Stigma and Shame Experiences by MSM Who Take PrEP for HIV Prevention: A Qualitative Study

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Abstract
Pre-exposure prophylaxis (PrEP) uptake has been extremely low among key groups. PrEP-related stigma and shaming are potential barriers to uptake and retention in PrEP programs. There is a lack of literature describing PrEP stigma. In order to fill this gap, we recruited online 43 HIV-negative Men who have Sex with Men (MSM) who use PrEP. Semistructured interviews were conducted to explore their perceptions and experience of stigma related to PrEP use. Data were analyzed using Strauss and Corbin’s grounded theory and constant comparison techniques to enhance understanding of the lived experiences of MSM who use PrEP. The participants experienced PrEP stigma as rejection by potential/actual partners, stereotypes of promiscuity or chemsex, and labeling of both the user and the medication. They connected PrEP stigma with HIV stigma, generational differences, moralization of condom use, and inability to embrace one’s own sexuality. These findings point to a need to develop tailored interventions to address PrEP-related stigma and shaming for individuals, health-care professionals, and the MSM community-at-large.

Keywords
Pre-exposure prophylaxis, HIV prevention, MSM, stigma, shaming

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Despite an array of evidence-based behavioral HIV prevention interventions, there has been little reduction in the ~50,000 new HIV infections annually in the United States, especially among most-at-risk populations (MARPs). The majority of these new infections in the United States are among men who have sex with men (MSM; CDC, 2012). Biomedical prevention with the combination of Emtricitabine /Tenofovir (marketed as Truvada) was approved by the Food and Drug Administration (FDA) in 2012 for prevention of HIV in high-risk persons based on the compelling data from several major studies (Baeten et al., 2012; Choopanya et al., 2013; Grant et al., 2010; Thigpen et al., 2012) and confirmed in a systematic review (Fonner et al., 2016) demonstrating that pre-exposure prophylaxis (PrEP) reduces the risk of HIV infection by as much as 92% (Holmes, 2012). The World Health Organization (WHO, 2012) and Centers for Disease Control (CDC, 2013) have issued public health guidance on PrEP prescription. Despite these recommendations, PrEP uptake has been extraordinarily low. The 2015 report from the CDC states that approximately one in four gay men should be taking PrEP on a daily basis to prevent HIV transmission, translating to about 1.2 million MSM in the United States. Currently, 49,158 people are taking PrEP (including about 10,000 women). This means that only about 3% of the targeted population is using this prevention method (Bush et al., 2016). PrEP uptake is low and can be explained by a number of factors, including a lack of awareness of PrEP...
(Eaton, Driffin, Bauermeister, Smith, & Conway-Washington, 2015; Krakower et al., 2012), a low perceived risk of HIV acquisition (Pérez-Figueroa, Kapadia, Barton, Eddy, & Halkitis, 2015), concerns regarding potential adverse effects (Golub et al., 2013), a dislike of taking medication (Rolle et al., 2017), the cost of medication (Cohen et al., 2015), the cost and inconvenience of required monitoring visits (Elopre, Kudroff, Westfall, Overton, & Mugavero, 2017), and the requirement to undergo repeat HIV testing prior to each new prescription (Mayer et al., 2015). In addition to concerns regarding low uptake of PrEP, public health specialists and researchers are concerned with PrEP adherence among users. Adherence is a key issue in ensuring PrEP effectiveness. Inadequate adherence is a major reason for PrEP failure, as highlighted by the PrEP trials. In iPrEx, participants with drug detected in blood were estimated to have a substantially higher reduction in HIV infection risk than seen in the intention-to-treat analysis (92% vs. 44%; Grant et al., 2010).

PrEP-related stigma and shaming are potential barriers to PrEP implementation and maintenance. The definition of stigma, traditionally used by many social science researchers, is taken from the seminal work by Goffman (2009). He defines stigma as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one.” Crocker et al. (1998) indicate that “stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context.” These definitions share the assumption that people who are stigmatized have an attribute that marks them as different and leads them to be devalued in the eyes of others. Stigmatizing marks may be visible or invisible, controllable or uncontrollable, and linked to appearance, behavior, or group membership. Scholars describe stigma as a social construct or a label attached by society that leads to discrimination, negative treatment, and stereotyping.

