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"It seemed like something I couldn't ask for…I knew I could, but I felt like I would be judged…I was worried about that interaction"

"It seemed like something I couldn't ask for": A Qualitative Analysis of Cis- and Transgender Women's Experiences Along the HIV Prevention Continuum in the South Bronx, New York City

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Background

- Cis- and transgender women (C/TGW) in the US lack access to HIV pre-exposure prophylaxis (PrEP) initiatives.
- Stigma and lack of awareness interfere with discussions of HIV risk and prevention among women.
- Continuum of care models help shape our understanding of PrEP use and service delivery, but few have been applied to women.
- This qualitative analysis explored the HIV prevention continuum as experienced by C/TGW participants (ppts) who completed a 12-month PrEP and HIV self-testing (HIVST) study in the South Bronx, New York City.

Methods

- We conducted 14 in-depth interviews (IDIs) with adult, non-pregnant, C/TGW.
- IDIs explored prior awareness and use of PrEP and experiences with PrEP and HIVST during the 12-month study.
- IDIs were audio recorded, transcribed, and deidentified.
- IDIs were analyzed using a preliminary set of codes derived from a four-stage PrEP care continuum model assessing awareness & willingness, access to healthcare, likelihood to receive a prescription, and adherence & efficacy (Kelley et al. 2015).
- Directed content analysis was used to expand the continuum to conceptualize ppt's experiences with HIV prevention and identify emergent themes.

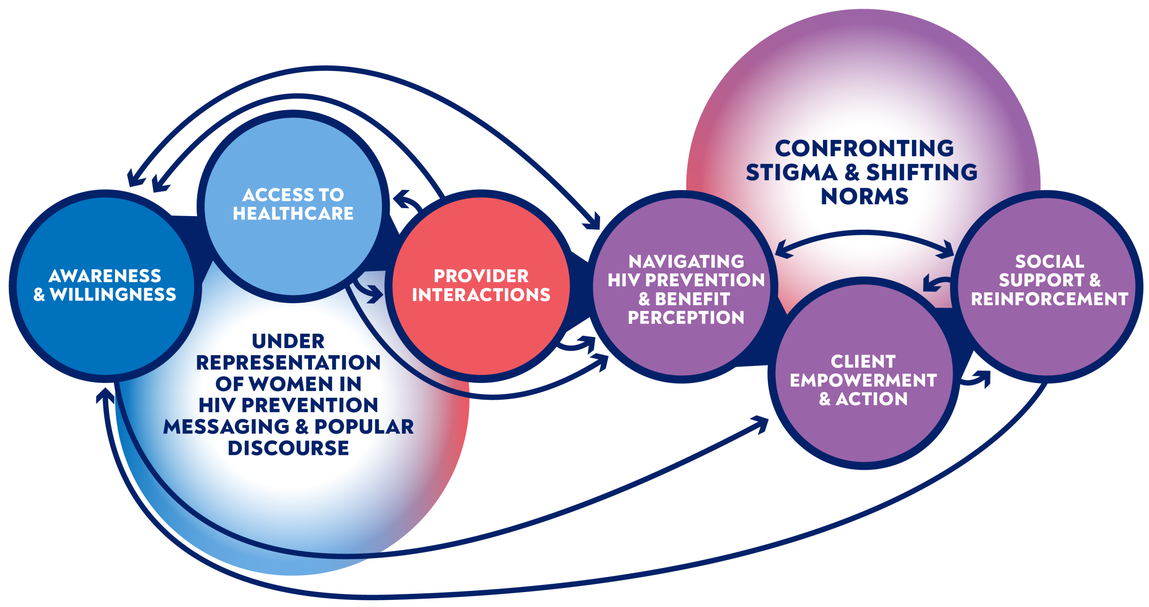
Results

- Among the 14 interviewed ppts, median age was 29 years; 10 identified as cisgender, 4 as transgender, 6 as Hispanic, 5 as Black; and only 4 reported prior PrEP use.
- Multi-level barriers to engagement in prevention included limited salience of HIV risk, mental distancing, stigma, low provider endorsement, and limited representation of women in HIV prevention messaging and popular discourse.
- Ppts described experiences that aligned with previously published PrEP continuum models, but highlighted additional dimensions of the HIV prevention experience, including how HIVST can reinforce confidence and self-management skills (Table).
- Ppts described HIV prevention as a journey characterized by internalizing protection as a norm, interacting with social networks, and confronting stigma.
- We expanded the four-stage continuum to include additional dimensions of the HIV prevention experience, encompassing both PrEP and HIVST and reflecting the dynamic social factors, contexts, and interactions that shaped how ppts experienced and navigated prevention (Figure).

