



# Representations of Pre-exposure Prophylaxis, Informal Antiretroviral Medication Use for HIV Prevention, and Diversion on Geosocial Networking Apps among Men Who Have Sex with Men

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## Abstract

The use of geosocial networking applications (e.g., Grindr) among men who have sex with men (MSM) is common. Yet scant research has examined how antiretroviral medications (ARVs)—including informal use—diversion and pre-exposure prophylaxis (PrEP) are presented inside of the applications. The present study examines this phenomenon. Data are drawn from a qualitative study (N = 39) of the scope and magnitude of the informal market of ARV use for HIV prevention among MSM. Twenty-five participants reported seeing references to ARVs inside the applications. Men described geosocial networking application users' presentations of ARVs as being related to: PrEP use among HIV-negative MSM, the sale and/or use of illicit drugs (e.g., methamphetamine), informal trade/sale for HIV-prevention, and PrEP use among HIV-positive men. Findings suggest continued desire for and acceptability of PrEP as HIV prevention tool and that geosocial networking apps are being used to facilitate the exchange and informal use of ARVs for HIV-prevention. Geosocial networking applications represent a promising and important platform to educate MSM about safe and effective use of PrEP and the risks related to diversion and informal ARV use.

**Keywords** Preexposure prophylaxis (PrEP) · Geosocial networking apps · Men who have sex with men (MSM) · Antiretroviral medication · Diversion

## Introduction

Geosocial networking applications (GSNAs) targeted to men who have sex with men (MSM; e.g., Grindr, Scruff, Jack'd) are smart phone “apps” which use GPS technology to facilitate communication and face-to-face encounters between users in close geographic proximity [1–3]. Limited research suggests that MSM use GSNAs to seek sex and drug use partners and engage in condomless sex and other risk behaviors [1, 3–7]. In addition, the use of GSNAs among some MSM is associated with testing HIV positive [8]. However, GSNAs are also used by MSM to connect with others, build

community, and socialize [3]. Thus, GSNAs represent a key and growing part of the social environment for MSM.

In this context, researchers have recently emphasized utilizing the popularity of GSNAs to investigate HIV risk and preventive behaviors among MSM. An important focus of this work has been pre-exposure prophylaxis (PrEP), in which individuals initiate a prescribed daily regimen of antiretroviral medications (ARVs) to prevent HIV infection [9]. GSNA-based research has examined the best means by which to increase awareness and uptake of PrEP and other HIV prevention practices [6, 10–13], but this research has focused on the formal use of PrEP as prescribed by a physician and taken under medical supervision. Studies investigating informal ARV use for HIV prevention, including PrEP taken outside of a medical context, among MSM in the U.S. are scant.

The practice of diversion—the unlawful channeling of regulated pharmaceuticals from legal sources to the informal marketplace [14]—of ARVs, including the medication used for PrEP, is occurring among HIV-positive MSM [15]. The non-prescribed and non-medically supervised

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(hereafter ‘informal’), use of ARVs for HIV prevention has been previously reported among some MSM study participants ( $\leq 2\%$ ), although many of the studies were conducted prior to FDA approval and CDC-issued guidance for PrEP [16–19]. Although recent data from the U.S. are limited, research has found that HIV-negative MSM, possessing limited HIV prevention information and seeking to protect themselves against HIV infection, obtain diverted ARVs and use them without a prescription or medical supervision [20, 21]. Moreover, research conducted among GSNA-using MSM demonstrate a lack of adequate information about HIV prevention and PrEP [21]. This scenario puts men at risk for HIV infection because the maximum preventive effect of PrEP is contingent upon consistent adherence to the prescribed regimen; frequent HIV testing and counseling; and a lack of risk compensation behaviors (e.g., reductions in condom use or increase in sexual partners) [22–24]. Individuals using ARVs informally for HIV prevention may be putting themselves at risk for HIV infection if they fail to adhere to the required PrEP regimen and associated monitoring [25].