The scholarship on PrEP-related stigma is limited (Eaton et al., 2017; Franks et al., 2018; Grace et al., 2018; Schwartz & Grimm, 2017). The recent PrEP demonstration project of 261 MSM in San Francisco reported that PrEP stigma poses a barrier to uptake and retention in PrEP program. The study concluded with a call for interventions aiming to combat PrEP-related stigma (Liu et al., 2014). Golub and colleagues (2017) identified two types of PrEP-related stereotypes that were reported in 80% of 160 qualitative interviews of MSM in New York City. The first stereotype was the assumption that PrEP users are actually HIV-infected and lying about it, while the second stereotype was the belief that PrEP users are highly promiscuous and resistant to condom use. In their commentary, Calabrese and Underhill (2015) call to overcome stereotypes and sex-negative messaging in guiding decision making about PrEP use. The belief that PrEP is for promiscuous people (stigma belief) was strongly associated with a lack of interest in using PrEP among 179 White and 85 Black MSM participating at a gay pride event in a large Southwestern U.S. city (Eaton et al., 2017). In a study by Biello and colleagues (2017) among MSM who recently engaged in transactional sex, anticipated PrEP stigma was the main deterrent for PrEP use.

Similarly, PrEP-related stigma has been prominent in the media, with a Huffington Post article labeling PrEP adopters as “Truvada Whores.” This term was later reappropriated by a number of activists who started to use the #TruvadaWhore hashtag on social media and wore it printed on their blue T-shirts (Duran, 2012). PrEP discourse within the MSM community has many instances of slut-shaming that are different from mere disagreement or criticism. Slut-shaming is defined as a form of social stigma applied to those who are perceived to violate traditional expectations for sexual behavior (Poole, 2013). Often this slut-shaming comes from other gay men believing that PrEP promotes reckless sexual behavior, and it is only to be used by sluts or whores. In the present study, we conducted semistructured qualitative interviews with gay men who use PrEP in order to explore their experiences with PrEP-related stigma. The main research question for this study is: What are the PrEP-related stigma experiences of MSM living in the United States who use PrEP for HIV prevention? We examined their narratives for experiences with felt and enacted stigma, and we describe its various manifestations and potential drivers.

**Methods**

**Study Design**

This study was part of a larger research project conducted to determine preferences for PrEP delivery among MSM in the United States (Dubov, Fraenkel, Yorick, Ogunbajo, & Altice, 2018) and Ukraine (Dubov et al., 2018) using stated preference method. From June to October 2015, purposive sampling was used to recruit a subsample of 43 MSM who use PrEP for HIV prevention and report PrEP-related stigma to participate in this qualitative study. The study was approved by Duquesne University IRB.

**Recruitment and Eligibility**

Participants were recruited online from a large national sample of MSM. The initial recruitment was conducted using social media (Facebook groups with MSM content), as well as smartphone apps and websites that cater...
to MSM communities (e.g., Grindr, Scruff, Hornet, Manhunt, Growlr). Grindr, Scruff, Hornet, and Growlr are MSM location-based social networking applications that have helped us to concentrate our recruitment efforts in major U.S. cities with a large MSM population. During the process of recruiting this larger sample \((N = 554)\), we were also able to recruit a subsample of PrEP users with a self-reported history of PrEP-related stigma. In order to be eligible for the larger study of preferences for PrEP delivery, MSM participants had to be age 21 years or older (per 2015 NIH definition of children) and to have no previous history of taking PrEP for prevention. When someone could not participate in the larger study due to their use of PrEP (approximately 250 MSM), we would then invite this person for participation in this qualitative study by asking whether he had ever experienced PrEP-related stigma, defined as a set of negative and unfair beliefs associated with one’s decision to use PrEP. Out of 250 subjects who were already on PrEP and asked to participate in this qualitative study, 43 MSM said they had experiences with PrEP stigma and agreed to participate.

Participants received no monetary compensation or incentives.

**Procedures**

Interviews were conducted in English by a trained interviewer either by phone or online (e.g., Skype). Signed informed consent was obtained from all participants using “click to consent” procedure. All interviews were audiotaped and transcribed. Interviews were designed to take approximately 30 minutes to complete. The interview guide included predominately open-ended questions and probes. The development of the interview guide was informed by the survey of previous studies related to HIV and stigma using an iterative process: during and after the initial interviews, questions were added, revised, or dropped based on information gleaned during the interview. The final guide included 10 questions (see Appendix).

