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Christina Sun

OHSU-PSU School of Public Health, christina.sun@pdx.edu

Kirsten M. Anderson

OHSU-PSU School of Public Health

Kim Toevs

Multnomah County Health Department

Dayna Morrison

Portland Veterans Affairs Research Foundation

Caitlin Wells

Cascade AIDS Project

See next page for additional authors

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Authors

Christina Sun, Kirsten M. Anderson, Kim Toevs, Dayna Morrison, Caitlin Wells, and Christina Nicolaidis

“Little tablets of gold”: An examination of the psychological and social dimensions of PrEP among LGBTQ communities

Christina J. Sun, PhD, MS^a, Kirsten M. Anderson, MSW, MPH^a, Kim Toevs, MPH^b, Dayna Morrison, MPH^c, Caitlin Wells, BA, BS^d, and Christina Nicolaidis, MD, MPH^{a,e,f}

^a School of Public Health, Oregon Health & Science University-Portland State University, Portland, OR, U.S.; ^bMultnomah County Health Department, Portland, OR, U.S.; ^cOregon AIDS Education and Training Center at Portland Veterans Affairs Research Foundation, Portland, OR, U.S.; ^dCascade AIDS Project, Portland, OR, U.S.; ^e Department of Medicine, Oregon Health & Science University, Portland, OR, U.S.; ^f School of Social Work, Portland State University, Portland, OR, U.S.

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Corresponding author:

Christina Sun, PhD, MS
E-mail: christina.sun@pdx.edu
Phone: 503-725-3616

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Abstract:

There are significant psychological, social, and cultural dimensions to the HIV epidemic in the United States, especially among lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities. Biomedical HIV treatment has been shown to impact these dimensions. However, there is little understanding of the real-world psychosocial and sociocultural effects of the latest biomedical HIV prevention strategy, HIV pre-exposure prophylaxis (PrEP). This study explored the psychosocial and sociocultural dimensions of PrEP use among LGBTQ adults. We interviewed 23 LGBTQ adults who were current or former users of PrEP. Results included that PrEP users' experiences were shaped by multiple forms of stigma. Participants were highly motivated to challenge PrEP stigma and to support PrEP use among other community members. Lastly, participants described positive impacts on their individual well-being and their sexual partnerships. Findings suggest that PrEP has significant impacts beyond biomedical outcomes for both the individuals who use PrEP and their communities.

Keywords: HIV/AIDS, pre-exposure prophylaxis, prevention, LGBT, social construction

Introduction

HIV holds great symbolic and cultural significance, especially for gay men and other members of lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities (Conrad, 1986; King, 1995; Treichler, 1999). Although the disease can affect anyone, it has been widely linked to sex between men ever since its emergence as “gay-related immune deficiency” (Herek & Capitano, 1999; Klein, 2009; U.S. Department of Health and Human Services, n.d.). HIV is a source of chronic stress and anxiety for communities of gay and bisexual men (Dean, 1995), and has caused lasting fragmentation and intra-community stigma (Smit et al., 2012).

Research has documented the psychosocial effects of biomedical HIV treatment, demonstrating that these drugs impact more than clinical outcomes (Bogart et al., 2000; Kalichman & Ramachandran, 1999; Siegel & Lekas, 2002; Thompson, 2003). The introduction of effective combination antiretroviral therapies was linked to shifts in identity, relationships, social and economic roles, and experiences of stigma (Kalichman & Ramachandran, 1999; Siegel & Lekas, 2002; Thompson, 2003). Although some researchers found that individuals living with HIV reported greater optimism and lower depression once these medications became available, results were mixed, and increased feelings of uncertainty were common (Bogart et al., 2000; Kalichman & Ramachandran, 1999; Siegel & Lekas, 2002; Thompson, 2003).