The potential of PrEP to prevent HIV infection is great [9] and MSM are known to be early adopters of new HIV prevention technologies [26]. Moreover, information about HIV, including the informal use of diverted ARVs for prevention, is shared through social and sexual networks, including among GSNA-using MSM [21]. The current study is informed by this context—the widespread and growing use of GSNA among MSM, HIV transmission risks associated with GSNA use, the desire to leverage GSNA to conduct research about and promote the use of PrEP, and emerging evidence that MSM are obtaining and taking diverted ARVs for HIV-prevention—and is guided by the research question, “How are ARVs for HIV prevention, including formal (e.g., PrEP) and informal use, presented and discussed on GSNA?”

## Methods

The data are drawn from a study of the scope and magnitude of the informal use of ARVs for HIV prevention among men and transgender women who have sex with men South Florida (Miami-Dade and Broward counties) conducted between September 2015 and May 2016. To be eligible for the study, participants were age 18 or over; and reported: (a) one or more male anal sex partners in the past 90 days, including at least one condomless event; (b) and obtaining and taking antiretroviral medications for HIV prevention without a prescription and/or providing (selling, sharing, or trading) ARVs to HIV-negative MSM to take for HIV prevention. Given the scope of the analyses presented here, the subsample ( $N = 39$ ) was limited to participants who reported current GSNA use and had an application downloaded on their

mobile phone. Although transgender women were eligible to participate, no transgender women participants met criteria for inclusion in the present study. Upon examination, we found no differences from men in the larger sample on measures of demographics, HIV-status, or recruitment location.

Participants were recruited through a variety of strategies. Study staff members engaged in community outreach at health and social service agencies, an LGBT community center, and community groups for MSM. Passive recruitment included placing flyers in public spaces, bars, and stores in zip codes with high concentrations of MSM, as well as ads on geosocial networking applications.

After providing informed consent, participants completed anonymous, individual, in-depth interviews (approximately 60–90 min). All interviews were conducted in private offices and participants were compensated with a \$50 gift card. Following the interview, interested participants were provided brief information about PrEP, and were referred to the PrEP Coordinator at the local LGBT community center and to prescribers who offer PrEP at low or no cost. Research protocols were approved by the university’s Institutional Review Board.

Guided by a semi-structured interview protocol, the primary focus of the interview was the initiation of informal ARV use for HIV prevention. One sub-section in the protocol specifically inquired about one’s personal experience with presentations, mentions, or discussions of informal ARVs for prevention on GSNA. A benefit of semi-structured interviews, especially when discussing sensitive information, is that they allow for some flexibility and participants are provided space to express themselves in their own terms and at their own pace [27]. Thus, interviews were conversational in style with topics being discussed as they naturally occurred, rather than maintaining a fixed format. The interviews were digitally audio-recorded and then transcribed by two independent transcriptionists. Two independent researchers reviewed the transcripts for accuracy. ATLAS.ti version 7 software was used for data management, coding, and analysis.

Interviews were coded using *descriptive* (words or short phrases to summarize passages of data) and *in vivo* (actual language from participants to name concepts and themes) coding schemes [28]. Memos were written after each participant was interviewed and after each interview was coded to reflect code choices, emergent themes and patterns, and to develop conceptual models [28]. Two independent researchers participated in the coding process, which included establishing codes and meanings and cross-checking code choices. Regular discussions were held between the coders that yielded insights to refine the coding scheme and facilitate agreement on code choices [29]. The final set of codes and their meanings were transformed into longer and more descriptive themes to organize recurrent meanings and

patterns. Themes and definitions of themes were constantly compared across interviews to ensure consistency and reliability. The presentation of findings includes the key themes related to informal ARV initiation, use practices, medications, primary motivations, benefits of use, concerns about efficacy, and limited knowledge about PrEP.