**Data Analysis**

All interviews were digitally recorded and transcribed. Transcripts were anonymized, and certain demographic details redacted, to protect participants' confidentiality. Qualitative analysis software Atlas.ti 8 (Friese, 2018) was utilized for organizing data and facilitating retrieval. We utilized Strauss and Corbin’s grounded theory and constant comparison techniques to inform our data analysis procedures (Strauss & Corbin, 1998). An inductive codebook with 67 different codes or sub-codes were developed based on iterations of independent analysis from two coders, giving particular attention to the following content areas: (a) manifestations of PrEP stigma and (b) potential drivers of PrEP-related stigma. Emergent findings were discussed with two other authors, experts in the field of HIV/AIDS and qualitative research. Disagreements on codes were discussed until consensus was reached. The resulting categories that emerged from the final coding scheme reflected the dominant themes used for the elaboration of study findings: manifestations of stigma as rejection, stereotyping, and labeling; potential drivers of PrEP stigma including relationship between PrEP stigma and HIV stigma, relationship between age and stigma, stigma and community norms, stigma and sexual expression. Illustrative quotations were chosen to provide justification for the definition or basis of themes. Differences in discussions by participants’ race were determined by number of coding references, content, density, and breadth of discussion. All names used with selected quotes are pseudonyms. To ensure systematic application of qualitative methods, analysis, and presentation of study findings, we utilized the COREQ checklist.

**Results**

**Participants’ Characteristics**

Of the 43 participants, 25 were Caucasian, 9 were African-American, 6 were Hispanic, 2 were Asian, and 1 was “other.” Participants ranged in age from 22 to 53 years \((M_{age} = 30.3, \, SD = 8.2)\) (Table 1). More than half were currently employed (62%). Similarly, over half (58%) had at least some college education, and most participants lived in a large city (80%). One-third of the sample was from the West, 28% from the Midwest, 16% from the Southeast, 14% from the Southwest, and 12% from the Northeast. Their average time using PrEP ranged from 2 months to 2 years.

**Manifestations of PrEP Stigma**

**Labeling (Both the Person and the Medication)**

Labeling is a powerful mechanism through which stigma operates. Especially in the area of prevention, labeling may have detrimental effects as people may refuse PrEP to avoid being labeled as a “whore.” John, 41 y/o, shared his conversation with a young Grindr user:

One guy wrote me on Grindr saying that he too has wanted to go on PrEP for the longest time but he doesn’t want to be known as a whore. After our chat, he said he will look into it because he doesn’t want to seroconvert but until the stigma is gone, he will keep silent about it.
His fears may not have been unwarranted, as a number of other participants shared similar experiences being labeled by other men as whores, sluts, dirty, or sick. Paul, 32 y/o, said:

Since I started PrEP, I’ve been described in many ways by a number of guys. I’ve been told that I’m naïve, and arrogant, and rude for thinking that I have all the answers to our problems in this pill. I’ve been told that I was dirty and probably full of STIs.

Scott, 26 y/o, told us about his experience: “Just a few days ago, I received a comment on Grindr that reads— ‘Look, one of those fags that’s proud to be a whore.’”

Labeling in the context of PrEP can be directed at both PrEP users and the medication itself. The label given to a medication can be stigmatizing, and it can negatively affect the uptake. Adam, 25 y/o, told us about his friends, who made reference to his use of PrEP in a number of derogatory ways:

For a few months, my friends continued to belittle me with their jokes about PrEP using language like ‘gay drug,’ ‘bareback pill,’ ‘slut pill,’ or ‘recreational pill.’ This felt more than just a disagreement or difference in opinions about our health choices. Each time, they were vindictive in the way they approached the subject. They also came across defensive—‘I’ll bring you down because it makes me feel uncomfortable’.

Similarly, Greg, 23 y/o, told us about his friends: “Some of my acquaintances on social media were interested to find out whether I am still on the ‘slut pill.’”

Stereotyping
Stereotyping, as another manifestation of stigma, involves a set of assumptions about one’s dating and sexual life based on their choice of prevention (PrEP). In this study, PrEP was the attribute that linked participants to stereotypes of promiscuity, chemsex, condomless sex, or sex work. For instance, Sean, 28 y/o, explained:

“I mentioned to my mom that I was doing a PrEP study to combat HIV. She asked me if I was a sex worker. I’ve been shamed by the guys I used to date, being told that I’m going to die of Hep C and that I’m transmitting HIV to everyone because I’m not using condoms (which was an assumption; I still do). Conversely, I’ve been shamed by HIV+ men because I turned them down for sex, or because I wouldn’t go bare. They’ve called me a waste of PrEP. [Shaming happens]... either because I wasn’t promiscuous enough, or because they assumed I was. Either because they had misconceptions about PrEP or they were making assumptions about me ... like I had lots of condomless sex, which wasn’t true.”

Chemsex, or “party and play” (PnP), is a term used within MSM communities to describe a subculture of gay men who combine sex with the recreational use of drugs such as methamphetamine, or MDMA. In some instances, PrEP users were associated with this PnP subculture.
Matthew, 31 y/o, shared his frustration with being stereotyped by other men as if he would belong to the PnP subculture: “I get a lot of people making references to PnP. People tend to (unfortunately) perceive PrEP = cum buckets = PnP.” Even in the absence of the PnP stereotype, men may still assume that PrEP users engage in nondiscriminatory bareback sex. Ralph, 41 y/o, said: “Someone on Scruff messaged me saying, ‘Your PrEP headline reads as “I take loads.”’ Shawn, 33 y/o, had a similar experience with men who assumed he practices a nondiscriminatory approach to bareback sex: “About once or twice every month, I am receiving messages from different people on Grindr or Scruff. Their messages were along the same lines as ‘Are you the local cumdump now that you are on PrEP?’”

