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The informal use of antiretroviral medications for HIV prevention by men who have sex with men in South Florida: initiation, use practices, medications and motivations

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ABSTRACT

Limited data suggest that some gay and other men who have sex with men are using antiretroviral medications informally, without a prescription, for HIV prevention. This qualitative study examined this phenomenon among gay and other men who have sex with men in South Florida. Participants initiated informal antiretroviral medication use as a means of protecting each other and because of the confidence in knowledge of antiretroviral medications shared by their friends and sex partners. The most commonly used medications included Truvada and Stribild. Motivations for use included condom avoidance, risk reduction, and fear of recent HIV exposure. Participants described positive and negative sentiments related to informal use, including concerns about informal antiretroviral medications offering sufficient protection against HIV, and limited knowledge about pre-exposure prophylaxis (PrEP). Because the antiretroviral medications used for PrEP have the potential to prevent HIV infection, future research must consider the informal antiretroviral medication use and related concerns, including adherence, diversion and viral resistance.

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Introduction

Biomedical interventions to prevent HIV transmission include post-exposure (PEP) and pre-exposure prophylaxis (PrEP), in which HIV-negative individuals initiate a prescribed regimen of antiretroviral medications to prevent HIV infection (Weber, Tatoud, and Fidler 2010). Studies have shown PrEP to decrease HIV incidence among gay and other men who have sex with men (Grant et al. 2014; McCormack et al. 2016). The co-formulation of tenofovir disoproxil fumarate and emtricitabine (TDF-FTC), branded as Truvada, received approval for PrEP from the US Food and Drug Administration in 2012 (FDA 2012). Subsequently, detailed guidelines for PrEP use were issued by the US Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) in 2014 (CDC 2014; WHO 2014).

Currently, the maximum preventive effect of PrEP occurs with adherence to the prescribed daily regimen, HIV testing and counselling and routine laboratory testing (e.g. renal function

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monitoring) (CDC 2014). It is also recommended that individuals confirm HIV-negative status prior to initiating PrEP (Smith et al. 2011). The development of 'on-demand' PrEP – taking four pills in a series of days before and after sexual activity (Molina et al. 2015) – is an important and recent scientific advancement. Yet, on-demand PrEP still requires adherence to a formal regimen and medical supervision.

Given these conditions, several concerns related to the potential effectiveness of PrEP in non-clinical settings have emerged. The non-prescribed and non-medically supervised (hereafter 'informal'), use of antiretroviral medications for HIV prevention has been reported among some gay and other men who have sex with men study participants (≤2%) (Liu et al. 2008; Mansergh et al. 2010; Mimiaga et al. 2009; Voetsch et al. 2007), although many of the studies were conducted prior to FDA approval and CDC- and WHO-issued guidance. Given the marked increasing trend in uptake of PrEP among men in the USA (Wu et al. 2017) and that gay and other men who have sex with men are known to be early adopters of new HIV prevention technologies (Kippax 2012), it is possible that the use of informal antiretroviral medications has grown since these early results were published.

Those using antiretroviral medications informally for HIV prevention may be putting themselves at risk for HIV infection if they fail to adhere to the recommended PEP or PrEP regimens and associated monitoring (Dimitrov et al. 2012). Informal antiretroviral medication use may contribute to the development and spread of antiretroviral resistance. Models indicate that the total prevalence of resistance and the numbers of new infections in which antiretroviral-resistant HIV is transmitted could potentially more than double if up to 10% of PrEP-prescribed users share medication. Informal antiretroviral medication use for PrEP by HIV-positive individuals with unknown infection also has the potential to increase antiretroviral medication resistance (Dimitrov et al. 2012). Likely contributing to both informal use and antiretroviral medication resistance is diversion – the unlawful channelling of regulated pharmaceuticals from legal sources to the informal marketplace (Inciardi et al. 2006) – of antiretroviral medications. Diversion has been reported among some HIV-positive patients prescribed antiretroviral medications for treatment, including gay and other men who have sex with men (Kurtz, Buttram, and Surratt 2014; Surratt et al. 2013).

