

'Get up, brush teeth, take PrEP': a qualitative study of the experiences of London-based MSM using PrEP

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Abstract

Pre-exposure prophylaxis (PrEP) is highly effective in preventing transmission of HIV among at-risk groups. A qualitative study with 13 PrEP-using men who have sex with men (MSM) recruited from London, UK, utilised semi-structured interviews to understand knowledge of PrEP, experiences of using PrEP and potential barriers and facilitators to its use. Thematic analysis of transcripts identified six themes: (1) PrEP and condom use; (2) lessened anxiety around HIV; (3) increased intimacy and pleasure; (4) sense of sexual liberation; (5) ease of using PrEP; and (6) activism as an 'early adopter' in current UK context. Findings indicate a PrEP-mediated shift in how 'risk' and 'protection' are conceived. While experiences demonstrate an overall positive affect of using PrEP, the potential impact of decreased condom use on STI rates requires consideration. Ensuring PrEP is embedded in sexual health services that provide adequate surveillance, testing and treatment for other infections may be a way to mitigate the change in behaviour and outweigh the potential risks other infections.

Keywords: PrEP, MSM, HIV prevention, motivations, risk

Introduction

Pre-exposure prophylaxis (PrEP) is a biomedical HIV prevention strategy that has been demonstrated to be highly effective in preventing transmission of HIV. The use of the antiretroviral combination therapy tenofovir disoproxil fumarate and emtricitabine (TDF/FTC) as an oral PrEP drug is supported by a number of placebo randomised control trials [1–4], and research is currently being undertaken to look at the efficacy of other similar oral antiretrovirals including tenofovir alafenamide and emtricitabine (TAF/FTC) [5]. PrEP has been endorsed as a risk-prevention strategy for individuals in groups who are considered high risk, including men who have sex with men (MSM) who engage in condomless anal sex [6].

In England, PrEP was first made available to MSM through the PROUD (Pre-exposure option for reducing HIV in the UK: immediate or deferred) study in 2013 and although the study reported similarly high levels of effectiveness as previous research [7], access to PrEP has faced organisational and institutional challenges preventing its widespread availability. Currently a proportion of MSM access PrEP through the IMPACT implementation study by NHS England and some through the aforementioned efficacy trial (DISCOVER). As there was some time lag between the initial studies and the research currently in progress some MSM began to source PrEP through other means, including private prescription services and international online pharmacies. Due to the nature of the methods of access, gaining an understanding of the number of MSM acquiring PrEP in this way is difficult [8].

In spite of supportive efficacy trials, so far there is limited evidence regarding the contextual factors of an individual's understanding and use of PrEP, and

little research explores how it has been incorporated into participants' existing HIV risk-reduction strategies, especially with a UK participant base. Older studies highlighted a lack of knowledge of PrEP [9,10], yet more recent studies suggest a much higher awareness of PrEP among MSM. PrEP is considered a significant advancement in HIV prevention and there are high levels of acceptability among users [9–14]. Some research suggests PrEP can help individuals manage the anxiety associated with the risk of HIV [11,12].

While PrEP allows individuals to have more enriched sexual experiences [11,12], there is conflicting evidence regarding increases in risky sexual behaviours in the context of PrEP. Some studies have noted an increase [15], or the cessation of other risk-reduction strategies [16], and others not [12]. For individuals already engaging in high-risk sexual behaviours and employing fallible risk-reduction strategies PrEP became a useful addition to their options for safer sex [12,16] or to protect themselves more effectively when using other imperfect risk-reduction strategies [11,12].

There are also some potential barriers to PrEP use among MSM, for example a lack of awareness of own HIV risk [14], and the stigma associated with PrEP use affecting adherence to medication [11]. There are also concerns about side effects associated with PrEP [17], or the impact of using PrEP on an individual's general health [8]. Concerns too have been identified about sourcing PrEP, such as the legitimacy of medication bought online [8], preference of prescription and oversight of a sexual health clinician [8,9].

Given the dearth of qualitative research exploring the experiences of UK PrEP users, this study aims to understand how PrEP is placed within the narratives of MSM who use it. By analysing discourses around

PrEP, covering areas such as risk, perceptions of self and others, and relationships, this qualitative study illuminates what we can learn from the MSM who use PrEP, paying particular attention to their motivations for using PrEP within the evolving landscape of HIV prevention. In the light of no established PrEP service on the NHS, results of this study may be of interest to policymakers and commissioners who would like to understand how PrEP is integrated into MSMs' sexual health strategies.

