

Stigmatizing Prevention: A Literature Review Analyzing Current Research on PrEP-related Stigma

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WRITER'S COMMENT: During the month of December, the LGBTQ-IA+ resource center at my school was holding workshops on the topic of HIV stigma. Soon after I was assigned to write a literature review for my UWP 104F class about any public health topic of my interest. I knew I wanted to write about the topic of HIV prevention, and for this reason I decided to do research on how stigma can have negative impacts on public health by deterring people from engaging in safe sex. I wanted to specifically look at PrEP and how any stigma that exists around it negatively impacts the consumption rates of PrEP. Upon researching about the topic, I was able to understand the role of stigma, particularly slut-shaming, on discouraging people from adopting PrEP and belittling people who did use it. My hope for this piece is that the reader can have an understanding of why it is important to combat PrEP-related stigma in the greater fight against HIV stigma as well as how slut-shaming has a negative effect on public health.

INSTRUCTOR'S COMMENT: When assigning the literature review in UWP 104F—Writing in the Health Professions, I always advise students to choose a topic about which they have a strong desire to learn more. They will spend more than half of the quarter working on this challenging assignment and, without the drive to acquire more knowledge, the literature review may come to seem like a burdensome obligation rather than an opportunity to explore the published research on their topics. Javier clearly understood this from

the start. In the initial proposal for his literature review, Javier wrote persuasively of his own interest in understanding why individuals who take the Pre-Exposure Prophylaxis (PrEP) treatment to protect against HIV are frequently stigmatized. What Javier uncovered while seeking answers to this question he shares with us, his readers, in this outstanding review, which not only synthesizes and explains recent research, but also conveys a compelling and, at turns, disturbing narrative on this crucial public health issue. One could not ask for more from a literature review.

—Melissa Bender, University Writing Program

Abstract

HIV has been a cause of concern for queer and transgender communities in the United States since the days of the AIDS epidemic. In 2012, the FDA approved the use of Pre-Exposure Prophylaxis (PrEP) as a prevention method for HIV. Despite its effectiveness preventing the spread of the virus, the use of PrEP by men who have sex with men (MSM) has been slow. The purpose of this review was to understand how PrEP-related stigma affects adoption of PrEP among queer men and transgender individuals assigned male at birth. Research on this topic was centered around MSM and was conducted by searching peer-reviewed studies which included the terms “PrEP,” “Stigma,” “MSM,” and “HIV” in the PubMed database. Background information was obtained through the CDC’s webpage on HIV statistics. All studies analyzed concluded that PrEP-related stigma in both the MSM community and the medical community is enacted through the association of PrEP with promiscuity, which causes people to avoid the treatment in order to not suffer shaming. Studies found that PrEP users faced rejection from potential partners due to non-PrEP users associating PrEP usage with immorality and higher rates STIs. Studies also discussed the difficulty PrEP users have when navigating the medical system due to ignorance and/or prejudice from health care providers. In both of those cases, it is evident that PrEP-related stigma emerges from both ignorance and sex-negativity and works to degrade PrEP users and to discourage potential PrEP users from adopting the treatment. Due to the benefits

of increasing the use of PrEP, further research must be done in order to understand the dynamics of stigma.

KEY WORDS: *PrEP, MSM¹, Stigma, HIV, HIV Prevention*

Introduction

The Human Immunodeficiency Virus (HIV) is a retrovirus that destroys the body's CD4 defense cells, thus weakening the immune system. If the number of CD4 cells becomes low enough the patients are considered to have Acquired Immunodeficiency Syndrome (AIDS), making them unable to effectively fight off infections. AIDS became stigmatized during the seventies and eighties as the epidemic ravaged the Queer community. Despite the high death toll, the disease was ignored by government researchers due to its association with homosexuality. In the present, HIV has continued to be stigmatized due to homophobia in addition to its perceived association with promiscuity (Dubov, & Galbo Jr., & Altice & Fraenkel, 2018, p.1832). Today HIV prevention is considered to be a public health concern. As in the past, the LGBTQIA+ community continues to be the most affected by the virus, with male-to-male sexual contact alone accounting for 66% of new cases in 2017 (CDC).