Informal antiretroviral medication use among gay and other men who have sex with men is possible, given recent and rapid changes surrounding PrEP (Kurtz, Buttram, and Surratt 2014). Data collected since 2014 demonstrate misinformation about PrEP and continuing reports of informal antiretroviral medication use among gay and other men who have sex with men (Eaton et al. 2017; Kurtz and Buttram 2016), yet the prevalence of informal antiretroviral medication use among such individuals is not clear. Research assessing the effectiveness of HIV interventions, including PrEP, must engage with 'real world' human behaviours, beliefs, and environments (Auerbach and Hoppe 2015; Kippax and Stephenson 2012). Given this context, the aim of this study was to investigate informal antiretroviral medication use for HIV prevention among gay and other men who have sex with men to elucidate data on how men initiated this practice.

Methods

The data are drawn from a qualitative study of the scope and magnitude of the informal use of antiretroviral medications for HIV prevention by gay and other men who have sex with men in 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 one or more male anal sex partners in the past 90 days, including at least one condomless event, and obtaining and taking antiretroviral medications for HIV prevention without a prescription.

Study staff recruited participants through health and social service agencies, an LGBT community centre and community groups. More passive recruitment included placing flyers in public spaces, bars and stores in postal codes with high concentrations of gay and other men who have sex with men and placing advertisements on social networking applications such as Grindr. Recruitment materials invited individuals to participate in an anonymous one-on-one interview. Interested individuals were invited to call the research office to be screened for eligibility.

After providing informed consent, participants completed anonymous, individual, in-depth interviews (approximately 60-90 min) and 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 centre and to prescribers who offer PrEP at low or no cost. This study was approved by Nova Southeastern University's Institutional Review Board.

A semi-structured interview protocol guided the interview and included questions related to background (e.g. place one grew up, prior HIV education) and demographics; participants were also asked to tell about the first time they used antiretroviral medications informally. Two trained interviewers, each of whom possessed graduate degrees and more than 8 years of interviewing experience, conducted the interviews with topics being discussed as they naturally occurred, rather than maintaining a fixed format. Although a primary focus of the interview was informal antiretroviral medication initiation, participants were also prompted to describe how antiretroviral medications were used and obtained; specific antiretroviral medications taken; and motivations for informal use. Participants were also free to describe related aspects of informal antiretroviral medications use (e.g. benefits of use and efficacy). The interviews were digitally audio-recorded and transcribed by two independent transcribers. Transcriptions were independently reviewed by the interviewers 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 summarise passages of data) and *in vivo* (actual language from participants to name concepts and themes) coding schemes (Saldaña 2013). Memos were written after each participant had been interviewed and after each interview was coded to reflect code choices, and emergent themes and patterns (Saldaña 2013). Two members of the research team 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 help refine the coding scheme and facilitate agreement on code choices (Barbour 2001). Employing a descriptive qualitative approach to analysis (Colorafi and Evans 2016), the final set of codes and their meanings were transformed into longer and more descriptive themes to organise recurrent meanings and patterns and describe the phenomena of interest. Themes and definitions of themes were compared across interviews to ensure consistency and reliability. The presentation of findings includes key themes related to informal antiretroviral medication initiation, use practices, medications, primary motivations, benefits of use, concerns about efficacy and limited knowledge about PrEP. Pseudonyms are reported for all participants.

Results

As shown in Table 1, participants in this study ($N = 30$) were racially/ethnically diverse and included Hispanic ($N = 12$), White ($N = 11$), and Black ($N = 7$) men. Ages ranged from 18 to 62 (median 38, interquartile range 24).

Initiation

Robert described initiating informal antiretroviral medication use based on the experience of his friend who had been raped and given PEP. He said, 'That put the idea in my head [to use antiretroviral medications for prevention] … so that's what I started doing'. Although Robert described self-initiating informal antiretroviral medication use, the remaining

Table I. Demographics and Informal ARV Use Characteristics ($N = 31$).

