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Social Representation, Identity and HIV Prevention: The Case of PrEP among Gay Men

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Introduction

HIV remains a major public health concern four decades after its first clinical observations. In Western, industrialised countries like the UK, gay men are disproportionately affected by HIV. According to Public Health England (2019), approximately 48% of the 103,800 individuals living with HIV in the UK are gay men. In London, it is estimated that one in 11 gay men is living with HIV. There is evidence of a higher HIV incidence in gay men of ethnic minority background, which has been attributed, in part, to socio-economic inequalities faced by 'a minority within a minority' (Jaspal and Bayley, 2019). Overall, these epidemiological data suggest that traditional HIV prevention methods, such as condom use, have not been entirely effective and that novel approaches are needed in the fight against HIV/AIDS.

In the last few years, pre-exposure prophylaxis (PrEP) has emerged as a significant tool for preventing HIV. At the end of 2016, a significant drop in HIV incidence was observed for the very first time since the beginning of the epidemic, which was attributed partly to PrEP (Brown et al., 2017). Although PrEP is clinically

effective – having contributed to this dramatic fall in new diagnoses – it has not been met with consensual approval from all sections of society. Uptake has not been sufficiently high in the groups at highest risk of HIV – not least gay men of ethnic minority background (Huang et al., 2018). Both public and patient acceptability of PrEP are important factors in determining its effectiveness – after all, if people are unwilling to use PrEP, they will be unable to benefit from it. There are differences in levels of PrEP awareness, acceptability and uptake of PrEP among distinct groups in society.

There have been studies of PrEP in many different groups, such as African women, transgender people and sex workers (e.g. Celum et al., 2015; Restar et al., 2017; Sevelius et al., 2016). However, the focus of much research into PrEP has been on gay men who are especially affected in Western, industrialised societies. It is important to note that PrEP is a global issue, and that there are varying levels of PrEP awareness, availability and uptake in distinct countries and societal contexts (e.g. Grant et al., 2010; Huang et al., 2018). This chapter focuses principally on PrEP among gay men in the UK. In this chapter, it is argued that social representations and identity play an important role in gay men's responses to PrEP. First, an overview of the HIV prevention tool is provided. Second, social representations theory and identity process theory from social psychology are described and their utility in PrEP research is outlined. Third, empirical research into public and patient understanding of PrEP is reviewed. Fourth, a broad set of principles for raising awareness among gay men at risk of HIV are presented.

PrEP: Science and Society

PrEP is a bio-medical HIV prevention option for individuals at high risk of HIV exposure. The drug Truvada®, consisting of the two reverse transcriptase inhibitors emtricitabine and tenofovir, is currently approved for use as PrEP in the United States.

Clinical trials in a number of countries and contexts and in distinct populations converge in evidencing the high effectiveness of PrEP as a means of preventing HIV infection (Anderson et al., 2012). A series of clinical trial studies, including iPrEx (Grant et al., 2010), Partners PrEP (Baeten et al., 2010), IPERGAY (Molina et al., 2015), and PROUD (McCormack et al., 2016), have demonstrated the effectiveness of orally administered PrEP, both on a daily and intermittent event-driven basis. Although PrEP is very effective, there have hitherto been six cases of HIV infection among gay men who were adherent to the drug (e.g. Cohen et al., 2018). These cases of PrEP failure have been attributed to exposure to drug-resistant strains of HIV and patient exposure to high volumes of HIV, both of which are extremely rare. However, these cases have contributed to social representations of risk and uncertainty concerning the effectiveness of PrEP.

In 2012, the Food and Drug Administration approved PrEP for use in the United States. However, in the UK and in other Western countries, PrEP has caused controversy, particularly in relation to its funding. Critics argue that the National Health Service (NHS) should not fund an expensive biomedical approach to preventing HIV given that condoms are also very effective (Jaspal and Nerlich, 2017). Following the promising data yielded in the UK PROUD study, NHS England began an economics evaluation in order to explore the cost effectiveness of offering the prevention tool on the NHS. In March 2016, NHS England decided not to commission PrEP, arguing that HIV prevention services are the responsibility of local authorities. In response to this decision, supporters of PrEP launched a petition calling for PrEP to be made available on the NHS.

