kevin. 2015. "Neighborhood Environment and Intimate Partner Violence: A Systematic Review." *Trauma, Violence, & Abuse* 16 (1): 16–47. doi:10.1177/1524838013515758.
- Biello Katie B., Psaros Christina, Krakower Douglas S., Marrow Elliot, Safren Steven A., Mimiaga Matthew J., Lisa Hightow-Weidman Patrick Sullivan, and Mayer Kenneth H.. 2019. "A Pre-Exposure Prophylaxis Adherence Intervention (LifeSteps) for Young Men Who Have Sex with Men: Protocol for a Pilot Randomized Controlled Trial." *JMIR Research Protocols* 8 (1): e10661. doi:10.2196/10661. [PubMed: 30694206]
- Black Michele C., Basile Kathleen C., Breiding Matthew J., Smith Sharon G., Walters Mikel L., Merrick Melissa T., Chen Jieru, and Stevens Mark R.. 2011. *The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report*. Atlanta, GA: Centers for Disease and Prevention, National Center for Injury Prevention and Control.
- Booth Robert E., Kwiatkowski Carol F., and Chitwood Dale D.. 2000. "Sex Related HIV Risk Behaviors: Differential Risks among Injection Drug Users, Crack Smokers, and Injection Drug Users Who Smoke Crack." *Drug and Alcohol Dependence* 58 (3): 219–226. doi:10.1016/S0376-8716(99)00094-0. [PubMed: 10759032]
- Boyd Mary R., Phillips Kenneth, and Dorsey Coretta J.. 2003. "Alcohol and Other Drug Disorders, Comorbidity, and Violence: Comparison of Rural African American and Caucasian Women." *Archives of Psychiatric Nursing* 17 (6): 249–258. doi:10.1053/j.apnu.2003.10.003. [PubMed: 14685949]
- Carley Tess, Siewert Emma, and Naresh Amber. 2019. "Interest in Pre-Exposure Prophylaxis (PrEP) for HIV Is Limited Among Women in a General Obstetrics & Gynecology Setting." *AIDS & Behavior*, 23 (10): 2741–2748. doi:10.1007/s10461-019-02529-1. [PubMed: 31065923]
- Catalano Shannon. 2015. *Intimate Partner Violence, 1993-2010*. Washington, DC: U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. doi:10.1016/B978-0-08-097086-8.35026-7.
- Centers for Disease Control and Prevention. 2015. "HIV among African Americans." Atlanta, GA: Centers for Disease Control and Prevention. www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html
- Centers for Disease Control and Prevention. 2018. "Preexposure Prophylaxis for the Prevention of HIV Infection in the United States--2017 Update: A Clinical Practice Guideline." Atlanta, GA: Centers for Disease Control and Prevention. <https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf>
- Centers for Disease Control and Prevention. 2019. "HIV and Women." Atlanta, GA: Centers for Disease Control and Prevention. https://www.uptodate.com/contents/hiv-and-women/print?search=pregnancyandhiv&source=search_result&selectedTitle=2~150&usage_type=default&display_rank=2
- Cook Robert L., and Clark Duncan B.. 2005. "Is There an Association between Alcohol Consumption and Sexually Transmitted Diseases? A Systematic Review." *Sexually Transmitted Diseases* 32 (3): 156–164. doi:10.1097/01.olq.0000151418.03899.97. [PubMed: 15729152]
- DeNavas-Walt Carmen, Proctor Bernadette D., and Smith Jessica C.. 2010. *Income, Poverty, and Health Insurance Coverage in the United States: 2009*. Washington, DC: U.S. Department of Commerce. <http://www.census.gov/prod/2010pubs/p60-238.pdf>
- Dickson-Gomez Julia, McAuliffe Timothy, and Quinn Katherine. 2017. "The Effects of Housing Status, Stability and the Social Contexts of Housing on Drug and Sexual Risk Behaviors." *AIDS & Behavior* 21 (7): 2079–2092. doi:10.1007/s10461-017-1738-1. [PubMed: 28243936]
- Doblecki-Lewis Susanne, Lester Larissa, Schwartz Bryanna, Collins Constance, Johnson Rai, and Kobetz Erin. 2016. "HIV Risk and Awareness and Interest in Pre-Exposure and Post-Exposure