**Rejection**

Many participants experienced rejection on dating apps and even in their relationships as a result of disclosing their PrEP use. Shane, 50 y/o, shared his experience of breaking up with his partner:

“I am recently single due to my partner not understanding why I take PrEP. He felt PrEP was interfering with the possibility of a commitment. He asked me to stop taking Truvada as a show of good faith for a relationship, but I knew his part was fickle at best.”

Gay dating apps, such as Grindr and Scruff, are slowly replacing gay bars and saunas as a way to meet, socialize, and find dates. Participants described PrEP stigma and rejection that happens within those online communities. While participants were being proactive in protecting themselves from HIV by taking PrEP, they were still at risk for other sexually transmitted infections (STIs). Online communities seemed to forget the former and put emphasis on the latter, making a number of unwarranted assumptions about PrEP users. Thomas 26 y/o explained: “It does sometimes make me feel angry that I get written off by someone I’m attracted to simply because of their preconceived notions about me based on my use of PrEP. It’s unfair.”

Paul, 32 y/o, discussed rejection from potential sexual partners:

“I found it interesting that guys are more ‘OK’ with me saying ‘I’m negative’ versus saying ‘I’m negative and on PrEP.’ Almost as if they question if I have something to hide. Craziest yet, I chatted with a guy who wanted me to bareback him since I said I was negative, but when I said I was negative and on PrEP, he said never mind. I can only assume he did so because of the stigma that being on PrEP makes you more promiscuous.”

Lee, 42 y/o, had a similar experience being rejected only because his online username contained the word PrEP: “I had said ‘Hi’ to a person on a social media app. Because my username contained the word PrEP, his response was: ‘The fact that you’re on PrEP says a lot about you. I’ve already lost respect.’”

**PrEP Stigma and HIV Stigma**

Thoughts about starting a PrEP regimen are intertwined with thoughts about the potential risk of acquiring HIV, which carries its own stigma. Andrew, 33 y/o, connected HIV stigma with the negative reaction of his gay friends to disclosure of his PrEP use. He also compared their reaction with the one coming from his straight friends who were not ashamed to talk about HIV:

“In order for my friends to react differently to my choices (of being on PrEP), they had to consider their own situation and risk. They were not willing to go there as for them the only kind of safe sex was with condoms and/or monogamous. However, I knew for a fact that they were practicing neither. The PrEP discussion hit close to home. I found a lot of support from my straight friends about my choices because they are not desensitized about HIV, and they are not ashamed to talk about HIV. Their reaction was, ‘What? There is a pill for that? Why in the world someone would not take it?’”

As noted by Golub et al. (2017), some PrEP users were perceived as being HIV positive and lying about it. For instance, James, 32 y/o, told us about one instance of such a suspicion:

“The most asinine thing anyone has said to me (on Facebook) is that I’m positive and using PrEP as a cover up. Probably because I was questioning the HIV stigma they were spouting about how destructive it is. I wouldn’t even say I was offended, because there isn’t anything bad about being positive on a moral level.”

Michael, 42 y/o, talked about this connection between HIV stigma and PrEP stigma. He identified the belief that “people deserve bad things that happen to them” as the connecting link between HIV stigma and PrEP stigma:

“It is almost like a cultural thing, this belief that we deserve the bad things that happen. Poor folks are this way because of poor choices. Hurricanes happen because people who live in affected areas somehow deserve them. Sexual shame follows the same pattern. We tend to assume that only bad, dirty, slutty guys get HIV. This type of thinking drives guys into bars and meth houses where they hope to get rid of inhibitions. This same thinking prevents us from engaging in PrEP.”

**PrEP Stigma and Generational Divide**

Age appears to play an important role in PrEP-related stigma. Older generations may hold an assumption that
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younger gay men should be more responsible in avoiding HIV infection because they have access to better HIV education and services than the older generation. Frank, 22 y/o, described his conversation with an older Grindr user:

“There was this guy who wrote me a long rant about how he hates PrEP because of young, sexually irresponsible guys like myself. He said young guys have sex as much as possible while they can’t even spell ‘condom’ let alone use it. In his words, we, the young ones, are not educated about HIV. This is why he thinks we feel it’s OK to take a pill and do whatever we want.”

