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**“Malicious Medicine”:
A Qualitative Study of Medical Mistrust and PrEP Perceptions for
African American and Hispanic Men and Women in New Haven, CT**

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Abstract

Objective: To understand how medical mistrust impacts perceptions of PrEP and willingness to use PrEP for African American and Hispanic men and women in New Haven, Connecticut.

Methods: This qualitative study utilized semi-structured interviews to examine medical mistrust, PrEP awareness, and willingness to use PrEP amongst African American and Hispanic men and women in New Haven, Connecticut.

Results: The majority of participants did not know about PrEP before their first interview of this study and the majority of participants did not decide to use PrEP over the course of this study. For those who are not interested in using PrEP, 3 common concerns accompanied their unwillingness to use PrEP, including: 1) concerns about PrEP as a medication, 2) need for improved provider care and knowledge; and 3) perceptions of patient prioritization based on past experiences. For those who did choose to use PrEP or who had partners who chose to use PrEP during the course of the study, perceived risk of HIV and a source of education about the benefit of PrEP outside of the medical establishment were common denominators. Discussions of perceptions of PrEP and participant willingness to use PrEP revealed how medical mistrust impacts perceptions of PrEP and willingness to engage with what is seen as an unnecessary preventative medication.

Implications: Medical mistrust impacts perceptions of PrEP and willingness to engage in HIV preventative measures such as PrEP. As a result, medical mistrust is a significant barrier to willingness to engage in HIV prevention measures using PrEP because it is not trusted. For those that do choose to utilize PrEP or have a partner that does, it is clear that sources of information alternative to traditional healthcare venues can educate about PrEP in a relatable and trustworthy way. Additionally, it is clear that provider education about PrEP is necessary for those patients that do choose to interact with medical systems to obtain PrEP, despite their mistrust.

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Introduction

An extensive body of literature has established that medical mistrust inhibits willingness to engage with the medical system, as well as to follow provider recommendations. Medical mistrust has been defined as a distrust of medical practitioners and organizations (Omodei & McLennan, 2000; Williamson & Bigman, 2018), and includes the tendency to not completely trust medical systems and health care providers perceived to represent the dominant culture (Bynum et al., 2012; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004; Boyas et al., 2018). Additionally, medical mistrust has been categorized as distrust of the medical system that results in a leeriness of the work and intentions of practitioners, identified to be self-preserving and derived from “a long history of race-based differential treatment, unequal dissemination of effective medical innovations, and other racist injustices within the medical establishment” (Tekeste et al., 2019). Medical mistrust has been linked to a multiple attitudes and actions of doctors, including perceptions that doctors are motivated by money, perception that doctors are unreceptive to patients’ self-diagnoses or patients’ expertise about their own bodies, and by perceptions that doctors are actually the root cause of events that have been extremely harmful to communities do color such as the opioid epidemic (Underhill, 2015).

Medical mistrust is particularly important to understand in the context of pre-exposure prophylaxis (PrEP) and HIV prevention, as it is often a barrier to interactions with the medical system for those who have experienced medical or institutional racism or homophobia, or who are simply aware of the generational mistreatment and discrimination that African American and Hispanic, as well as LGBTQ people have faced in the United States medical system to date (Cahill et al., 2017; Kalichman et al., 2016). Understanding and rectifying the institutional shortcomings that breed medical mistrust is particularly important as the largest number of new

cases of HIV annually occur among African American and Hispanic men who have sex with men (MSM) (CDC, 2020). It has also been well established by previous studies that pre-exposure prophylaxis (PrEP) is effective in preventing HIV when used as prescribed, yet it has not seen the uptake amongst African American and Hispanic men at risk of contracting HIV that it has seen for white men who have sex with men (MSM).

The United States medical system, primarily composed of white, male doctors has perpetrated intergenerational harm against people of color (Lee et al., 2018; Quinn et al., 2019). Doctors, healthcare systems, and the pharmaceutical companies make life or death decisions on a daily basis for their patients. Current experiences of medical mistrust are grounded in a reality that emerged from centuries of intentional decisions that impact who lives and who dies, who faces disability and who doesn't, and who receives treatment and who doesn't. When communities of color and LGBTQ people watch the healthcare system actively work against them, or even passively not work for them, it becomes extremely hard to discern who and what is worth trusting. This study builds on prior literature by expanding to include perceptions of diverse sexualities and genders within the same study. This research also expanded on current literature to include the perceptions of formerly incarcerated men and women whose unique experiences while incarcerated impact their views of institutions, including the medical system. It is important to identify and understand what factors contribute to medical mistrust, and how medical mistrust impacts willingness to engage in preventive medicine so that healthcare systems and providers can work to reach the patients most at risk for HIV.