In 2012, the United States (U.S.) Food and Drug Administration (FDA) approved the use of emtricitabine and tenofovir disoproxil fumarate (Truvada™) as pre-exposure prophylaxis (PrEP) against HIV (U.S. FDA, 2012), the first drug to prevent HIV among uninfected individuals. Research has shown that PrEP is both effective and safe (Centers for Disease Control and Prevention, 2018; Fonner et al., 2016; Grant et al., 2010; Grohskopf et al., 2013; McCormack et al., 2016; Spinner et al., 2016; Volk et al., 2015). From a biomedical perspective, PrEP is an incredibly valuable tool for HIV prevention. However, as the first drug to effectively

prevent HIV among those who are not infected, PrEP is also likely to have effects beyond clinical outcomes, making it a truly game-changing development (Auerbach & Hoppe, 2015; Goldenberg, 2016).

Although previous studies have examined attitudes about PrEP uptake (Bauermeister, Meanley, Pingel, Soler, & Harper, 2013; Brooks et al., 2011; Dolezal et al., 2015; Galindo et al., 2012; García & Harris, 2017; Goedel, Halkitis, Greene, Hickson, & Duncan, 2016; Grov, Whitfield, Rendina, Ventuneac, & Parsons, 2015; Holt et al., 2012; Peng et al., 2018; Thomann, Grosso, Zapata, & Chiasson, 2018; Young, Flowers, & McDaid, 2014), and impact of PrEP on sexual risk behaviors (Freeborn & Portillo, 2018; Grov et al., 2015; Holt et al., 2012; Koester et al., 2017; Storholm, Volk, Marcus, Silverberg, & Satre, 2017), there is little understanding of the sociocultural dimensions of actual PrEP use. Most previous U.S. studies about the emotional or psychological effects of PrEP have asked participants to consider hypothetical situations or have enrolled participants of clinical trials and demonstrations projects (Gilmore et al., 2013; Grace, Jollimore, MacPherson, Strang, & Tan, 2018; Koester et al., 2017). While these studies provide insights into the experience of PrEP in controlled research and practice contexts, little is known about the real-world psychological and social effects of PrEP among LGBTQ adults who use PrEP. The everyday context of PrEP use may differ significantly from formalized contexts due to the increased supports typically provided in clinical trials and demonstration projects. This study aims to fill this gap by exploring the psychological and social experiences of PrEP use among LGBTQ adults who are using or have used PrEP in the real world.

Methods

Community-Academic Partnership

This study was conducted as a collaboration between community and academic partners. Representatives from AIDS service organizations, local health departments, Oregon AIDS

Education and Training Center, and researchers at Portland State University and Oregon Health & Science University jointly developed the interview guide and recruitment strategies, met to finalize themes, and generated and enacted dissemination plans to share research findings. Regulatory oversight for this study was provided by the Portland State University Institutional Review Board.

Participants, Recruitment, and Eligibility

The 23 people included in this analysis were a subset of LGBTQ participants from a qualitative study of PrEP access and uptake in practice settings (Sun et al., 2018). We recruited participants who were 18 years or older, a resident of Oregon, and reported interest in using PrEP, or past or current PrEP use, through word-of-mouth and flyers (print and electronic) distributed by AIDS service organizations, LGBTQ community centers, and local health departments. For this analysis, we only included participants who reported current or past PrEP use.

Data Collection

Interviews focused on knowledge and attitudes about PrEP, experiences obtaining PrEP, PrEP adherence, and changes related to PrEP use. After conducting practice interviews with community partners and refining the interview guide, two co-authors conducted all interviews.

Data analysis

We conducted a thematic analysis using an inductive approach at the semantic level with a constructivist paradigm. All interviews were audio-recorded and professionally transcribed. Three co-authors (CJS, KMA, CN) developed a preliminary codebook after independently reviewing four transcripts. Two co-authors (CJS, KMA) then read and coded all transcripts, meeting periodically throughout this process to reconcile coding differences and refine the codebook. Three co-authors (CJS, KMA, CN) collaboratively identified preliminary themes and

the coders reviewed themes to ensure that they were grounded in the data. The community partners provided insight and feedback and the full team finalized themes. We used Atlas.ti 7 to manage, code, and analyze data.

