

PrEP and HIV prevention decision-making among social network members of women who have experienced incarceration: a qualitative study

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ABSTRACT

Incarceration and HIV are a syndemic for US women, yet very few women who have experienced incarceration use pre-exposure prophylaxis (PrEP) for HIV. We conducted semi-structured interviews with 32 participants recruited by women who have experienced incarceration from their social networks, informed by the modified social ecological model for PrEP. Emergent themes from the interviews included individual-level (low personal HIV risk assessment, personal responsibility for HIV prevention, and decisions in addiction versus recovery), network-level (influential sex partners and the importance of trust, supportive treatment peers, and high-risk but indifferent drug use networks), community-level (stigma, and mitigation of stigma in supportive substance use disorder treatment environments), and public policy-level (incarceration and PrEP cost and access) determinants. PrEP interventions for women who have experienced incarceration and their networks will need to incorporate contingency planning into HIV risk assessment, navigate complex network dynamics, and be situated in trusted contexts to address structural barriers.

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Introduction

Incarceration and HIV for US women constitute a syndemic, where interconnected and interrelated biological and social factors act to exacerbate and concentrate adverse health outcomes (Kelly et al., 2014; Koblin et al., 2015; Singer et al., 2006). Nearly half of women in a US cohort at risk for HIV had experienced incarceration at some point (Knittel et al., 2021). In addition, incarceration is associated with an approximately 3 per 100 person-years risk of HIV acquisition in the first 12–18 months in the community (Gough et al., 2010). These syndemic risks are driven by three underlying mechanisms. First, incarceration and HIV share a number of risk factors, including substance use and sex exchange (Fogel et al., 2014; Herbst et al., 2016). Second, the social and structural marginalization of women who experience poverty, racism, and substance use result in mass incarceration and heightened vulnerability to HIV acquisition in these groups (Blankenship et al., 2021; Herbst et al., 2016; Wise et al., 2017). Third, the disruption of social, sexual, and support networks due to women's incarceration may result in increased

risk for both re-incarceration (Herbst et al., 2016; Leverentz, 2018) and risk of HIV acquisition (Khan et al., 2011a; Khan et al., 2011b; Knittel et al., 2020, 2022).

Despite these syndemic risks, very few women who have experienced incarceration use pre-exposure prophylaxis (PrEP) for HIV (Dauria et al., 2021; Rutledge et al., 2018). A modified social ecological model for PrEP has been used to explore barriers to PrEP uptake among with who have experienced incarceration, identifying individual, network, community, and structural factors affecting PrEP decision-making (Figure 1) (Baral et al., 2013). Individual women identified unawareness of PrEP, the complicated navigation required to identify and manage evolving seasons of risk based on substance use and sexual relationships, and perceived interactions between personal medical conditions and PrEP as reasons they might choose not to use PrEP (Dauria et al., 2021; Knittel et al., 2023). At the network level, distrust of sexual partners and challenges with estimating risk in broader networks were also important for PrEP decisions (Dauria et al., 2021; Knittel et al., 2023). Barriers to PrEP

