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What motivates gay and bisexual men to participate in PrEP-related research?

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Abstract

Pre-Exposure Prophylaxis (PrEP) has been demonstrated effective at preventing HIV among key populations like gay and bisexual men (GBM). Yet, there remains a continued need to engage GBM in PrEP behavioral and clinical research (e.g., to monitor adherence and retention in the PrEP treatment cascade). We report on the factors motivating GBM to participate in a PrEP behavioral study, with the aim of our results to inform future recruitment efforts for future PrEP research. In 2015-2016, 103 PrEP-using GBM in NYC completed qualitative interviews about their experiences on PrEP. Participants were also asked about factors that motivated them to join the study. Thematic analysis was used to analyze the data. We identified five salient themes as rationale for joining the study: 58.3% cited altruistic reasons, 32% reported intellectual curiosity in the subject matter, 30.1% indicated that remuneration inspired them, 18.4% indicated that familiarity or referral to the research institute influenced their decision. Researchers attempting to enroll PrEP-using GBM may benefit from attending to the altruistic and intellectually curious nature of this population. Further, researchers may benefit from establishing familiarity among diverse communities of GBM. This in turn may contribute to the successful engagement of GBM for PrEP research.

Keywords

Pre-Exposure Prophylaxis (PrEP); recruitment; gay and bisexual men; HIV; qualitative data

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INTRODUCTION

Antiretroviral pre-exposure prophylaxis (PrEP) is emerging as a key strategy for HIV prevention. Although the clinical effectiveness of PrEP is now well-established, there is an ongoing need to engage PrEP users in both biomedical and behavioral research (Jiang et al., 2014; McCormack et al., 2016). Despite its promise, PrEP uptake significantly lags eligibility and need, and thus, requires continued efforts to improve PrEP initiation and adherence (Holloway et al., 2017; Rolle et al., 2017). Given the continued need for PrEP among those at highest risk for HIV acquisition, ongoing research efforts must include individuals who stand to benefit the most from PrEP's protection. Research efforts currently underway include PrEP-focused demonstration projects, feasibility and acceptability studies, and clinical trials for high-risk individuals (www.clinicaltrials.gov). The evaluation of PrEP in both real-world and experimental/clinical settings will continue to rely on the participation of those individuals at highest HIV risk, in research studies.

Historically, recruiting diverse samples of GBM has proven to be a significant methodologic barrier (Fuqua et al., 2012; Jenkins, 2012; Vial, Starks, & Parsons, 2014). Difficult-to-reach populations, like substance-using GBM and GBM of color, can present unexpected challenges for researchers, given the often-limited resources available for recruitment efforts (Groves, Bux Jr, Parsons, & Morgenstern, 2009; Jenkins, 2012). There is considerable evidence pointing to stigma, medical and institutional mistrust, and "prevention fatigue" as significant factors limiting GBM's participation in HIV prevention research (Chillag et al., 2002; Frew et al., 2013; Jenkins, 2012; Mayer, Chan, Patel, Flash, & Krakower, 2018). Moreover, researchers have routinely struggled to recruit substance-using GBM, who are at especially high risk of acquiring HIV, due to difficulty locating and subsequently enrolling substance-using men (Groves et al., 2009). Recruiting and retaining the most difficult-to-reach GBM remains vital for high quality results, which rely on large sample sizes needed to achieve sufficient statistical power to answer complex research questions.

To date, the limited research on factors facilitating GBM's participation in HIV prevention research has been conducted in the context of prophylactic vaccine trials (Newman et al., 2006; Strauss et al., 2001; Toledo, McLellan-Lemal, Arreola, Campbell, & Sutton, 2014). Qualitative findings of individuals at heightened risk for HIV indicate that protection against HIV, free medical care, altruism, monetary gains and stopping the spread of HIV were all common motivators that facilitated participation (Strauss et al., 2001; Toledo et al., 2014). Although these studies may provide some insight for researchers seeking to recruit PrEP-using GBM, it remains essential for us to gain a greater understanding of why GBM ultimately decide to enroll in PrEP-related research studies, along with the factors associated with their enrollment.