Results

Description of Participants

Of the 23 participants in this analysis, 22 were current PrEP users and 1 had previously used PrEP (see Table 1). All participants identified within the LGBTQ spectrum; most were cisgender gay men. Three-quarters were white, with a few identifying as Latino or multiracial. The average age of participants was 39.9 years (range: 21-67 years). All participants had at least some college, and yearly income levels ranged from less than \$10,000 to more than \$100,000.

Themes

We identified five themes. PrEP users' experiences were shaped by multiple forms of stigma. Participants were highly motivated to challenge PrEP stigma and support PrEP use. Participants described positive impacts on individual and community well-being.

Stigma is the context of PrEP. Participants described experiencing various forms of stigma, including community-level and interpersonal HIV stigma, stigma about their sexual behaviors, and stigma against their LGBTQ identity. These forms of stigma were often discussed at the same time, suggesting overlap between these various stigmas, as exemplified in the following interview excerpts: “And, of course, there was also some stigma attached to the idea of taking a medication to prevent contracting HIV. I think there’s a lot of shame in the gay community around sexuality,” (Participant [P] 13) and, “The issue [HIV/AIDS] was such a

morality issue before it was a medical issue that it skewed my mind and for a long time I've struggled with, is getting AIDS a consequence of being a dirty fucker?" (P21)

HIV/AIDS-related fear, discrimination, and stigma were a significant and underlying part of many participants' lives. Participants discussed how this fear negatively influenced their comfort with their sexuality. One participant explained, "You always worry you might test positive even though you don't have any risk. But there's so much stigma around your lifestyle that even a regular check-up can trigger all this baggage of your stigma." (P22)

These existing forms of stigma about sexuality and HIV contribute to the creation of stigma about PrEP. Nearly every participant discussed how PrEP was associated with being promiscuous, and several participants also linked it to HIV and sexual orientation stigma. For example, "There is a very specific stigma that comes with the idea that somebody is on PrEP ... they must be a very sexually active gay male who wants to have unprotected sex," (P18) and

When you make a post about Truvada somebody always goes on and tells what it should be used for and how you are abusing it because you're not with one partner and they call you a slut because they assume you are out there sleeping with everybody. (P5)

Participants often expressed concern that PrEP stigma could prevent others from accessing the medication. As shared, "It [seeing PrEP in profiles on dating apps] almost deterred me away from taking it [PrEP] because I thought, oh, here is this thing that you take ... only if you're promiscuous. There was some self-shame involved," (P13) and

I do get some backlash, like, 'Oh, you're just emotionless' and, 'You're a slut.' And I say I'm a slut because I own it, but I would imagine someone who takes that stigma more heavily, I think that's a huge barrier to even getting on PrEP. (P14)

PrEP users are changing the conversation about PrEP. As PrEP users, participants often reported challenging the stigma about PrEP, condom use, sexual behavior, and sexual orientation by discussing the utility of PrEP with analogies, such as birth control and other preventative health measures. For example, “I feel like it’s more like getting a flu vaccine. I just sort of tried to do my part to prevent spread of this disease. I just feel like this is sort of my responsibility to help,” (P23) and

It puts you in control of your sexual health, right? Just like a woman can go on birth control so she doesn't have to rely on the man to put on a condom. Much like someone who's on PrEP, they don't have to rely on the other person to put on a condom and/or tell them their HIV status. (P17)

Other participants more directly confronted and challenged the multiple stigmas that they saw as contributing to the stigma of PrEP. As one participant shared, “I had to have a conversation with them [friends who thought PrEP was promoting promiscuous sexual behavior] about how that might be some internalized homophobia.” (P13)

PrEP use engenders advocacy within the community. Participants described multiple challenges they had in acquiring and using PrEP, including resistance and concerns about bias from providers. “I never got to talk to him [provider] about Truvada. He was not very willing to talk about anything sexual... The only thing he would talk about was actual medical stuff like height and weight.” (P5)

These challenges and the cost of the medication made PrEP extremely valuable to users. One participant described them as “little tablets of gold,” explaining, “Well, I just mean that every one is precious because it’s been such a process to acquire them that you don’t want to lose them. And it’s like every single one counts because it’s such an expensive drug.” (P23)

Given these struggles, PrEP users reported disclosing their PrEP use so that they could inform, answer questions, assist friends with acquiring PrEP, and problem solve PrEP use issues.