## Results

As shown in Table 1, participants in this study were black (N = 11), Hispanic (N = 14), white (N = 13), and native American (N = 1). Ages ranged from 18 to 62 (mean = 38.27; SD = 11.90). The sample included HIV-negative (N = 21)

**Table 1** Sample characteristics (N = 39)

ID	Age	Race/ethnicity	HIV-status	Experienced ARVs on GSNA	Sex with another GSNA user	Used informal ARVs before/after sex with another GSNA user
1	39	Black	HIV-positive	No	No	
2	30	Hispanic	HIV-positive	Yes	Yes	
3	34	Black	HIV-positive	Yes	Yes	
4	29	White	HIV-positive	Yes	Yes	
5	43	Black	HIV-positive	Yes	No	
6	39	Black	HIV-positive	Yes	No	
7	26	Hispanic	HIV-positive	No	Yes	
8	45	White	HIV-positive	No	Yes	
9	24	Black	HIV-positive	Yes	Yes	
10	43	White	HIV-positive	Yes	Yes	
11	49	White	HIV-positive	Yes	Yes	
12	53	White	HIV-positive	Yes	Yes	
13	36	Black	HIV-positive	Yes	No	
14	48	Native American	HIV-positive	Yes	No	
15	53	Hispanic	HIV-positive	Yes	Yes	
16	28	Black	HIV-positive	No	No	
17	43	Hispanic	HIV-positive	Yes	No	
18	55	White	HIV-positive	No	No	
19	29	White	HIV-negative	No	No	Yes
20	25	Hispanic	HIV-negative	No	Yes	No
21	22	Black	HIV-negative	Yes	Yes	No
22	28	Hispanic	HIV-negative	Yes	Yes	No
23	53	Hispanic	HIV-negative	No	No	No
24	18	Hispanic	HIV-negative	Yes	Yes	No
25	45	Hispanic	HIV-negative	Yes	Yes	Yes
26	34	White	HIV-negative	Yes	Yes	Yes
27	52	White	HIV-negative	Yes	Yes	No
28	27	Black	HIV-negative	No	Yes	Yes
29	21	Hispanic	HIV-negative	No	No	No
30	52	White	HIV-negative	No	No	No
31	23	Hispanic	HIV-negative	No	Yes	No
32	62	White	HIV-negative	Yes	Yes	Yes
33	41	White	HIV-negative	No	No	No
34	42	Hispanic	HIV-negative	Yes	No	No
35	46	Black	HIV-negative	Yes	No	No
36	22	Hispanic	HIV-negative	No	Yes	No
37	23	Hispanic	HIV-negative	Yes	No	No
38	21	Black	HIV-negative	Yes	Yes	Yes
39	50	White	HIV-negative	Yes	Yes	Yes

and HIV-positive (N = 18) men. Of the 39 participants included in the study, 25 (64.1%) reported seeing references to ARVs on other users' profiles or having ARVs discussed while chatting inside of the apps, and 23 men (58.9%) reported having sex with someone they met on GSNAs during the past 90 days. Of the 21 HIV-negative men, 7 (33.3%) used informal ARVs either before and/or after sex with another GSNA user. Although some participants took informal ARVs after sex, this practice was still described as PrEP and no participant mentioned post-exposure prophylaxis (PEP).

### Mentions of ARVs on GSNA Profiles and in Chats

During the in-depth interviews, participants described how common it was to see other GSNA users include references to PrEP on their profiles or to have other GSNA users mention PrEP while chatting inside the apps, especially among HIV-negative men. Although the interview was focused on informal ARV use, many participants were unable to distinguish whether presentations of PrEP use by GSNA users were formal or informal. Participant 5 stated, "I see it all the time, 'Yeah, I'm HIV-negative but I'm prepping.' You can't believe it all the time, but you see that a lot." Similarly, Participant 27 described it this way, "I think there is a lot of people advertising for it on [GSNAs] like, 'Negative on PrEP.' I'm seeing it a lot on online profiles... hook-up sites like Grindr, Adam4Adam. It's that new buzzword. I see it on people's profiles like every day.' So yeah, there's a big online buzz out there."

When asked about why they might be seeing increasing mentions of ARVs on GSNAs, participants noted that many in the LGBT community have heard of ARVs, either because of the prevalence of diversion and informal use of ARVs or because of the availability of PrEP. Participants generally expressed thoughts similar to that of Participant 17 who said, "I think more so now people are mentioning that they are on PrEP. I think it's coming to a time where people are becoming more open to having a pill to use for protection." Participant 4 also elaborated and said that on GSNAs, "That's probably one of the most important questions that people ask, 'Are you on PrEP?'" Nearly all men in the sample described interpreting mentions of ARVs and PrEP as associated with HIV-preventive behaviors, yet Participant 14 had the opposite view. In his words, "[GSNA users] were like, 'Oh, I'm on PrEP,' which means, 'I don't want to wear a condom.'"