Harry, 24 y/o, agreed that older gay men may have a different experience with the HIV epidemic, and it may play a role in PrEP stigma:

“A lot of the shaming comes from people who grew up with the HIV break out, and they feel like we are letting the people who died down. They think it is an excuse for PrEP users to go out and have unprotected sex and have sex with whoever we want.”

Several respondents traced this generational divide in PrEP-related attitudes to the difference in experience with the HIV epidemic. The younger generation has experienced little or no grief over losing friends and loved ones to HIV. Wayne, 23 y/o, explained:

“I feel like, in general, younger guys are more open to hearing new ideas. Older men were often the ones who were upset about PrEP and angry. It makes sense, though. They lived through a different time regarding HIV/AIDS, and many of them lost all of their friends back then. It’s reasonable to still fear that outcome for yourself when the only way you’ve known your whole life is ‘condoms, or death.’”

Cody 21 y/o also experienced older men being more vocal or emotional in their disagreement with his decision to be on PrEP:

“I find that the older one is, the more emotional the reaction is when objecting to it. I really wish someone would (if not already) do a scientific survey that shed some light on how age plays into the views on PrEP. I find that guys in their 40s and beyond have some very well-meaning concerns about condomless sex.”

**PrEP Stigma and Moralization of Condom Use**

A consistent use of condoms holds a cultural value for many MSM. This is something that distinguishes good, responsible gay men from shallow, irresponsible party boys. During the early days of the AIDS epidemic, some gay activists and organizations used the “good gay versus bad gay” dialectic in their attempts to instill condom use as a community norm. A number of participants alluded to this community norm in their attempts to explain potential drivers of PrEP stigma. Larry, 50 y/o, explained:

“In the 80s and 90s, we were hard pressed to get people to use condoms, resistant to doing anything different, even in the light of an epidemic. Now, in the 10s, people have internalized the use of condoms—though their actions don’t follow—and are resistant to doing anything different, even in light of a (different) epidemic.”

In his interview, Sam, 43 y/o, referenced the history of safe sex campaigns and the resulting “us versus them” mentality:

Thirty plus years of conditioning alongside fear of sex has led to a sort of ‘brainwashing’ about condoms and also created an ‘us versus them’ mentality when it comes to people who use (or claim to) condoms consistently versus those who don’t.

This moralizing attitude in relation to prevention practices was prominent in a number of interviews. The study participants pointed out that HIV prevention decisions may not only be judged as wise or unwise but also as morally right or wrong ones. Tim, 33 y/o, told us about his friends who felt morally superior based on his prevention choices:

“I told five close friends of mine (that I was using PrEP) - platonic friends … One of them basically made it out to sound like what I was telling him was that I was a bug chaser. And that he was far superior to me because he always uses condoms. And that because I was now on PrEP, I would be letting the entire city pass me around and cum in me. Which was really awful to hear.”

Jim, 31 y/o, was scolded by a friend for his use of PrEP. His friend used morally-laden language to explain the reason for his reproach:

“A friend got into an argument with me over PrEP about a month ago, too. He threw phrases at me like ‘moral obligation’ regarding condom use, and that he doesn’t understand why anyone would need to take a pill when they could way more easily just use a condom. Again, the assumption that PrEPsters only use one or the other. It’s false.”

When reflecting on his experiences of PrEP stigma, Justin, 34 y/o, talked about the “condom only” culture and concurring resistance to any other form of protection:

“I believe the push for safe sex to mean condoms only for everyone is still very strong in a lot of people’s minds and they don’t see PrEP as a type of protection needed, even
though the science and numbers don't support a condom only life. Only speculation.”

**PrEP Stigma and Sexual Expression**

In many instances, one’s interest in PrEP correlates with an acknowledgment of one’s desire to practice more intimate and emotionally satisfying sex that involves fluid exchange and a deeper connection with one’s partner. Will, 41 y/o, explained that he believes that the root of PrEP stigma is found in the fear of intimacy and the projection of personal insecurities onto others:

“People who shame others about the use of PrEP often are simply projecting their own insecurities on others. I wouldn’t be surprised to learn that their shaming behavior stems from a deep desire to have unprotected sex but that they are too afraid to admit that. I can’t prove any of this but I can say that the root of the shame is fear.”

Daniel, 52 y/o, unpacked this idea, talking about denial of pleasure instead of embracing one’s own desires:

“Many gay men live in denial about what gives them pleasure. There is a denial about enjoying exchange of bodily fluids and condomless intercourse. Gay men never talk openly about it. They never embrace their drive and when they act on it, they feel guilty, disgusted, and ashamed. They may do it under the influence so they would not remember doing it, not feeling responsible for it. In this way, they end up both with HIV and drug addiction. I believe this denial is the driving force behind PrEP stigma and slut-shaming.”