ID	Age	Race/ethnicity	Primary use practices	Medications used	Primary motivations
Eduardo	25	Hispanic	Before sex	Truvada[a]	Condom avoidance
Michael	22	Black	Daily intermittent; before sex	Truvada[a]	Risk reduction
Danny	35	Hispanic	Before/after sex	Truvada[a]	Condom avoidance
John	25	Black	After sex	Truvada[a]	Feared HIV exposure
Gio	28	Hispanic	Before sex	Truvada[a]	Condom avoidance
Carlos	53	Hispanic	After sex	Truvada[a]	Feared HIV exposure
Jackson	34	White	Before sex	Videx[b]; unknown	Risk reduction
Nelson	18	Hispanic	Daily	Truvada[a]	Condom avoidance
Manny	45	Hispanic	Before sex	Truvada[a]	Condom avoidance
Juan	24	Hispanic	Before sex	Truvada[a]	Risk reduction
Ryan	22	White	Before sex	Truvada[a]	Risk reduction
Richard	34	White	After sex	Unknown	Risk reduction
Russ	52	White	Before sex	Truvada[a]; unknown	Condom avoidance
Jay	42	Black	Before sex	Truvada[a]; unknown	Condom avoidance
Mark	27	Black	Before sex	Truvada[a]; unknown	Condom avoidance
Jim	52	White	Daily	Truvada[a]	Risk reduction
Cesar	23	Hispanic	Daily	Atripla[c]	Condom avoidance
Paul	62	White	After sex	Truvada[a]	Feared HIV exposure
Will	41	White	After sex	Truvada[a]; Isentress[d]	Feared HIV exposure
David	42	Hispanic	After sex	Truvada[a]; Isentress	Feared HIV exposure
Robert	46	Black	Daily	Truvada[a]; Crixivan[e]; Stribild[f]; Viracept[g]; Combivir[h]; unknown	Condom avoidance
Leo	22	Hispanic	After sex	unknown	Feared HIV exposure
Andres	23	Hispanic	After sex	Stribild[f]	Feared HIV exposure
Miguel	51	Hispanic	Before/after sex	Stribild[f]	Risk reduction
Emmett	21	Black	Before/after sex	Stribild[f]; Crixivan[e]	Condom avoidance
George	57	White	Daily intermittent; before/after sex	Stribild[f]; Crixivan[e]	Condom avoidance
Kevin	50	White	Before sex	Truvada[a]; Combivir[h]; AZT[i]	Condom avoidance
Andy	45	Black	After sex	Combivir[h]; Zerit[j]	Risk reduction
Chris	50	White	Daily	Truvada[a]	Risk reduction
Sean	48	White	Daily; before sex	Truvada[a]; unknown	Condom avoidance

[a]tenofovir disoproxil fumarate and emtricitabine (TDF-FTC);
[b]didanosine;
[c]efavirinz, TDF-FTC;
[d]raltegravir;
[e]indinavir sulfate;
[f]TDF-FTC, elvitegravir, cobicistat;
[g]nelfinavir mesylate;
[h]lamivudine, zidovudine;
[i]azidothymidine;
[j]stavudine.

participants described others as facilitating the initiation process. As presented below, two sub-themes emerged: confidence in knowledge shared by others and protecting each other.

Confidence in knowledge shared by others

The most common sub-theme related to initiation was confidence in knowledge shared by others. Twenty participants explained that knowledge about informal antiretroviral medication use was widely shared among friends and sex partners, thus they trusted the knowledge and medications they were being given. Men said that knowledge of informal use was ubiquitous in some social circles, including among men who were unaware of PrEP, and among men who were very sexually active. Jay described it this way, 'It's like somebody spreading a rumour and if you say it to enough people it will get around to other people and people will know'. This same participant said, 'I heard more and more people talk about it more and more. I figured, just try it, you know?' When presented with the opportunity to initiate informal antiretroviral medication use, he did. He described the conversation with his sex partner like this, 'Yeah so it was suggested by [sex partner], "Oh hey I have these [antiretroviral medications], but they're not mine but you could take one and you should be all right". And I was like, "Fuck that. I'll take two"'. Emmett had a similar experience of hearing about informal antiretroviral medications use from within his social circle. He said, 'I was about 18 years old and I had just moved out of my mom's house. I met a couple of people and started asking them, "What's going on?" The medicine came up of course and HIV prevention might be something I want to, you know, look into. So, [my friend] had [antiretroviral medications] prescribed and he started giving me some'.