Methods

Study Design and Sample

This research was conducted as part of the Justice, Housing, and Health Study (JustHouHS) study, a five-year longitudinal study funded by the National Institute of Mental Health, which focuses on examining mass incarceration, housing stability, and subsidized housing policies, which are three interrelated social determinants of HIV/ STIs, to determine how they interact to shape sexual health risk. One aim of this study is to understand, from the perspective of vulnerable populations, how mass incarceration, housing stability, and experience with subsidized housing policies intersect to impact HIV/ STI related sexual risks, and how these factors interact to produce racial disparities in these risks. This was all based on self-report. Recent release from prison was defined as one year from date of screening, based on self-reported approximate last release date and controlling charge. This information was confirmed to be approximately correct using publicly available sentencing data available on CT's judicial branch website. Qualitative interviews were conducted every six months with a subset of JustHouHS survey participants.

Recruitment Methods

Participants for this research were recruited from New Haven, Connecticut. All those eligible for this study were identified as either low income or as having recently been released from prison. Low income was defined as: being homeless; residing in a low-income census tract area (defined as more than 20% of residents living below the federal poverty level), receiving housing assistance, receiving SNAP benefits within the past year, or being on Medicaid. Participants were recruited using convenience sampling, but to avoid under or over sampling

certain groups, regular data review and assessments were conducted to match study participant demographics as accurately to New Haven area low income and formerly incarcerated residents as closely as possible (N=400). A subset of the quantitative population was chosen from the total quantitative population randomly based on those who indicated their interest in participating in the baseline quantitative survey. A total of 54 participants were selected, with 27 being part of the low-income group, and 27 being part of the group of participants having experienced some type of criminal justice involvement in the past year. Enrollment took place between December 2017 and June 2018.

In order to examine the relationship between medical mistrust and perceptions of PrEP for communities of color, all participants who identified as white were excluded for the purposes of this paper, as were all participants that did not mention PrEP or pharmaceutical based HIV prevention in a single one of what could be up to four interviews conducted with each participant. As a result, this study includes only 33 of the original 54 participants. Of the 33 participants included for purposes of this study, 24 (72.7%) identified as African-American, 9 (31%) identified as Mixed or Other race. The majority of those self-identified as Hispanic. 7 (21.2%) identified as female, and 26 (78.8%) of identified as male. The average baseline age of participants was 43 years old, with a range of 24 to 64 years old. 17 (51.5%) had been incarcerated in the past year at baseline, and 16 (48.5%) self-identified as low-income. 4 (12.1%) were HIV positive, and 29 (87.9%) were not HIV positive.

Data Collection

Interviews were conducted in a central office to the urban area, accessible by public transportation. This building was not directly associated with Yale University, or Yale's campus,

but it was located adjacent to the campus. Semi-structured qualitative interviews were conducted every 6 months with 54 participants enrolled in the qualitative arm. A baseline, follow up 1 (conducted ~6 months following BL), a follow up 2 (conducted ~6 months following FU1), and a follow up 3 (conducted ~6 months following FU2) interviews were all conducted with participants over the course of two years for a total of up to five interviews each. The majority of interviews were completed in-person, although occasionally an interview was conducted over the phone if it was not possible for a participant to visit the office (e.g. in the case of an out of town move). All participants received a \$50 gift for each interview that they participated in. There interviewers conducted all interviews, and the same interviewer interviewed each participant for all of the interviews conducted with that participant.

Data Analysis

Data were coded using NVivo 12. Data analysis began by indexing interviews for major topics of interest for the project with the 54 enrolled in the interviews. I conducted open coding on the data already coded under “HIV”, which was a child node to the parent node, “Health.” The child node “HIV” included all references to HIV, HIV prevention, or opinions and thoughts around the subject including experiences, perceptions or opinions of PrEP. From the HIV data, a search was conducted for the word “PrEP” to determine which participants discussed PrEP in their interviews. We also created longitudinal analytic memos for relevant participants on the subjects of medical mistrust, perceptions of HIV testing and PrEP, as well as HIV stigma. Longitudinal memos served as short analytic reports created about relevant participants to further explore themes surrounding PrEP and medical mistrust over the course of all interviews conducted with each participant. Qualitative matrices, which were created to provide information on a variety of relevant topics were used to determine relevant background information to

participant's experiences and perceptions surrounding their health, particularly their sexual health. An additional matrix was created to include relevant participant mentions of PrEP.

