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PrEP Stigma: Implicit and Explicit Drivers of Disparity

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Abstract

Purpose of Review—Despite its promise as an HIV prevention strategy, PrEP uptake remains slow, especially among highest priority population. One factor that may be impeding implementation and driving disparities is PrEP-related stigma. This paper reviews the role of PrEP-related stigma in PrEP access, adherence, and persistence, and examines its antecedents and consequences.

Recent Findings—Although PrEP stigma is often experienced at the community-level (i.e., by potential and current users) can be reinforced and even amplified by public health programs, policy, and research. PrEP stigma disproportionately impacts disadvantaged groups, and impedes scalability by influencing behavior of both patients and providers.

Summary—Reducing PrEP stigma and its negative impact on the epidemic requires a significant shift in perspective, language, and programs. Such a shift is necessary to ensure broader reach of PrEP as a prevention strategy and improve its utilization by the individuals who need it most.

Keywords

Pre-exposure Prophylaxis (PrEP); Stigma; HIV/AIDS; Sexual Health; Prevention; Implementation

Introduction

The advent of highly active antiretroviral therapy (HAART) in the late 1990s revolutionized the HIV epidemic, dramatically lowering morbidity and mortality among infected individuals. The historic gains associated with this biomedical intervention were not distributed to all groups equally, however. Between 1997 and 2011, racial and socioeconomic disparities in HIV-related mortality skyrocketed [1], attributable largely to differential HAART access and utilization [2]. Almost twenty years later, not only do such

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treatment disparities persist, but they have contributed to widening gaps in infection rates among lower income individuals and people of color [3].

Effective biomedical prevention for HIV infection, in the form of daily oral pre-exposure prophylaxis (PrEP), is similarly poised to positively impact the epidemic, with estimates that broad PrEP uptake could significantly reduce new infections [4]. Unfortunately, overall uptake of PrEP has been slow [5–6], and analogous disparities in access are already apparent. PrEP access is unacceptably low for communities of color, who have disproportionate rates of new infections [7–8]. The scalability of PrEP as an effective prevention strategy must be measured not only by the pace of its dissemination, but also by its equitable distribution among highest priority populations.

This paper reviews the role of PrEP-related stigma in slowing uptake and driving associated disparities. It argues that although PrEP stigma is often experienced at the community-level (i.e., by potential and current users) it can be reinforced and even amplified by public health programs, policy, and research. Because it raises additional barriers to both seeking and receiving a prescription, PrEP stigma disproportionately impacts disadvantaged groups, including those without easy access to health care, individuals of lower socioeconomic status, and communities of color. Reducing PrEP stigma and its negative impact on the epidemic requires a significant shift in perspective, language, and programs. Such a shift is necessary to ensure broader reach of PrEP as a prevention strategy and improve its utilization by the individuals who need it most.

The Nature of PrEP Stigma

Stigma is classically defined as a personal attribute or characteristic that is socially "discrediting," i.e., that confers a negative judgment or value onto the individual [9]. PrEP is socially discrediting because of both what it is and what it does. Because PrEP is HIV medication, and is known to be the same medication taken by HIV-positive individuals, it is stigmatized by association. Both potential and current PrEP users report concerns that others will think that they are HIV-positive if they are seen taking PrEP [10–12]. Despite thirty years of progress and heroic efforts on the part of HIV advocates, the stigma associated with infection has not sufficiently abated [13–14]. At its root, HIV stigma stems from the assumption that HIV-positive individuals contracted the virus as a result of socially unacceptable behavior, i.e., promiscuity or injection drug use. The presence of HIV infection is a "stigma" in its literal sense, i.e., a mark or sign providing evidence of the socially discrediting attribute. The fact that PrEP medication is HIV medication confers HIV-related stigma – and/or fear of this stigma – on its users. When PrEP users worry that others will think they are HIV-positive, they are worried about being seen as engaging in the socially discrediting behaviors that are linked to HIV infection [15].

Ironically, PrEP stigma is also inextricably linked to HIV stigma because it is specifically designed to *prevent* HIV infection. Before PrEP, prevention of sexual HIV transmission required two types of behavioral restraint: limiting sexual activity and/or the number of sexual partners, and consistent condom use. But for individuals taking PrEP, these behavioral constraints are lifted, and they are free to engage in sexual activity and

condomless sex without fear of infection. However, rather than being seen as merely an alternative – and equally acceptable – prevention strategy, PrEP is considered a less honorable prevention choice [16]. In surveys of PrEP-related attitudes, participants believe that PrEP *causes* people to have more risky sex and that people should pick their sexual partners more carefully instead of taking PrEP [17, 18]. In qualitative studies, participants contrast PrEP with engaging in "safe" behavior and view PrEP as an excuse not to engage in prevention [19] What is particularly interesting about this construction is that PrEP use *is* prevention behavior and, by definition, PrEP users are having *less* risky sex than non PrEP users. Even suboptimal PrEP use (i.e., occasional missed doses) is more effective in preventing HIV infection than consistent condom use [20,21] and is astronomically more effective than picking partners one assumes to be HIV-negative [22,23].