The majority of participants described having limited knowledge about antiretroviral medications or PrEP, yet they still initiated informal antiretroviral medication use when it was suggested to them. Kevin told of his friend talking him into taking informal antiretroviral medications. He said his friend told him, 'This might work for HIV. Let's give it a try', and he eventually agreed. Ryan described needing little convincing when he learned of antiretroviral medications and initiated informal use while at a party. In his words, 'I was at a party one time and a friend had it and was like, "Oh well, here, have a few". So, I took a few… one guy had something called Truvada he handed out and I guess that was the PrEP medication. A guy handed me four of them and I just popped them all'.

Men said that they had confidence in knowledge shared by others, because the medication was a pharmaceutical product and came from what they considered a legitimate source (e.g. a doctor, pharmacy or hospital). For example, Carlos stated that he shared his anxiety of having condomless sex with a friend and started informal antiretroviral medication use because his friend had a prescription for Truvada. Ryan described two friends who had participated in a PrEP clinical trial. Hearing of their experience was the first time he became aware of PrEP. He said, 'A couple of my friends took the study and they had the pills so I took the pills. I was like, "Well I mean if you're using it and you're negative and I'm negative also, that means I can use it too so that's perfectly fine. So, you get your pills and you can just give me some and we will go from there"'. He continued, 'The first thing I thought of was, "Oh since you're using the pills, you don't have to use a condom, right"', and his friend cautioned that, 'Just because [the medication] prevents HIV, you still should use a condom'. In response Ryan said, 'Oh well, I'll be the judge of that, so...'. This young man trusted that the medication was effective in preventing HIV transmission so much so that he ceased using condoms.

That fact that his friends were obtaining the medication from a clinical trial in a hospital – a legitimate source – was the key in his decision.

Protecting each other

Five men said the initiation of informal antiretroviral medication use occurred through their sex partners. Men described feeling that informal antiretroviral use made sex safer and they also thought their sex partners were being responsible and trying to protect them from HIV infection. Men's experiences were similar to those of Nelson who said, '[A sex partner] suggested it for me. I mean, we were, like, sexually active together and he just wanted, like, to make sure that I was okay'. He went on to say that he was 'excited' about his sex partner offering informal medication because he only recently became aware that PrEP was an option for HIV prevention and he wanted to take it. Several men also said that protecting each other through informal antiretroviral medication use enhanced sex. Men described feeling safer about engaging in riskier sexual behaviours because they were taking the medication. Russ said, 'I think we were talking about [sex partner] trying to make me a bottom because he's well-endowed. Then we were talking about if I would ever let him cum up my butt and then I guess we started talking about meds. Then we might have discussed sharing his meds and stuff to help me, you know, or to help protect me'.

The act of protecting each other also occurred among friends who considered sharing informal antiretroviral medications with others to be an act of altruism. Participants believed they had people in their lives who wanted to help protect them. As an example, Manny said he has known men who came to him and said, 'Hey, if you ever need anything you can give me a call and I'll help you out, give you some pills'. Similarly, Jackson described an HIV-positive couple he was friends with who asked him how he would protect himself when he had sex, and how he would handle it emotionally if he were to become HIV infected. Following the conversation, the couple gave him some antiretroviral medication and told him that taking them, 'wouldn't hurt'.

Informal use practices

Many participants described continuing to use the medication in the same way they initiated it with most taking informal antiretroviral medications prior to sexual intercourse. Men recounted taking the medication the morning before and immediately before/during sexual intercourse. Jay said, 'I take one, sometimes two to five, a little while, like maybe an hour or so [before sex], you know, like let it take effect'. Similarly, Kevin stated, 'I always take it before. Like we talking about 45 min before I actually get into the sex act with somebody so it's in my system. I take two of them, I take the Truvada and I take the Combivir. I take them together, like a little cocktail thing'. Russ said that he took informal antiretroviral medications prior to sex, 'a couple of hours, usually during a party session', and described how antiretroviral medications were often combined with methamphetamine use, 'They have this little linkage between sex and drugs'. Likewise, Ryan described informal antiretroviral medications being consumed together with drugs during group sex.

For Michael, who obtained pills from his friend enrolled in a PrEP study, his informal antiretroviral medications use varied. He said, 'So I took it [daily] for like a week and then everything was fine I didn't feel no different. And then I was like okay, "I could get used to this". And then I slowed down and it was like every other day. And sometimes it was like right

before if I was gonna have an intercourse or something like that and then I'll just pop a pill and be like, "I'll be fine". So, I did it like that'.