Despite a growing number of studies about PrEP, and studies of GBM on PrEP, little is known about what motivates this new population to participate in PrEP research (www.clinicaltrials.gov). Given the novelty of PrEP as a promising biomedical prevention strategy, and the importance of understanding what motivates these individuals to participate in research—we conducted a qualitative study of PrEP-using GBM and included questions assessing their motivations for joining the study. We present those results here, with the hope

that our findings will be useful for future research efforts requiring recruitment of a diverse sample of PrEP-using GBM.

METHOD

Participant and Procedures

Data for this manuscript come from *PrEP & Me*, a prospective mixed-method study conducted in New York City about urban GBM's experiences with PrEP. The study and its methodology have been described in detail elsewhere (Groves et al., 2018; John, Parsons, Rendina, & Groves, 2018; John, Whitfield, Rendina, Parsons, & Groves, 2018). In brief, we recruited participants in 2015-2016 via targeted sampling (Watters & Biernacki, 1989). Recruitment methods consisted of advertising and preliminary eligibility screening in sexual-minority concentrated neighborhoods and settings (e.g., gay bars, pride events, LGBT community-based venues), and digital recruitment of GBM via social and sexual networking websites/apps, and various social media platforms.

To be eligible, participants had to be 18 years or older and male; identify as gay or bisexual; have been taking PrEP for at least 30 days, but not via a research study that provided the PrEP medication; reside in the New York City area so that they could attend in-person study visits; and have access to the internet such that they could complete the online study assessments (those data presented elsewhere). One goal of the primary study was to examine the role of club drug use on PrEP adherence. Thus, half of the sample self-reported club drug use within the past 30 days, and the other half denied club drug use within the past 30 days. The category of club drugs included ketamine, MDMA/ecstasy, GHB, cocaine, and methamphetamine. All participants provided evidence of PrEP use by bringing their prescription bottle with their name printed on it to a study visit. Participants were compensated \$40 for the assessment that included the semi-structured qualitative interview. All participants provided informed consent and procedures were approved by the IRB of the City University of New York.

Measures

Participants completed an in-person, one-on-one, semi-structured interview that lasted from 30-45 minutes. The interview covered a range of topics, including how participants first learned about PrEP and how they decided to begin taking PrEP. In one segment, the interviewer asked participants to recount what motivated them to join the study. In this manuscript, we focus on participants' responses to this question.

Participants also completed a computerized survey that assessed demographic characteristics, PrEP, sex behaviors, STIs, club drug use (ketamine, ecstasy, GHB, coke, methamphetamine) and mental health, using standardized measures when available.

Analysis Plan

Interviews were transcribed verbatim and verified against the original audio. Using the principles of thematic analysis, the research team reviewed the transcripts to code the narratives about participants' rationales for joining the study. Thematic analysis has shown

to be an effective method for evaluating this type of qualitative data (Miles & Huberman, 1994; Patton, 1990). A coding team comprising the Principal Investigator and the first author, developed a codebook from the interview guide and a close-read of a subset of 40 transcripts. One additional staff member was then trained to use the codebook to identify text that represented the codes (Neuendorf, 2002; Saldaña, 2013). Throughout the coding process, the team adjusted the codebook to reflect emergent data from the transcripts. Finally, codes were categorized and organized into themes based on patterns that emerged from the narratives and the codebook. Themes were finalized by the first author and Principal Investigator. The percentages reported represent those that endorsed a particular reason for enrolling in the study, divided by the total number of participants who responded to the question (N = 103). Of note, the percentages listed with each category are not exclusive, as many participants reported multiple reasons inspiring their decision to enroll in the study.

RESULTS

Table 1 details the self-reported demographic characteristics of the sample. The mean age was 32.5 years and 63.1% had been taking PrEP for less than one year. Nearly half (47%) of the participants were men of color, most (79.6%) had at least a 4-year college degree, and 42.8% reported an annual individual income over \$50,000.

