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“We have a stronger survival mode”: exploring knowledge gaps and culturally sensitive messaging of PrEP among Latino men who have sex with men and Latina transgender women in Los Angeles, CA

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Abstract

Latino men who have sex with men (LMSM) and Latina transgender women (LTGW) often lack access to HIV prevention information and strategies such as pre-exposure prophylaxis (PrEP). We explored knowledge gaps and culturally sensitive messaging about PrEP among HIV-negative LMSM and LTGW in Los Angeles. We recruited participants from a Latinx LGBT community-based organization. We conducted nine focus groups ($n = 91$ participants) with 52 LMSM and 39 LTGW. We used a rapid assessment process to create narrative reports that we analyzed using thematic analysis. Key quotes were transcribed verbatim; they were reviewed by the team, then uploaded to Dedoose to identify themes across sites and between groups. Three themes emerged for both LMSM and LTGW: knowledge gaps regarding PrEP remain; people who have knowledge about PrEP often served as its champions; highlighting positive aspects of culture could help improve PrEP's uptake and sustained use. Only LMSM worried that PrEP could impact condom use. Some issues were more pronounced among LTGW (e.g., more limited access to PrEP); others were unique to LTGW (e.g., worry about drug-hormones interactions). Collaborative research, programs, and policies, informed by LMSM and LTGW themselves, are needed to narrow existing knowledge gaps and promote PrEP uptake and sustained utilization.

Keywords

Pre-exposure prophylaxis; Latino men who have sex with men; Latina transgender women; HIV prevention

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Introduction

Although Latinos represent only 18% of the U.S. population (US Census Bureau, 2017), Latino men who have sex with men (LMSM) and Latina transgender women (LTGW) are disproportionately impacted by HIV (Centers for Disease Control and Prevention, 2017a, 2017c). Recent data from LA County – home to the country’s second largest HIV epidemic (Los Angeles County Commission on HIV and the Los Angeles County Department of Public Health Division of HIV and STD Programs) – indicated an estimated 15% HIV prevalence rate among LMSM (Division of HIV and STD Programs Los Angeles County Department of Public Health, 2014) and 17% among LTGW compared to 0.3% in the general population (Division of HIV and STD Programs Los Angeles County Department of Public Health, 2013).

Pre-exposure prophylaxis (PrEP) is a biomedical intervention that can reduce the sexual risk of contracting HIV by more than 90% (Centers for Disease Control and Prevention, 2017b); however, studies have documented that awareness and utilization of PrEP is low among racial and ethnic minority MSM and TGW (Bauermeister, Meanley, Pingel, Soler, & Harper, 2013; Galindo et al., 2012; Krakower et al., 2012; Kuhns et al., 2016; Mantell et al., 2014; Mimiaga et al., 2016). Even racially and ethnically diverse MSM and TGW respondents who knew about PrEP had ongoing concerns about its accessibility (Brooks et al., 2011; Galindo et al., 2012; Marks et al., 2017), hesitated to use PrEP due to medical mistrust (Galindo et al., 2012), and expressed concerns about potential side effects (Bauermeister et al., 2013; Galindo et al., 2012; García & Harris, 2017; Kubicek, Arauz-Cuadra, & Kipke, 2015; Nodin, Carballo-Diéguez, Ventuneac, Balan, & Remien, 2008). Research on the unique needs of TGW regarding PrEP has highlighted concerns about potential interactions between PrEP and hormones and has noted how PrEP marketing messages are not trans-inclusive (Sevelius, Deutsch, & Grant, 2016; Sevelius, Keatley, Calma, & Arnold, 2016). Questions remain about how to make messaging around PrEP more culturally sensitive. In this study, we characterized knowledge gaps regarding PrEP among LMSM and LTGW in Los Angeles County and make concrete recommendations about culturally sensitive PrEP messaging.

Methods

The study goal was to understand participants’ knowledge gaps and concerns regarding PrEP and identify ways to better integrate culturally sensitive language and content regarding PrEP.

Participants and procedures

Between February 2017 and March 2017, we conducted nine focus groups (FG), 8 in Spanish and 1 in English, with LMSM ($n = 52$) and LTGW ($n = 39$) at Bienestar, Inc., a community-based organization (CBO) with multiple locations in Los Angeles County. The FG were conducted in five locations: Hollywood (3 LMSM, 1 LTGW FGs); South Los Angeles (1 LMSM, 1 LTGW FGs); Pomona (1 LMSM FG); Long Beach (1 LTGW FG); and San Fernando Valley (1 LTGW FG). Inclusion criteria were: being 18 years or older; self-identifying as Latino; self-identifying as MSM or TGW; English or Spanish speaking;

having regular access to a mobile phone; and self-reporting as HIV negative. FG discussions targeted multiple issues related to HIV prevention strategies among MSM and LTGW, with special attention to PrEP. Data were collected as part of a larger HIV prevention intervention study that is described elsewhere (Linnemayr et al., 2018).