Five men explained their appreciation of seeing the presence of ARVs on GSNAs. In the words of Participant 10, "I just thought that it was so great to see that." Participant 2 expressed a similar sentiment, "It always brings a smile to my face because that means that people are taking precautions." Participant 6 described men who have conversations

about ARVs on GSNAs this way, "They try to break the stigma with their [GSNA] account." Only Participant 38 disagreed and said, "I feel like that should be something we speak about...when we see each other, like real human beings. That they [discuss ARVs] that tells me something about the person before I meet them. That's personal information. You shouldn't be advertising that to anybody, you know?"

### Associations of Informal ARV Use and Substance Use on GSNAs

Four participants stated that informal ARV use is associated with substance use. One man described, "Scrolling through and looking at a bunch of profiles...some people use it as a precaution because...they rely a lot on drug use, substance use, and party play mixed with sex," (Participant 2). Similarly, in the experience of Participant 5, GSNA users talked about informal ARVs in the context of, "going to party."

If fact, according to two participants, informal ARVs can be easily purchased or obtained from drug dealers. As Participant 3 stated:

Sometimes on Grindr or Adam4Adam or something like that, you will find a dealer who is selling meth or coke or crack or whatever, and HIV meds. I've seen it. I was talking to one guy about drugs and he was like, 'I also have the HIV meds if you need those.'

He went on to describe why drug dealers also sell informal ARVs,

Nine times out of 10 if you are high on meth or out of your mind on crack or coke you are not going to think about prevention. You are going to have all types of unprotected nasty sex and then you are going to wake up in the next morning and regret it. No, no, just buy the [ARV] pills too. They buy individual pills. They are like 20 bucks a pop.... Usually the people that sell Tina [methamphetamine] are the same people that sell HIV meds. You just look for the people that put 'P&P' – for 'party and play' – and that's usually how you find it.

Similarly, Participant 9 described GSNA users trading drugs for informal ARVs. "On Grindr there are people who are just like, 'I have PrEP if you need it,' 'cause people don't want to go to the doctor and get a prescription for it. They just rather get it on the black market." He continued and said, "If you go through enough profiles, you will start seeing things like, 'If you need PrEP, I have it.' People don't have their profile pics on [their GSNA profile]... Buy, trade, if you have meth, if you have weed, if you want to give someone a blow job. It's crazy."

## Interest in Obtaining ARVs from Other GSNA Users

Two participants described other GSNA users' interest in obtaining and taking informal ARVs. Participant 11, who is HIV-positive, described how HIV-negative GSNA users who are potential sex partners will often request ARVs to take informally; he said, "when I'm on [GSNAs], and I tell people that I am positive, they say it doesn't matter as long as I have a pill to give them." Participant 35 noted that some GSNA users put the word, "Meds," in their profile to signify that they are interested in obtaining ARVs. He went on to say, "They would say that, and you know what it means. Or they would have their profile up, 'Looking for meds.'"

## Mentions of PrEP Use Among HIV-Positive GSNA Users

Finally, two HIV-negative men described seeing references to HIV-positive GSNA users who are taking PrEP. "Poz on PrEP" was a phrase Participant 24 reported seeing in users' profiles. Participant 22 said that he has seen, "HIV undetectable and on the pill and PrEP." Neither of these men were fully aware of what PrEP is or how it is used. Thus, were unsure of what exactly these phrases meant.

## Discussion

This study has documented MSM's experiences of the presence of ARVs on GSNAs, with most participants reporting seeing many GSNA users who are taking ARVs for PrEP. Given the prevalence of HIV infection and sexual risk behaviors among MSM [30] including among GSNA-users [6–8], further research is needed to quantify the number of GSNA users on PrEP. However, the discussion and use of informal ARVs illustrates the desire for, and acceptability of, PrEP as an HIV prevention tool. Moreover, several men in the study described the open discussion of PrEP use on GSNAs as a positive development or a means by which to confront HIV-related stigma. GSNAs represent influential platforms in which many MSM are making social connections, communicating, and learning about HIV prevention. Thus, these findings suggest that interest in and uptake of PrEP will likely continue to expand among GSNA users.

