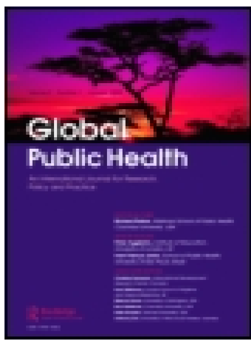

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Barriers and facilitators to PrEP for transwomen in Brazil

Erin C. Wilson [a], Emilia M. Jalil[b], Cristiane Castro[b], Nilo Martinez Fernandez[b], Luciana Kamel[b] and Beatriz Grinsztejn[b]

[a]San Francisco Department of Public Health, San Francisco, CA, USA; [b]Instituto Nacional de Infectologia (INI) Evandro Chagas, Fundacao Oswaldo Cruz, Fiocruz, Brazil

ABSTRACT

Pre-exposure prophylaxis (PrEP) is an important biomedical intervention that may help reduce the risk of HIV transmission among transwomen. To date, little research is available to inform interventions to increase uptake and adherence to PrEP among transwomen, especially in places outside the U.S. We conducted a qualitative study in 2015 with 34 adult transwomen in Rio de Janeiro, Brazil and assessed awareness, interest, barriers and facilitators to PrEP uptake and adherence for transwomen. Almost one third of participants had heard of PrEP, and most were interested and thought it would be beneficial for transwomen in their community. Barriers to PrEP included fear of being HIV positive resulting in low HIV testing and concerns about the ability to adhere to a daily PrEP regimen. The most prominent barrier to uptake was past experiences of transgender-identity related discrimination in the universal health care system that reduced willingness to seek PrEP or health care in general. Participants recommended technological solutions to PrEP health education information that could address uptake and adherence. This study informs efforts to increase PrEP use among transwomen in Brazil.

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Pre exposure prophylaxis; transgender women; HIV prevention; Brazil

Introduction

In low income countries, transwomen have a 37 times greater odds of having HIV than cisgender males and 77.5 times greater odds compared to cisgender females (Baral et al., 2013). Despite these data, globally transwomen are underserved in the response to HIV. In 2014, only 39% of countries addressed transgender people in their national AIDS strategies (UNAIDS, 2014).

Oral PrEP is a biomedical intervention that, among adherent users, has been shown to reduce the risk for HIV infection by 92% (CDC, 2018). Transwomen are good candidates for PrEP based on their risk for HIV (Wilson, Jin, Liu, & Raymond, 2015). To date, little research is available to inform the implementation of PrEP interventions specifically for transwomen. A population-based HIV behavioural surveillance study of 234 transwomen in San Francisco found that only 14% ($N = 32$) of transwomen had heard of PrEP (Wilson, Jin, Liu, & Raymond, 2015). Another study of young transwomen in the San Francisco Bay Area had similar findings, but youths who were older, white, and had health insurance were significantly more likely to know about PrEP, indicating a lack of information among groups most impacted by HIV (Wilson, Chen, Pomart, & Arayasirikul, 2016). A recent study of PrEP awareness in Brazil found that 42.9% ($N = 24$) of transwomen had heard of PrEP before the study (Hoagland, De Boni, et al., 2017).

CONTACT Erin C. Wilson erincwilson@gmail.com San Francisco Department of Public Health, San Francisco, CA, USA
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The multinational iPrEx trial evaluated the safety and efficacy of oral PrEP for the prevention of HIV acquisition among men and transwomen who have sex with men (Grant et al., 2010). A recent analysis of the iPrEx randomised controlled trial found that among the 339 individuals categorised as transwomen, 11 in the intervention arm seroconverted during the study (Deutsch et al., 2015). Seroconversion was not attributed to the failure of PrEP. Instead, authors hypothesised that non-adherence may explain the low efficacy of PrEP among transwomen. Transwomen are included in PrEP demonstration projects in Brazil. The PrEP Brasil prospective, multicentre, open-label demonstration project ($N = 450$) included 25 transwomen who demonstrated high PrEP adherence (Hoagland, Moreira, et al., 2017). Data are needed to inform PrEP implementation efforts to ensure transwomen are aware of PrEP and have the support and information needed to be adherent.

