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#### **Research Article**

# Why are More Men Who have Sex with Men not Using Prep? The Role Played by Lack of Awareness

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#### Abstract

Purpose: Despite being at the cornerstone of current initiatives to curtail the spread of HIV, Pre-Exposure Prophylaxis (PrEP) medication has been slow to proliferate among many "at risk" populations. This is true for men who have sex with other men (MSM), who account for the largest number of new HIV diagnoses in the United States. The present paper examines the role that lack of awareness of PrEP and lack of exposure to other PrEP users play regarding why more MSM are not using PrEP.

Methods: Purposive sampling was used to derive a sample of 273 diverse MSM. Men completed a brief questionnaire inquiring about their awareness of PrEP, willingness to avail themselves of various sources of information about PrEP, perceptions about PrEP-related stigma, and perceptions about obstacles to PrEP use. Odds ratios were computed to compare demographic subgroups of men with respect to their familiarity with PrEP and other PrEP uses.

**Results:** 70% of the participants had never heard about PrEP prior to taking part in this study, and many of the men who had heard of it did not have an accurate understanding of what PrEP is. PrEP awareness was significantly lower among: men of color, those who were not married or "involved" with someone, HIV-negative men, those under the age of 40, and those with a lower level of education.

Conclusions: Lack of awareness about PrEP is one of the main reasons why more MSM are not using PrEP, as is lack of exposure to known PrEP users. The subgroups of men who need to know about PrEP the most (based on known HIV risk behavior profiles) are the ones who, in actuality, are the least familiar with PrEP.

#### **INTRODUCTION**

Pre-exposure prophylaxis (PrEP) medications have been approved by the Food and Drug Administration to help curtail the spread of HIV for nearly a decade now, and they have been shown to be highly effective at reducing the risk of HIV infection. Current estimates suggest that regular, proper adherence to a PrEP medication regimen can reduce the risk of contracting HIV by approximately 86-93% [1,2,3]. Such high rates of success have led the National Institutes of Health and the CDC to promote the adoption of PrEP medications as a key strategy in the ongoing effort to combat the spread of HIV, particularly among men who have sex with men (MSM). This group represents the single largest category of persons contracting HIV in the United States [4].

Despite efforts to promote PrEP, evidence from the scientific community suggests that, among MSM, particularly minority MSM, both awareness and understanding of PrEP medications are low, as is actual adoption of PrEP. To date, fewer than 250,000 Americans have ever used PrEP, representing less than 15% of the persons recommended by the CDC to be regular PrEP users [5,6]. One recent study of 995 gay and bisexual men [6] found that more than one-half of the men who met the CDC's criteria for being considered "PrEP eligible" failed to reach even the contemplation stage of PrEP adoption. Research conducted with 400 MSM in San Francisco [8] revealed that 64% of the men were considered

PrEP-eligible based on the CDC criteria, but only 23% of the PrEPeligible Caucasians and fewer than 5% of the men of color actually used PrEP. In their study of 264 African American and Caucasian MSM, [9] reported awareness of PrEP to be 61%, but actual usage rates of only 9%. In a different study of 1,264 African American MSM attending black gay pride events, [10] found awareness of PrEP to be 39% with actual use being less than 5%. In a study of 224 lower socioeconomic African American MSM, [19] reported awareness of PrEP to be 33% with not a single study participant actually using these medications. Another, larger national study of 6,483 MSM reported that 60.8% of the men surveyed said that they would be willing to use PrEP, but that only 3.7% had actually done so [11], with Caucasians being twice as likely as African Americans to report PrEP use. A Baltimore-based study of 399 African American MSM [12] reported an 11% awareness figure for PrEP and a 0% usage rate. A small-scale study conducted with 20 Latino MSM couples [13] found that awareness of PrEP was only 8%. Recent data from the CDC suggest that African Americans and Latinos account for 69% of all newly-diagnosed cases of HIV yet men from these same "at risk" populations comprise a mere 22% of all new prescriptions for PrEP [13]. Recent data from New York City indicates that men of color were half as likely as their Caucasian counterparts to be prescribed PrEP [15,16] found that 64% of the 184 young African American MSM in their study said that they were interested in adopting PrEP, but 46% of these men had not attended any PrEP adoption meetings, oftentimes