Methods

Study design

This study employed a qualitative design to explore the experiences of PrEP-using men in London, UK. The inclusion criteria for participation were that participants: (1) were aged ≥ 18 years; (2) identified as MSM; (3) lived in the Greater London area; (4) were English-speaking; and (5) had taken PrEP in the last 6 months. Recruitment to the study took place through an advertisement on the social media page of Prepster, a UK-based non-profit community group. Once potential participants had indicated their interest they were contacted by the research team to obtain consent and a telephone interview scheduled. Ethical approval for the study was granted by the Research Ethics Committee in the School of Health Sciences at City, University of London.

Interview procedure

Semi-structured telephone interviews were conducted with participants. A topic guide was developed from emergent themes found within previous qualitative research and after the first few interviews the topic guide was refined to allow for other topics that had been discussed to be included for all interviews. It covered areas such as becoming aware of PrEP, perceptions of risk and reflections on how PrEP has impacted sexual behaviour; and general questions about the PrEP user's own experiences.

Participants

A total of 13 men took part in interviews for the study. Most participants had accessed PrEP either through online pharmacies or through the ongoing Public Health England IMPACT trial. All participants reported consistent use of PrEP on the daily dosing regimen and had been using PrEP for at least 6 months. Participants' age ranged 26–56 years with a mean age of 37 years. Of these, nine identified as White British, two were Black British, one was British Indian and one did not identify his ethnicity.

Data analysis

Interviews were recorded digitally and transcribed verbatim. Thematic analysis was used following the approach described by Braun and Clarke [18]. Initial codes were generated inductively to allow for an understanding of the nuances within PrEP user experiences and then higher-level codes relating to participants

motivations for using PrEP were identified to create grouped themes from the emergent initial codes. All emergent themes were discussed and agreed by the research team. Analysis and data management were aided by QSR NVivo 11.

Results

Six interconnected themes related to the experiences of men using PrEP were identified: (1) PrEP and condom use; (2) lessened anxiety around HIV; (3) increased intimacy and pleasure; (4) sense of sexual liberation; (5) ease of using PrEP; and (6) activism as an early adopter. Participant data presented in this article have been pseudonymised to protect the identities of those who took part.

PrEP and condom use

All participants reported that their initial primary motivator for taking PrEP was to reduce their risk of acquiring HIV. Some participants described previous occasions where they had knowingly engaged in risky sexual behaviours and the use of PrEP would now help eradicate the risk:

'I started taking PrEP because I'd just come out of a long-term relationship and my mental health wasn't the best, and I actually was having a lot of condomless sex, so I was taking risks.' (Andrew, aged 28 years)

For other participants, while they had not been engaging in condomless sex prior to adopting PrEP, they were motivated to use it because they felt they had a high theoretical risk of acquiring HIV. For some this risk was increased because they were a gay man. Others reported a high theoretical risk because they were from a particular ethnic group or because they lived in a certain part of London. For one participant, it was because of all three:

'In terms of my likelihood of catching it and stuff? Yeah, I would say it was probably relatively high, based on being black and gay, living in Kennington and having Grindr sex. Most of the time the sex was with a condom, but generally the odds are stacked against you in that fact.' (Paul, aged 29 years)

Almost all participants reported changing behaviours regarding their condom use since starting PrEP. For some, PrEP had completely replaced their use of condoms:

'It didn't really add to my inventory as such, I just kind of stopped using condoms and started using that [PrEP] instead.' (Stephen, aged years 32)

PrEP had now become a useful addition to their range of options when it came to making decisions about whether to use a condom or not. For example, John, who would normally use condoms and PrEP, in a situation where both parties were on PrEP decided that he could forego condoms as the perceived risks of acquiring HIV were minimal:

'I can't say that I put such an emphasis on condoms these days ... there have been occasions where we've both been on PrEP and we're like okay, the risks are low, so let's have some fun.' (John, aged 26 years)

In this new context, a few participants said that with the advent of PrEP, they would now seek out condomless intercourse only:

'I actually decided that I didn't want to have sex with condoms at all anymore, so it actually became a sort of ruling anyone out who would only use condoms ... I don't want to use them anymore because I don't have to.' (Stephen, aged 32 years)

However, it was more common that participants would allow the decision of whether or not to use a condom to be made by their sexual partner, even if their own preference was to not use a condom. They often felt, that as they were protecting themselves they didn't need to be part of the decision-making process:

'The only time condoms come into play now, is if the other person requests to use a condom.' (Paul, aged 29 years)

'Sex with a condom now tends to be a decision that the other guy makes. I let them make. I sort of don't mind either way.' (William, aged 45 years)

When faced with the option of having sex with a condom, some were unsure whether they would have sex with the person if condoms had to be used:

'If they wanted to use protection, I don't know whether I would have gone through with it ... It was a negotiated thing before ... This is after PrEP.' (Christopher, aged 42 years)

Lessened anxiety around HIV

All participants reported having suffered from anxiety prior to using PrEP due to the elevated risk of acquiring HIV as sexually active gay men. This applied to participants regardless of the actual risk associated with their specific behaviours and included those who were risk averse and who had numerous risk-reduction strategies in place. Through taking PrEP, anxiety was substantially reduced, and for some it was completely eradicated.

Some older participants recounted memories of the emergence of AIDS as an existential threat in the 1980s and the persistent internalised fear since then that their sexual behaviour, regardless of risk-reduction strategies, would somehow lead to an HIV diagnosis:

'I can always remember ... the campaigns in the 80s and 90s, if you were straight the worst thing that could happen to you if you had sex was you would have a kid. If you were gay, you died. That's the kind of thing that we were growing up with.' (Anthony, aged 45 years)

'Having gone through the 80s with that whole, don't die of ignorance kind of thing, slightly frightening, people died, it was a killer.' (William, aged 45 years)

For younger participants, most of whom came of age after effective antiretroviral therapies were already in widespread use, the desire to avoid HIV was no less strong:

'PrEP has got rid of the anxiety and the stress about contracting HIV, which you kind of live with, even if you are using condoms.' (Andrew, aged 28 years)

Many participants reported previous worries when having an HIV test as part of routine sexual health screening. Despite not necessarily having put them-

selves at risk, the fear of a positive test result still loomed large:

'There's been many times where I've, you know, felt really really anxious about getting tested and then getting my results, you know, it was a horrible, horrible place and it was all you could think about, like that's the only thing in your life that matters at that moment and then you realise everything's okay and you go back to normal; and then maybe in a few months' time you do it all again, you repeat and so I wanted to escape that because, you know, it's a horrible feeling and it's something that if you can get rid of then you would.' (Ian, aged 27 years)

Some participants described occasions when they irrationally worried about potentially seroconverting, through using PrEP these occasions no longer occurred:

'Like every time you get a head cold, is that a seroconversion? That moment, that kind of moment, has faded away ... if I wake up with a blocked nose, or a random head cold, I'm no longer thinking "Is this something bigger?" or is it that I've fallen asleep with the fan on again? Which is more likely.' (Paul, aged 29 years)

Increased intimacy and pleasure

Many of the participants described how their adoption of PrEP allowed them to enjoy sex more and some described associated feelings of being able to be more intimate with partners. For some it was an increased level of trust between partners that had an impact on their increased feelings of intimacy:

'There's a trust based thing. It's this whole romanticisation, oh he must trust me, he must care for me, that immediate feeling.' (Christopher, aged 42 years)

For others, a reduction in the anxiety related to HIV risk made sexual encounters feel more physically pleasurable:

'All these things would be going through your head while you're having sex with them and it would be pretty distracting, as you can imagine, when you're having sex with someone you want to be enjoying the moment, and I never really could before. Whereas now I don't have that at all, so there is that like, level of intimacy and pleasure that I can be a lot more involved in the ... it's definitely made it a lot more liberating.' (Ian, aged 27 years)

An increased physical pleasure was also felt by some participants, as demonstrated by Paul when talking about a sexual encounter since starting PrEP:

'It definitely feels easier. I definitely need less lube, I would say definitely, like a lot less messy in that regard as well ... sex just feels, it does hurt less without a condom for sure.' (Paul, aged 29 years)