The "high-risk" sex many individuals associate with PrEP use refers to condomless sex itself, regardless of the act's true risk for HIV infection. Therefore, at its root, PrEP stigma is sexual stigma. PrEP users are stigmatized because they are seen as *wanting* to engage in behavior that previously would have put them at risk for HIV infection, even if that risk has been eliminated by PrEP use. PrEP is stigmatized because it facilitates the same socially unacceptable behavior that would normally lead a person to become HIV-positive, while protecting its users from incurring the "mark." Seen in this light, PrEP stigma is a social threat that replaces the physical threat of infection PrEP users can now avoid. Understanding that PrEP stigma is inextricably linked to stigmatizing sexual desire and expression itself is critical to both understanding its role in impeding PrEP implementation and also identifying the changes necessary to overcome it.

PrEP Stigma Impedes Scalability

There is compelling evidence that PrEP stigma directly impacts its scalability as a prevention strategy, including the pace of uptake, rates of adherence and persistence, and disparities in dissemination among highest priority populations. Past research indicates that social stigma negatively impacts both individuals' perception of their own risk of stigmatized conditions [24,25] as well as their willingness to engage in prevention or screening behavior for these conditions [26,27]. Applied to PrEP, social stigma is likely to reduce individuals' perceptions that PrEP is an appropriate intervention for them. In the U.S., recent data indicate that the vast majority of individuals who meet criteria for PrEP eligibility do not see themselves as PrEP candidates [6,28]. Failure to identify as someone who might benefit from PrEP prevents individuals from seeking both information and care. Specific PrEP stigma beliefs, including the perception that PrEP is only for individuals who are promiscuous, have also been associated with lack of interest in PrEP among potential users [17]. In Kenya, PrEP stigma was identified as the most significant community-level barrier to PrEP implementation across target population [29]. And a recent meta-analysis of PrEP acceptability among men who have sex with men (MSM) indicated that PrEP related stigma was a significant barrier to acceptance worldwide [30].

PrEP stigma also negatively impacts individuals who have chosen to take it. In both clinical trials and demonstration projects, PrEP stigma has emerged as a critical factor in users' experiences, including their adherence and persistence behavior. Participants explicitly link

PrEP stigma to concerns about being seen taking PrEP pills by family and friends [12] and report that these concerns are significant adherence barriers [31]. For HIV-positive individuals, HIV stigma has been found to negatively impact adherence behavior [32, 33], and there is reason to believe that similar dynamics of shame and internalization may affect PrEP adherence. For many PrEP users, having to conceal pill-taking may also reduce PrEP persistence [31]. PrEP stigma was considered the most significant social harm experienced by PrEP users in the Demo Project [34], and was cited as a key reason for PrEP discontinuation.

PrEP stigma exacerbates health care disparities by creating additional barriers to access (e.g., internalization of negative attitudes, anticipated or experienced discrimination) for individuals who may already be struggling to receive care [33]. Intersectional stigmas (racism, classism, homophobia, substance use stigma) can compound the negative effects of PrEP stigma, making it particularly damaging [35,36]. Previous experiences of stigmatization in health care settings may make individuals more sensitive to PrEP stigma and more reluctant to seek care [37]. Reducing PrEP stigma is a critical first step in equalizing access and engaging populations who have been previously underserved by HIV prevention and care.

Current PrEP Policies, Programs, and Research Perpetuate PrEP Stigma

As noted above, PrEP stigma has been recognized as an important factor in successful implementation. To date, calls for eradicating PrEP stigma have been focused largely on community-level strategies: changing PrEP messaging to make it more engaging, sex positive or intimacy focused; providing targeted education to highest priority communities; utilizing celebrities or other opinion leaders to advocate for PrEP [16,38,39]. Scant attention has been paid to the ways in which current policies, programs, and public health research agendas *themselves* promote and perpetuate PrEP stigma. It will be difficult to substantially reduce PrEP stigma at the community-level, i.e., among potential users and their social networks, without first addressing the ways in which PrEP stigma is integrated into PrEP programs, policy, and research.