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despite repeated attempts on the part of project staff to get them scheduled. Some of the most promising findings regarding PrEP use were reported by one investigation into trends in PrEP use among MSM in San Francisco, which revealed that use of this medication increased dramatically during the period from 2014 to 2017, from 9.8% to 44.9% [17].

Preliminary evidence also has shown that, among MSM, there may be numerous barriers to adopting PrEP, including conspiracy-related beliefs [9], stigma perceptions associated with the use of PrEP [9,18], skepticism about taking a medication when one is not actually infected with a disease [19], concerns about the physical implications of taking an unknown medication over the long-term [19,20,21], language barriers in educating non-English-speaking MSM about PrEP and how/why to use it [13], attitudes in the population-at-large regarding making PrEP more readily available to MSM (particularly MSM of color) [22], misperceptions that using PrEP is linked with being HIV-positive [18], and concerns about affordability of PrEP medications [19,21,23,24].

Recently, a few studies have appeared in the scientific literature, addressing perceptions of barriers and obstacles to adopting PrEP. For example, [25] interviewed 254 MSM in the Boston area examined economic barriers to PrEP use (e.g., cost, insurance coverage), healthcare barriers to PrEP use (e.g., discussing PrEP with a personal physician), partnership barriers to PrEP use (e.g., fear of how one's partner would react to the prospect of commencing PrEP use), and individual barriers to PrEP use (e.g., perceived stigma), and determined that it was the partnership barriers that most affected men's decisions to use PrEP. As another example, [26] reported on a subsample of 37 mostly African American MSM from Harlem, New York, and found that concerns about partners' reactions to discovering their PrEP use were a driving factor underlying their decision-making process about using/not using PrEP. This study's participants also expressed concerns about friends' and family members' reactions to learning that one was a PrEP user, specifically noting the barrier that PrEP-related stigma perceptions would play in precluding many African American MSM from using PrEP. In their qualitative research with 100 MSM aged [19,20,24] found that Caucasians were much more suspect about adopting PrEP than men of color were. Additionally, the perception that PrEP is costly served as a barrier to its potential adoption, as did concerns about an inability to remember to take the medication on a daily basis and fears of developing a perception of being safer from HIV than one really was simply due to using PrEP. Research conducted with 20 PrEP-using and 19 PrEP-naive MSM in the Boston area [21] found that both groups of men expressed great interest in the prospect of PrEP as a way of avoiding the spread of HIV. Numerous concerns about PrEP were raised by these men as well, including stigma and discrimination linked by others with the use of PrEP, as well as issues pertaining to the mental health aspects of being a PrEP user.

Even with these published reports, more needs to be learned about the barriers to the adoption of PrEP. That is where the present paper comes into play. Here, the focus is on why it is that more MSM are not using PrEP and which subgroups of MSM (based on key demographic characteristics) are more/less PrEP- involved or PrEP-averse compared to others. The present paper specifically examines issues pertaining to awareness of PrEP and exposure to or familiarity with known PrEP users.

#### **METHODS**

#### Sample

A purposive sampling approach was used to derive the final research population for this study. By choosing this methodological approach, the principal goal was to assemble as diverse a sample of MSM as possible, thereby fostering the examination of different subgroups of MSM-for example, Caucasians versus African Americans versus Latinos, or younger men versus older menby virtue of each subgroup's representation in the final sample. Typically, it is this quality of purposive sampling that is cited as one of its main reasons for being selected [27-29], and it has been shown to yield results that are comparable to more-scientifically-sound methodological approaches [30].