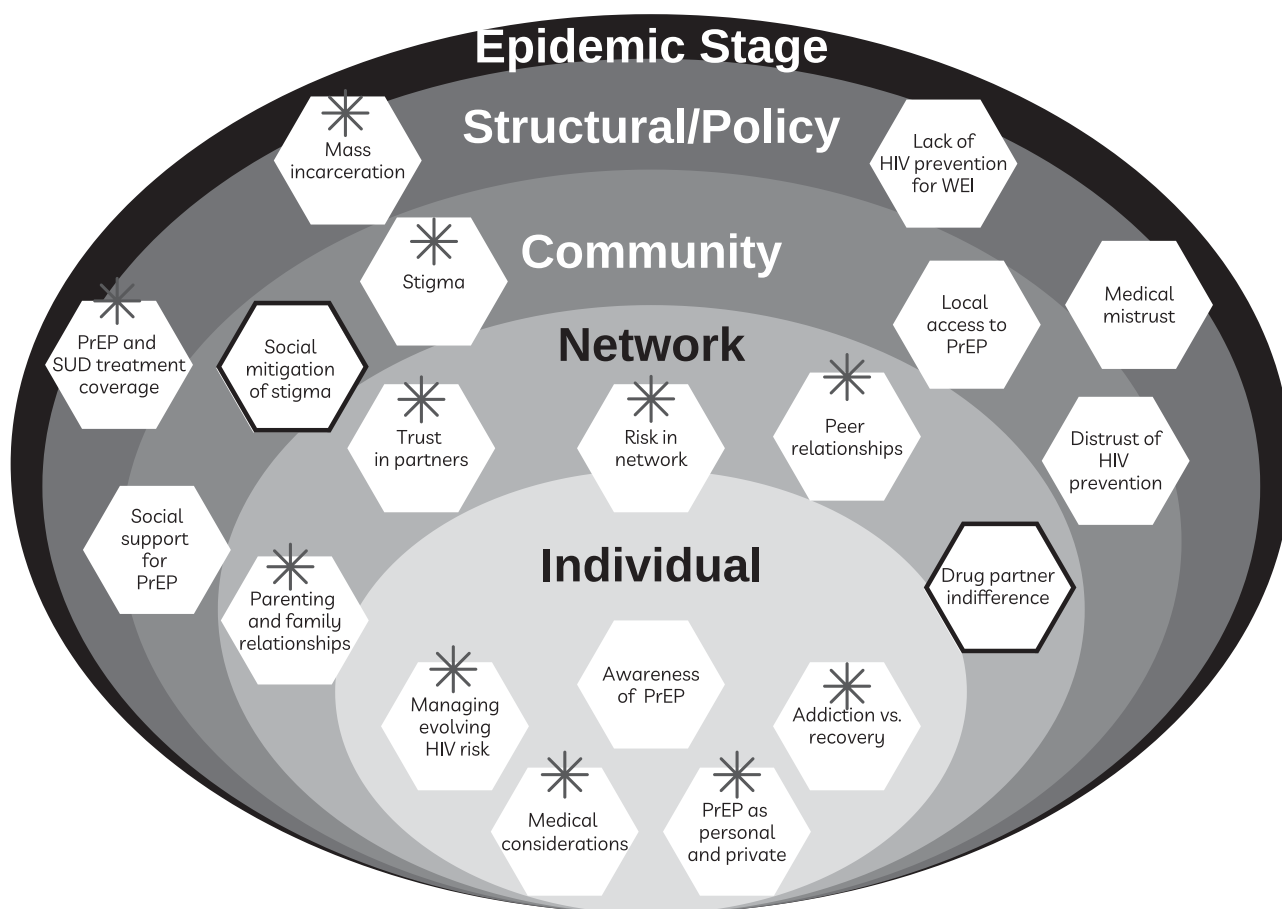


Figure 1. Modified social ecological model for PrEP for women who have experienced incarceration, with themes from the literature shown in white hexagons. Asterisks indicate recurrent themes and hexagons with borders indicate new themes from the current analysis of interviews with the network members of women who have experienced incarceration in the Southeast US, 2020.

uptake at the community-level include distrust in HIV prevention mechanisms and stigma from incarceration (Dauria et al., 2021; Knittel et al., 2023). Structural factors affecting PrEP decision-making for women who have experienced incarceration (WEI) include medical distrust, the cost and coverage of PrEP, and lack of focused HIV prevention efforts for WEI (Dauria et al., 2021; Knittel et al., 2023). Looking beyond barriers, analyses using the modified social ecological model have also identified important positive factors that WEI take into account when making PrEP decisions, including accurately assessing heightened personal risk for HIV, positive peer and parenting relationships, and viewing PrEP as a method of HIV prevention that does not require partner negotiation (Dauria et al., 2021; Knittel et al., 2023).

Substance use disorders are a critical determinant of both incarceration and HIV risk, and there is significant overlap between women with substance use disorders and WEI (Herbst et al., 2016). Studies of WEI and of women engaged in substance use treatment shed light on some ways that substance use disorders

and treatment may figure into the modified social ecological model specifically for WEI considering PrEP. At the individual level, WEI may use their experiences of substance use and recovery to assess relative HIV risk, both identifying periods of higher risk and potentially underestimating risk while in treatment (Beck et al., 2022; Knittel et al., 2023; Przybyla et al., 2020; Qin et al., 2020). Key determinants of PrEP use at other levels for women with substance use disorders echo those identified in studies of WEI, including network- (e.g., Partner risk and trust), community- (e.g., Stigma) and structural-level factors (e.g., Cost, carceral involvement) (Przybyla et al., 2020; Qin et al., 2020). **Figure 1** shows the modified social ecological model with constructs from the PrEP literature on WEI and women in treatment, including individual behavior, stigma related to substance use, and access to treatment services.