Participants reported a variety of motivations for their initial enrollment in the study. Broadly, these fell into five thematic categories: altruism, intellectual curiosity, remuneration, familiarity or referral to the research institute, and “other reasons.” These themes did not appear to be associated with club drug use, as they emerged at nearly equal frequency between groups.

Altruism

Over half of the participants (58.3%) reported that altruism motivated their enrollment in the study, with many expressing their rationale for enrolling by using language that was inherently altruistic by definition. This verbiage included expressing a wish to “give back,” to “do good,” to “contribute,” and to “share” in their response. Among those motivated by altruism, three sub-themes emerged, including those who wished to (1) give back to their community, (2) contribute to research, and (3) share their experiences with a broader audience.

Those who described hoping to give back to research often specified that they were moved to support HIV prevention research, novel research, and PrEP-specific research:

“I think it’s a good thing to have more information about health, and especially about HIV-related stuff for gay men... gay health. I’m a gay man. There’s limited research out there and I feel like participating is a good way of contributing.”

(Multi-Racial, Age 34)

Further, participants who reported a desire to give back to their community often expressed a civic-minded or community-oriented rationale for their participation:

“Well, I worked for about three years as an LGBT advocate. I mean, you just participate in studies and polls and things that are just generally part of an extended and broad view of being civically minded.” (White, Age 26)

“I love to give back to the community and anything—in any way that I can help, and this is one of the many ways I do so.” (White, Age 28)

Additionally, several participants indicated a desire to share their personal experiences while on PrEP in order to help others. Among this group, several participants hoped to offer greater representation of their racial, ethnic, or age group, while sharing their experiences within the study:

“Anything I can do to help advance the research or the awareness [of PrEP], I’m more than happy to help in that regard. Like I told you, the money was not the motivator. And also, I do skew older [in age], so I was hoping that it would give a little bit different perspective than probably some of the younger people that you have in the study.” (White, Age 52)

Additionally, two participants described the loss of a family member or friend to AIDS-related complications as their ultimate reason for participating in PrEP research:

“I came out in 1992, so it was very... it was a different time. I lost lots of friends and I was seeing what people have gone through and it just... For me, I’ve actually lost family members. And I do anything I can to make it better, for anybody.” (Black, Age 46)

Curiosity and Interest

The second most prevalent theme across participants’ narratives was intellectual curiosity in our research as a reason for participating in the study. This was endorsed by 32% of participants, although their curiosity took several forms. Some participants expressed interest in gaining information about PrEP for their personal use, while others expressed general interest in men’s sexual health and LGBT healthcare. “I’m for information. Finding information out... about PrEP and men’s health, sex, and all that stuff” (White, Age 40).

Further, some participants within this group expressed an interest in finding out “how PrEP is being used” and expressed interested concern regarding the potential for risk compensation behaviors among PrEP users:

“I’m just sort of fascinated by PrEP and fascinated about people’s behavior behind it. In my group of friends...there is a lot of back and forth between whose changing and if it’s the right thing to do, and does it change your behavior if you take it.” (White, Age 40)

A small sub-group of participants explained that their academic or professional background informed their interest in participating in PrEP research: some of these participants worked in the field of HIV, social science, and sex education. In addition, these participants sometimes expressed nuanced insight on the difficulties that accompany recruitment efforts for studies similar to this one. “I used to be a sex educator myself, so I find it rather odd that

even in 2016, sex is still a bit of a taboo subject. I've learned to be very comfortable with talking about anything sex related" (Latino, Age 27).

Compensation

Financial remuneration was cited as a reason for research participation by 30.1% of the participants. Of those endorsing this reason, compensation was the sole or primary reason for participating for 7.8%. "I figured, why not be on it and make a little extra money if I can? That's about it" (White, Age 27). Nonetheless, others cited it as a secondary reason (22.3%) following another motivation, such as altruism or interest in the study subject matter. "I thought "Why not?" You know. I need the money and I'm also interested in contributing to more research and knowledge on the PrEP issue" (Multiracial, Age 48). Notably, 39.2% of White participants cited remuneration as a reason for participating compared to only 19.6% of men of color.