For this study, which was conducted between November 2017 and June 2018, 273 men were recruited via four distinct vet strategically-chosen approaches: The first entailed approaching men participating in a few different social/activities/support groups for MSM and asking them to take part in the study. The second involved a research assistant asking men attending a local Gay Pride event if they would be willing to take part in the study. The third entailed posting a profile on one particular dating/sex site targeting MSM of all ages and racial/ethnic groups, logging onto that website, and sending a generic "hello" type of message to initiate a casual conversation with anyone who visited the profile while the researcher was logged on. The fourth approach consisted of asking participants enrolled into the study via any of the first three methods to speak with friends and acquaintances of theirs, to see if they could get some of them to take part in the study. The research protocol was approved by the institutional review board at California State University-Long Beach.

#### Procedures

After giving would-be participants the opportunity to ask questions about the study, informed consent was obtained before administering the questionnaire. The questionnaire took approximately 15 minutes to complete and no compensation was offered. The survey instrument consisted of a few brief sections. Basic demographic information was collected in one section. In another, familiarity with PrEP and other PrEP users was examined, as was their level of interest in obtaining additional information about PrEP. Participants were asked about their likelihood of availing themselves of various types of sources for obtaining additional information about PrEP. In the final section of the questionnaire, items comprising the PrEP Obstacles Scale (described below) and the PrEP Stigma Scale (described in a separate paper) were included. Participants who were given the opportunity to answer the questionnaire in the presence of the research assistant completed their survey manually and simply handed their completed answer sheet to that individual when they were done. Those who came to the project via contact referrals or from the dating/sex website were asked to email their completed answer sheet (or a photograph or scanned copy of their completed answer sheet) to a project-sponsored email

account. Participants were told that their identity would remain private, and that their answers and email addresses (used for returning completed answer sheets to the research team) would be kept confidential and would not be shared with anyone else. When they had submitted their completed answer sheet to the appropriate member of the research team, men were thanked for their time and participation, and then asked to contact other potentially-eligible and potentially-interested MSM they knew to help expand the sample. Respondents were not asked for their name, telephone number, email address, or any other personallyidentifying information, so that their participation could be as private and confidential as possible.

#### Measures

Demographic information collected in the questionnaire consisted of age (continuous), race/ethnicity (Caucasian, African American, Latino, Asian / Pacific Islander, Native American, or biracial / multiracial), relationship status (single, engaged or seriously involved with someone, married or involved in a longterm relationship), educational attainment (ordinal), sexual orientation (self-reported as gay, bisexual, or heterosexual), and HIV serostatus (self-reported as HIV-negative, HIV-positive, or serostatus unknown).

Knowledge of and Interest in PrEP consisted of items asking whether or not men had ever heard of PrEP prior to participating in this study (yes/no), whether or not they personally knew any PrEP users (yes/no), how accurate their understanding of PrEP was prior to participating in the study once they were given a project-provided explanation of what PrEP is (five-point ordinal measure, ranging from "not at all accurate" to "very accurate"), and how interested they were in learning more about PrEP (fivepoint ordinal measure, ranging from "not at all interested" to "very interested").

#### Analysis

The Statistical Analysis Software (SAS), version 9.3, was used to perform all analytical functions. The two main measures under study, *previously having heard about PrEP* and *already knowing someone who uses PrEP*, are dichotomous yes/no variables. For the sake of simplicity in understanding the data, to ensure adequate statistical power to undertake the intended analyses, and for analytical purposes, all of the demographic variables were recoded into dichotomous measures (e.g., single versus "involved," HIV-positive versus HIV-negative, and so forth). Odds ratios (*OR*) for bivariate comparisons were used as the primary analytical tool, with 95% confidence intervals (*CI*<sub>95</sub>) reported for each point estimate. Results are reported as statistically significant whenever *p*<.05.