Given the significance of network and community factors in prior studies, we sought to qualitatively explore decision-making about PrEP in WEI's social networks. We focused specifically on the PrEP and

HIV prevention decision-making of people identified as being in the social networks of WEI engaged with community-based organizations (CBOs), primarily those providing substance use disorder treatment. This exploratory, qualitative study was guided by the modified social ecological model for PrEP.

Method

Setting

The three partner CBOs are located in the urban and suburban Southeastern US. All provide re-entry services (e.g., Housing, health care, employment resources) and two provide residential substance use treatment. All serve more than 100 clients per year. The study was approved by the Institutional Review Board at our institution (#20-0219).

Recruiters

We used a two-step recruitment process to identify individuals within the social networks of WEI. First, recruiters – self-identified WEI, English-speakers, at least 18 years-old, and involved with a partner CBO – were recruited through visits to CBO virtual groups, tear-off flyers, and CBO staff referrals. We screened and consented interested potential recruiters by phone. Each recruiter received three unique ID numbers to recruit up to three unique network members – either sexual partners, drug-use partners, or treatment partners. Recruiters received a \$15 enrollment incentive and an additional \$15 if any network member made contact with our research team (maximum \$30).

Participants

Potential participants contacted the study team via phone, text, email, and CBO staff. Eligible participants were over the age of 18, English-speakers, not currently incarcerated, residing in North Carolina, and provided study staff the unique ID number from their recruiter. Individuals who were currently under community supervision or detained at the CBO as a condition of parole or probation were considered non-voluntary CBO participants and excluded. Participants completed phone calls for eligibility and consent procedures, basic demographic information, and semi-structured interview scheduling. The two-step recruitment process yielded 32 participants including treatment partners and sexual partners from the

networks of WEI; no drug partners were referred to the study.

Interviews

Interviews were conducted June 2020 through December 2020. One member of the research team (EF) experienced with qualitative interviews conducted all of the interviews by phone due to pandemic precautions. The interviews were recorded in their entirety. The interview guide included a qualitative network mapping exercise to identify important relationships in the prior six months, prompts about individual and network HIV risk, awareness of PrEP as an HIV prevention intervention, and barriers and facilitators to PrEP uptake. For participants unaware of PrEP, the interviewer briefly described PrEP as a daily oral medication that could prevent HIV. The guide was developed from the research questions using important domains from the modified social ecological model for PrEP and from the literature (Auerbach et al., 2015; Goparaju et al., 2017; Ramsey et al., 2021; Rutledge et al., 2018). Each participant received a \$25 gift card or a gift bag of body care products valued at \$25 at the conclusion of the interview; some participants were unable to receive gift cards due to their treatment program structure and so received the gift bag.

Data analysis

Interview transcripts were then analyzed using a general inductive approach with Dedoose qualitative data analysis software (SocioCultural Research Consultants, 2020; Thomas, 2006). Three members of the research team (AK, JJ, EF), including the interviewer (EF), created a preliminary codebook based on the domains in the interview guide and drawn from each level of the modified social ecological model for PrEP, including topical codes capturing the content of participants' comments (e.g., "risk awareness," "PrEP decision-making," "treatment program structure"). We then generated coding memos with potential additional codes, relationships between codes, and other observations while closely reading the first several transcripts. We expanded and revised the codebook based on these memos to include additional topical codes as well as interpretive codes capturing emergent cognitive or emotional aspects of the participants' comments (e.g., "protection," "addiction versus recovery") (Saldaña, 2009). Four members of the research team (AK, JJ, EF, and RS) participated in coding the interview transcripts, with at least two coders coding each transcript

independently and resolving discrepancies through discussion. We did not add additional codes during the coding of the remaining interviews, supporting some degree of inductive thematic saturation (Saunders et al., 2018). Through distillation of the coded data into thematic summaries and the creation of thematic memos, the entire research team identified relationships between the primary themes and the modified social ecological model for PrEP. The primary themes echoed across the interview transcripts, suggesting data saturation (Saunders et al., 2018).

Results

The 32 participants had a mean age of 34 years (SD 9 years), were majority female (n = 28, 88%), and recruited by individuals currently or recently in substance use treatment programs. Of those who shared racial and/or ethnic identities, 23 were white (72%), 6 were Black (18.75%), and 2 were Hispanic/Latinx. Most had experienced incarceration (n = 29, 91%). Pseudonyms and participant ages were assigned for quote attribution.