At the time of writing, there were varying levels of access to PrEP in the UK. The PrEP Impact Trial has provided free access to PrEP to thousands of gay men at risk of HIV, but it has soon become apparent that there are insufficient places on the trial to

meet the demand for PrEP among gay men in the UK. This means that many gay men unable to access PrEP may end up contracting HIV. PrEP can also be purchased privately. The only sexual health clinic to provide access to PrEP is 56 Dean St (an NHS sexual health clinic located in London), which offers Truvada privately at a heavily reduced cost. As an alternative to Truvada, many gay men have been purchasing Tenvir-EM (a generic version of emtricitabine and tenofovir) online – also at a much lower cost than Truvada. However, concerns have been raised about the authenticity (and, thus, effectiveness) of PrEP purchased online, as well as the wellbeing of patients whose condition (i.e. liver function) may not be consistently monitored by health care professionals. Indeed, this is concerning given that antiretroviral therapy (ART), such as emtricitabine and tenofovir, can cause side effects. In response to these concerns, several clinics in London, such as 56 Dean St and Mortimer Market Centre, now offer free PrEP clinics to monitor the condition of individuals who are purchasing PrEP privately. Moreover, evidence collected by 56 Dean St suggests that there have thus far been no cases of counterfeit drug preparations in gay men purchasing PrEP online and that it is thus protective against HIV (Wang et al., 2017).

PrEP activists argue that the provision of PrEP would prevent thousands of new HIV infections among gay men. Indeed, a mathematical modelling study of the effect of PrEP on HIV incidence among gay men in the UK suggested that rolling out PrEP to just 25% of high-activity gay men could greatly reduce HIV incidence in this population (Punyacharoensin et al., 2016). Furthermore, it is correctly pointed out that HIV prevention using PrEP is significantly less costly than life-long HIV treatment using ART. In view of these arguments and growing activism in favour of making PrEP available on the NHS, it is possible that NHS England will once again consider offering PrEP free of charge.

Given the high cost of PrEP, uptake has been rather low and it is likely that many of those individuals most vulnerable to HIV infection do not have access to the prevention tool. In order to stimulate political engagement and to challenge stigma, social activism around PrEP has emerged and gained significant traction among many groups in society. In general, activists have sought to educate others about PrEP in a bid to decrease stigma, to facilitate discussion and, crucially, to lobby policy-makers. Some gay men living with HIV have spoken publicly about their prior lack of awareness or rejection of PrEP, citing this as a cause of infection. There are many gay men living with HIV who have become vocal advocates of PrEP, engaging in advocacy on public platforms. Candid accounts of gay sexuality and sexual risk-taking have contributed to decreasing the silence surrounding these very sensitive issues in public discourse. Indeed, activism in relation to PrEP has attracted considerable support from the HIV medical community, leading to joint efforts to raise awareness of PrEP and to lobby policy-makers about its importance in the HIV prevention portfolio.

The UK-based 'I Want PrEP Now' website was launched 'to raise awareness of and access to PrEP, with all the information you need in one place so you can access PrEP now'.[1] Crucially, on the website individuals are informed about how to obtain PrEP online and how to access services vital to their wellbeing while on PrEP. PrEPster, another awareness-raising group, was created 'to educate and agitate for HIV PrEP access',[2] and has similarly been campaigning for PrEP to become available on the NHS. The US-based Facebook group 'PrEP Facts: Rethinking HIV Prevention and Sex' was founded by US psychotherapist Damon Jacobs in order 'to support discussions, debates, questions, and concerns that promote fact-based information, understanding, respect, and compassion'.[3] At the time of writing, the group had over 21,000 subscribers from all over the world, a voluntary editorial team, and consistent and lively discussion about PrEP.

The emergence of global activism has facilitated collaboration, and sharing and co-creation of social representations of PrEP. In the next section of this chapter, the role of social representations in awareness and understanding of PrEP is discussed.

Understanding PrEP: Social Representations Theory

Social Representations Theory (Moscovici, 1988) provides a useful framework for understanding how individuals come to acquire an awareness and understanding of PrEP, to predict the likelihood of its acceptability and uptake. The theory was originally designed to examine how science becomes 'common-sense' knowledge, that is, how it enters public consciousness and becomes a topic that can be debated. At a basic level, a social representation can be defined as a collective 'elaboration' of a given social object which in turn enables individuals to think and talk about it. This elaboration consists of emerging beliefs, values, ideas, images and metaphors in relation to any given phenomenon. Social representations provide a cultural group with a shared social reality or 'common consciousness'. Two principal social psychological processes converge in the creation of social representations:

- anchoring refers to the process whereby a novel, unfamiliar phenomenon is integrated into existing ways of thinking. For instance, Jaspal and Nerlich (2017) have noted that, in their reporting on PrEP, the UK media linked it to the contraceptive pill, encouraging readers to regard PrEP, a novel biomedical approach to preventing HIV, through the lens of the contraceptive pill. Furthermore, Spieldenner (2016) has observed that PrEP use is linked to sexual promiscuity, which has given rise to the terms 'PrEP Whore' and 'Truvada Whore' to characterise users. Anchoring can

lead individuals to generalise aspects of one phenomenon to another, which will have implications for understanding.