First, almost all provider education, clinical guidance, and patient education materials emphasize that PrEP is for “people at very high risk for HIV infection” [40, emphasis added]. This designation is inherently stigmatizing. As explained above, HIV itself is socially stigmatized, such that individuals “at risk” for HIV are socially discredited by association. Individuals at “very high risk,” therefore, must engage in an extreme form of these unacceptable behaviors. Identifying yourself as very high risk for HIV means acknowledging not only that you engage in these behaviors, but also that you are unable or unwilling to stop them. Decades of prevention research demonstrates that few people identify as a “high-risk” for HIV regardless of their objective behavior [41,42], and that concerns about being seen as high-risk for a stigmatized condition actually reduce individuals’ risk perception and prevention behavior [26,27]. Describing PrEP as an intervention for “very high risk” individuals simultaneously stigmatizes the prevention strategy and alienates potential users. There is evidence that the high-risk designation has also contributed to provider-level stigma, including both negative perceptions of patients

who might be eligible for or interested in PrEP, as well as a reluctance to prescribe PrEP for patients who are not considered risky enough [43–45].

Second, and relatedly, a great deal of PrEP implementation work focuses on eligibility assessment, i.e. identifying patients who are appropriate "PrEP candidates." On the one hand, this focus makes sense; providers want to make sure that they are offering PrEP to patients who need it most, while not over-prescribing a medication to patients who don't need it. However, in combination with the "high-risk" designation for PrEP, many assessment tools are confusing and may even be damaging to patients. Most PrEP risk assessments ask patients to report: the number of sex partners they've had, how many of those partners are HIV-positive, and the number of times they've engaged in condomless sex. But the actual criteria for PrEP eligibility are extremely broad; for example, most include any man who has engaged in even a single act of condomless sex in the past six months, regardless of the number of partners or their HIV status. By first asking patients their number of partners and acts, but then telling anyone who answers anything other than zero that they are high-risk, we are stigmatizing *any* act of condomless anal sex. A gay man who has had condomless sex twice with the same partner in the past six months and learns he is eligible for PrEP may be concerned or confused that he has been identified as high risk and may feel wrongly labeled as "promiscuous." This disconnect may cause him to reject the assessment and discourage his PrEP uptake. Patients with many partners or acts may feel targeted or shamed, which can also lead to disengagement from medical care. PrEP eligibility assessment is stigmatizing because it is designed to evaluate whether or not to *label* a patient as high risk. Complete control over the application of this label lies with the assessor (or assessment tool) rather than in the patients' own experience of themselves, their behavior, or the context within which they engage in sexual expression. As such, both the message of this type of PrEP risk assessment and the assessment experience itself can exacerbate and perpetuate PrEP stigma.

Third, PrEP implementation has been accompanied by an almost obsessive focus on risk compensation, i.e., the concern that PrEP uptake will lead to increased risk behavior among its users. Originally, the issue of risk compensation was raised when the iPrEx intent-to-treat data suggested that PrEP reduced infection risk by only 44% [46]. In this context, replacing condoms (estimated to be 70–80% effective in preventing HIV infection [21]) with a less effective strategy was a significant concern. But now that PrEP has been established to be over 90% effective when adherence is high [20], there is little reason to believe that reduced condom use among PrEP users will lead to increased rates of HIV infection. In fact, PrEP uptake has been associated with significant reductions in infection rates in both modeling projections and real world contexts [47–48]. According to a recent modeling study, risk compensation among individuals with high or moderate PrEP adherence might actually be associated with a *decline* in population-based HIV incidence, as more individuals would become eligible for and begin taking PrEP [49]. Yet researchers, policy makers, and providers continue to emphasize risk compensation concerns in the context of PrEP implementation [50]. The focus on risk compensation has been so extensive that some authors have referred to concerns about it as a type of "moral panic" both among providers and within the gay community [51].

The persistence of risk compensation discussions despite evidence that PrEP utilization does not increase infection rates underscores the extent to which the issue is actually a form of implicit PrEP stigma, rather than a genuine public health issue. Concerns about risk compensation are actually concerns about sexual behavior, i.e., that PrEP users will have multiple sexual partners or engage in condomless sex, even through this type of sexual expression no longer confers risk for HIV. In public health research, the term “unprotected” sex has been replaced with “condomless” sex to acknowledge the fact that PrEP users who have condomless sex are still protecting themselves from HIV infection. But this idea has not fully penetrated the consciousness of many providers. Similar to the discussion of community-based PrEP stigma above, negative judgments about these behaviors in the context of PrEP stem from negative attitudes about promiscuity or condomless sex *in and of themselves*, rather than resulting from their potential to increase HIV transmission risk.