Conclusions

- PrEP continuum models focused solely on service delivery overlook critical elements of women's HIV prevention journeys, including how stigma, social messaging, and popular discourse about PrEP and HIV risk influence benefit perception and willingness to engage with HIV prevention.
- This analysis highlights the importance of evolving perceptions, messaging, and norms about HIV prevention for C/TGW.
- Findings illustrate the potential synergistic benefits of including both HIVST and PrEP as a combination prevention intervention for C/TGW, supporting self-management and greater engagement in HIV prevention.
- Efforts to normalize PrEP, reduce stigma, and cultivate broader norms that support HIV prevention should reflect the experiences and social contexts of C/TGW.

Figure: ***HIV Prevention Continuum among C/TGW****



*Arrows illustrate multiple pathways and feedback loops along the dynamic HIV prevention continuum.

Table: ***Key themes and exemplary quotes along the HIV prevention continuum among C/TGW***

Stage in HIV Prevention Continuum	Theme(s)	Exemplary quote(s)
Awareness & Willingness	Limited salience of HIV risk	*"When it came to women, [HIV] was just so out of their universe that [PrEP] didn't make much sense to them" (CGW)*
	Mental distancing	*"I was in fantasy thinking like, 'Oh, it cannot happen to me'" (CGW)*
Access to healthcare	Navigating practical barriers	*"Insurance is hard to obtain, accessing a doctor in your area is hard, transportation to the doctor is hard" (CGW)*
Provider Interactions	Low provider endorsement	*"It seemed like something I couldn't ask for...I knew I could, but I felt like I would be judged...I was worried about that interaction" (CGW)*
	Relationship with healthcare provider	*"It's important to feel like you can trust your health provider. I had a doctor that didn't listen to my concerns, and I had to leave." (CGW)*
Navigating HIV prevention & benefit perception	Engagement in comprehensive prevention	*"I continued to get tested after every new sexual partner, and used other forms of birth control, like condoms" (CGW)*
	Expanding holistic health consciousness	*"It's an awareness of your health, which spreads into every other aspect of your life" (CGW)*
	HIV prevention as a journey	*"I have transformed my mindset where I'm not scared anymore… I am more conscious and aware and proactive with my health" (CGW)*
Client empowerment & action	Autonomy, self-management, and care	*"It's easy because [PrEP] is something I want…It's me, myself personally wanting to get it done" (CGW)*
	Negotiating sexual boundaries	*"I became uncompromising with knowing my partner's HIV status…it became a non-negotiable…to protect myself from HIV" (CGW)*
	Internalizing protection	*"I'm protecting myself and knowing my boundaries when it comes to being intimate with other people…[PrEP] helps with that." (TGW)*
Social support & reinforcement	Conversations around prevention	*"I'm educating [the young kids]…so that when they grow up, they won't be so scared and so unsure about things like taking PrEP" (TGW)*
	Empowering others through personal example	*"The best way to get somebody interested in something that you believe in is to tell them your story…I got all these people to believe in me and believe in themselves" (CGW)*
Confronting stigma & shifting norms	Representation in popular messaging and discourse	*"If more patients are asking for it, it becomes inherently less stigmatized" (CGW)*
	PrEP belongs in women-focused spaces	*"In places like clinics…where they help people with pregnancy and clinics where you go get tested for STDs…they should have flyers and things like that and maybe offer [PrEP] also" (CGW)*
	Mindset shifts	*"This is empowerment…the more you talk about [HIV], the less you give it power…It's a gradual process...which would possibly help humanity move forward" (CGW)*

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