Several participants alluded to the possibility that PrEP stigma and slut-shaming may stem from fear and discomfort with intimacy. Many gay men have a painful history of discrimination, homophobia, bullying, or rejection. People can respond to these stressors in a number of ways, but a common one is to avoid closeness and turn against other gay men. Tom, 42 y/o, made this connection between stigma and internalized homophobia:

“The shaming comes from fear and the majority of the stigma is within the LGBT community ... Within the LGBT community, there is a lot of internalized homophobia attached to PrEP and these people are afraid of having the sex they want. That is attached to shaming as well.”

Matt, 44 y/o, shared his thoughts about this culture of fear around sex:

“Our culture is pretty conservative when it comes to sex. Yes, we use sex to sell things, but we don’t like to actually talk or think about people having sex. We live in a society where abstinence is unrealistically espoused by many, creating a culture of fear around sexual activity.”

Andy, 51 y/o, said that he still struggles to adopt a positive approach to sex, and he thought this struggle could be a potential driver of PrEP stigma:

“I know I still work hard at not letting my own freedom of sexual expression and identity feel like anything but healthy and positive. I know that PrEP for me means embracing and owning that ‘I made it’ despite the risks ... There’s a bit of ‘survivor guilt’ ... All of that gets put in the mix when it comes to the shaming.”

Sean, 27 y/o, traced a connection between sex and trauma, while advocating for a trauma-informed approach to PrEP promotion:

“I think it's a cognitive linkage between sex and trauma. PrEP could mean that we finally get a meaningful grasp on slowing and potentially stopping new infections. That’s almost ‘fairytale’ reality against a past full of pain, suffering, intense personal and community loss, and the resulting stigma is powerfully hard to reconcile ... I hope that we can take a trauma-informed approach to PrEP promotion that lets us acknowledge this hurt.”

**Discussion**

This exploratory study examined PrEP stigma among MSM. In their interviews, participants discussed perceived difference between instances of ideological opposition to PrEP and PrEP stigma. Their discussion of PrEP stigma manifestation resembled the definition of stigma by Link and Phelan (2001): “stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows these processes to unfold.” This definition underlines several components of stigma: labeling, stereotyping, rejection, and status loss/discrimination. Labeling is the recognition of differences and the assignment of social salience to those differences. In the context of PrEP, labeling can be directed at PrEP users (whores) and medication (slut pill). Stereotyping is the assignment of negative attributes to socially salient differences. Participants named several stereotypes that resulted from their PrEP use, such as promiscuity, chemsex, condomless sex, or sex work. Rejection occurs when the reactions of others to these differences lead to a pronounced sense of “otherness.” Many participants experienced rejection on dating apps and even in their relationships as a result of disclosing their PrEP use.

Additionally, a number of assumptions about PrEP users (whores, cum buckets, bug chasers) was mentioned as the factor that separates PrEP stigma from a mere disagreement about prevention modalities. The literature describes this type of shaming as slut-shaming and defines it as an attack for perceived transgressions of accepted codes of sexual conduct and the stigmatization
of behaviors or desires that are more sexual than society generally finds acceptable. This type of shaming is discussed in feminist literature as a way of limiting women's sexual freedom (Dow & Wood, 2014). Slut-shaming is different from criticism or rational disagreement. It is intended to belittle, to label, to induce guilt, and to assign blame (Ringrose & Renold, 2012). Gay men can be victims of slut-shaming because of their sexual activities. There has been research showing that gay students were more likely to be stigmatized and called sluts than heterosexual students (Varjas et al., 2007). This slut-shaming may even come from within the LGBT community, even though it has traditionally promoted sex positivity. As the result of the 80s AIDS epidemic, when sexual activity could literally kill gay men, many sexual and HIV prevention choices remain highly moralized. In this context, gay men using PrEP may be shunned, both sexually and socially, because they are taking a prevention shortcut and stray from traditional practices. The experiences of participants in this study mirror those of slut-shaming.

