



Knowledge About Oral PrEP Among Transgender Women in New York City

Christine Tagliaferri Rael¹ · Michelle Martinez^{2,3} · Rebecca Giguere¹ · Walter Bockting² · Caitlin MacCrate⁴ · Will Mellman² · Pablo Valente³ · George J. Greene⁵ · Susan G. Sherman⁶ · Katherine H. A. Footer⁶ · Richard D'Aquila⁷ · Alex Carballo-Diéguez¹ · Thomas J. Hope⁸

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Abstract

This paper grows our understanding about PrEP knowledge in transgender women (TW) to improve PrEP-focused education/outreach. Research took place in New York City. We conducted four focus groups in English or Spanish (N = 18). Discussions focused on participants' perceptions and knowledge of oral PrEP. Most participants knew that PrEP is efficacious and requires consistent use. However, some participants were skeptical of medications; others acknowledged that false assumptions about PrEP exist among TW. Most TW in our focus groups were informed about PrEP through clinics or community-based organizations. Some participants felt that messages about medications were oversimplified, and wanted more information.

Keywords Transgender women · PrEP · PrEP knowledge · Pre-exposure prophylaxis

Introduction

Of the approximately 840,000 United States (U.S.) adults who identify as transgender women (TW; individuals assigned male at birth who currently identify as female), approximately 22% are living with HIV [1]. In 2013, the percentage of transgender people receiving a new HIV diagnosis was roughly three times the national average [2]. Biomedical HIV prevention strategies, such as oral pre-exposure prophylaxis (PrEP; oral Truvada) have the potential to mitigate HIV incidence in TW. However, some studies show that significant barriers to PrEP uptake exist in this population, including “lack of knowledge” about PrEP [3]. This paper aims to contribute to the emerging literature about TW and PrEP awareness to help public health workers improve PrEP education and outreach efforts.

Efforts to communicate information about oral PrEP to TW are widespread in New York City (NYC), compared to many other areas in the U.S. In NYC, this information is disseminated in three main ways: (1) community-based organizations (CBOs), including CBOs focused on the needs of TW (e.g., Translatina Network, which aims to gain equal and lasting rights for all TW of Latina ethnicity at the local, state, and federal levels [4]), (2) healthcare providers and clinics [5], and (3) the NYC Department of Health (DOH)[6]. These organizations provide online and

✉ Christine Tagliaferri Rael
Christine.Rael@nyspi.columbia.edu

¹ HIV Center for Clinical, Behavioral Studies, New York State Psychiatric Institute, Columbia University, New York, NY, USA

² Program for the Study of LGBT Health, New York State Psychiatric Institute/Columbia Psychiatry, Columbia University School of Nursing, New York, NY, USA

³ Columbia University Mailman School of Public Health, New York, NY, USA

⁴ CUNY School of Public Health, New York, NY, USA

⁵ Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

⁶ Department of Behavior and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

⁷ Division of Infectious Diseases, Department of Medicine, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

⁸ Northwestern University Feinberg School of Medicine, and Biomedical Engineering in the McCormick School of Engineering and Applied Sciences, Chicago, IL, USA

print information about PrEP and conduct PrEP outreach in-person in bars or clubs or via advertisements on mass transit or television. Using data from four focus groups with $N=18$ TW, this paper aims to further the understanding of the ways that knowledge and awareness of PrEP may affect TW in NYC's capacity to take full advantage of its availability.

Methods

This study was conducted as a collaboration between *Project AFFIRM* (a longitudinal study of transgender identity development) and Sustained Long-Acting Prevention against HIV (SLAP-HIV; a study that aims to develop and perform a phase I clinical trial of a long-acting biomedical HIV prevention product). All work was approved by the Institutional Review Board, Human Subjects Committee of the New York State Psychiatric Institute.

Participants and Procedures

Focus groups were used to understand TW's collective views on PrEP knowledge and the meanings behind these views. Data collection occurred from September 2016–February 2017. All participants in our focus groups were 18 years of age or older, living in the NYC area, HIV-negative by self-report, self-identified TW, and reported anal or vaginal sex with a non-transgender man.