Familiarity and Referral to the Research Institute

Some participants (18.4%) noted familiarity with the research organization or a referral from a friend as their reason for ultimately enrolling in the study. "I think it's good how you guys do this, find out how it's being used... I've done [studies] here. I did [redacted name of another study]. I'm familiar with the everything they do" (Latino, Age 30). Among this group, some men described previous experiences with the institution, while others were confident in joining due to a friend's referral or experience. "Friends told me about [blinded for review] and then I decided to sign up for it. I was like, 'Oh, that seems interesting. I'd like to participate'" (Multiracial, Age 35). Those who endorsed familiarity appeared to have high trust in the integrity and academic pursuits of the research team and institution. Similarly, several participants reported that they were encouraged to participate in our study by a friend who was familiar with the research institute, thus serving as a reliable source of information about the study's legitimacy.

Additionally, a small minority of participants (6.8%) expressed that the efforts of our research staff influenced their study enrollment. Several men explained that simply being approached by a recruiter was reason enough for them to agree to participate, while others cited the friendly demeanor or efficiency of follow-up from staff as their reason for joining. "Well, I joined a previous study with [my] husband and everyone here was amazing just like, even to chat. You know, professionalism... everyone was awesome" (Latino, Age 29).

Other Reasons

Approximately 7.8% of participants expressed that they simply enjoyed participating in research. In addition, 10.7% cited their perception that they would likely be appropriate candidates for the study, or their eligibility as their reason for enrolling. For these groups, it was difficult to determine exactly why they enjoyed participating or why they ultimately decided to enroll.

DISCUSSION

Congruent with previous findings, some of our participants indicated that compensation was an important factor for them. However, we also found that altruism and intellectual curiosity were strong motivators to join our study. Researchers seeking to engage GBM in PrEP-research may consider using language in their recruitment materials that taps into a potential participant's sense of altruism. Further, investigators planning longitudinal studies would be wise to foster participant engagement by fueling the intellectual curiosity of participants in their study over time. This could come in the form of a newsletter highlighting key information from early findings, or the dissemination of relevant information via in-person events or webinars, including current literature on PrEP, GBM's health, and sexual health overall. Employing multiple strategies over time has proven vital for high retention rates in longitudinal cohorts (Robinson, Dennison, Wayman, Pronovost, & Needham, 2007). Regardless of other motivators, remuneration was one of the top three reasons why participants chose to enroll. To that end, we acknowledge that future recruitment efforts should continue to highlight compensation when recruiting for PrEP studies. However, recruiters should be mindful of ethical considerations surrounding the use of remuneration to attract participants, especially those from resource-constrained communities (Garner, Anude, Adams, & Dawson, 2014; Mduluzi, Midzi, Duruza, & Ndebele, 2013).

In addition to these relatively straightforward participant motivations, others may not be as easily utilized in recruitment campaigns. However, we hope that researchers will consider them as general ideas with the potential to improve recruitment and retention efforts for projects working with GBM on PrEP. In response to our inquiry about why they chose to enroll in our study, 17.5% of participants reported that they were either referred by a friend, or were familiar with the research institute. Although this reason could seem distal to their ultimate motivation for enrolling, it is possible that a referral from a friend or prior knowledge of, or experience with, the research center implies that they trusted that the study was legitimate and of high quality. There is significant research identifying mistrust in academic and medical research as a significant barrier to recruitment and retention (Corbie-Smith, Thomas, & St George, 2002; Freimuth et al., 2001; Frew et al., 2013). Thus, participants who cited a referral or prior knowledge of the research institute in their rationale for enrollment may be using these reasons as a proxy for their trust in the study and the institution.