Results

Question: What are the social, structural, and institutional factors that shape medical mistrust in New Haven, Connecticut, and how does this impact willingness to use PrEP?

Three common themes emerged around medical mistrust and willingness to use PrEP in these interviews:

1. Concerns about PrEP as a medication;
2. Need for improved provider care and knowledge;
3. Perceived exploitation by a for-profit healthcare system

The results reflect the perceptions of African American and Hispanic residents of New Haven. Three main themes emerged when participants were asked about willingness to take PrEP as well as perceptions around PrEP. The majority of participants had not heard of PrEP prior to their baseline JustHouHS interview. Additionally, the majority of participants were not open to taking PrEP. The most common theme related to medical mistrust that contributed to participant unwillingness to take PrEP were concerns about PrEP as a medication, and general concerns surrounding PrEP as a fairly new medication meant to prevent a stigmatized disease. Additionally, another theme emerged through concerns around PrEP and HIV, indicating a need for improved provider care and knowledge as many participants discussed never having heard of PrEP, despite regular provider visits. Finally, many participants' perceptions of patient exploitation by a for-profit healthcare system contributed to willingness to use PrEP as a preventative measure against HIV. The majority of participants, whether or not they expressed

interest or willingness in potentially taking PrEP daily for HIV prevention did not begin to do so during the course of this study. Only three participants took PrEP over the course of this study, and their experiences were unique from those who did not take PrEP.

Concerns about PrEP as a medication

The majority of participants who were asked about PrEP had not heard of it prior to their first JustHouHS interview. However, both for those who had heard of PrEP as well as those who had heard of PrEP prior to their first interview, concerns surrounding PrEP as a medication abounded. Pharmaceutical preventative measures against HIV were seen as unnecessary at best and potentially extremely harmful, even hypothetically increasing HIV risk, at worst. When one participant, Jackson, is asked about PrEP in his second follow up interview, his first response is to question the side effects, particularly in relation to the relative newness of PrEP.

Shit. Do you think they even know? Probably not, right, 'cause it's kind of new?
[Jackson, male, 24]

The idea that even pharmaceutical companies or prescribers might not be aware of the full extent of potential side effects, especially in the early stages of prescribing was concerning to many participants, regardless of whether or not they had some prior knowledge of PrEP. Participants expressed a great deal of institution-based medical mistrust for pharmaceutical companies as well as the products that they create. In a follow up interview, Jackson brought up PrEP himself, without a prompting question. When he talked about PrEP in this follow up interview his perceptions imply that his distrust for the medication extended to distrust for those who create it.

Have you heard about that medication, the Truvada thing?...I heard people are getting HIV from it. Crazy. [Jackson, male, 24]

When Jackson conflated PrEP with other disease preventative methods, such as vaccines which may actually contain live viruses, his medical mistrust only increased. Participants value control over what goes into their body, and without explicit understanding of the potential impact of taking a pill, particularly a preventative, it is seen as unnecessary or even potentially harmful.

Cole is one participant who anticipated extremely negative likely side effects from taking PrEP when he learned about it. Cole was incarcerated in the past year prior to his first interview, and in his first interview he discussed being sexually active with multiple female partners he knew were sexually active with other men. When Cole was first asked if he was interested in taking PrEP in his first follow up interview, he turned the question back on his interviewer. He asked the interviewer if she has taken PrEP as a gauge for whether or not he should. When the interviewer replied that she hasn't ever taken PrEP, he acted almost resentful that she would ask him to try it.

Then don't try to get me to take that shit...It's all the side effects, my ears would be bleeding, eyes fall out, rolling down the street...What the fuck, dude? Is that gonna stop me from getting chlamydia or herpes? [Cole, male, 33]

Like other participants, Cole was very leery of potential side effects of a medication that is relatively new, and that he deemed unnecessary for himself. For Cole, the potential benefits of PrEP are outweighed completely by the potential risks to his body. He expressed not wanting to be negatively impacted by what he perceived could be a failed pharmaceutical experiment of a potentially malicious medicine.

Avery is one of the few participants who had heard of PrEP prior to his involvement in the JustHouHS Study. Despite having some prior knowledge of the medication, he was still extremely leery of how it could impact him and his body.