Participants were identified from a convenience sample of 160 diverse TW contained in *Project AFFIRM's* database and screened for eligibility criteria over the telephone. Procedures for recruitment, enrollment, and consent are described elsewhere [7]. After completing the eligibility screening, participants were invited to our research offices to complete an hour-long, interviewer-administered, tablet-based survey in English or Spanish. Then, participants ($N=28$) completed a rapid HIV test (OraSure Advance®). Participants who had a negative HIV test were invited to participate in one of four focus groups at a medical center in New York City, which took place at a later date. Of the $N=28$ individuals who completed quantitative surveys, 27 were eligible for focus groups. Of those, 18 participated (10 individuals who were eligible but did not attend could not be reached by phone or could not attend the group at the scheduled time).

Four 90-min focus groups were completed in English (3 groups) or Spanish (1 group) (Group 1: $n=3$; Group 2: $n=5$; Group 3: $n=7$; Group 4: $n=3$). Groups were co-led by the lead author (CR) and a trained research assistant (MM). Discussions focused on participants' perceptions and knowledge of oral PrEP. Participants were compensated \$50 for surveys and an additional \$50 for focus groups, to offset time/travel expenses.

Measures

To understand what participants already knew about oral PrEP, focus group attendees were asked, "What have you heard about PrEP or Truvada?" Then, participants were probed to understand: where they had heard the information they shared; how they felt about oral PrEP if they had used it; and what they had heard from friends or other people in the transgender community about oral PrEP.

Data Analysis

Audiotapes of interviews were transcribed and data were analyzed using Dedoose. CR and MM independently identified codes using a multilayered strategy. To begin, a list of a priori codes was developed by the research team [8], based on topics addressed in the focus group guide. Then, coders analyzed text to identify in vivo codes (e.g., language participants used to describe their thoughts/experiences with oral PrEP) [9]. Both coders independently developed a list of recurring themes, which included a priori and in vivo codes. Codes were intended to represent the presumed meanings underlying participants' responses [10].

To encourage consensus between coders, comparisons of a priori and in vivo codes were made following the first pass through the data. Discrepancies were discussed until consensus between coders was reached. To ensure that codes represented the data reasonably and realistically, codes were analyzed alongside text they were intended to represent. A priori codes that were absent from or poorly represented by the text were eliminated. Lastly, coders re-examined the data for an all-inclusive assessment of possible themes. Coders met again to discuss a priori and in vivo codes, verify that examples of text illustrated the themes they were intended to represent, and ensure consensus.

Results

Focus group participants had a median age of 29.9, were overwhelmingly of non-white race (82.4%), and over half had completed high school/GED (64.7%). Our findings, summarized in Table 1, show that our focus group participants knew that PrEP is highly efficacious, especially when users adhere to the consistent daily dosing recommendation. However, some were skeptical of PrEP and/or acknowledged that false assumptions about this medication exist. False assumptions were primarily focused on STI prevention (e.g., believing that oral PrEP eliminates all STI risk) and medication resistance (believing that starting and stopping PrEP could make it ineffective or cause resistance to

Table 1 Participant themes about oral PrEP knowledge and illustrative text examples