Consent/permissions

The study was approved by the Institutional Review Boards at collaborating institutions. Before FG discussions began, facilitators described the purpose and procedures of the FG and answered participants' questions. All participants were given a copy of the informed consent that they reviewed together with the facilitator. Verbal informed consent was obtained from all participants.

Data collection

Participants were recruited through HIV-negative support groups and through study flyers posted in five Bienestar locations. Discussions lasting 60–90 min were conducted in-person by two bilingual (Spanish and English speaking) researchers with experience working with the Latinx LGBT community. All participants received a \$30 gift card for their time.

Data analysis

We used a rapid assessment process (RAP) to ensure that issues surfaced in the discussions but not included in the interview script could be explored later. We recorded the FG and used the narrative reports for analysis, structuring them according to guidance on conducting RAP in health services research (Hamilton, 2013). We created domain names for each focus area in the interview script. We developed summary templates to capture key information, and refined them after each FG to adjust for new information. We integrated field notes into the summaries and transcribed key quotes to create a narrative report for each FG. The research team reviewed the narrative reports; the reports were entered into Dedoose to ensure that themes across sites, and between groups (i.e., MSM and LTGW), could be comprehensively reviewed and analyzed.

Results

The FG highlighted three crosscutting themes with respect to PrEP. However, in several areas, distinct differences between MSM and LTGW emerged.

Crosscutting Theme 1 – substantial knowledge gaps regarding PrEP remain

Although most participants had heard of PrEP, they often confused PrEP and post-exposure prophylaxis. Most participants knew they could not purchase PrEP over the counter but did not know how to get a prescription or how much PrEP would cost without insurance. Participants knew little about the drug regime (e.g., should the medication be taken daily or only before a specific sex act?) They speculated about how long they needed to take PrEP before achieving optimal protection. One MSM participant in South Los Angeles explained "... [many] don't understand that for PrEP to work they have to wait a certain amount of time." In particular, participants wondered how best to use PrEP given dramatic fluctuations in their sex lives. They wanted to better understand the medication's benefits and side

effects, especially long-term effects. Participants wanted concrete statistics (e.g., percent reduction in risk of HIV transmission as a result of taking PrEP) to inform their decision-making.

Crosscutting Theme 2 – participants who knew about PrEP often served as its champions

Participants who knew most about PrEP emphasized its importance, often turning to other participants to share their knowledge. One LMSM participant in Hollywood emphasized that condom use was imperative because “PrEP is to prevent [HIV] but one should always use a condom because you are at risk for other illnesses.” PrEP advocates urged using PrEP and a condom as the ideal HIV protection. Another LMSM participant in Hollywood provided the following analogy, “... PrEP is to prevent, for me it is not 100% safe, because for me what is ideal is to combine the use of condom and PrEP, the condom is like a shield, while I take PrEP, I have the shield and the armor.”

Crosscutting Theme 3 – participants underscored the need for culturally sensitive messaging around PrEP

Both LMSM and LTGW participants wanted to talk about the positive aspects of their culture (e.g., Latinos as hardworking), not just about negative stereotypes (e.g., hyper masculinity and homophobia). Frustrated with the constant reference to negative stereotypes, they felt shifting the focus could influence messaging around PrEP. Several participants said that some female figures in their life (often their grandmother) cast these traditionally negative stereotypes in a positive context by suggesting that “being a man” meant being their authentic selves. Participants were receptive to the idea of reframing traditionally negative aspects of Latino culture in a positive way in relation to PrEP and to HIV prevention (e.g., “being a man” meant “protecting yourself against HIV at all costs” and staying well to provide for the family).

Among LMSM only, PrEP sometimes complicated decision making about condom use

When queried about the importance of using condoms while taking PrEP, participants gave a range of responses. Several said that PrEP use would complicate their decisions about condom use. For example, some participants noted that although using condoms was ideal, they were not generally used whether or not the individual was taking PrEP. Many participants said this was especially true if alcohol had been consumed. Another LMSM participant explained that once he started taking PrEP “and the body [got] used to it” he no longer needed to use a condom. Several participants who were not using PrEP said they actually preferred using a condom and felt it provided sufficient protection.