We identified themes within each level of the modified social ecological model for PrEP. Table 1 shows the structure of the themes nested in the levels, along with the codes that contributed to those themes. Illustrative quotes for each theme by level are shown

in Table 2 (Individual), Table 3 (Network), Table 4 (Community) and Table 5 (Public Policy).

Individual level

"I didn't care in my addiction at all." Many participants emphasized their de-prioritization of HIV prevention and PrEP during periods of substance use. They described making decisions and engaging in behaviors that they wouldn't otherwise do. Emily (age 22) said that she would be unlikely to use PrEP if she were to start using drugs again (Table 2). Interviewees linked being *"sober"* with having *"a good mind"* about HIV prevention (Lauren, age 37), and valuing themselves and their health more during periods of recovery (David, age 53) (Table 2).

"It's your decision." Throughout the interviews, participants shared perspectives that attributed individual decision-making to HIV prevention behaviors, rather than social decision-making. One participant described in detail how people in her network might affect her HIV risk in different ways, and also emphasized the private nature of HIV prevention (Table 2). Participants used *"protection"* both to suggest condom use for HIV prevention and also in a broader sense, explaining *"[You're] more at risk if you're not protecting yourself,"* (Melissa, age 29). Individual strategies for prevention were the most frequently recommended: *"Know your partner. Get tested multiple times. Protect yourself. That's it,"* (Rebecca, age 45).

Table 1. Levels of the modified social ecological model and the themes identified at each level, with the primary codes within that theme from interviews with participants recruited from the social networks of women who have experienced incarceration in the Southeastern US, 2020.

Level	Theme	Primary Codes
Individual		
	<i>"I didn't care in my addiction at all"</i> Addiction versus recovery	Addiction versus recovery, HIV Prevention (Individual), PrEP Reaction (Self)
	<i>"It's your decision"</i> Individual responsibility	HIV Prevention (Individual), Protection, Parallel Decision Making, HIV Risk Influence
	<i>"They don't feel like they're at high risk for it"</i> Personal risk assessment	PrEP Decision Making (Individual), HIV Risk Influence, PrEP Reaction (Self)
	<i>"If it's even worth taking"</i> PrEP awareness and knowledge	HIV Risk Awareness/Knowledge, PrEP Decision Making (Individual)
Social and sexual networks		
	<i>"It's like a ripple effect"</i> Partner and network risk assessment	HIV Risk Influence (Sex Partners), Linked drug and sexual risk, Network risk, PrEP Decision Making (Network/Relationship), PrEP Reaction (Network), PrEP Reaction (Sex Partner)
	<i>"What are you trying to tell me?"</i> Communication and trust	HIV Risk Influence (Sex Partners), PrEP Reaction
	<i>"We're staying clean together"</i> Support from (treatment) peers	HIV Risk Influence (Friends), HIV Risk Influence (Treatment Peers)
	<i>"My family and them"</i> Family	HIV Risk Influence (Family), HIV Risk Influence (Children)
	<i>"They probably wouldn't care"</i> The difference with drug use networks	HIV Risk Influence (Drug Partners), PrEP Reaction (Drug Partner)
Community		
	<i>"I think it would have some stigma to it"</i> Stigma	HIV Prevention (Social), HIV Risk Influence, PrEP Decision-making (Individual, Network, Social), PrEP Reaction (Self)
	<i>"That's the thing here in this program"</i> Program structure as a social norm	Treatment Program Structure, PrEP Reaction (Self)
Public Policy		
	<i>"It's not cheap, is it?"</i> Cost, insurance, and access	HIV Prevention (Structural), PrEP Decision Making (Structural)
	<i>"How it is in prison"</i> Incarceration	Incarceration

Table 2. Illustrative quotes for each individual-level theme from interviews with participants recruited from the social networks of women who have experienced incarceration in the Southeastern US, 2020.