| Description | Text | FGs in which theme discussed |
|---|--|------------------------------|
| Participants' overall knowledge about oral PrEP | | |
| Participants knew that PrEP is highly efficacious | <p>"I heard that it can prevent... prevents the person 90% from contracting HIV or AIDS from unprotected sex while having sex with someone that's been exposed." (Focus Group 3)</p> <p>"I mean the last thing I heard was that it is used, you know, for people that are usually sexually active and so that they won't...so it protects them from the HIV virus." (Focus Group 2)</p> | 1, 2, 3, 4 |
| Participants knew that consistent daily dosing of PrEP is recommended | <p>"... the way I had it explained to me was, 'This [oral PrEP] is the birth control, whereas PEP is the day-after pill.' And that's the thing that I remember just because it's a weird analogy. And also that you have to consistently take it everyday. And if you miss one it doesn't, like, go all the way to the bottom, but it slowly chips away at it, I think. So you have to be really on target." (Focus Group 2)</p> <p>"Well, you have to say, 'I take my pill every day at like, 10:00 pm. That's the hour I've picked. I have nothing to do but take my pill.' Also you have to say to yourself, 'No. You have to take this pill everyday and you can't miss a day.' Otherwise you'll change your risk situation You'll probably raise your risk of contracting HIV or infecting yourself with HIV and so you have to take your pill everyday." (Focus Group 4)</p> | 1, 2, 3, 4 |
| Some participants were skeptical of PrEP | <p>"Like a pill just pops up. And from all these years, it's like no one had an answer, but now: Truvada! You know what I'm saying? It's like, PEP, PrEP, 'Oh try it. It's going to help you. It's going to save you.' And in reality, it may be something that's possible. Only reason why I can believe a pill can do something is because through the transitioning process, hormones really change a person. So, understandable. You know what I'm saying? Like when you think about it like, 'I don't really believe it, but I believe it.' I'm more of a person that just watch certain things and see what it does." (Focus Group 2)</p> <p>"I feel like I haven't heard a lot about effectiveness and that's one of the reasons I've been holding off." (Focus Group 1)</p> | 1, 2 |
| False assumptions about oral PrEP | | |
| Some transgender women believed oral PrEP eliminates all STI-related risk | <p>"A lot of the stuff I've heard about it is that it's kind of like a cure all. Like, 'If you take this then you don't have to worry anymore.'" (Focus Group 1)</p> <p>"...There's many people who unfortunately contract other infections because of the simple detail that they think, 'I use PrEP. I don't need a condom. You can have sex with me. I can have sex with whoever. I'm protected.'" (Focus Group 4)</p> | 1, 3, 4 |
| Some TW thought that starting and stopping PrEP could make medications ineffective or cause resistance to antiretrovirals | <p>"...there's a possibility that if you do stop taking it that the benefit that the pill provides can backfire and not work at all so you can actually...how do you say it? It can, your body can become immune to the medication so it won't respond to the medication anymore." (Focus Group 3)</p> <p>"...I heard of a case where a guy ended up coming out HIV positive, and because they were on PrEP before, it ended up that they were... their immune system was resistant toward HIV and he ended up passing away." (Focus Group 2)</p> | 2, 3 |

Table 1 (continued)

| Description | Text | FGs in which theme discussed |
|---|--|------------------------------|
| Sources of information on oral PrEP | | |
| Participants got information about oral PrEP from health clinics | <p>“I think at my doctor’s office they have a pamphlet about it, and also when you fill out an information form they’re like, ‘Have you asked your doctor about PrEP?’” (Focus Group 1)</p> <p>“I’ve heard it at a health clinic center because they were trying to introduce the patients to it so as they were telling me about it I remembered all the things they had to say about it.” (Focus Group 3)</p> | 1, 2, 3, 4 |
| Participants got information about oral PrEP from community-based organizations | <p>“[I heard about PrEP from] ...A friend of mine was working with a program called Quick Force. She worked a lot with – she did the linkages to care for the people who wanted to start taking PrEP.” (Focus Group 4)</p> <p>“Well we talk about it...we have a trans group on Wednesday. We was talking about it. When I first heard they said it was going to be a good thing to take, you know? And that’s when I first heard about it. They said it’s good. They said talk to your doctor or provider more. They said it’s good, it’s healthy, and it’s a very good thing to take, I guess. So that’s where I heard about it. I went to my group and I heard about it.” (Focus Group 1)</p> | 1, 2, 3, 4 |
| Oversimplified messaging about oral PrEP | | |
| Some participants felt like they didn’t have enough information about PrEP to make a truly informed decision about medication use | <p>“With pretty much every other medication there is pros and cons that you get right off the bat...and even if not, you have some sort of background. Like over the counter pain pills, like that kind of stuff. You kind of know what class it is and with PrEP its like what do you really compare PrEP to? It’s just kind of like on its own... For example when I started hormones they were like ‘Here’s all the benefits and here’s all the info and take all of it’... and for PrEP it was pretty much just like ‘You should take this because it will help prevent HIV’. And they didn’t really specify beyond that.” (Focus Group 1)</p> <p>I worked at an LGBT center and I would administer HIV tests...We were given a piece of paper to basically memorize to talk about PEP and PrEP and in kind of a rude way...They dumbed it down because for whatever reason they think that people coming in who need PEP and PrEP can’t understand words bigger than four letters.” (Focus Group 2)</p> | 1, 2, 3, 4 |