Sense of sexual liberation

Numerous participants recounted how their adoption of PrEP had help engender a personal sense of liberty and agency influencing how they perceived themselves as sexual protagonists. The ability to minimise their risk of HIV via PrEP, as well as dispensing with condoms, meant they were able to explore and experiment in ways they had previously eschewed:

'I kind of liked the idea of not having to worry about condoms I suppose. And I thought it would help improve

my sex life a little bit and you know, I've always been, sort of, up for trying new things. (Stephen, aged 32 years)

For those participants who sought out sex in sex clubs, many felt that starting PrEP had allowed them to be more at ease when seeking encounters in these venues, and also felt freer to explore the option of condomless sex in these clubs:

I do also have sex in sex clubs ... it was becoming almost the norm for guys to be having sex without condoms ... I'd observed that, but not been part of it ... and now because I'm on PrEP, I'm, you know, not concerned, or less concerned about, about my sexual health because of PrEP. So in a sense it opens up opportunities and I behave slightly different in that environment. (James, aged 56 years)

For some participants, PrEP was perceived as enabling them to embrace a more uninhibited side of themselves which had been hitherto been repressed. For Stephen, engaging with another aspect of his sexuality was felt to be a positive experience, and had been facilitated through PrEP:

It changed my behaviour by turning me into a bit of a cum whore. I developed a new fantasy of being given multiple loads by different guys over a day/weekend. (Stephen, aged 32 years)

Additionally, some participants described how their adoption of PrEP had transformed and normalised their perceptions of gay sex in general. Free of the risk of HIV and no longer restricted by obligatory condoms, it was deemed repositioned as 'normal' and compared favourably with the perceived experiences of their heterosexual counterparts:

I think we're finally in a position where gay men can have the sex they want ... we just want to have the sex that straight people are having, and I don't see the issue with that. (Andrew, aged 28 years)

Ease of using PrEP

The simplicity of the PrEP drug regime was recounted by many of the interviewees where taking a daily tablet as a method of HIV prevention was seen as streamlined and straightforward. Many participants had integrated taking PrEP medication into their daily routine:

I do the daily in the morning time ... It's just easier. Get up. Brush teeth. Take PrEP. Shower. It's quite easy. (Paul, aged 29 years)

Most participants described occasions where they had difficulty using condoms. These difficulties included occasions where the need for a condom interrupted the flow of sex, its use impacted on erectile function, or indeed occasions where condoms were not available:

On the whole, [PrEP] gets rid of that clumsy awkwardness right in the middle of the moment. (Michael, aged 37 years)

I have a physical disability ... which makes putting condoms on very difficult. If I want to put them on myself ... faffing about with a condom is not my ideal activity. I've always found them difficult and so not using them, and preferably not using them, has been liberating. (Christopher, aged 42 years)

Activism as an early adopter

A majority of the participants had initially sourced their PrEP from online pharmacies (and later via trials), with their decision to purchase the drug partially predicated on a desire to make a political statement and help engender a paradigm shift in how gay sex is perceived and experienced. David remembered being sexually active when HIV first emerged in the 1980s, and how since then wearing a condom became a badge of responsibility in the context of efforts to control spread of the disease. For him, the adoption of PrEP had similar connotations:

'As many of us as possible were consistent condom users for blocks of time, that was something we did, I always saw that as an act of solidarity ... right now, this [PrEP] is one way collectively we can do something and by doing it, I think it's actually an act of erm, it's almost like an act of civil disobedience, it's an act of advocacy, it's an act of activism.' (David, aged 50 years)

Using PrEP generated a sense of contributing to a 'greater good' which could potentially improve the health of others, and these perceptions further reinforced their motivations for using it. Some participants said that they recognised that PrEP was a relatively new way of preventing HIV, and that they often encountered other gay men who were less informed. On these occasions, some saw opportunities to inform others about the benefits of PrEP:

'Especially more where I go to, well I go to Scotland and Glasgow quite regularly, every couple of months ... there's less knowledge about it up there. They're often like "what is that" and then we have a conversation about it.' (Paul, aged 29 years)

Sometimes participants actively sought out the opportunity to share their experiences with others, and they generally saw this as a positive thing:

'Well, it makes me feel like a teacher and an educator and the next generation up, and quite old! ... It's like helping someone who needs directions, you know. Helping someone on the street ... If I can give them the correct information then I will.' (Christopher, aged 42 years)