# RESULTS

#### Sample

The purposive sampling approach yielded a diverse research sample, consisting of 273 men. The sample ranged in age from 18 to 72, with a mean age of 34.4 (SD = 13.1). Nearly one-half of the participants were aged 18 to 29 (48.7%), with another onequarter of them being aged 30-39 (23.4%) and the remainder (28.8%) being aged 40 or older. Slightly more than one-third of the participants were Caucasian (37.0%), with African Americans (27.1%) and Latinos (18.3%) comprising the two next-largest groups. The remaining 17.6% of the sample was comprised by Asians and Pacific Islanders (8.8%), Native Americans or Native Alaskans (1.5%), and men who self-identified as biracial or multiracial (7.3%). Most of the men self-identified as gay (69.6%) but there was excellent representation as well from bisexual men (16.1%) and MSM who self-identified as heterosexual (14.3%). The large majority of the participants (80.6%) said that they were single and not involved in a steady relationship with anyone, compared to 8.8% who said that they were seriously dating or engaged to someone and 10.6% who said that they were married. The large majority of the respondents (82.1%) said that they were HIV-negative at the time of interview. Approximately 1 out of 9 men (11.0%) said that he had not completed high school or earned a general equivalency diploma (G.E.D.). This compares to 37.0% who had graduated from high school or earned a G.E.D., 34.1% who had some college education without the completion of a bachelor's degree program, 8.4% who had completed college, and 9.5% who had earned either a master's degree or a doctorallevel degree.

#### **Familiarity with PrEP**

Fewer than one-third of the study participants (30.4%) said that they had heard of PrEP before taking part in this study. Among men who said that they had heard about PrEP prior to their involvement in the present study, nearly one-quarter (23.3%) said that their prior level of understanding of PrEP was "not at all accurate," "not very accurate," or only "somewhat accurate."

Prior familiarity with PrEP definitely was not equal across demographic groups. Caucasian men were significantly more likely than all others to say that they had heard of PrEP before participating in the present study (58.4% versus 14.0%; OR =8.66, *CI*<sub>95</sub> = 4.82–15.55, *p*<.0001). Conversely, African American men were much less likely than men of other racial groups to say that they had heard of PrEP prior to their involvement in the present study (16.2% versus 35.7%; OR = 0.35,  $CI_{95} = 0.18-0.69$ , p=.002). The same was true for Latino men when compared to men who were not Latino (8.0% versus 35.4%; OR = 0.16,  $CI_{95}$ = 0.06-0.46, p=.0001). Men who were single were, generally speaking, less likely than those who were married or involved in a relationship to say that they had heard about PrEP before taking part in the present study (27.7% versus 41.5%; OR = 0.54,  $CI_{q_5} = 0.29-1.01$ , p=.050). Men who self-identified as gay were somewhat more likely than their bisexual or heterosexual counterparts to report having heard about PrEP prior to their involvement in this study (33.7% versus 22.9%; OR = 1.72,  $CI_{os}$ = 0.94–3.10, *p*=.075). HIV-negative men were substantially less likely to have heard about PrEP than their peers who were HIVpositive or serostatus-unknown (19.2% versus 81.1%; OR = 0.05,  $CI_{05} = 0.02-0.12$ , p<.0001). Men aged 40 or older were much more likely to have heard about PrEP when compared to their counterparts aged 18 to 39 (79.0% versus 11.7%;  $OR = 28,37, CI_{os}$ = 14.06–57.26, *p*<.0001). Prior PrEP awareness was much less common among men with no more than a high school education than it was among their better-educated peers (12.2% versus 47.2%; OR = 0.16,  $CI_{95} = 0.08-0.29$ , p<.0001) and, conversely much more common among men who had graduated from college

when compared to their less-educated counterparts (57.1% versus 24.6%; OR = 4.10,  $CI_{95} = 2.16-7.79$ , *p*<.0001).