Transwomen in Brazil could benefit from access to and support in using PrEP. Transwomen in Brazil most often identify as travesti or transsexual. Transsexuals are those who tend to identify more as women, while travestis have similar feminisation practices but may not identify as women, want to keep and use their penis, and may identify as homosexual (Kulick, 1998). Many transwomen in Brazil suffer discrimination, resulting in lack of education, employment opportunities and income (Grinsztejn et al., 2017; Veras et al., 2016). These challenges may present barriers to HIV prevention, including uptake and adherence to PrEP. PrEP will soon be made available, regardless of income, through the Brazilian universal health system, or *Sistema Único de Saúde (SUS)*. Implementation of SUS began in 1990 to provide free universal health care access to all Brazilians. As of 2008, 93% of Brazilians seeking health care received it because of the availability of SUS (Paim, Travassos, Almeida, Bahia, & Macinko, 2011). However, transwomen may have less access to health care in SUS because of discrimination related to their gender identity (Rocon, Rodrigues, Zamboni, & Pedrini, 2016). As PrEP rollout continues, research is needed to inform efforts to ensure transwomen know about PrEP and can access it in SUS.

This analysis uses data from qualitative focus group discussions about PrEP with transwomen in Rio de Janeiro, Brazil. Data were gathered to determine awareness and interest in PrEP. The study also identified barriers and facilitators to PrEP uptake and adherence among transwomen in Brazil, especially as they relate to accessing PrEP in SUS where most transwomen receive their medical care.

Methods

Qualitative focus group discussion data were collected in preparation for a larger population-based HIV risk and PrEP knowledge survey study that took place subsequently in the metropolitan area of Rio De Janeiro, Brazil. Participant sampling was focused on gathering a demographically diverse group of individuals (i.e. diverse by age, race, gender identity and education). Some of the participants recruited had taken part in PrEP trials in Brazil. Data were collected from March to May 2015. Four focus groups were conducted with 34 participants ($N = 7$, $N = 8$, $N = 9$, $N = 10$). Participants were eligible for the study if they (1) self-identified as a gender different from that typically associated with their male sex assigned at birth, (2) were aged 18 years or older, and (3) reported living in Rio de Janeiro or the metropolitan area. Focus group data were collected through in-person focus group discussions using a semi-structured focus group guide. Eligible participants were then scheduled for a two-hour focus group held at FioCruz. Participants received R$20.00 (~$7 U.S. in 2015) of travel reimbursement for participating in the focus groups. The focus group discussion was conducted in Portuguese, audio-recorded and transcribed for data analysis. Written consent was obtained from all participants with human subjects approval from the Committee on Human Research at National Institute of Infectious Diseases (INI), Oswaldo Cruz Foundation (FIOCRUZ), Brazil.

The focus group guide consisted of a number of topics including PrEP awareness, interest, barriers and facilitators to accessing and using PrEP. It was explained to participants that PrEP is a daily pill taken to prevent the acquisition of HIV. Participants were asked if they knew about PrEP and

what they had they learned about it. Participants were then asked about transwomen's specific barriers and facilitators to PrEP uptake and adherence in the context of Rio de Janeiro, Brazil.

Data analysis

Audio recordings of the focus group discussions were transcribed verbatim in Portuguese. The complete record of data was reviewed and then coded for analysis. Transcripts from audio files were analysed using content analysis to determine the presence of specific words or concepts within the text (Krippendorf, 1980). We used Lehoux's analytic template for assessing the contexts in which individual's contributions occur and how they position themselves within the group as either experienced experts or advice-seekers (Peterson et al., 2007). Initial inductive analyses involved discovering emergent themes and important ideas as they related to these differences, assessing the impact of trans-specific experience with violence and discrimination and social ecological contingencies to develop a preliminary codebook. Local researchers in Brazil coded each focus group discussion transcript separately and then the U.S. and Brazilian research team members met online to reconcile discrepancies in coding. Code names and definitions were refined during iterative analyses of the transcripts and major codes were developed. Themes were developed as a team by identifying clusters of major codes from the analysis and individual ideas that emerged as relevant and important considerations for PrEP scale up with transwomen in Brazil. Analyses were conducted collaboratively between U.S.-based and Brazilian colleagues using Dedoose qualitative analysis programme. All data directly affecting participant interest in taking PrEP are provided.