The participants identified some underlying causes of stigma. They made a connection between PrEP stigma and HIV stigma in the fact that both outcomes—the use of PrEP to prevent seroconversion and being HIV positive—lead to being labeled “slut,” “whore,” “dirty,” or “irresponsible.” HIV-related stigma persists even 35 years into the epidemic (Rao, Kekwaletse, Hosek, Martinez, & Rodriguez, 2007). The same HIV stigma that leads gay men to postpone HIV testing (Chesney & Smith, 1999), to avoid discussions about the risks of infection with their partners (Smith, Rossetto, & Peterson, 2008), or to assume that only promiscuous gay men get HIV (Jeffries et al., 2015), may lead to avoidance of the medication that will keep them from seroconverting (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). Social research describes stigma as having three dimensions (Link & Phelan, 2001): enacted (overt behavior), perceived (awareness of stereotype), and internalized (self-stigma). These dimensions are prominent in HIV-related stigma within MSM communities: social segregation based on HIV status (enacted), social withdrawal due to changes in physical appearance (perceived), and feelings of being “dirty” or “irresponsible” (internalized; Van Brakel, 2006). HIV stigma among MSM is very prevalent. For instance, the Dutch HIV Association surveyed 667 people living with HIV, most of whom identified as gay men (79.5%). Most (70.2%) gay respondents said they had experienced HIV stigma within MSM communities (Stutterheim, Bos, & Schaalma, 2008). This HIV stigma also leads to PrEP-related stigma. Alex Garner (2014), an LGBT activist and writer, explains: “When I seroconverted, I encountered stigma for being perceived as ‘stupid and slutty’ enough to get HIV. Now negative men encounter stigma for being perceived as ‘stupid and slutty’ enough to prevent HIV.” PrEP stigma seems to follow the same pattern as HIV stigma with some signs of social segregation based on PrEP use (PrEP status displayed on online dating profiles, at times leading to rejection); perceived stigma where participants felt people were expecting certain behavior from them based on their PrEP use (i.e., barebacking); and internalized stigma when participants were made to feel “dirty” and “irresponsible” because of PrEP use. It is assumed that only irresponsible, reckless, slutty people become HIV positive. This same assumption covers those who are seeking PrEP as a new additional layer of protection. Thus, stigma in this way is pervasive either for getting or preventing HIV, and it serves as an additional deterrent to PrEP uptake.

The generational shift in attitudes toward HIV also promotes PrEP-related stigma among MSM. Younger MSM have not had similar grief experiences related to losing friends from HIV. According to the Kaiser Family Foundation report (Hamel et al., 2014), only 8% of young gay men (18–34 years) said they “lost someone close to them to the disease,” while 47% of older MSM (over 34 years) had done so. Unlike older MSM, who perceived HIV not as a matter of “if,” but rather of “when,” they would get infected, younger MSM may not perceive the same risk and give less priority to prevention. This shift in priorities can be observed in the 2013 CDC report concluding that condom use is also on the decline among MSM, with unprotected sex between MSM increasing by 20% between 2005 and 2011. Another recent study suggests that only 16% of sexually active MSM use condoms every time they have sex (Rosenberger et al., 2012).

Many theoretical models (Kasprzyk, Montaño, & Fishbein, 1998; Teng & Mak, 2011), and empirical studies (Paz-Bailey et al., 2016; Smith, Herbst, Zhang, & Rose, 2015), of condom use have focused on perceived risk or decreased pleasure as potential drivers of condom failure among MSM. However, the more recent evidence suggests that MSM may perceive condoms as a barrier to intimacy (Theodore, Durán, Antoni, & Fernandez, 2004). A recent study of Black MSM found that seeking more intimacy with sexual partners was the most common reason they cited for not using condoms (Gamarel & Golub, 2014). A large sample of gay and bisexual men recruited in the New York City metropolitan area prioritized intimacy over pleasure as the primary reason for not using condoms (Golub, Starks, Payton, & Parsons, 2012). For over two decades, the overwhelming focus on HIV prophylaxis has suppressed considerations of intimacy and pleasure. PrEP is the first self-protective option for HIV-negative partners seeking more intimacy. However, unlike previous prevention strategies geared toward more intimacy such as TasP.
or serosorting, PrEP puts the control in the hands of HIV-negative partners. As the result, it focuses the stigma and blame on the person engaging in the self-protective role. Previously, the power of control was in the hands of HIV-positive partners, who were already believed to be a “whore” or a “slut” since they had likely done something to seroconvert. In the case of PrEP, the power of control and the corresponding stigma have shifted to the HIV-negative partner. This may in part explain the connection between HIV stigma and PrEP stigma.

Finally, PrEP stigma may have roots in the “condom only” culture prevalent among MSM. Even though this culture is not as strong now as compared to the 1980s and 90s, condoms still have powerful meaning for MSM. For a generation of gay men, the condom was their “magic bullet,” their answer to the epidemic, the only thing that kept them alive. At the peak of the epidemic, public health campaigns went beyond information-only messaging to include value-laden appeals to morality, altruism, or even “fear mongering.” For instance, the playwright and activist Larry Kramer (2005) asked rhetorically in one of his writings, “Has it never, ever occurred to you that not using a condom is tantamount to murder?”