Other men reported taking informal antiretroviral medications after sexual intercourse out of fear of HIV exposure. Leo and Andres described taking a pill given to them by their partner immediately after sexual intercourse. Others waited several days before taking the medication after speaking with friends and obtaining the medication that way. As Paul noted, 'Usually within 24 hours I was able to procure a pill or two'. None of these men's informal antiretroviral medications use cohered with standard PEP regimens.

A few men preferred to take the pills both before and after sex. Although this practice more closely aligns with on-demand PrEP, none of the participants were unaware of its existence; rather they used informal antiretroviral medications in this way because they were unsure of the appropriate way to use the medication. Danny described his practice this way, 'Let's say I'll see [sex partner] today. I would take [informal antiretroviral medication] yesterday or two days before, and I'll probably take it tomorrow or a couple days after. There's no schedule to it. I don't know exactly how to take the medication, but I would do it that way'. Similarly, Emmett stated, 'Before and after... I didn't really know how [antiretroviral medications] worked so, you know, I took one before and I took the one after just to be safe'. George described taking informal antiretroviral medications daily during an 'active week' when he engaged in frequent sexual activity but he would also 'take precautions' and use the medication for another two to three days afterwards.

Seven men described experiences of taking informal antiretroviral medications daily or near-daily, which more closely conforms to the CDC recommended PrEP regimen (CDC 2014). Sean said, 'I take it probably twice a week. Just you know, as a preventative measure, regardless of whether [I'm having sex or not]'. One heterosexually married man, Jim, who engaged in sex with other men only once a year during an annual two-week retreat, said he took informal antiretroviral medications 'For 28 days. A week before, two weeks during and a week after'. Mark stated that initially he took informal antiretroviral medication a few hours before sex and, 'then I started doing it like every day because I was having too much unprotected sex'. Cesar took his HIV-positive boyfriend's extra medication daily for some time. However, eventually he decided to quit using the medication and only take it if he became infected with HIV.

Following the suggestion of HIV-positive friends who provided the medication, Nelson and Robert took informal antiretroviral medication daily. Robert said, 'I take one in the morning and one at night. Sometimes, yeah there are days when I don't take it. I don't take – sometimes I miss a couple days…but I try to build up a… defence to it. If I do have sex, I already have some in my blood'. He reported taking the medication a minimum of four days per week; both men stopped taking informal antiretroviral medication when they lost access to the diverted medication.

Medications

Several participants did not prefer a specific informal antiretroviral medication and used the medications that were available to them, and multiple participants reported a history of taking more than one antiretroviral medication informally. Five men described using a combination of pills, or a 'cocktail'. However, the most commonly used medication among men in the study was TDF-FTC. Jay stated, 'A lot of people say to use Truvada. I don't know why.

They said it was newer and it was apparently supposedly the best one'. Some men reported a limited familiarity with Truvada. Gio stated, 'Way before [using informal antiretroviral medication] I read it online... the Truvada, they had just recently come out, like, the FDA approved it. Then like this person, they had, you know, the medication so I took the pill and then without a condom, I had sex'. Similarly, Jim said, 'My [sex partner] up in North Carolina – he, he got it when they were doing studies on it and… found out it wouldn't kill you, so he said, "Hey, let's try this". And then it became, you know, the PrEP drug. I take the 200 mg and that's fine for my weight'.

Stribild (a combination of TDF-FTC, elvitegravir, cobicistat) was also a preferred medication for some men. This is because of its limited side effects compared to other medications that men had tried. Three men described experiences like that of Robert who said, 'I used to take Crixivan … there were a couple of other ones. I had to find one that didn't give me diarrhoea, so... [Stribild] really doesn't give me the side effects…so I'm sticking with it. I'll hunt and hunt until I find the specific one. I got a person I go to now that gives me that specific one'. George stated that in addition to experiencing fewer side effects from Stribild, he preferred to use the informal antiretroviral medication recommended by his friends who provide the medications.