Results

The total number of participants was 34 people. The mean age of participants was 35 years old, with 32% being 29 years old or younger, and 32% being older than 40 years of age. Three quarters of the sample were from Rio de Janeiro, while the remaining 25% lived outside the metro area of Rio de Janeiro. About 32% of the sample identified as black, 24% as mixed and 38% as white, while only 6% identified as indigenous. More than half of the sample had not completed high school (62%), 26.5% completed high school and 12% had more than 11 years of schooling. Most transwomen in this qualitative study identified as transsexual (58.8%), while 32.4% identified as travesti. The remaining three identified as a woman, declined to state, or as a person.

Awareness and interest in PrEP

Ten transwomen in the focus group discussion had heard of PrEP (29%). A number of participants had already used PrEP as participants in a PrEP efficacy trial in Rio de Janeiro ($N = 9$; 27%). Most reported that they would keep using it if it were available. Those who had heard of PrEP but had not taken it before reported that they would use PrEP if it were available in Brazil because it would help them protect themselves from acquiring HIV. Most participants who had not heard of PrEP before the focus group discussion were interested in taking PrEP. Altogether, there was a general excitement about the availability of PrEP as a method of HIV prevention for transwomen, but there were also some concerns, as we discuss below.

PrEP as empowerment

Many transwomen participants were interested in PrEP because it gave them power over their sexual health. This was especially true for those who did sex work. One participant appreciated that there is a way for her to have condomless sex with her boyfriend and be protected from acquiring HIV while doing sex work. Another participant explained that she felt protected with PrEP. She now had the possibility of condomless sex with sex work clients allowing her to have more clients, charge more money, and most importantly, not be worried about acquiring HIV.

> I mean, [if] I am immunized, then I will use it [PrEP] … When clients say 'six and a half, six and seventy [Brazilian real]' and so it goes … [Transwoman, 29 years old]

The same participant also explained that many transwomen doing sex work are forced to have sex with police officers and PrEP could help them prevent HIV acquisition in situations where they did not have the power to use condoms.

> When it comes the time, he takes his gun, gets his gun, puts to the girl's head and says: 'you are going to have sex with me without[a] condom'. [Transwoman, 31 years old]

PrEP barriers

Low utilisation of HIV prevention methods

HIV risk was discussed at the onset of the discussion about barriers to PrEP. Many participants reported that they and other transwomen are highly vulnerable to HIV in Brazil and agreed that discussions about PrEP were appropriate. An important barrier to PrEP was a reluctance to get tested for HIV. A participant explained that some transwomen do not want to know their HIV status because they are worried they are already living with HIV.

> Oh, I don't even want to know. I [would] rather stay the way it is. Why would you want to know the truth? [Travesti, 47 years old]

Participants reported low overall use of HIV prevention methods. Only some participants reported ever using condoms, and among those transwomen, none said they used condoms consistently. Participants also had heard of post exposure prophylaxis (PEP) but did not use it.

> So, you won't see me going to doctors or hospitals. And I'd never heard even of PEP, which is older. [Transwomen, 21 year old]

Some participants also had concerns that PrEP would create risk compensation, worrying that transwomen in the community would no longer use condoms at all once they were taking PrEP.

> They think that they can have a lot of condomless sex if they take PrEP! [Transwoman, 29 years old]

Adherence

A commonly reported concern transwomen had about PrEP was adherence. Some participants acknowledged that it is hard to take their hormone pill every day. One transwoman described that when faced with an exposure to HIV, it can be hard to complete a PEP regimen too.