LTGW expressed strong concerns about PrEP and raised additional issues

Questions about access to PrEP appeared more pronounced among LTGW: they felt they had fewer economic opportunities than LMSM and more limited access to health care, insurance and other support services. Many LTGW shared that without a formal job they did not have insurance and could not access PrEP. Some said that it was too difficult to access (e.g., having to pretend to be homeless to receive it). Other LTGW participants said they knew many LTGW who were purchasing PrEP from the “black market” that was largely supplied

by individuals who were using PrEP but were subsequently diagnosed with HIV. Another concern unique to LTGW was how PrEP might interact with hormones and other body affirming procedures.

Discussion

Three themes emerged from LSM and LTGW focus groups: knowledge gaps regarding PrEP remain; people who have knowledge about PrEP often served as its champions; highlighting positive aspects of culture could help improve PrEP's uptake and sustained use. Only LSM raised concerns regarding how PrEP could impact condom use. Some concerns were more pronounced among LTGW (e.g., less access to PrEP through insurance due to fewer economic opportunities); others were unique to LTGW (e.g., drug interactions between PrEP and hormones). Previous studies have highlighted how immigration status affected PrEP uptake among Latino communities (Page et al., 2017). However, despite being queried on how their immigration status may impact engagement with health services, respondents did not mention it as a significant barrier to PrEP access.

Substantial knowledge gaps regarding PrEP among LSM and LTGW have been documented nationwide (Galindo et al., 2012; García & Harris, 2017; Kuhns et al., 2016; Martinez et al., 2016). All participants in our study wanted more information about PrEP (e.g., where to access it, how to use it, and how it works). LTGW in particular expressed concerns about their ability to access PrEP. Since LTGW face pervasive employment discrimination, informal employment opportunities limit their access to insurance and their ability to get a PrEP prescription and seek the regular medical care associated with PrEP (e.g., urine tests to evaluate toxicity levels). Consistent with the peer-reviewed literature, participants expressed concerns about side-effects, especially longer-term effects (e.g., damage to kidneys, sexual dysfunction, and bone damage) (Bauermeister et al., 2013; Galindo et al., 2012; Kubicek et al., 2015). Such concerns, in addition to other documented barriers to accessing PrEP (e.g., medical mistrust, homophobia, incompetent medical staff) (Galindo et al., 2012; Marks et al., 2017) must be addressed if knowledge gaps about PrEP are to be reduced. Other studies have also identified the importance of providing concrete information about PrEP's efficacy (Mimiaga et al., 2016).

The fact that knowledgeable participants often served as its champions highlights an opportunity to leverage peer advocates. Little research has explored using peer advocates to support PrEP use, but studies have documented how peers (e.g., generally HIV-positive individuals who help newly diagnosed adults) can improve initiation and continued access to the HIV care continuum among the general population (Bradford, Coleman, & Cunningham, 2007), as well as other key populations (Lillie et al., 2017) especially TGW of color (Lillie et al., 2017; Oldenburg et al., 2014; Rebchook et al., 2017). Our study suggests that peer educators may play a crucial role in increasing uptake of HIV prevention interventions such as PrEP.

Our results highlight the potential of using the positive effects of Latino culture to frame PrEP uptake and sustained use (García & Harris, 2017). Much of the literature on Latino culture focuses on how the culture poses barriers for HIV prevention (Wilson, Durantini,

Albarracín, Crause, & Albarracín, 2013). In our study, both LMSM and LTGW participants felt it was important to view Latino cultural characteristics positively. Studies have reported how familism can sometimes serve as a barrier to care if an individual places family before his or her own needs and wellbeing (Wilson et al., 2013). However, emphasizing how an individual's health affects the family can increase the effectiveness of HIV prevention efforts (Koniak-Griffin et al., 2008). In the context of PrEP, it would be important to stress how remaining HIV negative enables the family protector to provide ongoing support.

Participants also discussed the role of hyper masculinity. They recalled how female figures in their family played a role in defining hyper masculinity or what it meant to “be a man”. Research has documented hyper masculinity as an important value for some Latinos (Saez, Casado, & Wade, 2010). While often framed in a negative context, hyper masculinity can also be seen as a positive trait. Studies have shown how men and women value a “macho” man because he is strong and protects the family (Marín, 2003) and has a sense of assertiveness, responsibility, sincerity, and emotional responsiveness (Mirandé, 1997; Torres, Solberg, & Carlstrom, 2002). Tapping into positive perceptions of Latino culture may help LMSM and LTGW better connect with the messaging around PrEP. For example, an expanded definition of hyper masculinity offered by one participant focused on the work ethic of Latino culture, “... We have ... a stronger survival mode, skill, and work ethic ... that's machismo right there, you have to do it. You can't be lazy.” Messages could connect taking PrEP, which requires both a daily pill for protection and persistence in taking it, with the idea that Latinos are familiar with hard work and are committed to doing a job. An example of a message might be, “Latinos are hard workers and take care of their own. To provide for your family, you need to stay healthy. Take care of your health by taking PrEP and prevent HIV.” To increase PrEP knowledge and use among LMSM and LTGW, messaging must be reframed in a culturally sensitive way.