Some of our findings mirror previous data highlighting altruism enhanced personal knowledge, and monetary incentives as important factors for inspiring GBM's participation in HIV prevention efforts (Newman et al., 2006; Strauss et al., 2001; Toledo et al., 2014). One novel finding was that intellectual curiosity fueled enrollment. However, the newness and cutting-edge nature of PrEP may mean that participants joining PrEP studies are uniquely motivated by the research focus. Further, compared to previous studies, our interviews allowed us to include a more nuanced breakdown of the altruistic motivators cited by our participants. In delving into the different elements of altruism as a primary motivator, we hope to offer researchers a greater understanding of the variability embedded in altruistic motivations. Moreover, a small minority acknowledged the friendly nature and efficiency of

the research staff as their reason for joining the study. Similar to our findings, results from clinical trials have emphasized the importance of a positive, friendly rapport in recruiting and retaining research participants (Penckofer, Byrn, Mumby, & Ferrans, 2011).

Limitations

Data for this study were extracted from qualitative interviews in which participants recalled their motivation for joining the study. This open-ended approach illuminated those motivators most salient for the participants, offering an in-depth exploration of their reasons for joining the study. However, these questions were not the primary focus of the interview and, thus, interviewers did not probe participants as deeply as we would expect for a primary aim. Thus, there may have been additional reasons that GBM chose to enroll in the study that ultimately were not discussed. Indeed, qualitative methods are used for hypothesis generation and not hypothesis testing and, thus, an adequately powered quantitative study would be needed to assess true prevalence.

Participants were overall well educated, employed, and made a living wage. This may be emblematic of “who” could gain access to PrEP at the time the study was conducted. Our data were collected in 2015 and 2016, when PrEP was beginning to be adopted on a larger scale in NYC. We believe that many of our participants could best be classified as ‘early adopters.’ It may be that both GBM on PrEP at the time, as well as GBM willing to participate in a research study about their PrEP use, are different from those adopting PrEP today. Additionally, although we did observe some differences in findings between the White participants and the participants of color, our findings cannot be used to verify significant differences between racial or ethnic groups due to the study’s qualitative design.

Conclusion

Although compensation was an important motivator for participants to enroll in PrEP research, the majority also cited altruistic intentions. Our findings suggest that recruitment efforts should attend to altruism and interest in the study subject matter when creating advertising campaigns. Further, the reputation of and familiarity with the research institute may influence recruitment success, in that it may allay concerns about untrustworthiness of the investigators or illegitimacy of the research. Recruitment and retention efforts should consider an array of factors, including altruism, curiosity, remuneration, social networks, and trust in the research setting to optimize recruitment efforts with GBM in PrEP research.

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Table 1.Descriptive demographic characteristics of gay and bisexual men taking PrEP in NYC 2015-2016, *N*= 103

Characteristics	<i>n</i> (%)
Age	
Mean (SD)	32.5 ± 8.7
Minimum - Maximum	21 - 61
Race/Ethnicity	
Black	12 (11.7)
Latino	27 (26.2)
White	52 (50.5)
Multiracial	9 (8.7)
Other	3 (2.9)
Education	
High School diploma, GED or less	6 (5.8)
Some College	23 (22.3)
4-year College Degree	53 (51.5)
Graduate School	21 (20.4)
Employment	
Full-time	60 (58.3)
Part-time	24 (23.3)
Unemployed	19 (18.4)
Income	
Less than \$10,000	13 (12.6)
\$10,000 - \$19,999	7 (6.8)
\$20,000 - \$29,999	14 (13.6)
\$30,000 - \$39,999	11 (10.7)
\$40,000 - \$49,999	14 (13.6)
\$50,000 - \$74,999	22 (21.4)
\$75,000 or more	22 (21.4)
Length of time on PrEP	
1-3 Months	15 (14.4)
3-6 Months	24 (23.1)
6-12 Months	27 (26)
1-2 Years	28 (26.9)
More than 2 Years	10 (9.6)
Missed taking PrEP in the last 90 days?	
Yes	63 (61.2)
No	40 (38.8)
How long ago did you miss a dose? Among <i>n</i> = 63	
Today	1 (1.6)

Characteristics	<i>n</i> (%)
Yesterday	2 (3.2)
2-3 days ago	9 (14.3)
4-7 days ago	18 (28.6)
2-3 weeks ago	15 (23.8)
4-6 weeks ago	9 (14.3)
7-9 weeks ago	6 (9.5)
10-12 weeks ago	3 (4.8)

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