#### **Exposure to Actual PrEP Users**

Few of the men (24.9%) who participated in this study said that they knew at least one person who used PrEP. Caucasian men were far more likely to know at least one PrEP user than their nonwhite counterparts were (53.5% versus 8.1%; OR = 12.97, *CI*<sub>95</sub> = 6.62–25.39, *p*<.0001). HIV-negative men were much less likely to know any PrEP users than their HIV-positive or serostatus-unknown counterparts were (14.3% versus 73.5%; OR = 0.06,  $CI_{q_5} = 0.03 - 0.13$ , p < .0001). Men aged 40 or older were substantially more likely to know one or more PrEP users than their younger counterparts were (72.4% versus 6.6%; OR = 37.07, *CI*<sub>95</sub> = 17.43–78.82, *p*<.0001). Men who had no more than a high school education were much less likely to know any PrEP users than their better-educated counterparts were (9.9% versus 38.7%; OR = 0.17,  $CI_{05} = 0.09 - 0.34$ , p<.0001), whereas men who had at least graduated from college were significantly more likely than their less-well-educated peers to know a PrEP user (44.9% versus 20.5%; *OR* = 3.15, *CI*<sub>95</sub> = 1.65–6.04, *p*=.0004).

#### DISCUSSION

#### Limitation of the Study

Before discussing the implications of this research, the present authors would like to acknowledge a few limitations of this study: The findings presented in this paper are based on a research sample that was not derived via random sampling. Instead, the data were collected via a purposive sampling approach that was designed to maximize diversity within the target population, so that analyses could be performed with different subpopulations of MSM fostering comparisons of men based on their age, race, educational attainment, and so forth. The adoption of the purposive sampling approach accomplished this goal, while making it impossible to know the extent to which these findings may or may not be generalized to MSM in general. The present authors also acknowledge that, even with the diversity of the final sample, group sizes for many subpopulations (e.g., bisexuals, Latinos, and some others-Table 1) were not large, thereby limiting the researchers' ability to examine the impact of these measures/groups as carefully as the present authors would have liked.

Additionally, ideally, information would have been available as to the number of men who were recruited into the study by each of the recruitment methods. This information was not captured, however, and that precludes the present researchers from examining the potential impact that recruitment method might have had on the findings obtained in this study.

Finally, along the same line, as a small-scale pilot study, the present research did not include variables assessing various other factors that might have proven to be influential on men's awareness of PrEP. Key among these are extent of "outness" as gay or bisexual men, measures of family and/or social support systems, and extent of integration into or contact with the broader MSM community. Future studies focusing on the barriers to PrEP use would be well-advised to consider examining these (and other relevant) measures.

#### **CONCLUSIONS**

Despite the study limitations outlined above, the present authors believe that the results of this pilot study offer several insights into the issue of why more MSM have not been using PrEP. First, most of the respondents in this study had never heard of PrEP before they took part in it. Even among those who had heard of PrEP prior to participating in the present study, nearly one-quarter indicated that, prior to taking part in this research; they did not have a good understanding of what PrEP is. Simply put, men cannot be expected to consider adopting PrEP if they have never even heard of it or if, upon hearing about it, they do not have accurate information about what it is, how it works, who should consider taking it, and why they themselves might be excellent candidates for PrEP adoption. Considering the present study's findings, more work needs to be done to spread the word throughout the MSM community about PrEP if we want to see increases in the number of men using the medication. Some recent studies have undertaken this very task and seemingly met with some success [31].

Second, the present research discovered that men's familiarity with PrEP was extremely unequal among different key demographic groups. Analyses based on race, for example, revealed that Caucasians were far more likely to have heard about PrEP prior to participating in the present study than their African American and Latino counterparts. Considering that it is the latter two groups who comprise by far the largest numbers of people who have contracted HIV during recent years [32], this racial disparity in PrEP awareness is cause for great concern. Concerted efforts must be undertaken to reach out to minority communities of gay and bisexual men, as well as their "down low" counterparts, to inform them about PrEP if researchers and practitioners are to make inroads in the ongoing fight against HIV.