Oh yeah, I seen it, but I wouldn't be interested in doing that. Because why would I be interested in something that's to prevent HIV – like I feel that's probably gonna get me HIV. Who knows? I don't know how they ever experimented and tested with that. It's like a male birth control to HIV? No, I'm not trying. What if that does something to my body eventually – I think it's like taking an ibuprofen when you ain't even got a headache.
[Avery, male, 25]

Additionally, Avery viewed the preventative nature of PrEP as entirely unnecessary for him, and possibly even harmful. A drug that is purely for prevention is viewed as something that could cause bodily harm, particularly when participants doubt that there is a significant knowledge base surrounding the drug. Avery equated PrEP to a risky “male birth control” that could fail and result in HIV contraction.

Unknown and untested side effects made many participants extremely leery of taking a preventative medication for HIV, particularly if they did not view themselves as at high risk for HIV. When Chase is asked if he would be willing to take PrEP for HIV prevention, and focused on potentially detrimental side-effects.

Uh, I'm real sketchy depending on the side effects, because nowadays everything that you take...it's worse than the actual, like, what it's supposed to help you with. Like you'll see [referencing tv pharmaceutical ads talking about side effects]—and then they try to say it all fast but nobody really pays attention. Like, they got, like, um...uh, medication for, like, asthma, and they're like, 'side effects may, um, occur in bloody stools, and this, that and the third.' It's like, wait, what? So, any time I fart I'm gonna be bleeding and I may want to kill my wife but I won't cough as much. That's crazy... It's FDA-approved too, like that's insane. [Chase, male, 35]

Like Chase, many participants believed that taking PrEP may be more detrimental than beneficial to them based on what they perceived to be potentially life altering side effects that those who prescribe the medications as well as pharmaceutical companies are far from transparent about. These participants perceived their potential HIV risk as less than the potential risk of taking a preventative medication.

Need for improved provider care and knowledge

For participants already mistrustful of systems and institutions, primary care providers that cause confusion and unnecessary concern only exacerbate participant medical mistrust. Multiple participants indicated a strong need for improved provider care and knowledge in order for PrEP utilization rates to increase. Providers that use fearmongering tactics to educate about HIV prevention, providers that are not knowledgeable about PrEP, and providers that do not offer PrEP to patients that would benefit from it all contribute to low PrEP uptake levels.

Overexaggerating how easy it is to get HIV can be extremely detrimental to participants. This is particularly true because a belief in the efficacy of preventative healthcare methods is vital to believing that PrEP has the capacity to effectively prevent HIV. If patients do not believe that HIV is something that can be prevented by PrEP, they will be extremely unlikely to ever take PrEP for HIV prevention. Even when participants received (arguably) accurate medical information that they trust, participants reported having providers that used fear mongering. This generated a feeling of skepticism that served as a barrier to medical system trust, obstructing participants' willingness to trust medical knowledge in general. One participant, Elijah, believed that he had an adequate understanding of HIV transmission prior to receiving more minute detail from one provider.

When I came home [from prison], when I took— when I first took my [HIV] test, the lady told me, she said, 'There's so many ways that you can catch it now.' That it's now – it's not just, you know, the intercourse. It's just, if you get a cut. Today, it could be anything. And I'm like, 'So, what, did it change?' Because before, I thought it was just, um, if you had sex, unprotected sex or if you had a cut and if somebody else had a cut and...Now they saying it's saliva. They say you can get.... if you got chapped lips and you're smoking with somebody, you're smoking a cigarette. [Elijah, male, 41]

While the information that Elijah was given is technically factual, it is extremely odd that a responsible provider would emphasize what his provider did, as the level of transmission she described occurs extremely rarely (if at all). This fear mongering made this participant doubt his prior knowledge of HIV and instilled a new fixation on novel possibilities that could result in him contracting the virus. Following this encounter with a primary care provider, Elijah felt that, when it comes to HIV, it is nearly impossible to engage in seemingly benign behaviors without a small risk that something extraordinary could happen. When HIV is portrayed as something sinister, it is difficult for participants, like Elijah, to imagine that a preventative drug such as PrEP has the capacity to prevent HIV with any reasonable level of certainty.

In addition to encountering fear tactics in their interactions with providers, some participants noted that providers seemed to be uneducated about PrEP, what it does, and how it works, which also impeded participants' willingness and ability to engage in PrEP. Bently is one participant who prioritized his own HIV prevention and was on PrEP at his first interview. He hasn't experienced any side effects and felt that PrEP was working well for him. However, as someone who was unstably housed and did not have a consistent primary care provider, he found himself using PrEP on and off while he worked to get this prescription refilled. Having to renew PrEP prescriptions with a variety of different providers forced Bently to experience how multiple different providers interact around PrEP. Unfortunately, he described often having to educate providers on what PrEP is and why he wanted to be prescribed it.