- objectification refers to the process whereby an abstract phenomenon is rendered concrete and tangible, often through the use of metaphors. Jaspal and Nerlich (2017) have noted the use of militaristic metaphors of PrEP as a 'weapon' in the 'battle' against HIV. This encourages the perception that PrEP can defeat HIV in the way that an army defeats its military adversary.

Social representations do not all possess the same status. In his overview of the theory, Moscovici (1988) described three types of representation: hegemonic, emancipated and polemic.

- A hegemonic representation is coercive, uniform and consensually accepted by members of a community. For instance, the social representation that HIV is a serious, potentially life-limiting condition can be regarded as hegemonic. Most people believe this to be the case and few would deny that ART constitutes a lifeline for those living with HIV. Those who do not accept this social representation are often regarded as denying reality. As highlighted in this chapter, there appear to be few hegemonic social representations of PrEP because it is a relatively novel biomedical innovation and is characterised by much polarised debate and division. For instance, in a survey of 328 healthcare professionals in the UK (Desai et al., 2016), just 54% of those surveyed believed that PrEP should be available outside of a clinical trial, suggesting that a large minority does not support this.

- An emancipated representation is developed by subgroups within a community as a result of outgrowths of information and developments of new knowledge in these subgroups. For instance, the social representation that PrEP is an effective HIV prevention tool, though scientifically accurate, is not yet consensually shared by everyone in the gay community (Jaspal and Daramilas, 2016). Some people are unaware of the clinical data demonstrating its effectiveness, while others simply doubt their veracity. Furthermore, the six cases of PrEP failure that have been reported globally have contributed to scepticism and uncertainty surrounding PrEP. PrEP effectiveness is, however, a social representation that is championed especially by PrEP activists – a subgroup within the gay community.
- A polemic representation is one that is generated in the course of social conflict and generally characterised by antagonistic relations between groups. An example of a polemic representation is that PrEP constitutes a 'magic bullet' in HIV prevention. While advocated by PrEP activists and those who themselves utilise the prevention drug, this representation is vehemently opposed by those gay men who, conversely, view PrEP as promoting irresponsibility and sexual risk-taking behaviours (Williamson et al., 2019).

The field of HIV is populated by many different social representations – some hegemonic, and others emancipated or polemic. They affect perception and behaviour differently. Hegemonic representations are more likely to shape individual perceptions and behaviours in a community because of the consensus surrounding them. Conversely, emancipated or polemic representations may initially lack the social credibility required to impact perception and behaviour at a large scale. Yet some

emancipated or polemic representations do eventually become hegemonic over time. This is especially likely if the representation is disseminated by a wide range of (influential) individuals, groups and institutions. In the context of PrEP, social representations disseminated by HIV physicians, researchers and the scientific community are more likely to become hegemonic than those disseminated by other stakeholders.

Anchoring and objectification occur in a wide range of contexts, including the media, film and literature, political discourse, patient–practitioner interactions and in everyday conversation. Interactions in these contexts all contribute to the genesis and development of social representations of PrEP. Although introduced in one context, the representation may subsequently be taken up, elaborated or challenged in other contexts. No social representation is static. It is constantly subject to debate, revision and, sometimes, extinction. It is important, therefore, to examine the multitude of social contexts in which discussions about PrEP take place in order to discern more accurately its social representations.

Social representations theory is an important tool for determining how PrEP science makes its transition into societal discourse. Breakwell (2014) has further developed the theory by outlining the processes that underpin the individual's relationship with a social representation. The individual takes a stance on a given social representation, that is, they differ in the extent to which they are aware of, understand, accept and assimilate to their thinking a social representation. For instance, while an individual may be aware of PrEP, they may understand it in similar terms to the contraceptive pill due to the societal *anchoring* of PrEP to the contraceptive pill. This could have important implications for how they engage with and behave in relation to the preventive tool. However, behaviour is determined not only by social representation but also by individual identity processes. This is the focus of identity process theory.

Becoming a PrEP User: Identity Process Theory

Identity process theory (Jaspal and Breakwell, 2014) provides an integrative model of identity construction, threat and coping. The theory postulates that individuals construct their identity by engaging in two social psychological processes:

- Assimilation–accommodation refers to the absorption of new information (such as new self-labels or social representations) into identity and the creation of space for it within the identity structure. For instance, using PrEP may require the absorption of new information about oneself, that is, one's new status as a PrEP user (assimilation). The assimilation of this novel information may lead some individuals to re-think other elements of identity, such as their status as a condom user (accommodation).
- Evaluation refers to the process of attributing meaning and value to the components of identity. For example, given the stigma that appears to surround PrEP use, individuals may evaluate this new identity element negatively and, thus, conceal it from others (Jaspal and Daramilas, 2016).