> I can't take my morning-after pill yet [PEP] … I have no commitment to the medication. Ah, why do I have to … ? Because it has to be taken every day. Then, that's a [hassle] … Right? Because it's not just taking it, like 'I can take it today, or when I feel like it' … [Transwomen, 24 years old]

PrEP stigma

One transwoman explained that there is a lot of misinformation or lack of information about PrEP for HIV prevention. She explained that she was in a fight with a young cisgender man on Facebook who posted on her page that LGBT people are vectors of disease. This young cisgender man also commented that her posting of information about PrEP on her Facebook page was confirmation that she was sick.

> Because, like that, people of [neighbourhood in Rio] think that if you are taking medicine you are sick, [even if it is] a dietary supplement. If you are taking medicine … it is because you are sick … [Transwomen, 30 year old]

She also explained that her family and people in her neighbourhood of Rio de Janeiro do not believe that HIV is a real disease. Her point was that there is a real lack of information and proliferation of misinformation that will be a barrier to people accessing PrEP.

Discrimination in the public health system

The barrier to PrEP most transwomen expressed was discrimination in health care. All participants had used the Brazilian universal health system or SUS. Transwomen reported that health professionals knew little to nothing about people with non-conforming gender identities and many thought transwomen were gay men dressed as women. Participants reported that primary health care in Rio de Janeiro and the metropolitan area did not fulfil their trans-specific health needs. They reported that an overall lack of training and trans-health competence (e.g. the ability to accurately prescribe hormone therapy or knowledge of what specific health questions they should ask) were barriers to health care access. Few primary care services were available in Rio de Janeiro that provided a comprehensive approach to trans-specific health care, such as hormone therapy and surgeries. Where limited services existed, wait lists for care were long. Consequently, most transwomen in the sample reported undergoing a self-managed regimen of non-prescribed hormones and soft tissue fillers in order to meet their transition needs. The few who did access services for hormones and other trans-specific services found that the clinicians they visited knew little about the right hormones and dosage to prescribe and did not offer sexual health information.

Beyond systemic discrimination in the form of incompetent an inadequate care, transwomen also reported overt discrimination from the staff at SUS clinics. Participants reported that they were misgendered by clinic staff who did not use their 'social name' (i.e. Brazilian term for using trans peoples' correct name as opposed to their birth name) when registering participants and calling their name. One participant described.

> Yeah, it all depends what kind of people you will find there: those that are mean spirited or the nice kind. Because I have already been to a SUS clinic and said: 'My social name is this, this and this'. And they said: 'OK, we know' … And when they called me for my appointment … . He called me by my [birth] name. Then I said out loud: 'Didn't I tell you [what my name was]? I could sue you because you are not stupid. I told you and you said that you knew it' And even so, got it? Why? Because they do what they please. I have noticed that. [Transwoman, 31 years old]

Many transwomen in the study refused to return to SUS after experiencing discrimination. Transwomen reported that many people in their community only accessed SUS when they were very sick. As one participant stated,

> Which health services do you have access to here in Rio?
> Almost none. They don't respect our social name and orientation. That's why we die. When we get to a hospital we're already sick, and you just go there to die, pretty much.' [Woman, 42 years old]

PrEP facilitators

Use of technology

Participants reported that almost all transwomen had access to mobile phones. Transwomen agreed that mobile phones could be an important tool in communication strategies for engagement in HIV treatment and prevention. A number of transwomen mentioned the importance of the app 'WhatsApp', which many agreed was an app often used by transwomen in the community, and they regarded it as practical, confidential and free. They pointed out that another possibility of creating a WhatsApp group, which they reported was more confidential than Facebook. Although Facebook is widely used by this population, they did not consider it as private.

> I think Whatsapp is widely used these days, everybody has it … This is easy to check, just save the number. If the person doesn't have, send a SMS. [Transwoman, 27 years old]

Some participants reported the importance of using other strategies for engaging transwomen in PrEP, such as phone calls and phone messages, which would be useful because some transwomen did not have access to smartphones and could not access apps.