Further research into HIV treatments has led to the development of antiretroviral therapy (ART) to lower HIV levels in the patient's blood, thus diminishing the effects of the virus in the immune system. In 2012 the FDA approved the use of a form of ART as an HIV prevention measure. This treatment is composed of a mix of Emtricitabine and Tenofovir (sold under the brand name Truvada in the United States). The treatment is most commonly referred to as Pre-Exposure Prophylaxis (PrEP) and consists of a pill taken on a daily basis by HIV-negative individuals. PrEP's goal is to kill the virus once it enters the system and

¹ While the medical community employs the term "men who have sex with men" it is important to note that "men" in MSM is used to describe individuals assigned male at birth. This definition excludes transgender men and puts transgender women and non-binary people in the category of "man."

its effectiveness has been observed to be as high as 92% in preventing infection (Dubov et al., 2018, p.1832). PrEP, however, does not prevent any other sexually transmitted diseases (STDs), nor does it prevent pregnancy.

Despite PrEP's proven effectiveness, adoption of the treatment has been rather slow. Studies cite lack of awareness of PrEP from both the public and healthcare providers, conflicts with health insurance, the treatment's cost, and the social stigma caused by the medication's association with promiscuity as explanations (Brooks et al., 2018; Dubov et al., 2018; Eaton et al., 2017; Schwartz & Grimm, 2017). This review will focus on PrEP-related stigma, and will look specifically at the research conducted around how stigma affects the adoption of PrEP among people who were assigned male at birth who have sex with other people who were assigned male at birth (referred to as men who have sex with men or MSM). This will be achieved by examining different studies focused on the MSM community. These studies consisted of qualitative interviews, focus groups and trend analysis whose primary objective was to better understand the dynamics of PrEP-related stigma and how it affects perception of the treatment. A better understanding of this stigma and its consequences would allow the medical community to better promote the use of PrEP among the general public, especially among populations whose rates of HIV infections are disproportionately high. Despite this benefit, the literature on the subject continues to be limited and most of it seems to be focused on cisgender men. Given the topic's relevance, it is imperative that more studies on the dynamics of PrEP and HIV stigma within the queer community be carried out in order to comprehend how to better fight it in hopes of increasing PrEP consumption and thus decreasing infection rates.

PrEP-related stigma among MSM

Reception of PrEP among the MSM population is mixed, with opinions ranging from acceptance of the treatment to total rejection of PrEP and its users. Of the studies analyzed, five of them had mentioned MSM praising PrEP and describing it as both "revolutionary" and "liberating" (Brooks et al., 2018; Dubov et al., 2018; Franks et al., 2017; Grace et al., 2018; Pawson & Grov, 2018). The study conducted by Eaton et al., which focused on interest in taking PrEP, found this interest

as high as 44% among the MSM in the sample (p.1239). Despite positive views on PrEP and interest in the treatment, studies describe the existence of anti-PrEP sentiment among some members of the MSM community. Anti-PrEP sentiments lead to men refusing to engage in sexual encounters with PrEP users and might go as far as wanting to reduce access to the treatment (Dubov et al., 2018; Eaton et al., 2017; Franks et al., 2018; Pawson & Grov, 2018). All studies describe this stigma as being the result of PrEP usage being associated with promiscuity, with some making note of the distrust felt among some MSM towards those who use it.

A trend in the literature of PrEP-related stigma is the continuous mention of PrEP users being perceived as overconfident about the drug's effectiveness; thus, they are assumed to be more sexually active in a non-monogamous setting. Five articles mention the label "Truvada Whore" being used by non-PrEP users to mock PrEP users and label them as "sexually deviant" (Brooks et al., 2018; Dubov et al., 2018; Eaton et al., 2017; Pawson & Grov, 2018, Schwartz & Grimm, 2019). Furthermore, participants who were taking the treatment across all studies experienced rejection from potential sexual partners when they disclosed they were on PrEP. Researchers note that the main drivers of this rejection were the perception of PrEP takers being more prone to STIs, with many MSM describing PrEP as a party drug instead of as a valid form of HIV prevention (Pawson & Grov, 2018). The promiscuity stereotype associated with PrEP users results in the association of PrEP with precarious sexual practices caused by the perceived arrogance of PrEP users. Studies mention that PrEP users are often assumed to desire unprotected sex and are thus blamed for spreading other STIs (Brooks et al., 2018; Dubov et al., 2018; Franks et al., 2018; Eaton et al., 2017; Pawson & Grov, 2018). Pawson & Grov point out that older MSM believe PrEP discredits the previous HIV prevention strategy that was pushed before the release of PrEP. This strategy was behavior-based and consisted of promoting condom use and monogamy as the most effective ways to prevent spread of the virus (Pawson & Grov, 2018). In a different study from 2017, a generational divide was also observed, with those who were willing to adopt PrEP tending to be younger (Eaton et al., 2017). However, Schwartz & Grimm's study found that non-PrEP users who believed that PrEP users were more prone to contract STIs tended to engage in more high-risk sexual practices (p. 85). Simultaneously, other studies which surveyed MSM on PrEP had participants describe personal

experiences of either continuing to use condoms while on the treatment or not being interested in using condoms before starting the treatment and using PrEP as harm reduction (Pawson & Grove, 2018).