Findings from this study suggest potential areas of concern that require more attention from researchers and public health officials. First, the use of GSNAs to facilitate the exchange and informal use of diverted ARVs for prevention among the sample may be a result of several contextual factors: (1) Miami reports the highest HIV infection rate and one of the lowest health insurance coverage rates of large U.S. cities [31, 32]; (2) the diversion of ARVs is well-documented in South Florida [33], including

among MSM [15]; and (3) in a follow-up assessment of MSM participating in PrEP demonstration trials in Miami and San Francisco, MSM in Miami were less likely to report successful PrEP access from community sources and more likely to be uninsured [34]. Although a recent global survey found that some patients were prescribed PrEP "off-label" or procured PrEP from other sources (e.g., Internet), the majority of these patients reported receiving recommended tests and services (e.g., HIV/STI tests; serum creatine test; HIV counseling) from medical providers [35, 36]. This is not the case in South Florida, where MSM describe using diverted ARVs to protect themselves against HIV infection, despite having limited knowledge of PrEP (e.g., recommended daily regimen; the prescription requirement) or having no awareness of the existence of formal PrEP [20, 21]. These contextual factors highlight the need to address barriers to PrEP knowledge and access through formal channels.

At the same time, building on men's desire to protect themselves from HIV infection and use GSNAs to connect with others and build community [3, 20], future GSNA-based HIV prevention interventions should address diversion and non-prescribed use of ARVs, as well as substance use. Findings from this study indicate that many men are unable to distinguish PrEP obtained through formal channels from informal ARVs used for HIV prevention that may not be used effectively. Under these conditions, men are unable to make accurate and informed sexual health decisions. GSNA-based interventions should be used to increase knowledge and awareness of PrEP, connect men to providers who offer PrEP at low or no cost, limit the informal ARV market, and educate men on the risks related to non-prescribed ARV use.

Several men described the diversion of ARVs occurring alongside the sale or trade of illicit drugs on GSNAs. This finding suggests that some MSM who use drugs desire to reduce their risk of HIV infection, even though they may engage in risky behaviors. However, given prevalent misunderstandings of PrEP among GSNA-using MSM who use drugs [20, 21] and documented cases of seroconversion among MSM who engage in informal ARV use [37], greater outreach to MSM who use drugs is needed to support their access PrEP through formal channels together with ongoing medical supervision and testing.

Finally, two men reported seeing GSNA-users who represented themselves as both HIV-positive and taking PrEP. If these profiles were accurate, neither of these participants fully understood the meaning of PrEP. Given the ongoing scientific advances in biomedical HIV prevention technologies, including "on-demand" and long-acting PrEP formulations [38, 39], it is imperative that public health campaigns spread knowledge of and expand access to effective regimens. GSNAs represent powerful platforms for these campaigns to reach MSM.

Some limitations must be noted. With all qualitative research, there is a potential for recall bias, interviewer effects, and social desirability bias. However, the use of a semi-structured interview guide and strong rapport between the participants and the interviewer likely mitigated these effects. In addition, participants described their own experiences using GSNAs, including profiles they saw and chats they engaged in, but that they were unable to confirm the veracity of profiles or statements made to them by other GSNAs users. Participants were drawn from a small convenience sample in South Florida, a region with well-documented ARV diversion [15, 33]. This context, together with the study eligibility criteria, also limit the ability to generalize findings to other populations.

In conclusion, ARV medications and PrEP represent great advances in preventing the transmission of HIV. To contribute the success of scientific advances like PrEP, researchers must understand the “real world” behavior of MSM. This includes the ways in which men use GSNAs and communicate about HIV prevention and ARVs. Given their popularity and widespread use among MSM, GSNAs represent a promising platform for disseminating accurate information about safe and effective use of PrEP, as well as risk related to diverting and using non-prescribed ARVs.

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### Compliance with Ethical Standards

**Conflict of interest** All authors declare that they have no conflicts of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the university’s institutional review board and with the 1964 Helsinki declaration and its later amendments.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

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