Ongoing concerns regarding how PrEP may impact condom use (Brooks et al., 2012; Golub, Kowalczyk, Weinberger, & Parsons, 2010; Hoff et al., 2015; Mansergh, Koblin, & Sullivan, 2012) are echoed by LMSM participants in our study. For instance, a study with racially/ethnically diverse MSM in New York City identified as high risk for HIV found that 70% of the group would likely use PrEP. But among those, more than 35% reported that they would likely decrease condom use while taking PrEP (Golub et al., 2010). Another study found that individuals who reported not using condoms said that PrEP minimized their concerns about contracting HIV (Hubach et al., 2017). Other studies have found that participants view PrEP primarily as a supplement rather than as a replacement for condoms (Brooks et al., 2012; Mimiaga et al., 2016). Our findings underscore the need to clearly articulate a dual strategy: PrEP can protect against HIV, and condoms can protect against sexually transmitted infections (STIs). A combined approach is critical, especially given the recent increase of STIs among all MSM, including racial ethnic minority MSM (Centers for Disease Control and Prevention, 2015).

Studies have underscored the importance of addressing the unique differences between MSM and TGW (Bauer et al., 2009; Sevelius, Deutsch, et al., 2016; Sevelius, Keatley, et al., 2016)— an issue also identified in our study. Participants referenced additional barriers to PrEP for LTGW, and many participants had concerns about interactions between PrEP and

body modification and hormone use. A recent study (Sevelius, Deutsch, et al., 2016) suggested several ways to address the unique needs of TGW with respect to PrEP. It recommended communication strategies that not only portray cisgender men (e.g., pictures of men hugging men), but also include TGW. It called attention to concerns about interactions between hormone use and PrEP. The study also emphasized the need to address sex work more explicitly and to suggest how PrEP may be an empowering tool, increasing the sense of personal control over HIV prevention (Sevelius, Deutsch, et al., 2016). Our findings add to the growing body of evidence calling for strategies tailored to the unique needs of TGW (Sevelius, Deutsch, et al., 2016; Sevelius, Keatley, et al., 2016).

This study has both limitations and strengths. Limitations include the lack of individual demographic information. All participants were recruited from Bienestar, which might have led to some selection bias. Because participants were connected to the CBO, they may have had more familiarity with PrEP than other LMSM and LTGW, who may have more substantial knowledge gaps and different concerns. FG discussions were not transcribed in their entirety due to limited project funds. Study results may be unique to California because policies regarding PrEP access differ across states. Strengths include that the multi-site study covered a large area of Los Angeles and include a relatively large number of FG. The study also compared and contrasted the unique and distinct needs of LMSM and LTGW.

Conclusion

Research, programs, and policies need to focus on improved access and continued uptake of PrEP among LMSM and LTGW. The meaningful participation of LMSM and LTGW in the research process can help ensure that interventions address cultural barriers to PrEP and identify sensitive framing of other cultural norms as potential sources of resilience.

Programs to promote uptake and use of PrEP could be improved. Service providers will need to reaffirm the importance of using PrEP and condoms for optimal protection. Additionally, marketing materials should include pictures of LTGW and information that directly addresses their specific concerns (e.g., hormone interactions with PrEP). Further, these PrEP-specific issues must be addressed in concert with more general programmatic efforts to improve provision of transgender healthcare. For example, it is important to ensure that providers have adequate knowledge of TGW-specific health issues in addition to understanding the importance of appropriate pronoun use (e.g., referring to individuals with their preferred gender pronoun rather than the pronoun consistent with their sex assigned at birth).

Finally, existing policies for PrEP use need to be clarified. Many individuals are not sure if insurance is needed to access PrEP. Some websites provide information about medication assistance programs and copay programs for PrEP; however, the literacy level required to understand the information is high and state-specific nuances remain unclear. The ready availability of easily understood information on current PrEP policies is vital to increasing its uptake and sustained use. Especially for Latinos who may be undocumented, dual language information regarding where PrEP can be accessed without insurance is critical.

LMSM and LTGW bear an especially heavy HIV burden and face many obstacles in accessing information about effective prevention methods. Collaborative research, programs, and policies that are informed by LMSM and LTGW themselves are needed to promote the uptake and continued utilization of PrEP among these vulnerable populations.

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