- Prophylaxis among Sheltered Women in Miami.” *International Journal of STD & AIDS* 27 (10): 873–881. doi:10.1177/0956462415601304. [PubMed: 26384947]
- Dunkle Kristin L., Gina M Wingood Christina M. Camp, and Diclemente Ralph J.. 2010. “Economically Motivated Relationships and Transactional Sex among Unmarried African American and White Women: Results from a U.S. National Telephone Survey.” *Public Health Reports* 125 (Suppl 4): 90–100. [PubMed: 20626196]
- El-Bassel Nabila, Gilbert Louisa, Rajah Valli, Foleno Anthony, and Frye Victoria. 2000. “Fear and Violence: Raising the HIV Stakes.” *AIDS Education & Prevention* 12 (2): 154–170. [PubMed: 10833040]
- El-Bassel Nabila, Gilbert Louisa, Witte Susan, Wu Elwin, and Chang Mingway. 2011. “Intimate Partner Violence and HIV among Drug-Involved Women: Contexts Linking These Two Epidemics--Challenges and Implications for Prevention and Treatment.” *Substance Use & Misuse* 46: 295–306. doi:10.3109/10826084.2011.523296. [PubMed: 21303249]
- Epperson Matthew W., Platais Ingrida, Valera Pamela, Barbieri Raye, Gilbert Louisa, and El-Bassel Nabila. 2009. “Fear, Trust, and Negotiating Safety: HIV Risks for Black Female Defendants.” *Affilia* 24 (3): 257–271. doi:10.1177/0886109909337377. [PubMed: 20445827]
- Flash Charlene A., Adegboyega Oluwatobi O., Yu Xiaoying, Avalos Carmen, Johnson Syundai, Mayer Kenneth H., and Giordano Thomas P.. 2018. “Correlates of Linkage to HIV Preexposure Prophylaxis among HIV-Testing Clients.” *Journal of the Acquired Immune Deficiency Syndromes* 77 (4): 365–372. doi:10.1097/QAI.0000000000001605.
- Garfinkel Danielle B., Alexander Kamila A., Reagan McDonald-Mosley Tiara C. Willie, and Decker Michele R.. 2017. “Predictors of HIV-Related Risk Perception and PrEP Acceptability among Young Adult Female Family Planning Patients.” *AIDS Care* 29 (6): 751–758. doi:10.1080/09540121.2016.1234679. [PubMed: 27680304]
- German Danielle, Trang Quynh Nguyen Christine Powell Ogbue, and Flynn Colin. 2015. “Condomless Anal Intercourse among Males and Females at High Risk for Heterosexual HIV Infection.” *Sexually Transmitted Diseases* 42 (6): 317–323. doi:10.1097/OLQ.000000000000275. [PubMed: 25970308]
- Gilbert Louisa, Nabila El-Bassel Robert F. Schilling, Wada Takeshi, and Bennet Barbara. 2000. “Partner Violence and Sexual HIV Risk Behaviors among Women in Methadone Treatment.” *AIDS & Behavior* 4 (3): 261–269. doi:10.1023/A:1009568718804.
- Gilbert Louisa, Raj Anita, Hien Denise, Stockman Jamila, Terlikbayeva Assel, and Wyatt Gail. 2015. “Targeting the SAVA (Substance Use, Violence, and AIDS) Syndemic among Women and Girls: A Global Review of Epidemiology and Integrated Interventions.” *Journal of the Acquired Immune Deficiency Syndromes* 69 (Suppl 2): S118–S127.
- Henry Meghan, Watt Rian, Rosenthal Lily, and Shivji Azim. 2017. Part 1: Point-in-Time Estimates of Homelessness--The 2017 Annual Homeless Assessment Report (AHAR) to Congress. Washington, DC: U.S. Department of Housing and Urban Development. <https://www.hudexchange.info/resources/documents/2017-AHAR-Part-1.pdf>
- Institute of Medicine. 2008. *Methodological Challenges in Biomedical HIV Prevention Trials*. Washington, DC: The National Academies Press. http://books.nap.edu/openbook.php?record_id=12056&page=R2.
- Jiang Junjun, Yang Xiaoyi, Ye Li, Zhou Bo, Ning Chuanyi, Huang Jiegang, Liang Bingyu, et al. 2014. “Pre-Exposure Prophylaxis for the Prevention of HIV Infection in High Risk Populations: A Meta-Analysis of Randomized Controlled Trials.” *PLoS ONE* 9 (2): e87674. doi:10.1371/journal.pone.0087674. [PubMed: 24498350]
- Konstantopoulos Wendy L. Macias, Dreifuss Jessica A., McDermott Katherine A., Parry Blair A., Howell Melissa L., Mandler Raul N., Fitzmaurice Garrett M., Bogenschutz Michael P., and Weiss Roger D.. 2014. “Identifying Patients with Problematic Drug Use in the Emergency Department: Results of a Multisite Study.” *Annals of Emergency Medicine* 64 (5): 15–19. doi:10.1016/j.annemergmed.2014.05.012.
- Kwakwa Helena A., Bessias Sophia, Strugis Donielle, Walton Gina, Wahome Rahab, Gaye Oumar, and Jackson Mayla. 2018. “Engaging United States Black Communities in HIV Pre-Exposure Prophylaxis: Analysis of a PrEP Engagement Cascade.” *Journal of the National Medical Association* 110 (5): 480–485. doi:10.1016/j.jnma.2017.12.006. [PubMed: 30129509]