Another example is a poster from the late 80s containing a large, visible slogan, “A bad reputation isn’t all you can get from sleeping around,” accompanied by a picture of a graveyard (Geiling, 2013). This poster was designed to instill fear (and shame sexual behavior), while information on how to prevent the spread of HIV was buried in small print. The message gay men are accustomed to receiving is that lack of consistent condom use violates obligations to other gay men, that it is the “right” thing to do, and it is the gold standard of HIV prevention. While casual condomless sex, resulting from a lapse of judgment or condom failure, may not be morally criticized by other MSM, the intentional practice of casual condomless sex (barebacking) is often stigmatized within the gay community. This bareback sex is often socially constructed as irresponsible, reckless, and dirty (Dean, 2009). The clean/dirty and responsible/irresponsible dichotomies have their roots in the history of the AIDS epidemic (Spieldenner, 2016). This mentality may lead to an inability to consider other prevention methods and stigmatizing those who use them.

It is important to notice that almost half of our sample (42%) were racial/ethnic minorities. Additional analysis shows systematic differences in PrEP concerns among White and minority participants (frequency of PrEP stigma, being labeled due to PrEP use, negative assumptions about personal sex practices related to PrEP use). These findings reflect reports related to disparities in PrEP uptake (Pérez-Figueroa et al., 2015) and higher instances of PrEP skepticism (Cahill et al., 2017) among minorities.

Some study limitations must be noted. First, due to the size of the sample, the convenience methods used for recruitment, and the purposeful sampling strategy, our findings lack generalizability. We purposefully selected individuals out of a larger non-random sample on the basis of their stated experience with PrEP-related stigma. It is important to note that out of approximately 250 MSM who reported PrEP use, only 43 participants (or less than 20%) reported instances of PrEP-related stigma. Therefore, the study results cannot be generalized to other MSM communities. Like most qualitative research, our goal was not to draw conclusions about a larger population; rather, we wanted to gain insight into a set of topics from the perspective of MSM using PrEP. Second, during the interviews, participants were asked to share their experiences of PrEP stigma and sexual risk behavior (such as looking for sex partners on apps like Grindr or Scruff). These recollections may be subject to recall and social desirability biases. It is known that recollection of past experiences may result in suboptimal accuracy of recall. Qualitative data is often subject to recall and social desirability bias as well as interviewer effects. However, the use of a trained interviewer likely mitigated social desirability and interviewer effects. Third, some of the questions from our interview guide may have induced participants to conceptualize their experiences as stigmatizing. Despite these limitations, this study has enriched our understanding of the various manifestations of PrEP-related stigma and its potential drivers.

Findings from this study highlight the importance of understanding how PrEP-related stigma may impede access to this prevention modality among most at-risk groups. Potential PrEP candidates may resist PrEP in order to avoid being labeled as dirty, a slut, or a whore. There is a need for public health campaigns focused on “normalizing” PrEP and breaking these associations between PrEP and promiscuity, which may result in improved uptake. According to PrEP open access studies in San Francisco (Gilmore et al., 2013; Liu et al., 2014), not only uptake, but also PrEP adherence, which is essential to its effectiveness, can be undermined by stigma surrounding PrEP use. MSM may want to dissociate themselves from the stigmatized group of “PrEP users,” or they may miss doses of PrEP to avoid disclosure of their PrEP use. Therefore, reduction in PrEP stigma may positively influence both uptake and adherence. Public health messaging about PrEP aiming to normalize its use should emphasize the use of PrEP for those who are sexually active regardless of number of partners or types of behavior. Additionally, PrEP messaging may present it as an additional level of protection against HIV together with condoms and other prevention strategies. This may challenge the existing perception that PrEP and condoms are mutually exclusive.
Appendix

Interview Questions

1. Describe your experiences with PrEP-related shaming. Please describe one or more examples of shaming that you have experienced.
2. How frequently have you experienced similar shaming? If there were many occasions: Why did you choose to share that specific experience?
3. Let’s talk more about the experience/experiences you just shared with me. Describe the context in which this shaming took place (online dating or hook-up sites, other social media, bars, face to face, friends or acquaintances).
4. What was the age group of the person who tried to shame you?
5. Did the person who tried to shame you know your sexual preferences (top/bottom/versatile)?
6. Was it a single attack or did they continue to harass you?
7. Describe how you handled the attack. PROBE: Did you become angry? Did you fight back? Did you attempt to educate the attacker? Did you ignore them?
8. Describe how this experience differed from just an ideological disagreement regarding the use of PrEP.
9. Describe how this shaming experience make you feel. Did it make you rethink your choice to use PrEP?
10. What do you think the underlying causes of shaming might have been? Did your attacker allude to why he might have shamed you?

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