Primary motivations

Some men stated that their motivation for using informal antiretroviral mediations was to avoid condom use. Emmett said, 'I don't feel like I need to use [condoms], 'cause I know all of [sex partners] personally. But I still use the medication because I don't know who they're messing around with'. Manny noted, 'I disregarded the condom after I was taking [informal antiretroviral medications]. Most of the people I was with preferred without a condom'. Russ said, 'Those of us that like to bareback, either the condom doesn't fit, or you don't like it'. Others, including Mark and Cesar, described the desire to increase physical pleasure and emotionally connect with their sex partners as the motivation to use informal antiretroviral medications rather than condoms. Emmett summed it up in this way, 'Condoms, I don't use. The medicine is pretty much my prevention. [Sex] feels a lot better. That's what it boils down to'. Finally, Kevin expressed his belief that antiretroviral medication use was safer than using a condom and said, 'You got this here works 100% [antiretroviral medication] and this ain't [condoms]. So, which one you gonna pick? You not gonna take something that's gonna throw you in the boat to where it's a 50–50 chance that thing can bust anytime. And if it busts and there's any blood, semen contact, you're fucked. Now if you take [antiretroviral medication], whether busting a condom, and it's keeping you from catching [HIV], I'm gonna keep taking that'.

Some men described informal antiretroviral medication use as a risk reduction strategy. Much of the time, participants used condoms alongside informal antiretroviral medications. Miguel said, his HIV prevention strategy consists of, 'rubbers and taking pills'. Others said they used informal antiretroviral medications as a risk reduction strategy when they felt their sexual activities were especially risky. Illustrative of this practice was Jackson who described using informal antiretroviral medication and condoms with his HIV-positive long-term partner because, 'Using the condom…they are not 100% and so, you know, better safe than sorry'. Others, including Michael, stated that they did not use antiretroviral medication informally with regular sex partners, 'Because it was people that I already knew so it's like, I was

comfortable with them'. Yet, he also occasionally engaged in transactional sex and said, 'But when it came to the whole sex and money and things like that, that's when I wanted to start taking the pills more because it's like, I want to take the extra precaution with that'. Several participants noted that while they simultaneously used condoms and informal antiretroviral medications on occasion, the preferred method was the latter.

Seven men reported that antiretroviral medications might be taken informally following an 'accident', a condom breakage, the discovery of a sex partners' HIV-positive status following intercourse and, in one case, a participant experienced a needle stick injury from a used epinephrine pen that belonged to an HIV-positive friend. All of these men described being aware of their risk behaviours and generally protecting themselves against HIV. However, on occasions when participants felt HIV exposure might have occurred, they used informal antiretroviral medication as PEP in response to feelings of guilt, worry and 'emotional anxiety'.

Positive and negative sentiments

When asked about their informal antiretroviral medication use, the most common response men gave was that it made them feel more 'confident' or 'comfortable'. In the words of Kevin, 'It makes me feel a lot better because I feel confident and competent that I'm not gonna catch something. To me, that's very important, that I can lay there and be comfortable with whoever I'm with and I don't have to worry about, you know, being nervous or all the other crazy stuff'. Nelson expressed similar comments stating, 'I was just more confident that you couldn't get, like, a viral infection'.

A small number of men stated that informal antiretroviral medication use improved their sexual lives and allowed them to be free to have many sexual experiences with limited worry. 'I'd say I kinda feel bullet proof actually… it's a mix of the alcohol and I got the [antiretroviral medication] pills so I just feel like, "Wow! I can fuck anybody"', (Ryan) and, 'Now I can fuck without having to worry about it. Yeah, I'm glad that [sex partner] told me that because I really didn't know anything about it', (Manny).

Finally, three participants described informal antiretroviral medication use as being beneficial to their relationships. Danny said and taking antiretroviral medication informally left him with less worry because he did not know for certain if his partner was monogamous. Men also said sex partners found their informal antiretroviral medication use to be beneficial. In the words of Sean, '[Informal antiretroviral medication use] makes [sex partners] feel at ease too, if I discuss it with them'. Similarly, Jackson said that his sex partner, 'wasn't angry at all… no remorse. He was happy. It was good'.