PrEP-related stigma among Healthcare providers

Another setting in which PrEP-related stigma is enacted is in the medical field, where it interacts with pre-existing prejudice and ignorance from providers. According to Kuzma et al., existing anti-gay stigma in clinical settings prevents effective communication between patients and providers, leading to suboptimal care for LGBTQIA+ patients as providers themselves refuse to discuss gender identity and sexuality (p. 3). From all of the studies analyzed for this review, only Schwartz & Grimm's looked specifically at the dynamics of HIV/PrEP-related stigma in the medical field. This study described patients as being alienated by the way in which their doctors described "the gay lifestyle" and how doctors associate it with increased risk for STIs (p. 86). According to Schwartz & Grimm, anti-gay bias in the medical field can take the form of stigmatizing language and attitudes, with nearly two-thirds of participants in their study reporting at least one instance of stigma from their providers. The same study described how this type of interactions, combined with the body language of providers, discouraged them from discussing their sexual orientation and bringing up the usage of PrEP, thus affecting the effectiveness of communication.

The study goes on to further analyze how MSM patients navigated anti-gay bias from healthcare providers. These included providers purposely ignoring their harmful attitudes and trying to diminish their effects on patients (Schwartz & Grimm, 2017, p. 86). However, most of the participants in the study who possessed background knowledge on the medical and pharmaceutical settings were able to engage in conversation with their healthcare providers and inform them about PrEP. A few other studies have observed ignorance about PrEP within the medical community itself, with instances in which the patient was the one responsible for educating the healthcare provider on the treatment (Schwartz & Grimm, 2017, p. 88). Schwartz & Grimm conclude that, in order to minimize stigma and increase usage of PrEP, it is necessary for providers to receive training on how to better communicate with their MSM patients, strengthen their knowledge of the treatment, and fight

misinformation about PrEP among their patients. Furthermore, Kuzma et al. suggests that anti-LGBT bias can be dismantled by having providers promote safe spaces, reduce the amount of assumptions providers make (e.g. stop assuming patients are heterosexual, stop assuming patients' genders, etc.) and emphasize the necessity of healthcare being judgment-free (p. 6).

Fighting off PrEP-related stigma

A majority of studies discuss how PrEP users deal with stigma and how they resist it. Pawson & Grov's study, in which the participants were placed into focus groups, described instances in which the participants who used PrEP advocated for the treatment to the participants who held negative beliefs about it. The participants who were against the usage of PrEP employed stigmatizing language against PrEP users and advocated for decreasing its prescription by narrowing down the number of possible candidates for the treatment (p. 1397). By contrast, the participants who advocated for PrEP usage refuted the myths that PrEP caused people to engage in condomless sex and that PrEP users hold no interest in monogamy. These pro-PrEP arguments included discussing the high rates of non-monogamous condomless sex already occurring in the gay community, which highlighted the failure of behavior-focused HIV prevention campaigns, and the myth of PrEP reducing condom usage (Pawson & Grov, 2018, p. 1398-1399). These same participants also described PrEP as a helpful addition to their HIV-prevention regime in addition to condom usage, which one user mentioned he was already engaging in. PrEP users in the same study also referred to PrEP as a form of harm reduction for people who were already engaging in high-risk sexual intercourse (p. 1398). Participants in other studies also recall instances in which they tried to educate potential sex partners who had originally expressed disapproval about PrEP by addressing common misconceptions (such as the idea that PrEP is a form of HIV medication and not a form of prevention) and stereotypes regarding the treatment (Dubov et al., 2018; Franks et al., 2018).

Additionally, some MSM who use PrEP have found themselves having to fight against medical ignorance by informing their doctors about the existence of PrEP and pushing the discussion even when the providers avoid the topic. Participants in a 2019 study recall having to

introduce PrEP to their health care providers as well as being forced to bring up the topic when their own doctors would refuse to do so (Schwartz & Grimm, 2019). Participants in the Schwartz & Grimm study recall their doctors' surprise upon learning about PrEP, with some of their providers being incredulous about the treatment.