The two identity processes are in turn guided by various motivational principles, which essentially specify the desirable end-states for identity:

- Self-esteem refers to personal and social worth.
- Self-efficacy can be defined as the belief in one's competence and control.

- Distinctiveness refers to feelings of uniqueness and differentiation from others.
- Continuity is essentially the psychological thread between past, present and future.
- Coherence refers to the perception that relevant aspects of identity are coherent and compatible.

When these principles are compromised, for instance by changes in one's social context, identity is said to be threatened. Identity threat is generally aversive for psychological wellbeing. For instance, stigma from a potential sexual partner on the basis of one's PrEP use may undermine the self-esteem principle of identity, making it difficult for an individual to derive a positive self-conception on the basis of their PrEP use. Events, experiences and social representations can threaten identity. It is also important to bear in mind that some events and experiences can actively enhance the identity principles, which is the opposite of threat. For instance, an individual may derive feelings of control and competence over their sexual health by using PrEP, that is, the self-efficacy principle may be enhanced by one's PrEP user identity. It is likely that an individual will seek to maintain and foreground an event, experience or behaviour that enhances identity processes. This can be attributed to the benefits that this has for overall psychological wellbeing.

When identity is threatened, people attempt to cope. Coping strategies are said to function at three levels of human interdependence:

- Intrapsychic strategies function at a psychological level. Some can be regarded as deflection strategies in that they enable the individual to deny or re-conceptualise the threat or the reasons for occupying the threatening position, while others are acceptance strategies that

facilitate some form of cognitive re-structuring in anticipation of the threat. For instance, a gay man who engages in condomless sex with multiple partners may deny, rather than acknowledge, his risk of HIV because of the stigma appended to his behaviour. It is easy to see how such denial may in turn preclude access to PrEP.

- Interpersonal strategies aim to change the nature of relationships with others. Most are maladaptive given that the threatened individual may isolate himself/herself from others or feign membership of a group or network of which they are not really a member, in order to avoid exposure to stigma, for instance. An example of a proactive interpersonal strategy is that of self-disclosure, given that this can facilitate the acquisition of support from others. For instance, a gay man who faces the stigma of being 'sexually high-risk' may share this information with a trusted other who provides support, validation and, crucially, information. This could lead to increased self-esteem but also access to PrEP.
- Intergroup strategies aim to change the nature of our relationships with groups. Most are proactive. Individuals may join groups of like-minded others who share their predicament in order to derive social support. They may create a new social group to derive support or a pressure group to influence social representations. For instance, gay men who use PrEP may seek social support from others in this situation and advocate for PrEP use in order to counteract the negative social representations associated with this prevention method.

In his application of identity process theory to gay men's sexual health, Jaspal (2018) postulates that the choice of coping strategy will depend on at least three factors: personality, the availability of social support, and healthcare practitioners. First, some personality profiles predispose the individual to a particular type of coping strategy. For instance, the introvert is unlikely to favour social support as a first-line coping strategy but may elect to isolate himself/herself when facing threat. Second, it is hard to see how an individual can make use of a group network and derive the benefits of a pressure group if no such social support group is available, although it can of course be created. Third, healthcare practitioners play an important role primarily because of their ability to impose on others particular social representations. As 'experts', by virtue of their role and from the perspective of the patient, they will enjoy a level of credibility that other disseminators of social representations do not. They can channel the patient towards particular strategies for coping and away from others.

A significant contribution of identity process theory is its capacity to describe and predict the factors that can inhibit the assimilation and accommodation of a PrEP user identity, which appears to be important for PrEP acceptability, uptake and adherence. It can be hypothesised that when PrEP is perceived to threaten, rather than enhance, identity processes, it will be resisted by the patient notwithstanding their objective risk of HIV infection. The principles of self-esteem, continuity, self-efficacy and so on will be key to determining the psychological impact of PrEP on the individual. An additional, and equally significant, contribution of identity process theory is its focus on coping strategies. Some threats to identity – even those that are unrelated to PrEP – may lead the individual to use coping strategies to reduce access to PrEP. For instance, the stigma of being gay in a homophobic society may lead the gay man to isolate himself, to avoid discussing his sexual behaviour with healthcare professionals and,

thus, to miss the opportunity to learn about and acquire PrEP (see Jaspal and Bayley, 2019).