- Lane Sandra D., Rubinstein Robert A., Keefe Robert H., Webster Noah, Cibula Donald A., Rosenthal Alan, and Dowdell Jesse. 2004. "Structural Violence and Disparity in HIV Transmission." *Journal of Health Care for the Poor and Underserved* 15 (3): 319–335. doi:10.1353/hpu.2004.0043. [PubMed: 15453172]
- Meyer Jaimie P., Springer Sandra A., and Altice Frederick L.. 2011. "Substance Abuse, Violence, and HIV in Women: A Literature Review of the Syndemic." *Journal of Women's Health* 20 (7): 991–1006. doi:10.1089/jwh.2010.2328.
- Moore Todd M., Stuart Gregory L., Meehan Jeffrey C., Rhatigan Deborah L., Hellmuth Julianne C., and Keen Stefanie M.. 2008. "Drug Abuse and Aggression between Intimate Partners: A Meta-Analytic Review." *Clinical Psychology Review* 28 (2): 247–274. doi:10.1016/j.cpr.2007.05.003. [PubMed: 17604891]
- National Institute on Alcohol Abuse and Alcoholism. 2015. "Drinking Levels Defined." <http://www.niaaa.nih.gov/alcohol-health/overview-alcohol-consumption/moderate-binge-drinking>
- Nydegger Liesl A., and Dickson-Gomez Julia. 2017. "Structural Factors, Syndemics, and Sexual Health among High-Risk Black Women in Milwaukee, WI." In *American Public Health Association Annual Meeting*, Atlanta, GA, November 4 – 8, 2017. <https://apha.confex.com/apha/2017/meetingapp.cgi/Paper/382099>
- Roberts Sarah T., Haberer Jessica, Celum Connie, Mugo Nelly, Ware Norma C., Cohen Craig R., Tappero Jordan W., et al. 2016. "Intimate Partner Violence and Adherence to HIV Pre-Exposure Prophylaxis (PrEP) in African Women in HIV Serodiscordant Relationships: A Prospective Cohort Study." *Journal of the Acquired Immune Deficiency Syndromes* 73 (3): 313–322. doi:10.1097/QAI.0000000000001093.
- Rountree Michele A., Granillo Teresa, and Bagwell-Gray Meredith. 2016. "Promotion of Latina Health: Intersectionality of IPV and Risk for HIV/AIDS." *Violence Against Women* 22 (5): 545–564. doi:10.1177/1077801215607358. [PubMed: 26472666]
- Rubtsova Anna, Wingood Gina M., Dunkle Kristin, Camp Christina, and DiClemente Ralph J. 2013. "Young Adult Women and Correlates of Potential Adoption of Pre-Exposure Prophylaxis (PrEP): Results of a National Survey." *Current HIV Research* 11 (7): 543–548. doi:10.2174/1570162X12666140129104952. [PubMed: 24476352]
- Sales Jessica M., and Sheth Anandi N.. 2018. "Associations Among Perceived HIV Risk, Behavioral Risk and Interest in PrEP Among Black Women in the Southern US." *AIDS & Behavior* 23 (7): 1871–1876. doi:10.1007/s10461-018-2333-9.
- Sales Jessica M., Steiner RJ, Brown Jennifer L., Swartzendruber Andrea, Patel Anar S., and Sheth Anandi N.. 2018. "PrEP Eligibility and Interest Among Clinic- and Community-Recruited Young Black Women in Atlanta, Georgia, USA." *Current HIV Research* 16 (3): 250–255. doi:10.2174/1570162x16666180731143756. [PubMed: 30062969]
- Seth Puja, Wingood Gina M., DiClemente Ralph J, and Robinson LaShun S. 2011. "Alcohol Use as a Marker for Risky Sexual Behaviors and Biologically Confirmed Sexually Transmitted Infections among Young Adult African-American Women." *Women's Health Issues* 21 (2): 130–135. doi:10.1016/j.whi.2010.10.005. [PubMed: 21276736]
- Singer Merrill 1994. "AIDS and the Health Crisis of the U.S. Urban Poor; the Perspective of Critical Medical Anthropology." *Social Science & Medicine* 39 (7): 931–948. [PubMed: 7992126]
- Singer Merrill 2006. "A Dose of Drugs, a Touch of Violence, a Case of AIDS: Conceptualizing the SAVA Syndemic." *Free Inquiry in Creative Sociology* 24 (2): 99–110.
- Stockman Jamila K., Ludwig-Barron Natasha, Hoffman Monica A, Ulibarri Monica D., and Penniman Dyer Typhanye V.. 2012. "Prevention interventions for human immunodeficiency virus in drug-using women with a history of partner violence." *Substance Abuse and Rehabilitation* 3 (Suppl 1): 45–57. doi: 10.2147/SAR.S21293. [PubMed: 24500422]
- Straus Murray A., and Douglas Emily M.. 2004. "A Short Form of the Revised Conflict Tactics Scales, and Typologies for Severity and Mutuality." *Violence and Victims* 19 (5): 507–520. doi:10.1891/vivi.19.5.507.63686. [PubMed: 15844722]
- Tekeste Mehrit, Hull Shawnika, Dovidio John F., Safon Cara B., Blackstock Oni, Taggart Tamara, Kershaw Trace S., et al. 2019. "Differences in Medical Mistrust between Black and White Women: Implications for Patient–Provider Communication about PrEP." *AIDS & Behavior* Epub ahead. Springer US. doi:10.1007/s10461-018-2283-2.