My friends have called me an evangelist about PrEP. I post about it on Facebook all the time and I like to get the information out there. I think that basically the role I've been playing with my friends is like, 'Are you on PrEP? Maybe you should consider it.' (P24)

Another participant explained, "There [is] a good community of people who are talking about it and helping like spread the word, and sort of destigmatize any ideas that people may have about it." (P3) For some participants, their PrEP use became part of their identity: "It's become part of my life. It's part of who I am now... There's a community of people that are promoting it and I am part of that community now." (P15)

PrEP use influences individual well-being. Participants detailed the multiple ways they felt PrEP empowered them and influenced their lives in addition to reducing their biomedical risk for acquiring HIV. Nearly all participants described a reduction in fear or stress: "In the past, anytime I got a cold and felt sick really soon after having sex I'm ultra paranoid that I got infected, but now it's not this thing that's in the back of my mind all the time." (P11) Many participants also described feeling more comfortable with their sexuality. For example, "PrEP helped me feel not so shameful with men. It made me feel like I reclaimed a part of my sexuality that had been co-opted from me a long time ago by the stigma of HIV and anti-queer forces." (P3) Additionally, participants described that being on PrEP resulted in a greater awareness of their health. In particular, participants connected PrEP to increased frequency of testing for HIV and sexually transmitted infections (STIs). After seeing his doctor for PrEP, this participant shared, "I learned I missed some actual essential vaccines... but that was the first time I actually knew

exactly where I stood on all STDs [sexually transmitted diseases], just general health, was when I started going for PrEP.” (P14)

Another area where some participants described changes were in sexual behavior and condom use. Most participants described few changes in sexual behaviors, viewing PrEP as a back-up or additional layer of protection rather than an alternative to other safer sex practices. As described by a participant, “Basically, people just take it as an extra precaution.” (P23) Several participants indicated that their increased attention to their sexual health also included a heightened awareness of their sexual behavior; “I think once you get into it and start the treatment, it makes you more conscious about your decisions.” (P22) For some participants, this awareness resulted in a reduction in their number of partners.

I’m having a little mini conversation with myself daily about my sexual behavior... am I being promiscuous? Who am I choosing to have as sexual partners? I would say that the number of new sexual partners has decreased since getting on PrEP. (P13)

The influence of PrEP use on condoms was mixed. Some participants did report a reduction in condom use and a shift in norms around condom use: “A downside of PrEP is people that used to routinely insist on condoms aren't anymore, including a couple of my partners.” (P7) However, other participants, who had reported not using condoms prior to starting PrEP described that PrEP did not change their condom use but did make them feel safer.

Honestly, one of the biggest factors was I hate condoms and they're just, they do not work for me, at all. I can't stand them... There was a lot of risks that I took back then. So now those risks aren't as risky. (P15)

Another participant explained, “I don’t do the condoms. I never have... it’s given me the confidence of having the ability to protect myself in a way that condoms are just not making it in my world.” (P21)

PrEP use encourages intimacy and trust with partners. Participants explained how PrEP use changed their relationship with partners. Participants’ view of PrEP as a way to control and improve their health, coupled with increases in comfort about their sexuality, resulted in greater trust and intimacy with partners: “I think it allows you to trust more easily, especially if that person is on PrEP because you know that they are testing regularly for infections and taking a lot more responsibility for their health.” (P11)

When they compared their communication with partners before using PrEP and after, participants remarked that they were not only disclosing to partners that they were on PrEP, but also discussing partners’ HIV and STI testing and condom use: “It opened up communication just to ask, ‘Are you doing anything to take care of your sexual health?’” (P14)

Participants described how HIV shaped interpersonal relationships and influenced how they interacted with sexual partners and other members of the LGBTQ community. Participants remarked that they had been unwilling to partner with people with HIV before using PrEP and upon reflecting on their previous stance realized it was often because of HIV stigma. Participants reflected that PrEP improved how partners with HIV are treated.