As Breakwell (2014) has indicated, the heuristic power of identity process theory increases when it is aligned with social representations theory. After all, social representations will, at least in part, determine whether any given label, event or experience enhances or threatens self-esteem, self-efficacy and so on. In the remainder of this chapter, tenets of both theories are applied to existing research into public and patient acceptability of PrEP.

Media Representation and Public Understanding of PrEP

Public understanding of PrEP is important because public opinion can decisively shape policy and practice in relation to public health (Burnstein, 2003). In order for PrEP to be made available on the NHS, it will require the investment of public resources, which is possible only if there is public support for such investment.

Accordingly, in an empirical study of public understanding of PrEP, Jaspal et al. (2019b) attempted to understand the factors that influence public endorsement of PrEP for particular social groups. They hypothesised that social identity and prejudice play a role in determining how the public responds to PrEP in that people are less likely to endorse a prevention tool that is socially represented as benefiting a stigmatised minority group like gay men. Gay men and Black Africans – two social groups that are disproportionately affected by HIV and that may therefore benefit from PrEP – were presented to study participants as potential recipients of PrEP. Participants' attitudes towards PrEP were measured using the Attitudes toward PrEP Scale (Jaspal et al., 2019a). Using structural equation modelling, the authors found that gender, ethnicity and religion all impacted on attitudes towards gay men – female, White and atheist

participants all expressed more positive attitudes towards this group. Moreover, only gender impacted on attitudes towards Black Africans, with females expressing more favourable attitudes towards this group. Crucially, both attitudes towards gay men and attitudes towards Black Africans predicted more positive attitudes towards PrEP, suggesting that social identity and prejudice do indeed play a role in determining attitudes towards this prevention tool.

These preliminary findings suggest that homophobia and racism may underpin opposition to PrEP that is observable in some people. This in turn means that, regardless of the science of PrEP or the effectiveness with which it is communicated, there will be little endorsement of PrEP among those individuals who have underlying prejudices towards the groups that are socially represented as benefiting from PrEP. Therefore, a more effective method of promoting PrEP, which would enable individuals to reap the benefits of this highly effective tool, would be to challenge outgroup prejudice (in this case, towards gay men and Black Africans). The role of social representations is key. It will be necessary to challenge negative, stigmatising social representations of minority groups – focusing on the ways in which anchoring and objectification function in social forums, like the media, political rhetoric and everyday conversations. This reiterates the important work of anti-homophobia campaigns and, at a more basic level, the dissemination of more humanising social representations of gay people that are attempted, but often resisted, in different forums. A noteworthy example is in schools – some parents may cynically believe that homosexuality is being 'promoted'. More generally, given that HIV affects many groups in society and some of these groups are not represented in debates on HIV prevention, it is important that PrEP is socially represented as a biomedical tool that can prevent HIV in humans, rather than in specific minority groups only. Indeed, Jaspal and Nerlich's (2017) study revealed that PrEP was presented almost exclusively as a tool for preventing HIV in gay and bisexual men,

omitting other potentially vulnerable groups, such as ethnic minorities, women and trans women. There is now a body of research that shows that these groups too are at risk of HIV and can therefore benefit from PrEP as well (e.g. Jaspal et al., 2018).

In order to assess public and patient understanding of PrEP, it is important to explore the social representations (that is, the images and constructions) of PrEP that have been emerging in the public domain. The print media constitute a major source of societal information concerning science and medicine and can shape the ways in which people think and talk about PrEP. It must be noted that any study of the media will provide only a snapshot of social representations during any given period, as both media reporting and social representations evolve over time. However, this snapshot provides insight into an important social context and, particularly in conjunction with subsequent studies, can shed light on the ways in which social representations are developing over time. Accordingly, using social representations theory, Jaspal and Nerlich (2017) conducted a thematic analysis of all of the articles on PrEP which were published in UK national and regional newspaper outlets from 2008 to 2015. This was the first media study of PrEP in the UK. The authors generated a modest corpus of 57 articles, of which most were published in *The Independent*, *The Guardian* and *The Daily Mail*. Although the number of articles published was relatively small, demonstrating the limited media interest in this topic, the articles were subsequently reproduced in other forums and used as the basis for furtherdiscussion. Indeed, as noted above, the movement of topics between distinct forums and contexts contributes to the formation, development and dissemination of social representations.