A lot of people don't even know what PrEP is, like, I swear to God, at least half the doctors that I've seen, they are, like, 'you're out of PrEP—what? I don't know what that is'...And then I gotta explain it for 20 minutes and it's annoying. Seriously...Yeah, you'd think they would. They don't. They have no idea. [Bently, male, 27]

When primary care providers were not knowledgeable about PrEP and patients such as Bently needed to educate their own physicians, it did not inspire confidence that these doctors understood the medication or knew how it might impact their patients. When patients had to educate their providers, they lost the belief that their providers are knowledgeable and worthy of their trust. This is particularly harmful for patients who would be ideal candidates for PrEP, but had providers entirely unaware of PrEP. Provider ignorance should not impede PrEP uptake for those who would most benefit from it, particularly for those who have identified the benefits of PrEP for themselves on their own.

Another dimension of patient/provider relationships that impacted PrEP uptake and medical mistrust was the failure of health care providers in institutionalized settings to offer PrEP to their patients. For formerly incarcerated participants in particular, providers in prison are seen as equally a part of medical institutions as health care professionals outside of prison. For formerly incarcerated participants, a failing on the part of prison primary care providers is a failing representative of the healthcare system in general. Multiple participants who had been formerly incarcerated expressed that PrEP is not something offered in prisons, despite prison populations being particularly at risk for contracting HIV. Carlos is one participant who could not understand why the health care providers in prison did not educate prisoners about PrEP and work to increase HIV prevention methods available in prison.

The first time I ever heard of it is from you guys. They don't even talk – that's something they should talk about in jail. They should let people know about that...'Cause there's a lot of people in jail with AIDS – HIV, AIDS, one or the other. [Carlos, male, 30]

Carlos also could not understand why information about a medication to prevent HIV would not be readily available to all who could benefit from it. This made him question the integrity of health care providers that serve prisoners, which contributed to his general institutional mistrust.

Isaiah is another participant who believed providers should offer PrEP to their patients, particularly to patients in the homeless community.

I think that they could advertise it more in a homeless community, you understand, because I had to go to them in reference to PrEP. They didn't come to me...like I said, I shouldn't have had to go to them in reference to that. And they knew that I was a gay man, so... They could have asked me...You know, so stuff like that makes you think. [Isaiah, male, 46]

Isaiah lamented the lack of advertisement for PrEP in the homeless community, because he believes many in the community he once belonged to could benefit from PrEP. Additionally, he feels resentful and mistrustful that as an openly gay man, no provider of his ever offered him PrEP.

When participants begin to feel that community providers have caused and continue to cause more harm than healing, it can be difficult to trust medications and the providers involved in distributing them, particularly in a community with a sub-culture surrounding pharmaceuticals sold outside the confines of traditional pathways to obtaining medications. Jackson is one participant who has heard of the existence of counterfeit PrEP in the same context as other counterfeit goods and drugs that are sold outside the confines of medical institutions.

It could be a counterfeit PrEP that's giving people stuff [like HIV], 'cause there's a lot of counterfeit medications. Think about it. How the hell do you have Fentanyl in drugs?...Everybody's talking about it online. Plus, even doctors are talking about it...It's like Fentanyl. How the hell did Fentanyl get into heroin and, like, weed and stuff? Where do you get Fentanyl from? You get it from a pharmacy or you get it from a hospital. How is Fentanyl coming onto the streets like in large bulks like that? There's only a couple ways. The nurse want—the nurses want to make money. It could be nurses simply stealing it from the thing. There's nurses that do that all the time. Or the nurse could be fucking with somebody on the streets or whatever and doing it for, you know, money, staying, sex with him. There's a lot of different ways stuff, you know, goes apart. But I feel like sometimes the truth is just—it's in front of our face. [Jackson, male, 24]

Medications used for prevention are often seen as particularly worthy of mistrust, as medical providers often intentionally emphasize that prevention methods such as PrEP are not infallible. Consequently, prevention methods can be conflated with an increased susceptibility to a disease or virus. Jackson's medical mistrust has left him vulnerable to information that, while medically inaccurate, seemed plausible based on what he has heard about PrEP and other pharmaceuticals. In a system built to prioritize profit over patient care, it can be difficult to trust provider intentions or even medication legitimacy. Conspiracy and rumors about one medication or drug can easily be conflated with those of others, creating ideas that corporate medical institutions and those that work in them do not have the best of intentions, and that they do not prioritize their patients.