It is true that more recently, the conversations about PrEP-related risk compensation have focused on concerns about increases in other sexually transmitted infections (STIs) [52,53]. STI infection rates are a critical public health issue, and efforts to reduce STI incidence are critical to promoting sexual health. However, focusing on STI infection rates as a rationale for questioning PrEP’s efficacy is misguided [54,55]. Restricting access to prevention for one illness because of its association with another is not sensible or ethical practice. Many patients with high cholesterol levels may also develop diabetes because of dietary patterns associated with both conditions [56]. But there are few who would advocate withholding cholesterol-lowering medication from such patients, because of concerns that lowering their cholesterol will give them less incentive for healthy eating. Because it is based on the undesirability of certain sexual behavior regardless of its HIV risk, there are three reasons why a focus on risk compensation at the program or policy level perpetuates PrEP stigma and may be more damaging than the phenomenon itself.

First and foremost, concerns about risk compensation are associated with reduced willingness to prescribe PrEP [45] and these concerns are most likely to negatively impact individuals who need PrEP most. Providers who believe that patients will not use condoms while on PrEP have more negative attitudes toward PrEP as a prevention strategy and are less likely to have prescribed PrEP [44]. And data suggest that providers are least likely to prescribe PrEP to patients they believe are not using condoms. Ironically, individuals who are not using condoms are, in fact, the patients who would most benefit from PrEP. But providers’ internalization of risk compensation arguments has the potential to encourage such nonsensical behavior by focusing provider attention on the potential dangers of PrEP rather than its proven benefits. Data suggests that providers are most comfortable prescribing PrEP in the context of serodiscordant monogamous relationships [43], even though the risk of transmission is actually very low if the HIV-positive partner is successfully viral suppressed and regularly monitored. But these data may demonstrate implicit belief about the “deservingness” of individuals in monogamous relationships, compared to those who may have multiple partners. Regardless of the behavior of individual providers, data suggest that general patient perceptions that providers associate PrEP with sexual risk taking may discourage uptake or persistence [16,57].

Second, there is evidence that risk compensation arguments may be used to support providers' implicit, or unconscious, biases against patients of color. In a seminal experimental study [58], not only were medical students less likely to prescribe PrEP to patients they believed would engage in risk compensation, expectations regarding risk compensation were responsible for lower willingness to prescribe PrEP to Black patients in particular. These findings are consistent with other research suggesting that implicit bias leads to systematic discrimination and health care inequality in HIV treatment [59,60]. To the extent that providers believe erroneous stereotypes suggesting greater sexual risk taking among men of color [61,62] a focus on risk compensation could significantly negatively impact access to PrEP and exacerbate existing disparities.

And third, risk compensation arguments bend the focus of PrEP conversations back toward threat and fear. One of the most revolutionary aspects of PrEP as an HIV prevention strategy is its ability to reduce HIV-related anxiety in its users [63]. Efforts to reduce both PrEP- and HIV-related stigma at the community level have recognized the importance of prevention messages that emphasize sexual health, agency, and intimacy [38,]. But such efforts are undermined to the extent that providers, policy makers, and researchers emphasize concerns that PrEP will result in more sex or more condomless sex among its users. This emphasis may exacerbate concerns about PrEP's actual efficacy and recapitulates messages that try to motivate condom use through fear. It is well established that fear is an ineffective motivator of health behavior [64–66], but perhaps more important, data indicate that fear-arousing public health campaigns are disproportionately damaging for individuals who lack psychological and social resources [67]. The development of new and innovative strategies to control rising STI rates are critical, but relying on risk compensation arguments to scare patients and providers perpetuates PrEP stigma and is unlikely to positively impact sexual health behavior.

Conclusion: Alternative Approaches to Mitigate Stigma

Above, this paper has argued that PrEP stigma is, at its core, sexual stigma, i.e., a conscious or unconscious discomfort with the idea of sexual expression unfettered by the threat of HIV infection. PrEP stigma significantly impedes PrEP acceptability, uptake, adherence, and persistence, by creating barriers to acceptance at the patient-, provider-, and community-levels. This paper has identified three aspects of PrEP programs, policy, and research that exacerbate and perpetuate PrEP stigma: language suggesting that PrEP is only for those at "very high risk" of infection; PrEP eligibility assessments that provide mixed messages about the definition of "high risk" behavior; and a focus on risk compensation as a critical element of PrEP efficacy.