Jaspal and Nerlich (2017) explored the tone of media reporting, and the major themes, tropes and metaphors drawn upon to describe PrEP. They identified two competing social representations of PrEP – the *hope representation*, on the one hand, and the *risk representation*, on the other. In creating the hope representation, metaphors

of momentous change such as ‘revolutionary’, ‘silver bullet’, ‘the key’ and ‘making history’ were employed in relation to PrEP. These articles not only emphasised the positive characteristics of PrEP as an HIV prevention method, they also implicitly positioned it as being superior to existing methods, such as condom use and TasP. Furthermore, war metaphors such as ‘battle’, ‘fight’, ‘weapon’ and ‘besieged’ served to position PrEP as decisively changing the course of HIV prevention. Conversely, HIV was positioned as being weakened by PrEP. This pattern of media reporting tended not to acknowledge the potential shortcomings or limitations of PrEP, such as potential drug toxicity, poor drug adherence, and exposure to drug-resistant strains of HIV.

Conversely, the risk representation accentuated the risks and uncertainties associated with using PrEP and positioned the prevention tool as a hazard. This representation generally questioned the effectiveness of PrEP as a prevention tool, on the one hand, and as a mechanism for reducing risk-taking in gay men given its association with condomless sex, on the other hand. The press constructed PrEP as leading to greater condom fatigue in gay men and, thus, to more sexual risk-taking in a population already vulnerable to infection. There was a clear element of social stigma in relation to gay sexuality and to the sexual practices said to be associated with this identity, which is echoed in Spieldenner’s (2016) research into ‘whore shaming’ among gay men. In short, sexual risk-taking and condom fatigue among gay men were cited as key reasons why PrEP should be regarded as a risky HIV prevention method.

Social representations observable in the UK media are likely to contribute to public and patient understanding of PrEP. There is, however, no straightforward, unidirectional relationship between social representation and public understanding – some representations will be challenged and others accepted. The relationship between representation and understanding is likely to be mediated by other social psychological

factors, such as identity and prejudice. In the next section of this chapter, patient understanding of PrEP is discussed.

Patient Understanding of PrEP

The media make important contributions to social representations in the general public and among patients. In addition, as an 'expert community', healthcare professionals are of course key to the development of social representations of PrEP. The social representations that they disseminate have the potential to influence both public policy and patient engagement. In a survey of 328 healthcare professionals in the UK, Desai et al. (2015) found that just 54% of those surveyed endorsed PrEP for patients outside of the clinical trial, and raised concerns about the current evidence base, patient adherence to PrEP, and the potential for increased sexual risk-taking in patients. It is important to examine how healthcare professionals think and talk about PrEP – especially with patients – because their approach to PrEP is likely to influence that of patients. Indeed, in previous research, it has been noted that stigmatisation from both healthcare professionals and other gay men was a common experience for participants in a qualitative study of PrEP users (Schwartz and Grimm, 2019). It is easy to see how stigma can challenge self-esteem among patients and, thus, inhibit access to PrEP and also interfere with adherence to the drug, which itself can reduce its effectiveness (Vaccher et al., 2019). It has also been found that perceived stigma from healthcare professionals can decrease engagement with sexual healthcare (Jaspal and Williamson, 2017).

Although PrEP is scientifically effective, its effectiveness depends on its acceptability among potential users. Given that gay men are one of the groups in society that are disproportionately affected by HIV, it is necessary to assess perceptions and

acceptability of PrEP in this group. There have been several studies of PrEP awareness, understanding and acceptability among gay men (e.g. Jaspal, Lopes, Papaloukas & Bayley, 2019; Williamson et al., 2019). In a survey study of 386 HIV-negative gay men, Frankis et al. (2016) found that just a third of respondents had heard of PrEP but that over half would be willing to utilise it if it were available. Those who tested for HIV every six months were more likely to be aware of PrEP. In their survey study of gay men in Leicester, Jaspal, Lopes et al. (2019) found socio-economic inequalities in HIV knowledge and HIV testing, both of which are important predictors of PrEP acceptability. More specifically, it was found that gay men who have high levels of HIV knowledge and perceived HIV risk and who test for HIV regularly are most likely to perceive PrEP to be of personal benefit. Their findings indicated that one must first view oneself as being at risk of HIV (possibly through consultation with a healthcare professional) in order to accept PrEP as a viable HIV prevention method for oneself. In a US study, Raifman et al. (2019) examined awareness of PrEP among gay men presenting at a sexual health clinic from 2013 to 2016 and found that awareness increased over time, although Hispanic and Black gay men manifested consistently lower PrEP awareness than White gay men. Furthermore, Elopre et al. (2018) studied perceptions of PrEP among Black gay men and found that interviewees perceived a multi-faceted stigma in relation to their Black, gay and Southern identities, a lack of discussion regarding HIV prevention in the Black community, and low HIV risk perception.