One participant reflected upon his role of being an educator to his peers, and, after hearing of a friends' new HIV diagnosis, was even more motivated to be a role model for other gay men:

'Most of my friends are all gay guys so, you know, I talk to them about this sort of stuff ... I've mentioned, oh guys I'm on PrEP you should think about doing it ... One of my team mates got diagnosed with HIV and it was quite a shock really and I kind of just thought, oh why didn't you just come to me before, I could have helped you know, I could have helped him get on PrEP, it was so frustrating.' (Ian, aged 27 years)

Discussion

This study aimed to illuminate the experiences of PrEP-using MSM in London. Men in this study primarily used PrEP because of its ability to prevent HIV. Participants also used PrEP for its psychosocial benefits, in particular, managing the anxiety associated with acquiring HIV. Furthermore, with respect to identity as a PrEP user,

many felt that taking PrEP and advocating its use, allowed them to show solidarity against HIV. Finally, almost all participants had stopped using condoms.

A strength of this study is that it is one of the first UK qualitative studies to capture the experiences of PrEP-using MSM in London. One of the limitations of this study was that it used a digital sampling strategy through PrEPster, leading to possible social desirability bias. The majority of participants were early adopters of PrEP, and access medication through the IMPACT trial, as such they may not necessarily be representative of MSM in general.

PrEP is still a relatively novel HIV-prevention strategy and much of the research focus to date has been on MSM, little is known about other at-risk populations, such as minority ethnic communities, heterosexual men, women and transgender people. The impact of decreased condom use among PrEP users on STI rates, and monitoring of novel STIs such as *Mycoplasma genitalium* requires careful consideration. Although participants cited ease of use, evaluation of 'real-world' PrEP use (missing doses, taking friends' ARTs etc.) would be prudent to explore. Finally, the longer-term impact on wellbeing and reductions in HIV-related anxiety, including in low-risk individuals, warrants further research.

The reduction in condom use among participants is in contrast to other studies [19], and is something that PrEP sceptics have outlined since its advent [15]. Risk compensation raises the issues of other STIs, which is a particular concern given that a recent meta-analysis of PrEP studies found very high rates of STIs among MSM PrEP users [20]. That said, notions of 'risk' and 'protection' in the PrEP era among patients may be changing, and perhaps requires a redefinition of these terms that incorporates the protection afforded by this biomedical intervention [21].

Consistent with other studies this research suggests that PrEP may also reduce HIV-related anxiety [11,12] and positively contribute to wellbeing [22,23]. This may be a motivator for many, including low-risk behaviour PrEP-using MSM, which until now has been unaddressed by other HIV prevention strategies. This is of particular importance in a population who are statistically more likely to suffer from mental health illnesses [24] and experience inequalities in access to mental health services [25]. In low HIV-risk MSM however, needs should be weighed against possible risks associated with PrEP (e.g. renal impairment), and that some MSM may be misclassifying themselves and be at a significant risk of HIV acquisition [26].

Conclusion

PrEP is an acceptable HIV-prevention intervention for MSM in London, however motivations to use PrEP extend beyond HIV prevention. This qualitative study noted increases in condomless anal sex among participants, which has possible implications for STI risks. Given PrEP efficacy in preventing HIV acquisition, consideration should be given to how 'risk' and 'protection' is discussed with patients. Early adopters

of PrEP, such as the participants in this study, may have an important role in promoting PrEP and shaping services as PrEP becomes more widely available.

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Conflicts of interest

The authors declare no conflicts of interests.

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CPD: HIV, disability and rehabilitation

Answers to self-assessment quiz

1. Medical model of disability.
2. The International Classification of Functional, Disability and Health (ICF).
3. Identifying 'uncertainty' or worrying about the future as a key dimension of disability, plus the episodic nature of disability over time.
4. Any physical, cognitive, mental and social health-related challenges that can be experienced as episodic in nature.
5. Functioning.
6. UK Equality Act disability definition.
7. World Health Organization Disability Assessment Schedule (WHODAS) and Model Disability Survey.
8. The presence, severity and episodic nature of disability in people with HIV.
9. Education and supportive strategies based on rehabilitation philosophy, goals and concepts to optimise functioning.
10. The evidence-informed e-module for HIV rehabilitation.