Theme	Quotes
"I didn't care in my addiction at all" versus recovery	<p>Drugs, or, like, alcohol ... makes you have low awareness of things, and you do things out of character that you wouldn't necessarily do.</p> <p>Jessica, age 37 [If I were to start using drugs again, I would] go back to not caring about what happens [and] ... probably wouldn't use PrEP.</p> <p>Emily, age 22 You know your worth – it's just pretty much higher when you're clean and sober than it was when you're in active addiction.</p> <p>David, age 53</p>
"It's your decision" Individual responsibility	<p>I think it's just something they talk to their self about or talk to ... like, one individual, maybe that they have a relationship with, but it's never really talked about, like, openly. It's like a discreet conversation that you would have ... like, a one-on-one type situation.</p> <p>Rachel, age 33</p>
"They don't feel like they're at high risk for it" Personal risk assessment	<p>I'm less at risk "cause [I'm] using protection. I know they have some kind of pill out now that you can take. I've heard about that, but ... Yeah, that's probably somethin" that I would do just to be safe, you know, when I'm done at [treatment program], just "cause you never know what can happen to you. I know when I was doing drugs I was in pretty bad situations and some things happened.</p> <p>Christina, age 37 But I know, like, out there if I was, like, using or something maybe I would be more intrigued to using something like [PrEP].</p> <p>Samantha, age 29</p>
"If it's even worth taking" PrEP awareness and knowledge	<p>I wouldn't take it just because I don't wanna have to take a-a pill every day, you know, and I don't know the side effects of it. I don't know enough about it to even take it.</p> <p>Amber, age 31 I think there might be a pill that you could take ... to make you less at risk. I don't know.</p> <p>Sarah, age 27 [I'd want to know] that it's 100% sure or 99-point-whatever sure it is.</p> <p>Mark, age 56 No headache, no, like, tiredness, no – I do a lot of stuff around here and the last thing I need to be is groggy.</p> <p>Brittany, age 25</p>

"They don't feel like they're at high risk for it." Closely tied with the theme of changed perspectives around HIV prevention from active substance use compared with periods of recovery was the theme of personalized risk assessment. Some participants expressed that while they were in a structured program, their risk was less, but that this could change (Table 2).

"If it's even worth taking" Many participants were not aware of PrEP as an option for HIV prevention prior to the interviewer describing it briefly in the interview. Once the idea was introduced, and even among a few who were aware of PrEP, the majority endorsed not having enough information about it to make a decision. Participants also expressed concerns about adherence to a daily medication, side effects, and efficacy.

Social and sexual network level

"It's like a ripple effect" Most participants identified their individual sexual partners as affecting their HIV risk both through the actions they took as a dyad, like using condoms or not, and through their partners' current and prior sexual networks, substance use, and sexually transmitted infections. Other participants emphasized aspects of their partnerships as contributing to HIV risk – new partners, "one-night stands," and

transactional sex partners were all identified as higher risk, as were partnerships affected by infidelity. Participants also perceived a different level of risk in a partnership if it took place during recovery rather than during active substance use. Partners and relationships in recovery were often described as "good" relationships. Some participants also indicated that when a sexual partner was engaged in substance use, whether or not the participants themselves were currently using, uncertainty increased about whether a partner might be engaged in substance- and/or sex-related risk behaviors (Table 3).

"What are you trying to tell me?" After condoms, one of the more commonly discussed HIV risk reduction methods among participants was being familiar with a sex partner and their STI history, and many participants talked about communication and trust as key determinants of HIV risk and prevention decision-making. One participant described the conversations about past risk that she had had with a potential partner (Table 3). When the possibility of introducing PrEP into these conversations was discussed, however, many participants shifted to suggest that discussing PrEP would introduce distrust and suspicion into the relationship (Table 3).

"We're staying clean together" Although participants described many friendships that did not influence

Table 3. Illustrative quotes for each social and sexual network-level theme from interviews with participants recruited from the social networks of women who have experienced incarceration in the Southeastern US, 2020.