Perceived exploitation by a for-profit healthcare system

Participants leery of taking PrEP often discussed instances of perceived patient exploitation occurring at the hands of a health care system believed to prioritize profits over patient health and well-being. When participants believed that healthcare institutions did not have their best interests in mind, medical mistrust and unwillingness to engage in preventive medicine was exacerbated. A research institution dominates the small urban area in which this study took place, and has a complicated relationship with the small urban area and its community members. As in many small cities home to large research institutions, the cities' most disadvantaged have been enlisted in countless research studies. As a result, trusting the same institutions that have perpetrated harm to also provide healing in the form of medical care can be difficult. Research studies, and their potential harm are well known here. The majority of low-income people, particularly amongst communities of color, in this small city have either

participated in research studies, or know someone who has. These studies included pharmaceutical trials of drugs with unknown side effects that could have had unknown life-long effects. Some participants referenced these experiences with pharmaceutical drug trials when asked about PrEP. Cole is one of multiple participants that equated PrEP research studies with harmful side effects for low income and vulnerable people.

There's the people right here down at, um, on the Green, the lab, the people that they test out here. Right there...Yeah, that's what they did for PrEP...[Laughs] Yeah, it was done at Pfizer for Yale and now they're out here on the Green looking crazy from the side effects. [Laughter]...From them Yale studies. [Laughs] Nah. [Cole, male, 33]

To Cole it is clear that those around him have been exploited for the gain of the institution that dominates his city, which makes trusting a preventative medication coming from a health institution known to have its own agenda difficult. When an institution clearly holds its self-interest paramount it makes genuine attempts to encourage patients to engage in pharmaceutical-based preventative health care seem disingenuous.

Furthermore, for participants, it has seemed obvious in these for-profit institutions that there might be more knowledge and medicine available for those that can pay for it, or those privy to the intimate workings of medical institutions, which Cole perceived his Yale-affiliated interviewer to be. When the interviewer inadvertently blinked before she asked Cole about his opinions surrounding HIV, he questions whether she might have been granted access to information ordinary community members would not be privy to.

Why'd you close your eyes when you said that?...Why, you know a secret or something? [Laughs]...You close your eyes; what you heard about it [HIV]? [Laughter] What, you got the cure, I'm sayin? [Laughs]...Do you work at Yale? [Laughs] You know somebody that knows somebody. [Laughs] [Cole, male, 33]

When the interviewer assured him that she has not received access to a cure, he continued to push because he associates the institution that she works for as having access to health care, including preventative medicine and cures unavailable to everyone. Many participants such as Cole perceived a stark contrast between those “in the know” at a giant, powerful research institution, and average community members. Participants such as Cole understand the nuances of the relationship between the average members of his community and the powerful and wealthy medical research institution that is part of the fabric that created modern medicine and influenced modern research practices. Cole equated institutional power with knowledge he perceives as inaccessible to him. Cole does not believe that institutions actively help those that they treat to the full extent of their capabilities, because he believes that medical institutions have the capacity to do more than they have done for the low-income communities of color in the institution’s backyard.

For another participant, having family in the healthcare field has impacted his perceptions of the medical system and its integrity. Johnny’s wife’s family member worked at a hospital and witnessed a fellow employee breaking hospital rules at the expense of their patients.

[Wife’s] family member worked in a hospital. Out of jealousy, she went and told and made some false accusations and I brought that to the doctor. She [the doctor] said, ‘You know what? They just fired somebody for looking at somebody else’s files when they shouldn’t’ve have been.’ ...She was working at the same medical clinic that I attend now, but this was years ago. But out of jealousy, you never know what people will say...But she said, ‘You know what, Johnny? You raised a valid point. They just got rid of somebody for doing the exact same thing. [Whispers] Like come here, look.’ So, one lady, her son died. Somebody took pictures of him at the autopsy and posted them on Facebook...So now they’re suing the hospital. [Johnny, 46, male]

Johnny no longer trusts institutions as a whole because he does not trust the individual people that work within these systems. Participants question whether institutions are only as trustworthy as their least trustworthy employee. Health is extremely valued and lost or damaged health may

be irreversible. When government institutions have the power to positively impact health but choose not to do so, they are causing harm.