This research suggests that social representations of PrEP are developing and being disseminated to people at risk of HIV, such as gay men, but that there are some subgroups of gay men that have less access to these social representations. Furthermore, it has been shown that gay men who participate in the gay community are more likely to be aware of PrEP than those who do not (Zarwell et al., 2019). Several empirical

studies (e.g. Jaspal, 2019; Jaspal and Cinnirella, 2010) have revealed that ethnic minority gay men are less likely to be open about their sexual identity and less involved in the gay community. This can mean that they are less aware of social representations of issues that affect the gay community, such as HIV and PrEP. They may not be exposed to the social representations that ordinarily circulate in gay social contexts. Furthermore, in order to protect self-esteem, individuals may avoid exposure to stigma, thereby reducing access to PrEP.

In addition to awareness, complex psychosocial factors like risk appraisal and perceived stigma also shape PrEP acceptability in gay men. Frankis, Young, Flowers and McDaid (2014) found that few of the gay men they interviewed regarded themselves as candidates for PrEP because of low perceived risk of HIV and existing HIV prevention strategies that they were utilising. In view of the low uptake of PrEP in groups at high risk of HIV, Dubov et al. (2018) conducted semi-structured interviews with 43 HIV-negative gay men to explore their perceptions and experiences of stigma in relation to PrEP use. They found that interviewees experienced stigma from potential and actual sexual partners and reported being stereotyped as ‘high risk’. Participants associated PrEP stigma with HIV stigma. In a qualitative interview study of Latino gay male PrEP users in Los Angeles, Brooks et al. (2019) found that the social representations that PrEP users engage in sexual risk behaviours and that they are in fact HIV-positive underpinned the stigma that participants faced. Moreover, interviewees described the risk of difficulties in relationships as a result of their PrEP use. Given the higher levels of internalised homophobia and motivation to conceal their sexual identity, ethnic minority gay men at risk of HIV may express concerns about involuntary disclosure of their sexual orientation and about potential exposure to HIV stigma as a result of PrEP use. Avoidance may constitute a strategy for coping with threats to self-esteem associated with potential or actual stigma.

In a qualitative interview study, Jaspal and Daramilas (2016) explored perceptions and understandings of PrEP among 20 HIV-negative and HIV-positive gay men, focusing on their beliefs about the potential impact of PrEP on their own lives and behaviours. They found three themes: uncertainty and fear; managing relationships with others; and stigma and categorisation. HIV-negative participants appeared to manifest uncertainty and fear in relation to PrEP as they believed that it would not be completely effective and that it would leave them feeling uncertain due to the 'invisibility' of PrEP once it is taken (versus a condom which can be examined physically to ensure that it has remained intact during sex). Conversely, HIV-positive gay men were generally of the view that PrEP would reduce uncertainty and fear (primarily of onward HIV transmission to HIV-negative partners). It is possible that this might provide a sense of self-efficacy in that individuals feel more empowered to prevent onward transmission than they previously did with condoms as their sole prevention approach. There was a stark difference in how HIV-negative and HIV-positive men perceived the potential impact of PrEP on their relationships with others – while HIV-negative gay men felt that their use of PrEP could induce social stigma, HIV-positive men foresaw an improvement in relations with serodiscordant partners who they believed might feel less anxious about sex given the advent of PrEP.

Although both cohorts acknowledged the possible benefits of PrEP, they nonetheless manifested stigma in relation to the prevention tool, which led some HIV-negative gay men to reject PrEP for personal use. It is clear that social stigma underpins attitudes towards PrEP both at social (i.e. in the media) and individual levels. The prevalence of social stigma appears to have infiltrated thinking at an individual level, which has led individuals who may benefit from PrEP to reject it as an HIV prevention tool that people 'at high risk' might utilise. This enables individuals to deflect from themselves the social stigma associated with PrEP and thereby protect the self-esteem

principle of identity. In response to social stigma and political inertia, social activism around PrEP has begun to emerge and it has taken shape in a number of ways. In general, activists have sought to educate others about PrEP in a bid to decrease stigma and, thus, to facilitate discussion. This may be regarded as an intergroup strategy for protecting self-esteem.

Raising awareness of PrEP among gay men

As a group in society that continues to be disproportionately affected by HIV, many studies have focused on the ways in which awareness and understanding of PrEP can be increased among gay men. PrEP will not be appropriate for everyone but it has been argued that the prevention option should be accessible to those individuals who could benefit from it. As demonstrated in this chapter, many gay men are unaware of PrEP, reject it outright, or experience difficulties in adhering to it. The causes are multifarious but often share common social psychological underpinnings: stigma, decreased risk perception, desire for positive self-presentation among others. Using social representations theory and identity process theory, some suggestions for raising awareness of PrEP among gay men at risk of HIV can be offered.