Five men felt at ease using antiretroviral medications informally, in part because they considered it to be, 'a birth control for gay guys', or like, 'a Plan B' emergency contraceptive. Among men with an awareness of it, FDA approval of Truvada supported the perception that using informal antiretroviral medication was a safe choice. As Gio stated, 'I was like, "It must be like a birth control; it's supposed to be effective", you know? I'm like, "It's FDA approved", so I kind of trust it'. Michael added that having such a 'birth control' affords one the freedom to engage in risky behaviours without worry.

Although most men described positive sentiments about using antiretroviral medication informally, four participants expressed negative feelings associated with antiretroviral medication use and such feelings caused anxiety. Andy said, 'It didn't make me feel good for

using [antiretroviral medications informally], when I think about it. You ain't supposed to use drugs so, um, I didn't feel bad at the time, but after a while I felt worse about it. I ain't even talk about it 'cause I don't want nobody to know I did that'. Describing similar sentiments, Mark said, 'I know it's not right to take other people's pills… I don't think it's the safest thing to do, but, I do it anyway'. Richard, who received antiretroviral medication from his sex partner experienced anxiety after using them and said, 'It made me think about him and if he was truly negative or not'. As is seen in these statements, men's negative statements raised ethical concerns about taking another person's medication and doubts about one's relationship.

Concerns about sufficient protection

Even among men who reported positive experiences with informal antiretroviral medication use, there were men who reported concerns about whether the informal use of antiretroviral medication offered sufficient protection from HIV transmission. This is striking considering that all participants in the study reported informal use and the majority described the practice in positive terms. This contradiction in thinking is best exemplified by Ryan, who said that informal antiretroviral medication use made him feel 'bullet proof', yet later in the interview he posed this question, 'If I actually knowingly screwed somebody with AIDS… would [the antiretroviral medication] actually work?' Others, including George, asked similar questions, 'Is it really working, as far as a good preventative?' Among participants who described concerns, three men did so because they lacked education about the appropriate means by which to use the medication. Illustrative of this is Danny who said his informal use, 'kind of helped me mentally', but went on to share his concerns stating, 'I don't feel like I'm taking it the right way and I don't know much about it'.

Limited knowledge about PrEP

Even after initiating informal antiretroviral medication use, five participants were unaware of the existence of PrEP as an option for HIV prevention and these men stated that they had not received any education or information about it. Jay expressed disbelief in PrEP's existence. He said, 'When wonder drugs come… Viagra, Cialis… it's the commercial. It gets played 24 hours a day. So, if something came out and it actually worked and it is FDA-approved and all that other shit, then there would be commercials, prescriptions, government programmes'. Because this participant had never seen PrEP promoted or heard it mentioned, he was completely unaware of its existence. This is remarkable, considering that he was informally using antiretroviral medication for HIV prevention.

The remainder of men described themselves as being somewhat familiar with PrEP, but were largely unaware of basic details (e.g. recommended regimen, medication prescription requirement), and this created concerns. Miguel said the informal use of Stribild gave him 'peace of mind' but during the interview he asked many questions about antiretroviral medication and PrEP. After completing the semi-structured interview protocol and receiving some information about PrEP, including the FDA-approved medication, Truvada, he said, 'And now I get to doubt, 'cause you said they have specific pills [for PrEP]'.

Men's ignorance of the approved PrEP regimen was illustrated in the informal antiretroviral medication use practices. For example, Jim described the benefit of taking the medication

intermittently with weeks of heavy use and weeks without using the medication. Using it in this way, he said, 'I would imagine it would work better because my body wouldn't have built up a tolerance to it'. George described similar thoughts and stated that taking informal antiretroviral medication regularly could lead to the body becoming immune to the medication and, 'over time it may become null and void. If you're using it constantly, you know, day to day to day, it's like penicillin. If every time you got some kind of virus or sore throat, penicillin is eventually not gonna work'.