Participants who chose to use PrEP

The experiences of participants who have chosen to use PrEP can provide insight into ways that participants navigate varying levels and types of medical mistrust. All participants who have chosen to go on PrEP at some point during the study were either men who have sex with men (MSM) or people who have a long-term partner that is HIV positive. Other participants who are HIV positive have had partners who use PrEP to protect themselves. The largest group of people who use PrEP or have partners on PrEP do so because one partner in their dyad has been diagnosed as HIV positive. Tyler is one participant who has been diagnosed as HIV positive and wants to be absolutely sure that his partner is protected against HIV.

Yeah, listen, if I'm gonna have sex with you, I'm gonna tell you that I'm HIV positive. Now it's on you, you know what I mean? I'll protect myself. We'll do everything possible to protect ourselves to have sex. Okay, you're protected, but you gotta be careful, because sometimes rubbers break. These things happen, all that. That's why it's good for your partner to take the pill, just in case something like that happens. She's got backup, and that's what I do with [current partner]. [Tyler, male, 50]

Tyler views PrEP as a preventative measure that is necessary for his partner because he is HIV positive and does not want his partner to get HIV.

For two men who both identify as MSM, medical mistrust was satisfactorily addressed enough to enable them to take PrEP because they received positive messages surrounding PrEP from social sources outside the realm of medical institutions. One participant, Isaiah, recounted originally seeing PrEP in the context of an MSM dating site which positively influenced his

decision to go on PrEP, despite not always trusting his provider or the medical system to work for the betterment and maintenance of his health.

I had actually heard about PrEP. I was on a dating site and I kept seeing – it kept saying PrEP user... So, these individuals were actually saying or telling you... 'I'm on PrEP'... And that made me think about it. I said, 'Well, let me ask my – ' 'cause they – Cornell Scott [Community Health Center] never mentioned PrEP to me, [laughs] so I said, 'I'll mention it to them.' ... And when I mentioned it to them, they said, 'okay,' and they gave it to me, but the requirement is that every three months you get your HIV test. I said, 'I don't have a problem with that... That's even better.' [Isaiah, male, 46]

Isaiah discussed the trust he gained in PrEP's capability to prevent against HIV when he heard about its efficacy from peers. When he heard about the benefits of PrEP from people actually using it, Isaiah was inspired to request it from his primary care provider. Isaiah's chose to use PrEP is despite his medical mistrust. His baseline level of medical mistrust was accompanied by an anger that he was forced to be his own advocate to his primary care provider, despite clear indications that he might have been a good candidate for PrEP. Isaiah felt frustrated that he had previously disclosed to his provider that he was sexually active with men, yet he had to tell his provider that he wanted to be on PrEP. His provider had never mentioned PrEP to him. Isaiah also recounted other experiences that made him mistrust his provider and turn him into his own fiercest advocate. Isaiah realized that he must advocate for himself staunchly to his provider, even when his healthcare provider does not want to listen to him.

Discussion

Participants highlight three main reasons for their medical mistrust surrounding PrEP, which often negatively impacts their willingness to use the drug. Many participants emphasize concerns about PrEP as a medication, the need for improved provider care and knowledge, and perceived exploitation by a for-profit healthcare system as the main contributors to their medical

mistrust, which impacts willingness to engage with PrEP. Medical mistrust surrounding medications is justified by participants because it is common knowledge that different medications can have extremely negative side effects. Participants may have experienced extreme side effects firsthand, learned about them from others, or they may equate previously unbeneficial medication treatment courses to PrEP. When a medication is new, it is seen as particularly potentially harmful, as there is a long history of medications approved as safe having extreme adverse effects shortly after many people begin to use them.

When it is clear that community members are suffering from research gone wrong, it impacts the capacity to trust the same institutions to take the health and wellness of all community members equally seriously. Trusting medical providers is difficult enough after generations of research that was often harmful to patients involved. Knowledge that similar research continues today, often by medical research institutions on the very same vulnerable community members that they serve does not bolster community institutional trust. Questioning whether or not a doctor really has their patients, particularly their black and brown patients' or sexual and gender minority patients', best interests at the forefront of their decision making results in patients questioning the medical advice that they receive, which results in them seriously entertaining the possibility of negative consequences of the cures and preventative services offered by these institutions.