It's actually nice to hear them [people with HIV] say that attitudes of other people that they're interested in dating or solely having sexual relations with, that attitudes of those folks have changed greatly and the amount of stigma and sort of negativity there is significantly different than it used to [be before PrEP] and that makes me feel good. (P20)

These changes were linked to the biomedical protection that PrEP provides and increased sexual health awareness and knowledge that related to PrEP use.

Actually, being on PrEP has changed my viewpoint of who I do have relationships with because before PrEP I wouldn't have had a relationship with anyone HIV positive, but now that I'm on it and now that I actually understand how HIV is spread... I feel comfortable dating and sleeping with HIV positive individuals. (P5)

Discussion

The analysis of these in-depth interviews with LGBTQ adults who were currently or formerly using PrEP in real-world settings demonstrates that PrEP represents much more than an effective biomedical HIV prevention option. We found that PrEP use exists in a context of stigma, and that existing stigma about HIV, sexual behavior, and sexual orientation coalesced to create stigma around PrEP; however, PrEP also became an opportunity for participants to resist stigma. Many participants described how they were able to reframe conversations about PrEP and engage in advocacy to support and encourage others' use of PrEP. Finally, participants reported that they viewed PrEP use as an empowering experience that increased emotional well-being, contributed to other positive health outcomes, and enhanced relationships with partners.

Our findings about stigma are consistent with previous research identifying stigma as an important factor influencing PrEP use (Arnold et al., 2017; Collins, McMahan, & Stekler, 2017; Franks et al., 2018; García & Harris, 2017; Grace et al., 2018; Haire, 2015; Liu et al., 2014; Taylor et al., 2014; Thomann et al., 2018; Young et al., 2014; Young & McDaid, 2014). In our and other studies, PrEP stigma is closely tied to stigma around HIV, "risky" sexual behavior, and sexual and gender identity (Franks et al., 2018; Grace et al., 2018; Haire, 2015). Just as we found, other researchers have observed that stigma can be an obstacle to PrEP use, but that PrEP is also an opportunity to expose and combat stigma around HIV and sexuality (Grace et al.,

2018; Storholm et al., 2017). Additionally, we noted, as did others, that PrEP users had a sense of pride around PrEP (Grace et al., 2018). Our findings add new insights about the PrEP stigma by further illuminating strategies that LGBTQ PrEP users adopt to challenge stigma and reframe conversations about PrEP use and HIV prevention. For instance, many participants gave examples of metaphors they used to help others think of PrEP in less stigmatizing ways. PrEP users in our study also reacted to the challenges and stigma they faced in accessing PrEP by discussing and recommending PrEP widely, with several stating that they felt that wider public knowledge of PrEP could be an important factor in decreasing PrEP stigma.

Additionally, our results reinforce and expand on previous studies that have started to demonstrate the individual positive outcomes of PrEP use beyond biomedical outcomes (Grant & Koester, 2016). For instance, previous qualitative research reported relief from stress and fear associated with PrEP use among participants in clinical trials, substance-using men who have sex with men (MSM), and MSM in Seattle (Collins et al., 2017; Koester et al., 2017; Storholm et al., 2017). Furthermore, a previous study of real-world patient experiences identified increased HIV and STI screening as a frequent outcome of PrEP adoption (Parker et al., 2015). Our results suggest that engagement with PrEP services could also increase overall awareness of sexual health and possibly lead patients to seek other health services as well.