Theme	Quotes
"It's like a ripple effect" Partner and network risk assessment	<p><i>I mean, they've engaged in risky behavior with other people besides me and then that affected my risk.</i> Elizabeth, age 38</p> <p><i>I told him that ... because he cheated on me – so, I went and got like the STD screen, and I got an HIV test.</i> Lauren, age 37</p> <p><i>So in the past, I would just sleep with somebody to get the things that I would want. So there was never really any type of communication, or trust, or connection emotionally, or—it wouldn't even have to be a physical attraction. The person that I'm with today, there's respect, and trust, and communication, and honesty, appreciation, like, just things that base a good relationship off of.</i> Rachel, age 33</p> <p><i>[Her sexual partner]'s a shooter and whatever not, so like I don't know what he's doing out there, but I know it's not good. So he's probably not trying to prevent himself from doing anything like that [that would increase risk].</i> Courtney, age 28</p>
"What are you trying to tell me?" Communication and trust	<p><i>We both have engaged in risky behavior, and I know that he has hepatitis. So I will, you know, when we do engage in sexual activity, we've talked about being careful. And just because I want a future with him, that also affects me in not making bad decisions.</i> Elizabeth, age 38</p> <p><i>I don't think that [PrEP] would be a big deal ... I mean, I'm sure it wouldn't be—if I decided to take it in my current relationship. I don't believe it would be a problem that I should take it. I don't believe that my partner would have an issue with it. Besides just wondering, I guess, why he thought I needed it. Unless—and I don't believe I would be taking it in my current relationship unless I had just a bad feeling that something wasn't right and he—and maybe I thought, you know, he was cheating on me or something, or if I was cheating on him— then, you know. I wouldn't take it unless I felt like that.</i> Chelsea, age 34</p>
"We're staying clean together" Support from (treatment) peers	<p><i>[A friend in the program,] she just helps me stay on the right path.</i> Stephanie, age 30</p> <p><i>We [friends in the program] just talked like how men do, just tell "em how I feel. They'd just tell me, you know, straight up—I mean, I could make a decision, and they would support it.</i> John, age 34</p>
"They probably wouldn't care" The difference with drug use networks	<p><i>So I don't think - I don't think in the culture [of people engaging in substance use]—that culture, that somebody's gonna care that I'm protecting myself, you know. They're like, "All right, cool. Whatever."</i> Megan, age 35</p> <p><i>They probably wouldn't wanna share a needle with me [if I were using PrEP], "cause you can tell someone you're using it just to be safe, but unless they have knowledge on the medication—when I first saw it, back in the day, I would've been like, "Well, damn. Something must happen for this person to need to take that,"</i> Rachel, age 33</p> <p><i>I think like most people, I mean, the people that I was around far [out] west, like, they didn't care either way.</i> Amber, age 31</p>
"My family and them" Family	<p><i>[An older female relative] sits there, and she'll tell me, you know, not to be out here screwing everybody to get some kind of disease. It's, you know, she's tough love only.</i> Courtney, age 28</p> <p><i>But I never shared needles, so—the only person I ever shared-shared a needle with was my sister. And she gave me hep C.</i> Christina, age 37</p> <p><i>[My daughter] was young, growing up with me. And, I don't know, I think just, like, not wanting to have any needles and stuff around her made me, like, I kinda had to shelter her so I could – so it kept it away from me.</i> Angela, age 36</p> <p><i>I just wanna be here for [my daughter] forever. So, I would always protect myself from here on out.</i> Jessica, age 37</p>

their HIV risk or prevention decision-making, the friendships formed in the context of substance use treatment were substantially different. Participants described treatment peers as supportive of recovery and healthy decisions and as confidants and counselors. One participant described receiving advice from a friend in treatment, and another talked about a group of supportive friends (Table 4).

"They probably wouldn't care" In contrast with supportive conversations in treatment, many participants expressed surprise at the idea that the people they used substances with in the past might care at all about PrEP or the participants' potential use of PrEP. Even one participant who described her own

use of a local needle exchange program didn't think that any of the people in her network were thinking about risk reduction. Participants suggested that disclosing or recommended PrEP use to those in their substance-use networks would have prompted some distrust or assumption about the participants' own risk (Table 3).

"My family and them" Some participants described family members who provided HIV prevention advice or support for sexual health care. One participant shared that her sister, "—she's taken me to get tested before, like, when I was younger. She's made sure, like, as far as me having birth control," (Samantha, age 29). A larger number of participants had not

Table 4. Illustrative quotes for each community-level theme from interviews with participants recruited from the social networks of women who have experienced incarceration in the Southeastern US, 2020.

Theme	Quotes
"I think it would have some stigma to it" Stigma	Because previously, the things that [we were] doing, I feel like it would make me look like I was doing the things that I was trying to hide. Like sleeping around or sharing needles, like, just bringing up that conversation makes people question why you feel you need to take anything for that. Rachel, age 33
"That's the thing here in this program" Program structure as a social norm	I think [PrEP is] a lot easier to, to talk about in here than it would be with, you know, a friend that I've just been on the streets with ... Like, you know, it's, it's not shamed upon. It's not looked down on. Angela, age 36 Of course, [we] talked about—actually, here, in [program], before you can date somebody and have an overnight, you have to get STD tested—and HIV tested, and to be open and honest about, like, if you do have—like, if I—if he had Hep C, he would have to sit down and tell me that in front of somebody. Emily, age 22

ever discussed HIV prevention with family members. For example, "[My aunt] doesn't really talk about things like that," (Lauren, age 37). For participants who used drugs with their family member, these relationships were described as negatively affecting HIV risk and decision-making (Table 3).