Health education for PrEP adherence

Despite concerns around adherence, participants came up with methods they thought would encourage PrEP adherence among transwomen. They mentioned that health professionals needed to be trained on ways to encourage patient adherence. Another method for increasing adherence was social marketing. One participant suggested that detailed explanations of how to take PrEP and guidance for use would help bolster adherence.

> You all, may I be honest? I think that an information service and a drug pamphlet as for other drugs with an explanation from a health care provider that is brief, such as, in a primary care, like there is for PEP (post exposure prophylaxis), could be helpful … And the drug pamphlet, because honestly people who can afford it [PrEP] will buy it if it is available at drugstores, and will not have the information they need. Since it is something good for the population, it has to be easily available (…). [Person, 43 years old]

Discussion

Findings from this study point to the promise of PrEP for HIV prevention among transwomen in Brazil, though concerns about access barriers exist. We found that transwomen in our study were interested in PrEP once it was explained to them what it is and how it is used for HIV prevention. Interest observed in this study is consistent with our previous quantitative research ($N = 345$) wherein after a brief explanation, almost all HIV-negative transwomen in the study were interested in using PrEP (93.1%) (Jalil, 2016). The one third of transwomen in the study who had previously taken PrEP as part of a clinical trial may have been positively biased by the difference between taking PrEP in a research study compared to experiences they might have in SUS. However, the remaining two thirds of the sample who also had positive responses to PrEP suggests overall high interest and excitement for this prevention method among transwomen in this study.

The most prominent barrier to PrEP identified in this study was discrimination in SUS, which may serve as a critical roadblock to PrEP uptake among transwomen in Brazil. The PrEP provision requires that patients obtain PrEP from a medical provider and engage in regular follow up care to monitor health status over the course of this preventive treatment (US Public Health Service, 2014). Transwomen in this study reported that past experiences of discrimination in SUS would be a barrier to seeking PrEP. Findings pointing to anti-trans discrimination as a barrier to HIV prevention among transwomen are consistent with other studies. Discrimination is one of the main barriers to HIV prevention among transwomen in Latin America who similarly mistrust the medical system (Silva-Santisteban, Eng, de la Iglesia, Falistocco, & Mazin, 2016). One study found that a history of discrimination was significantly associated with healthcare avoidance among transwomen in Brazil (Costa et al., 2018). Another study found that discrimination through misgendering by clinic staff and creating fear of using public bathrooms was a barrier to health care utilisation (Saggese et al., 2016). In our previous research, among 345 transwomen in Rio de Janeiro we found that only half (49.4%) of the sample accessed health care in the last six months and only 15.9% had access to trans-specific health care, like breast augmentation surgery (Grinsztejn et al., 2017). Specific examples of discrimination in SUS we identified were lack of trans-specific health related services like hormone therapy and surgeries, clinic staff unwillingness to use transwomen's social name, and misgendering.

Another barrier to PrEP was HIV status awareness. Transwomen in this study reported not wanting to be tested for HIV because they did not want to know if they were HIV positive. This finding is consistent with data from our previous research and a study in the U.S. showing that many transwomen are unaware of their HIV status (Jalil, 2016; Rapues, Wilson, Packer, Colfax, & Raymond, 2013). Transwomen may not know they are at risk for HIV because they are not being routinely screened, or they may suspect they are at risk but do not want to know if they are living with HIV. Data with men who have sex with men suggest that being tested for HIV is associated with knowing about PrEP (Raifman, Flynn, & German, 2016). Less utilisation of HIV testing may translate to or be the result of fewer transwomen knowing about PrEP. In our previous research, only 3

out of 345 transwomen refused to get tested for HIV, which suggest that transwomen will get tested for HIV in a trans-competent, safe and anonymous setting (Grinsztejn et al., 2017; Veras et al., 2016).