Finally, it is interesting to note that while we asked all participants about how PrEP changed their sexual experiences, few participants reported that they had made significant changes in their sexual behaviors. Some participants did note that they might be less likely to use condoms or more likely to engage in casual sex than if they were not on PrEP. However, similar to other research, other participants described having fewer sexual partners because PrEP use led to more thoughtful decision-making about sexual behavior and risk (Arnold et al., 2017; Franks

et al., 2018; Sagaon-Teyssier et al., 2016). Arnold and colleagues (2017) also noted increased discussion of safer sex with partners, which many participants in our study reported.

Findings should be considered in light of several limitations. These results come from a sample of predominantly white, gay, cisgender men, most of whom lived in one urban area (characteristics that parallel this state's HIV infection epidemiology) and all participants had some college education. Although we did not see notable variance in themes by sociodemographic characteristics, it is possible that a more diverse sample might identify additional significant themes. Previous research has shown that there may be demographic differences in PrEP-related stereotypes (Golub, Gamarel, & Surace, 2017). White and college-educated participants, such as those who made up the majority of our sample, were more likely to mention promiscuity-related stereotypes (Golub et al., 2017).

Given the continued efforts to increase PrEP use, these findings have important intervention implications. Most of the limited research about PrEP messaging has focused on describing the effectiveness of PrEP (Mimiaga et al., 2016; Underhill et al., 2016). However, previous research found that an intervention framing PrEP as part of a healthy sex life increased adherence (Golub, Peña, Hiley, Pachankis, & Radix, 2017). Based on our findings, we would suggest that interventions also describe other positive and meaningful changes that PrEP can induce, which may motivate uptake more than fear- or risk-based approaches. Previous research has suggested that reduction of HIV-related stress is an important motivator of PrEP use, as is the feeling of being part of a community and contributing positively to the health and well-being of that community (Taylor et al., 2014). Additionally, our results reinforce previous calls for PrEP messaging that proactively addresses and reframes PrEP stigma through focus on the positive aspects of PrEP (Calabrese & Underhill, 2015; Haire, 2015; Herron, 2016). Finally, the

PrEP users who participated in our study identified an important role for peer support in initiating and continuing PrEP use and expressed significant enthusiasm for sharing their own experiences. This finding adds to previous research demonstrating that peer support or approval can facilitate PrEP uptake (Hannaford et al., 2018; Koechlin et al., 2017). While peer-to-peer or patient navigation interventions are recommended for promoting retention in HIV care, more research is needed to explore how similar interventions may be used to support PrEP use.

Conclusion

Participants in our research perceived that PrEP has positive impacts beyond biomedical outcomes. Participants reported experiencing decreased fear and stress and increased awareness of sexual health and health generally. Although stigma is a central aspect of the social context of PrEP, current PrEP users described being actively involved in resisting stigma by reframing conversations, encouraging others to learn more about PrEP, and confronting stigma directly.

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Table 1. Participant Description (n=23, current or former PrEP users)

	M ± SD (Range) or n (%)
Age	39.9 ± 10.61 (21-67)
Gender	
Cisgender male	20 (87.0)
Queer	1 (4.3)
Transgender male	1 (4.3)
Transgender female	1 (4.3)
Sexual identity	
Bisexual	1 (4.3)
Gay/homosexual	19 (82.6)
Lesbian	1 (4.3)
Pansexual	1 (4.3)
Queer	1 (4.3)
Race	
Latino	4 (17.4)
Multiracial	2 (8.7)
White	17 (73.9)
Education	
Some college	6 (26.1)
Bachelor's degree	8 (34.8)
Any graduate school	9 (39.1)
Income	
\$0-9,999	6 (26.1)
\$10,000-19,999	0 (0.0)
\$20,000-34,999	5 (21.7)
\$35,000-49,999	6 (26.1)
\$50,000-74,999	5 (21.7)
\$75,000-99,999	0 (0.0)
\$100,000+	1 (4.3)
Relationship status	
Single	13 (56.5)
Partnered	6 (26.1)
Married	4 (17.4)
Geographic location	
Portland metropolitan area	16 (69.6)
Other urban area	5 (21.7)
Rural	2 (8.7)