Additionally, men who said that they were not married or involved in any kind of marital-type relationship were much less likely than their married/"involved" counterparts to report having heard of PrEP prior to their involvement in the present study (27.7% versus 41.5%, respectively). For the most part, however, it is the men who are not involved in a relationship who are likely to be at greater risk for contracting HIV, because these are the men who are, presumably, dating and/or engaging in sexual activities with a number of partners.

Similarly, the present study discovered that participants who were HIV-positive were far more likely to have heard about PrEP than HIV-negative men were (81.1% versus 19.2%). While unmistakably, HIV-positive men can play a key role in the ongoing efforts to prevent new HIV infections, it is the HIV-negative men who have the most to lose by remaining unaware of PrEP and the advantages that PrEP could have for them. Various intervention and risk reduction initiatives that have enlisted the involvement of HIV-positive MSM to try to educate their sex partners about ways to stay safe from HIV have been shown to be successful [33,34]. This suggests that HIV-positive men, who currently appear to be more aware of PrEP than their uninfected peers are, could play an important part in future initiatives to promote PrEP. At the same time, practitioners need to develop creative public health campaigns to spread the word about PrEP throughout the MSM community, with special emphasis on how to reach currently-HIV-negative MSM.

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Also consistent with the preceding, the present research discovered that it is the older men-defined herein as being aged 40 or older-who were more likely to have heard of PrEP than their younger counterparts. Research has shown that younger MSM tend to have more sexual partners than older MSM do [35,36]. Therefore, the present study's findings have revealed that it is the men who are likely to have the largest number of sex partners-and therefore, the ones who are likely to be at the greatest risk for contracting HIV-who are the least likely to be aware of PrEP [37] also found that PrEP awareness was lower among the younger men in their study. A number of recent articles have examined age differences in various aspects of PrEP use, such as awareness of PrEP [37,38], willingness to adopt PrEP [39,40], with these studies generally finding age to be a relevant factor (although not consistent from study to study in terms of whether younger or older men are more/less willing to consider PrEP, more/less aware of it, and so forth). More work is needed to develop a better understanding of exactly what the role is that age plays in PrEP awareness, perceptions about PrEP use, and actual PrEP adoption.

This study also revealed significant differences in PrEP awareness based on educational attainment, with the least-welleducated persons being far less likely to know about PrEP (12.2%) than the best-educated of their peers (57.1%). [41] conducted a meta-analysis of the PrEP acceptance literature and reported that higher levels of educational attainment were associated with greater acceptance of PrEP as an HIV prevention strategy. Another study focusing on MSM who were not highly sexually active and who had decided to use PrEP on an event-planning basis reported that the event-planning use (versus the regular, daily use) of PrEP would be better suited for men with higher levels of education [42,43], reported that the least-well-educated men in their study were the ones who were most receptive to considering future PrEP use. As with age (discussed above), more research is needed on the role that educational attainment may play in the awareness-willingness to consider-adoption equation for PrEP. The present authors would like to point out, however, that with fewer than one MSM out of eight in this study who had not completed high school or its equivalent even being aware of PrEP, unmistakably, this low-education cohort is in great need of targeted efforts to inform them about PrEP.

Corresponding with all of the preceding, it is unsurprising-yet nonetheless important to note-that very few of the men who took part in the present study had specific personal knowledge of or experience with anyone who actually uses PrEP. Only 24.9% of the respondents in this study had, to their knowledge, met someone who currently uses or who previously used PrEP. Such individuals are likely to be the main sources of information-at least initial information-about PrEP and key gatekeepers in the process of learning about PrEP. If men do not know such individuals, then it is less likely that they will be able to learn about the PrEP using experience in a comfortable way. One likely beneficial approach for future HIV educators and interventionists to implement would be to enlist men who are currently using PrEP as part of their personal HIV prevention strategies and then have them interact with, answer questions for, and provide information to currently-HIV-negative MSM who are not using PrEP. This type of approach, which is often referred to as a gatekeeper approach or a key informant approach to prevention, has been shown to be effective at helping at-risk groups to become more aware of HIV and, subsequently, to reduce their risk for acquiring the virus [44-46].

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