First, social representations of PrEP are important. As PrEP gains greater societal traction, diverse social representations will emerge. It is important to ensure that social representations grounded in scientific fact are disseminated to populations at risk of HIV. These should be disseminated in clinical, public health and social forums. Clearly, healthcare practitioners and community leaders will be especially influential in the dissemination of accurate, scientifically grounded social representations. Furthermore, it is important that inaccurate and stigmatising social representations are actively challenged, as misinformation concerning PrEP can lead to unfounded fears concerning its effectiveness, decreasing access to it. It must be acknowledged that, although social

representations are circulated, individuals vary in the extent to which they understand and accept them. One of the key demographic factors identified in this chapter is ethnicity. A culturally competent approach to disseminating social representations of PrEP and HIV prevention, more generally, is necessary, as this will increase the likelihood that they resonate among gay men of ethnic minority background (Jaspal and Williamson, 2017).

Second, the role of identity processes in thought and action must be acknowledged. It has been noted that the category 'high risk' is stigmatising and that it may challenge the self-esteem principle of identity among some patients who could benefit from PrEP. They may not wish to perceive themselves as 'high risk' and, thus, fail to see PrEP as an effective option for themselves. Furthermore, stigmatising responses from healthcare professionals, family members and sexual partners can, collectively, have an adverse impact on the self-esteem and continuity principles of identity. Clearly, there is a need for an effective stigma reduction campaign in order to address the risk of identity threat among potential beneficiaries of PrEP. However, there are important steps that can be taken at a more localised level. Healthcare professionals should present PrEP to patients in a non-stigmatising manner (Jaspal, 2018). Individuals should re-focus their attention on the benefits of PrEP for HIV prevention, rather than make assumptions about the behaviour or character of PrEP users.

Third, it must be acknowledged that identity threat is a common experience and that individuals attempt to cope with threat. Jaspal (2018) has described a multitude of social psychological stressors that gay men face, such as homophobia, internalised homophobia and a high incidence of childhood sexual abuse, among others. In response to such events, experiences and social representations that are threatening for identity, gay men will attempt to cope with the ensuing threat. They may pre-emptively deploy behaviours designed to reduce the risk of identity threat. As indicated earlier in this

chapter, not all coping strategies are effective in the long term. Strategies such as isolation or denial may preclude access to PrEP because gay men may be unable to access positive social representations of the HIV prevention tool. Conversely, strategies such as self-disclosure and the derivation of social support may increase the likelihood that people at risk access PrEP. Healthcare practitioners have a particularly important role to play in channelling gay men at risk of HIV towards more proactive, rather than maladaptive, strategies for coping with identity threat.

Finally, activism has played a significant role in increasing PrEP acceptability among gay men. Since the introduction of PrEP on the HIV prevention landscape, awareness-raising pressure groups have developed in online spaces, such as Twitter and Facebook, providing an important forum in which gay men can consider HIV prevention and, more specifically, the potential role that PrEP might play in their own HIV prevention strategy. Global activism has facilitated collaborative work between US- and UK-based advocates for PrEP. The key challenges that PrEP activism engages with are social stigma and decreased public understanding of PrEP, both of which can inhibit public support for PrEP and ultimately lead to increased HIV incidence. Moreover, PrEP activists view social stigma and low awareness of PrEP as obstacles to making PrEP available on the NHS. It is likely that PrEP activism will continue to play a key role in increasing public awareness and understanding of, and facilitating political engagement with, PrEP.

Conclusion

This chapter has noted that there are varying levels of awareness, availability and uptake of PrEP in distinct groups. It has been argued that accurate social representations of PrEP must be disseminated so that people at risk of HIV who may benefit from PrEP are more able to access it. Moreover, these representations are likely to contribute to public attitudes to PrEP, which in turn contribute to policy-making. After all, public

and political institutions attempt to represent the views and wishes of the people that they serve. It must be acknowledged that identity processes and coping strategies will have an impact on patient responses to PrEP, leading either to endorsement or rejection of the HIV prevention tool. It appears that gay men of ethnic minority background, who are at especially high risk of HIV, possess the least awareness and understanding of PrEP. These groups are increasingly being targeted in PrEP awareness-raising campaigns using culturally sensitive and competent approaches. Social representations theory and identity process theory provide some of the tools necessary for designing high-quality campaigns and interventions for increasing access to PrEP among those who need it most. It is hoped that there is input from social psychology in future campaigns and interventions so that society can reap the full benefits of PrEP.

Notes

Retrieved from https://www.iwantprepnow.co.uk/about-us/

[1] Retrieved from https://prepster.info

[1]Retrieved from https://m.facebook.com/groups/PrEPFacts/permalink/692805047505330

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