



Forming Genuine Bonds: Retention Strategies for Cisgender Women in HIV Research

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Declaration of Presenting Author

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HIV & Cisgender Women in the U.S.

- In 2022, cisgender women accounted for 1 in 5 (~19%) of new HIV diagnoses in the United States^{1,2,3}
- Cisgender women are historically underrepresented in HIV research, and retention in existing HIV research studies is challenging⁴

Barriers to Research Participation

- Social stigma
- Medical distrust
- Low resource access
- Gender inequalities

Why This Matters

- A lack of adequate representation of those most vulnerable to HIV acquisition in HIV prevention research

→ Missed opportunities

- Factors related to HIV risk
- Effective prevention strategies



Study Objectives

- Using the Social Ecological Model (SEM), explore multilevel barriers to retaining cisgender women in HIV prevention research
- Apply findings to develop effective retention strategies in a large national HIV prevention cohort study

Methods

- Semi-structured interviews conducted virtually from March 2023 to February 2024 (n=114)
- Participants recruited nationally through convenience sampling via social media and community organizations
- Directed content analysis used to identify retention factors across individual, environmental, intervention, and structural levels

Group 1

HIV-negative
cisgender women
with increased HIV
prevention needs
(n=34)

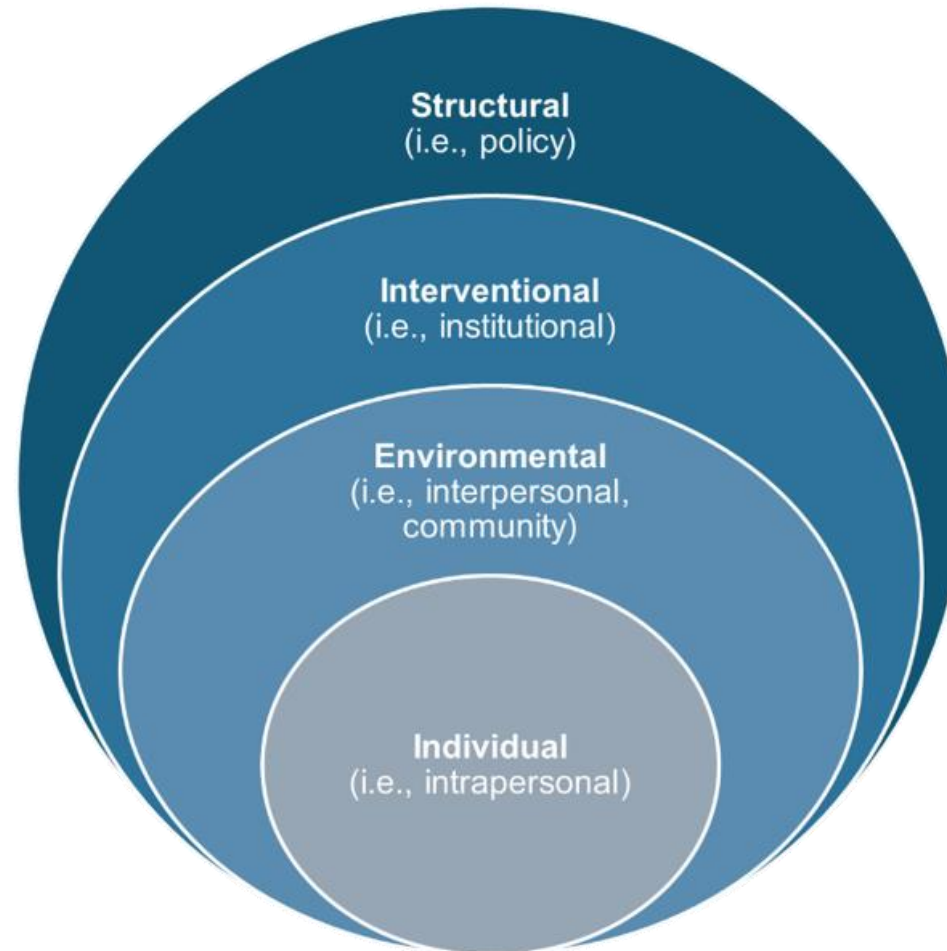
Group 2

Cisgender women
living with HIV (n=40)

Group 3

HIV prevention and
treatment
stakeholders (n=40)

Social Ecological Framework



Individual Level Findings

Substance Use

*"Vulnerable women...are unaccustomed to doing anything long-term but bad stuff. And, when there is that self-loathing, even though this will be good for a woman, she may feel undeserving...Those are some of the things, those inside voices, those negative voices, that's going to be something to deal with."
(Community Stakeholder)*

Study Duration

Anxiety & Frustration

*"I feel like my fear going into that first [study visit] was that I wasn't going to understand why I was being studied, which feels a little bit vulnerable and out of control."
(Woman with Increased Need for HIV Prevention)*

Environmental Level Findings

Poor Rapport

**Intimate Partner
Violence & Stigma**

**Historical Research
Exploitation**

"...there could be a danger if they're in a violent relationship and the man found out she was doing this. He might get angry." (Woman with Increased Need for HIV Prevention)

"...the community, especially anyone who has an STI, has been harmed oftentimes. And then...of course, anyone who is a part of a marginalized community, people of color, Black people in particular, you know, Tuskegee...truly that has impacted generations of folks who are absolutely are not going to be another one of your numbers and part of your data that then contributes to the harm that's been caused to my community." (Community Stakeholder)

Intervention Level Findings

**Study Visit Gaps &
Research Staff
Accessibility**

"I just didn't like when it was hard to get ahold of the staff, or like when something was confusing, and it wasn't explained correctly, or it takes forever to get ahold of somebody to answer questions..." (Woman with Increased Need for HIV Prevention)

**Compensation
Methods**

"...Cash App and Venmo are like gods...If you send someone a digital card, they might not be able to go to the corner market, but if you Cash App \$50 to their Cash App card, they can automatically go to that supermarket...It's definitely a big deal, especially for someone who doesn't have money in hand. They're going to be like, 'You're going to email a what in a week? No.'" (Community Stakeholder)

Structural Level Findings

Severe Resource Limitations

"...the majority of people that have HIV or have contracted STD, they're homeless, and they bounce around from place to place where they're not really in a stable situation...like the home they give you today, it's not going to be their home in six months."
(Woman Living with HIV)

"...there is a lot of intersectionality of mental health issues and homelessness. Even with people living with HIV, there are a lot of barriers and other things in place that are stopping people from accessing and staying connected to care..."
(Community Stakeholder)

"...I lose a ton of people...And those are the highest-risk folks...I think that to get somebody to retain them for the two years, it's going to be...like a more vanilla group of people that have access to that. And they stay consistent. And they're in the same place almost. They're not putting themselves at risk." (Community Stakeholder)

Facilitators

Individual

Clear expectations, flexible scheduling, safe & affirming environments

Environmental

Genuine relationships, discrete communication, transparent & community-centered research procedures

Intervention

Virtual options, personalized communication methods, flexible compensation

Structural

Multiple contact methods, accommodation for structural barriers in research design

Key Takeaways

- Women most vulnerable to HIV may be most difficult to retain in HIV prevention research.
- There is a need for comprehensive, multi-level retention approaches.
- Building genuine relationships and maintaining flexibility is critical.
- The structural constraints of participants must be considered in the research design.



Questions?

Let's connect!

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References available upon request