Discussion

Limited data have suggested that gay and other men who have sex with men are using antiretroviral medications informally in the USA, but this study is the first to examine the phenomenon in-depth. Some men described informal antiretroviral medication use practices similar to the recommended PrEP regimen (CDC 2014) or the on-demand PrEP protocol (Molina et al. 2015). However, individuals who use PrEP require frequent testing, regular health monitoring and ongoing behavioural support (Koenig, Lyles, and Smith 2013; Smith et al. 2011; Weber, Tatoud, and Fidler 2010). Participants who reported informal antiretroviral medication use on the other hand are not engaged in these services and many informal antiretroviral medication use practices described by study participants differ from recommended PEP and PrEP regimens or CDC guidance. Moreover, participants described using a range of medications not approved for PrEP and combining several medications as an HIV prevention 'cocktail'. Intermittent or sporadic use of antiretroviral medication, inconsistent access to medication and the use of medications not approved for PrEP may potentially leave men with less protection against HIV infection, and contribute to HIV transmission, resistance or adverse effects including drug toxicity, drug interactions and hypersensitivity reactions (Dimitrov et al. 2012; Günthard et al. 2016; Smith et al. 2011).

Previous research has documented antiretroviral medication diversion, misinformation about PEP and PrEP, and raised concerns about the use of diverted antiretroviral medications for HIV prevention by HIV-negative men (Kurtz and Buttram 2016; Kurtz, Buttram, and Surratt 2014). Initiation of informal antiretroviral medication use among HIV-negative individuals in this study often occurred at the instigation of HIV-positive sex partners, friends and relatives. The data also indicate that HIV-negative participants are sharing antiretroviral medications and initiating others into the practice. Participants also described obtaining diverted medication that originated from men with PrEP prescriptions and other unknown sources. Continued research on antiretroviral medication diversion and informal use, including the examination of associated factors (e.g. race/ethnicity), is needed.

Motivations for use included condom avoidance and risk reduction, especially among participants who reported taking informal antiretroviral medications more frequently and regularly before sex. These data also reinforce existing research which documents the feasibility and acceptability of PrEP use among men and the desire to use this HIV prevention technology (Adams, Shinefeld, and Brady 2016; Hood et al. 2016). The willingness to use antiretroviral medications for HIV prevention among study participants is noteworthy, considering that most men reported limited or no knowledge of PrEP or PEP. While the intermittent and informal use of antiretroviral medications may provide some level of protection against HIV transmission, the benefits of antiretroviral medication use in these unconventional and untested ways is unknown.

Several recommendations derive from this study. Given that nearly all men described having limited knowledge of PrEP and five participants were unaware of its existence, PrEP education needs to become more widespread. Gay and other men who have sex with men, including those who are HIV-positive and those with and without a PrEP prescription, need to know the proper use of and benefits associated with PrEP and potential risks related to diversion and informal use. Increased PrEP education would also address the concerns related to the efficacy of the medication, and potentially contribute to greater uptake of and adherence to medically supervised PrEP regimens.

Potential PrEP education dissemination sites include traditional locations (i.e. HIV testing sites and LGBT-based health and social service providers). However, multiple study participants described receiving information about antiretroviral medication use through peers. Social networking applications targeted toward gay and other men who have sex with men such as Grindr offer opportunities to provide PrEP education, influence the sharing of correct information and combat misinformation. Including specifically tailored messages for Black men and other sub-groups of gay and other men who have sex with men is also needed (Thomann et al. 2017).

In addition to education, enhanced engagement between clinicians and patients regarding informal antiretroviral medication use and diversion is also be needed. Given the present findings and previous reports of antiretroviral medication diversion (Kurtz and Buttram 2016; Kurtz, Buttram, and Surratt 2014), it may be beneficial for clinicians to discuss concerns related to informal antiretroviral medication use and diversion with their patients. Decreasing antiretroviral medication diversion would likely reduce informal use and potential risks it may carry.

Several study limitations must be noted. As with all qualitative research, there is a potential for interviewer effects and the underreporting of social undesirable behaviours. The interviewers' training, experience and the use of a semi-structured interview guide likely mitigated these effects. Participants were drawn from a convenience sample in South Florida and the findings are not generalisable to other locations or populations.

To conclude, given the potential of PrEP to prevent HIV infection, efforts should be made to enhance access to this HIV prevention technology. As more individuals start using PrEP, informal antiretroviral medication use and related concerns – including adherence, diversion and antiretroviral medication resistance – must be considered. Enthusiasm for biomedical HIV interventions among gay and other men who have sex with men appears to be high. Building on this enthusiasm, efforts should be made by researchers, public health officials and community and social services agencies to increase PrEP awareness and acceptability and decrease informal use and diversion.

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