Our analysis suggests that it is a mistake to attempt to promote safer sex in a way that makes individuals doubt their own knowledge and understanding of how HIV is transmitted. Instead, providers should educate their patients about HIV preventative measures such as PrEP. Furthermore, patients should not have to serve as their own advocates in order to begin a PrEP prescription for HIV prevention. Primary care providers, particularly those that work with

populations particularly vulnerable to HIV, should have a strong understanding of PrEP and feel comfortable prescribing it to any of their patients.

Additional research is needed to determine how institutional medical racism and homophobia can be combated to ensure that those who would benefit from PrEP are not deterred by medical mistrust that may have led to an unwillingness to continue to engage with a healthcare system that they perceive to be more harmful than helpful. Since medical institutions operate within a capitalistic, for-profit medical industrial complex, it is often difficult for lower income or already stigmatized individuals to receive the healthcare or medication that they need directly from the sources available to those with money or power. Institutions that deliver healthcare as well as current infrastructure used to address and treat disease rely on their reputations to engage with patients and offer advice that is seen as trustworthy. However, when institutions run by the same government are seen not to work for people of color time and time again, they lose their credibility. When people begin to feel that they live in a state in which governmental institutions do not value human life, they begin to question whether all medicine isn't made to be malicious for those most vulnerable to disease.

Additionally, when institutions that are seen as responsible and make catastrophic mistakes that negatively impact a specific group of people substantially more than others, this can have a huge impact on how they are perceived. This impacts the ability of these organizations to successfully serve as healthcare and health practice authorities. When institutions fail to take precautions to protect their patients, they lose patient faith, regardless of whether those failures are seen as negligent or malicious. However, when institutions are maliciously irresponsible, they decrease patient trust further.

Clinical Implications

Our data suggest that all physicians, particularly physicians involved in primary care in any capacity should be thoroughly educated about PrEP as an effective form of HIV prevention. No one should have their institutional mistrust amplified by ignorant providers. Additionally, providers should be trained to understand that PrEP does not increase promiscuity. Providers should be trained to describe and offer PrEP to all of their patients without stigmatizing it as a preventative measure meant only for certain “at-risk” populations to increase PrEP uptake. Additionally, peer education programs would be extremely beneficial for those at risk of contracting HIV who have disengaged from medical institutions and primary care due to chronic medical mistrust and the tiresome nature of having to constantly navigate institutional racism and homophobia.

Implications for public health policy

It is not enough to simply make PrEP available to Medicare and Medicaid receipts, as it has been in the state of Connecticut. It is vital that programs be created to provide PrEP, and all necessary appointments and HIV tests to maintain a PrEP prescription to all. Providing these services free of charge to all, regardless of citizenship status in the United States, as other countries have done, would increase institutional trust and allow some who are currently unable to engage with the healthcare system as they should be to do so.

Limitations

Important limitations of this study must be acknowledged. First, the number of participants interviewed for this study represent a small sample of New Haven, Connecticut. Additionally, PrEP was not intentionally a main focus of the interviews conducted. The fact that

not every participant was asked or spoke about PrEP in their interviews may have impacted what opinions of PrEP were sampled. Questions related to PrEP may have been primarily asked to participants that the interviewers perceived to be at higher risk for HIV or with who HIV came up easily in the course of the interview, which may have impacted the findings in this paper. Additionally, as this is a qualitative study, these findings cannot be extrapolated to represent the beliefs and perceptions of the entire communities sampled.

Conclusions

Understanding PrEP perceptions, stigma surrounding HIV and PrEP, and the origins and manifestations of medical mistrust in various forms is crucial to understanding why some are willing to try (and trust) PrEP and others are not. Historically, institutions have perpetrated large-scale injustices against people of color under the guise of advancing research. It is no surprise that institutional-based medical mistrust continues to be a massive barrier to engaging people of color in healthcare, particularly preventative health care that involves pharmaceuticals. Increased institutional accountability is paramount. PrEP is a valuable tool that can be leveraged as the United States works toward its goal of eliminating HIV.

However, it is not enough to simply offer PrEP for HIV prevention. It is not even enough to offer PrEP free of charge. Instead, it is vital that PrEP is offered in conjunction with adequate sexual health education. PrEP must be clearly differentiated from disease-causing agents. All primary care providers should be well educated about PrEP, and PrEP should be offered, without judgement, to all patients. No one should get HIV because their provider was not knowledgeable about HIV. Additionally, fear-based HIV prevention campaigns should be a thing of the past.

Further research is needed to determine how primary care providers can work to overcome generations of medical mistrust to better serve their African American and Hispanic patients.

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