antiretrovirals). Additionally, we found that TW in our focus groups received most of their information about PrEP from community-based organizations and health clinics, but messages about oral PrEP were thought to be oversimplified, without full disclosure of risks versus benefits (e.g., sample participants felt like they did not have enough information about PrEP to make a truly informed decision about its use).

Discussion

This study contributes to the growing literature on TW and PrEP knowledge.

Participants in this study knew that PrEP is effective at preventing HIV in exposed individuals, particularly when used everyday. This may be due to consistent, focused information delivery about PrEP from CBOs, healthcare providers, and NYC advertising campaigns. Previous work with other populations supports this finding, showing that consistent messaging about PrEP can promote greater awareness, use, and willingness to recommend medication to friends [11, 12].

Communication about PrEP is especially important in light of other findings from this work; messaging should be tailored for TW’s needs. Specifically, TW in our focus groups felt that current messages about oral PrEP were oversimplified, and encouraged uptake without fully explaining potential costs and benefits of use. Participants wanted to

have a more complete picture of what they can expect while using this medication. Findings from other work show that TW are particularly interested in the safety, efficacy, and potential medication interactions in individuals using hormones as a part of gender affirmation therapy [7]. Future studies of biomedical HIV prevention products in the development pipeline should consider evaluating the effects that PrEP and gender affirming hormone use have on one another.

Additionally, some participants were skeptical of oral PrEP. That is, some participants felt that they hadn't heard very much about PrEP's effectiveness; others felt like PrEP had "popped up" out of nowhere, (e.g., PrEP was developed very quickly), and were wary about this. This issue could potentially be overcome by presenting potential PrEP candidates with a brief history of Truvada medication and the clinical research on its effectiveness and use for PrEP.

Though some participants felt messages about PrEP may be oversimplified or abrupt, they appear to have effectively communicated basic information about this medication. All focus group participants had heard of oral PrEP prior to enrolling in this study. Nevertheless, some participants endorsed false assumptions or revealed that others in the community believed untrue things about oral PrEP. These included believing that PrEP eliminates the risk for all STIs, and that discontinuing PrEP could cause future medication resistance. False assumptions persist, even though most TW learned about oral PrEP from healthcare providers or community-based organizations. Acknowledging and addressing these misconceptions with transgender individuals who are considering PrEP during patient/provider discussions could help to clarify these issues at the outset. Additionally, this information could be included in written or online informational materials intended for TW who are considering PrEP. Addressing these rumors could prevent TW from taking unnecessary risks while using PrEP, and/or encourage uptake by lessening the perception that users cannot stop taking medications once they start.

It is important to note that participants in this study were drawn from an existing cohort of TW in New York City, Project AFFIRM. Therefore, TW in our focus groups may differ from TW in the general population; they may have been exposed to HIV prevention information (e.g., PrEP) that others not involved in AFFIRM were not.

Conclusions

Messaging about oral PrEP in NYC appears to communicate basic information about this medication to TW. However, some gaps in knowledge and misinformation persist, despite that most TW learn about PrEP from credible sources. Healthcare providers and public health workers could help to overcome this issue by presenting a more holistic picture of oral PrEP to transgender patients, and addressing specific

false assumptions during patient/provider interactions, and in written or online informational materials.

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