Children, however, were much more often identified as participants' motivation to protect themselves, and also as needing protection for HIV (Table 3). One participant expressed her desire to provide parental guidance from her treatment program stating, "I know I'm gonna have that conversation with my daughter here." (Christina, age 37). Another shared how protecting her child from seeing needles also motivated the participant to protect herself.

Community level

"I think it would have some stigma to it" Many participants shared concern that using PrEP would be interpreted by others as an admission of high risk sexual or substance use behavior, including sexual contact with gay men. Stigma was linked with the individual theme of maintaining privacy and discretion around HIV prevention, in order to avoid speculation by others. "'cause if certain people would find out, they're like, 'Why the hell's he—why's he usin' that?'" (John, age 34). Some participants also shared a related concern that PrEP use would indicate to family and friends a return to substance use (Table 4).

"That's the thing here in this program" Although many participants discussed stigma surrounding HIV and PrEP, many of those who were in a substance use treatment program emphasized that the social norms within the structure of the program were very different from outside the treatment program. For some participants, this was primarily related to being embedded in different social networks within the treatment program (Table 4). Others emphasized the formal structure of the program as establishing norms around communication

and prevention (Table 4). Some participants shared their plans to continue to follow these norms after completing the program.

Public policy level

"It's not cheap, is it?" In response to a question about barriers to PrEP use, a large number of participants identified cost and insurance as potential determinants of use. One participant suggested that she would use PrEP, "... just as long as it's not hurtin' my pockets too bad, you know?" (Jessica, age 37). Participants identified free, streamlined access to PrEP through health departments, harm reduction services like needle exchange programs, and substance use disorder treatment programs as structural interventions that would improve PrEP uptake. (Table 5)

"How it is in prison" Participants identified incarceration as a disruptive force that contributed to HIV risk. Participants did not talk about PrEP or HIV prevention opportunities in the context of incarceration. Instead, they emphasized the churn of incarceration and re-incarceration. Sandra, age 58, said that "[she] just kept goin' to jail for [substance use]."

Table 5. Illustrative quotes for each public policy-level theme from interviews with participants recruited from the social networks of women who have experienced incarceration in the Southeastern US, 2020.

Level	Theme	Quotes
	"It's not cheap, is it?" Cost, insurance, and access	Having insurance or Medicaid would make it easier [to take PrEP] ... I don't know if Medicaid covers it. Amber, age 31
	"How it is in prison" Incarceration	When he got out of prison, like, that was, uh, something that was pretty serious. "Cause bein' in prison for that long, you never know, like, where somebody's at. And, um, so I, like, I immediately had him tested for everything before we could even begin a sexual relationship again. Angela, age 36 So, every time I would get incarcerated, she would end up bein' somewhere else ... I mean, she would sleep around ... I can't really blame her. I mean, we were unstable. John, age 34

Discussion

This study identified potential determinants of PrEP use in the networks of WEIs at all levels of the modified social ecological model for PrEP. Members of the networks of WEI may underestimate their HIV risk and are only minimally aware of PrEP for HIV prevention, despite recognizing high-risk periods associated with substance use. Participants identified positive network determinants of HIV risk and PrEP use, including influential, potentially supportive networks of sexual partners, peers in treatment, and some family. These contrasted with high-risk and indifferent drug use networks. Stigma and mitigation of stigma in supportive substance use disorder treatment environments were the key community-level themes. Incarceration was an important structural determinant of HIV risk, and PrEP cost and access was the primary public policy level theme related to PrEP decision-making. [Figure 1](#) shows where these findings strengthen and expand on prior themes in the modified social ecological model for PrEP.