- Tetteh Rayond A., Yankey Barbara A., Nartey Edmund T., Lartey Margaret, Leufkens Hubert G. M., and Dodoo Alexander N. O.. 2017. "Pre-Exposure Prophylaxis for HIV Prevention: Safety Concerns." *Drug Safety* 40 (4): 273–283. doi:10.1007/s40264-017-0505-6. [PubMed: 28130774]
- Tsai Alexander C., and Venkataramani Atheendar S.. 2016. "Syndemics and Health Disparities: A Methodological Note." *AIDS & Behavior* 20 (2): 423–430. doi:10.1007/s10461-015-1260-2. [PubMed: 26662266]
- United States Census Bureau. 2018. "QuickFacts: United States." <https://www.census.gov/quickfacts/fact/table/US/RHI225216#viewtop>
- Willie Tiara, Kershaw Trace, Campbell Jacquelyn C, and Alexander Kamila A. 2017. "Intimate Partner Violence and PrEP Acceptability among Low-Income, Young Black Women: Exploring the Mediating Role of Reproductive Coercion." *AIDS & Behavior* 21 (8): 2261–2269. doi:10.1007/s10461-017-1767-9. [PubMed: 28409266]

Table 1.

Structural and syndemic factors experienced over the 6 month study period

Factor	<i>n</i>	%
Housing		
Remained substandard/doubled up/environment ^a	12	40.00
Remained homeless	1	3.33
Remained adequate ^b	4	13.33
Moved substandard to unstable/substandard housing/homeless	9	30.00
Moved adequate to substandard	2	6.67
Moved substandard to adequate ^b	2	6.67
Income		
Remained same impoverished income ^c	13	43.33
Remained same adequate income (FT employment)	2	6.67
Income worsened ^d	6	20.00
Improved income (still impoverished) ^e	6	20.00
Income improved then worsened ^f	3	10.00
IPV		
Physical	15	50.00
Psychological	27	90.00
Sexual	19	63.33
Previous Trauma		
CSA	9	30.00
Child physical abuse	4	13.33
Rape	7	23.33
Any IPV	20	66.67
Substance Use		
Problematic alcohol use	11	36.67
Problematic marijuana use	15	50.0
Problematic other drug use ^g	6	20.00
Coping alcohol use	14	46.67
Coping marijuana use	14	46.67
Previous problematic substance use		
Alcohol	10	33.33
Marijuana	16	53.33
Other ^h	8	26.67
Risky sexual behaviour		
Sex without a condom	29	96.67
Multiple/concurrent sex partners	21	70.00
Sex exchange	6	20.00

Factor	<i>n</i>	%
Sex under the influence of alcohol	14	46.67
Sex under the influence of marijuana	7	23.33
Sex under the influence of crack cocaine	1	3.33

^aNote. 9 participants wanted to move but could not afford to.

^b2 participants (in each category) had parents or significant others paying for housing or they were living with them.

^c9 participants on SNAP,

^d2 participants on SNAP,

^e1 participant on SNAP,

^f1 participant on SNAP.

^gOther drug use included crack cocaine, cocaine, pain pills, and K2 (synthetic marijuana).

^hOther drug use included crack cocaine, cocaine, anxiety and antidepressants.