However, there are several key actions that can be taken by the public health community to shift the focus away from PrEP stigma and mitigate its negative effects. First, we can change the narrative about who and what PrEP is "for." Instead of perpetuating the message that PrEP is "for people at very high risk for infection," perhaps PrEP guidelines could emphasize that PrEP is "for people who want to reduce their anxiety about HIV infection and take greater responsibility for their sexual health." Individuals may be more willing to recognize or admit that they have anxiety about HIV infection than they are able to

recognize or admit that they are at risk. Wanting to reduce anxiety about HIV is not stigmatizing and does not necessarily imply that individuals are engaging in socially undesirable behavior. Focusing on PrEP as a strategy for taking greater responsibility for sexual health construes PrEP as a socially desirable behavior, and may even promote condom use by promoting what has been termed a "preventionist identity" [16, 68]. Allowing individuals to identify themselves as potential PrEP users because they want to feel better and stay healthy may increase acceptability and interest while creating a positive social association. It is possible that this type of description would increase the number of individuals interested in PrEP and could result in an influx of PrEP requests from the "worried well." However, given the number of individuals identified by the CDC as benefiting from PrEP [69], the benefits of this strategy are likely to outweigh the costs.

Second (and relatedly), we can replace traditional risk assessment with questions that emphasize patients' sexual health concerns and sexual health goals. Asking patients about their own HIV and STI concerns (e.g., "What are your concerns about your sexual health? Tell me about how much you worry about HIV or other STIs and why") makes it more likely that providers will learn about patients' true behavior, attitudes, and risk perception. It is also possible that patients have other sexual health concerns (pain, difficulties with sexual functioning) that are not identified by traditional risk assessment. Asking patients about their sexual health goals (e.g., "What's your ideal for your own sexual health? What would you need to improve your sexual health?") helps patients feel that providers are trying to give them what they need rather than evaluate and judge. This type of assessment is also more likely to identify individuals who need PrEP because of future or anticipated behavior, even if they have not engaged in risk behavior in the past six months. Consider a young man who has recently moved to a big city from a rural area and just downloaded Grindr on his phone. This patient might screen ineligible for PrEP based on a traditional *retrospective* risk assessment tool, when a brief conversation about HIV-related concerns would suggest that PrEP is highly indicated.

Such an assessment strategy could work both for patients actively seeking PrEP, but also for those who may not even be aware that PrEP exists. Patients' statements about their concern or lack of concern about HIV can result in critical teachable moments, in which a provider directly addresses the patient's behavior and knowledge, rather that their risk-score. For example, a patient might say: "I'm not at risk for HIV because I don't sleep around, but I'm anxious about HIV because I know a lot of women in my neighborhood who are HIV-positive." This patient may not have been identified as high-risk in an eligibility assessment (perhaps she has sex only with her boyfriend of seven months), but this one-sentence answer about her own perspective and experience allows the provider to raise PrEP with her, provide education about the risks associated with community-level prevalence, and better evaluate whether PrEP would be an appropriate prevention choice.

It is true that this type of assessment requires a sexual health conversation that is likely to take more time than a "flag" in a medical record or a four to six question risk assessment, and there are legitimate constraints on provider time within a clinical encounter. But arguing that we are unable to provide higher quality, de-stigmatizing, affirming, and more effective care because we simply don't have the time seems like a prototypical case of the tail

wagging the dog. Promoting sexual health and significantly reducing (if not eliminating) new HIV infections requires creative and innovative solutions.

Finally, we need to replace our preoccupation with risk compensation with a passion for sexual health. Several authors have argued for learning from past experiences with oral contraceptives to guide PrEP implementation, and perhaps HIV prevention would do well to adapt language from the American College of Obstetricians and Gynecologists (ACOG) guidance on planning to prevent unintended pregnancy, which describes an reproductive life plan as “a set of personal goals regarding whether, when, and how to have children based on individual priorities, resources, and values” [70]. An adapted statement might read: “A sexual health plan is a set of personal goals regarding how to engage in fulfilling sexual expression while preventing HIV infection and other sexually transmitted diseases based on individual priorities, resources, and values.” Framing PrEP as part of a person’s sexual health plan is empowering, de-stigmatizing, and motivating. It acknowledges that PrEP is not the only option for HIV prevention, it emphasizes choosing strategies that prevent both HIV and other STIs, and it legitimizes sexual fulfillment as a core component of sexual health. We have spent the past thirty years stigmatizing sexual behavior, but in the past decade have seen stagnation and/or increases in STI and HIV infection rates, especially among most vulnerable populations. We are now seeing the ways in which this stigma can impede progress on a promising new avenue for prevention. Only by addressing and reducing PrEP stigma will we be able to improve access, utilization, and equitable distribution that will have a truly sustained impact on the epidemic.

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