The study does acknowledge, however, that most of the participants surveyed were medically literate, and thus gained more credibility in the eyes of their doctors and had less difficulty understanding medical language, which is a situation that might not hold true for all MSM who are interested in getting PrEP. The study also suggests that in order to create a better environment for MSM patients to openly discuss their sexuality with their providers it was imperative for medical staff to receive training that reduced their bias and better prepared them to interact with queer patients (Schwartz & Grimm, 2019).

Conclusion

This review focused on the existing literature discussing stigma related to Pre-Exposure Prophylaxis (PrEP) for HIV in the MSM community. This was achieved by identifying and analyzing research articles on the topic from peer-reviewed scientific journals. The articles discussed the dynamics of stigma in the MSM community, discussion about PrEP between patients and providers, and the efforts led by PrEP users to fight off negative perceptions of the treatment. Since PrEP was approved by the FDA relatively recently in 2012, the literature surrounding PrEP-related stigma and its effects on the LGBTQIA+ community is not extensive. Despite limited research on the topic, the existing literature's findings are consistent regarding origins of the stigma and its consequences, particularly as its correlation with the slow uptake of PrEP by the MSM community.

All reviewed studies discussed how negative perceptions of PrEP discourage potential users from adopting the treatment. All studies make note of non-PrEP users associating PrEP with higher rates of condomless sex and STIs, even when no real basis exists for this association. The negative perception created around PrEP users leads to rejection and humiliation of PrEP users, with many being labeled as "Truvada Whores" (Brooks et al., 2018; Grace et al., 2018; Pawson & Grov, 2018).

In addition to rejection from their own community, MSM who

intend to use PrEP face poor medical treatment due to healthcare providers' ignorance of the treatment and lack of sensitivity when discussing queerness (Schwartz & Grimm, 2019). Difficulties communicating with healthcare providers and distrust of the healthcare system were cited as factors contributing to unwillingness to adopt PrEP (Eaton et al., 2017; Schwartz & Grimm, 2019). A study suggests that in order to fight anti-gay bias within the medical community it is imperative for medical institutions to promote informational campaigns about PrEP targeted at medical staff, having sensitivity training targeted at healthcare providers to help them better communicate with LGBTQIA+ patients, promoting PrEP as a beneficial form of HIV prevention among patients, and having medical staff promote safe spaces where LGBTQIA+ patients can feel comfortable discussing their sexuality and gender identity (Kuzma et al., 2018).

The reviewed studies also discuss instances in which PrEP-using MSM fight against both PrEP-related stigma and anti-gay bias in both casual conversations with other MSM and in clinical settings. Pawson & Grove describe instances in which PrEP users in the study's focus groups refuted statements made by men in their groups who opposed PrEP due to associating it with promiscuity and high-risk sexual encounters. They did so by pointing out that condomless sex and non-monogamous sexual relationships are already occurring at high rates, thus indicating PrEP's usefulness as a form of harm reduction for people who are already engaging in high-risk sexual activities as well as for people who were not necessarily consistent with their condom usage (p. 1398). Similarly, Schwartz & Grimm's study mentions instances of MSM fighting medical providers' ignorance about PrEP by being the ones who educate their healthcare providers on the treatment. Schwartz & Grimm do, however, point out that participants who engaged in these conversations with their healthcare providers had a background knowledge of the medical field and thus could easily educate their providers, which might not be the case for all MSM who seek to discuss PrEP with their doctors (p. 89).

While more research needs to be conducted on the dynamics of PrEP-related stigma in the MSM community, the existing literature provides a solid foundation as it points to how PrEP-related stigma is enacted through slut-shaming and ignorance. These studies, however, do not fully analyze the influence of intersectionality on the perception of PrEP users. This could be achieved by studying PrEP stigma on different

communities rather than using samples with participants of different communities. This would allow researchers and public health officials to develop campaigns normalizing PrEP tailored to each community's cultural sensitivities. Eradicating anti-PrEP bias, especially in communities historically considered to be at greater risk of contracting HIV, is an essential step in fighting HIV by preventing its spread. Elimination of anti-PrEP prejudice also plays an important role in fighting HIV-related stigma as both PrEP-related stigma and HIV stigma are based on a sex-negative mindset that seeks to discriminate against those who are perceived to be "promiscuous" by labeling them as "Truvada whores" (in the case of PrEP users) and "unclean" (in the case of HIV-positive people). Both HIV prevention and elimination of HIV stigma make eradication of PrEP-related an urgent public health concern.

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