Some participants were also concerned about risk compensation, or the idea that their peers will be less inclined to use condoms if using PrEP. This fear was common in the beginning of PrEP roll-out. Researchers and physicians were worried there would be a sizeable uptick in the rates of sexually transmitted infections as a result of less condom use among PrEP users (Grov, Whitfield, Rendina, Ventuneac, & Parsons, 2015). Early research confirmed these fears (Newcomb, Moran, Feinstein, Forscher, & Mustanski, 2018). However, the iPrEX study that included transwomen did not report a reduction in condom use or an increase in sexually transmitted infections for those on PrEP (Marcus et al., 2013). A qualitative study of MSM in the U.S. PrEP Demonstration project found that risk reduction behaviours were not abandoned once men started taking PrEP (Carlo Hojilla et al., 2016). Recent research with a large clinic population of MSM found increases in the identification of bacterial sexually transmitted infections but attributed STI increases to more prevalent routine screening from being in PrEP care (Mayer et al., 2017). Our study participants reported that they did not engage in many risk reduction behaviours like condom use, PEP or HIV testing; therefore, concerns around risk compensation may be irrelevant. Instead, access to PrEP for transwomen in Brazil may be an important way to engage transwomen in health care, HIV prevention and increase their overall sexual health.

Transwomen did report concerns about adherence. A sub-analysis of data on transwomen in the iPrEx trial found that transwomen were less likely to have protective drug concentrations than MSM, and none of the transwomen who seroconverted had detectable drug levels at their seroconversion visit (Deutsch et al., 2015). There was speculation that drug–drug interactions between Truvada and feminising hormones reduced the protective effect of PrEP, but it was more likely that transwomen struggled with adherence. Similarly, transwomen in this study explained that taking their hormone pills daily was difficult and those who had taken PEP described being unable to complete their regimen. Research is needed to identify adherence challenges transwomen have and how to overcome these barriers.

Importantly, transwomen in this study did not express concerns about drug interactions between hormones and PrEP, and so it is unclear whether this concern exists among transwomen in Brazil. A U.S. study that asked transwomen about this concern found transwomen did have concerns about drug-drug interactions (Sevelius, Keatley, Calma, & Arnold, 2016). Studies evaluating the interaction of PrEP and feminising hormones are underway.

Transwomen noted a number of facilitators to PrEP. Transwomen interpreted PrEP as a form of empowerment. With PrEP, they can control their risk for HIV even when they may not always have control of their exposure to risk. This is especially the case in situations of sexual assault where a condom may not be used but transwomen can be on PrEP and avoid acquiring HIV. Transwomen also described ways of using technology to disseminate information about PrEP and discussed the need for health education information about how to use PrEP and promote the importance of adherence. Framing messages around empowerment and using technology might be an appropriate approach for social marketing focused on transwomen.

The primary limitation of this study is that it was conducted in one metropolitan area of Brazil, which may limit generalizability to transwomen in other parts of Brazil. Also, one third of the participants in the study were already on PrEP as part of a clinical efficacy trial. Findings from these participants were likely biased by their experience with PrEP in the context of a clinical trial, which may have reduced their fears regarding barriers to PrEP in SUS, among other differences. However, we believe the inclusion of these participants brought depth to the discussions as their experiences were not hypothetical and so they could discuss the real-world barriers related to taking PrEP such as their struggles with adherence. Despite limitations, this study uncovered important barriers and facilitators to PrEP for transwomen in Brazil. Our findings suggest that PrEP uptake will be low among transwomen in Brazil until SUS addresses systemic discrimination towards transgender people. While such efforts are underway, alternative models of providing PrEP in settings that

are safe and non-discriminatory and possibly outside SUS may be warranted. Interventions will also have to be in place that help transwomen cope with their fear of HIV and provide relevant strategies for maintaining adherence. Most importantly, this analysis may contribute to efforts to better scale interventions and programmes providing PrEP for transwomen.

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ORCID

Erin C. Wilson http://orcid.org/0000-0002-0237-495X

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