These findings among the network members of WEI support and extend previous work identifying important determinants of PrEP use among WEI themselves. Many of the individual-level (overall low personal HIV risk assessment, the recognition of periods of higher risk related to active substance use, and low PrEP awareness), network-level (trust/distrust of sexual partners, positive peer relationships, and recognition of high network risk), community-level (stigma), and public policy-level (cost, coverage, incarceration) themes from this analysis echo those described in the literature ([Beck et al., 2022](#); [Dauria et al., 2021](#); [Knittel et al., 2023](#); [Przybyla et al., 2020](#); [Qin et al., 2020](#); [Rutledge et al., 2018](#)). Participants in this analysis contributed novel concepts around PrEP decision-making in this population, including perceived individual responsibility for HIV prevention and a nuanced view of how different types of networks may affect PrEP decision-making, emphasizing different degrees and valences of influence among friends (i.e., Treatment peers versus prior substance use networks) and family (i.e., Children versus adult relatives).

The themes that emerged at the structural/public policy level among these interviews with WEI network members also add new detail and complexity to previous calls for general HIV prevention and specific PrEP interventions to target WEI by qualitative study participants, such as that described by [Dauria et al. \(2021\)](#). In a non-Medicaid expansion state, it is somewhat predictable that WEI network members identified a variety of providers of free or public-insurance funded services, such as health departments, needle exchange

programs, and treatment programs, where they might feel comfortable and confident that they could access PrEP services. They notably did not identify prisons or jails as places for intervention, despite these facilities serving as a potential access point for health care. This is consistent with prior research suggesting that these facilities are not trusted providers of health care generally, and sexual or reproductive health care specifically ([Knittel et al., 2023](#)). This has important implications for future PrEP implementation, as many programs under study leverage carceral infrastructure and/or community surveillance programs to recruit WEI for PrEP interventions ([Gilbert et al., 2021](#); [Ramsey et al., 2021](#)). A diverse array of interventions in multiple settings will likely be necessary in order to maximize PrEP uptake and persistence among WEI and their network members.

Due to the woefully low rate of PrEP use among WEI, the focus of this study was PrEP decision-making as a part of PrEP uptake in this population. However, the themes also likely have important implications for broader PrEP implementation and for adherence and retention once individuals are engaged in PrEP care. For example, relationships may be as important for adherence as for uptake, as among young South African women, where disclosure of PrEP use was associated with higher adherence ([Giovenco et al., 2022](#)). Stigma has also been shown to be an important determinant of not only PrEP uptake, but also retention in other populations in the South ([Arnold et al., 2017](#)). Additionally, WEI who initiate PrEP in the community and then experience re-incarceration will need to navigate their distrust of medical services inside carceral facilities to avoid discontinuities in PrEP use ([Biello et al., 2018](#)).

Qualitative research is, by design, hypothesis-generating and locally specific. Although the racial and ethnic make-up of our sample did parallel regional demographics, our overall small sample size means that experiences specific to minoritized racial and ethnic groups may not have emerged as themes in the analysis. Larger quantitative studies are needed to broaden our understanding of how WEI and those in their networks make decisions about PrEP and their preferences for HIV prevention interventions. Another limitation of this study is that WEI recruited relatively few male-identified network member participants into the study; as a result, there was no attempt to qualitatively identify differences between the perspectives of men and women. Finally, network members who were currently incarcerated or under community supervision were excluded from our study. In our state, most carceral facilities do not offer PrEP and many are hesitant to collaborate on PrEP-focused research. As such, the focus of

this study was PrEP determinants in the community, although the perspectives of these excluded individuals would broaden future studies.

Despite these limitations, to our knowledge this study represents one of the first attempts to understand the perspectives of members in the social and sexual networks of WEI. Figure 1 highlights where the themes identified in this study reinforce and build on those that have previously been described among WEI themselves. By enriching the conceptual models of PrEP decision-making that center WEI and their network members, this study contributes to the evidence base that will be the foundation for critical interventions to improve PrEP uptake in this group.

Conclusions

Members in the social and sexual networks of WEI experience many of the same HIV prevention and PrEP decision-making determinants that are also important to WEI themselves – this may be a result of the fact that many of these network members have also experienced incarceration. Interventions to increase PrEP uptake among WEI's network members will need to incorporate contingency planning around current and future HIV risk into personal HIV risk assessment, leverage PrEP as an individual strategy that can be undertaken privately, navigate complex dynamics within familial, social, sexual, and substance-use networks, and address structural barriers to PrEP access. These types of interventions will be critical to minimize the harms of syndemic HIV and incarceration, while ending the syndemic will require eliminating entirely the churn through the carceral system that contributes significantly to the differentially high HIV risk that WEI experience.

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