## HIV and gay men in the era of antiretroviral therapy

# Rusi Jaspal

## De Montfort University, Leicester, UK

In the UK, HIV disproportionately affects gay men. Even in the era of antiretroviral therapy (ART), social stigma surrounding HIV has persisted, generating adverse consequences for both prevention and care. First, the science and epidemiology of HIV among gay men are presented. Second, social representations theory and identity process theory are outlined as tools for exploring awareness, understanding and behaviour in relation to HIV. Third, some of the psychosocial challenges associated with HIV prevention and care are outlined and the potential coping strategies among gay men are discussed. Fourth, patient engagement with care and adherence to ART are considered in relation to psychosocial factors. Fifth, a model for enhancing HIV prevention and care is presented. It is argued that greater focus on psychosocial factors can enhance health outcomes among gay men living with, or at risk of, HIV.

#### Introduction

In the era of effective antiretroviral therapy (ART), infection with human immunodeficiency virus (HIV) has gone from being a terminal illness to a largely manageable chronic condition. HIV disproportionately affects gay, bisexual and other men who have sex with men. Many factors that increase the risk of infection are psychosocial in nature. Moreover, interventions to prevent HIV often focus on increasing awareness and understanding of HIV and its risk factors, and on changing sexual attitudes and behaviours. Although the physical prognosis of an individual living with HIV has improved, significant social psychological challenges remain. Some of these challenges can in turn have an adverse effect on physical prognosis. The role of social psychology in the prevention and management of HIV is a significant one. In this article, some of the psychosocial challenges associated with HIV are outlined. In particular, there is a focus on the potential contribution of social representations theory and identity process theory from social psychology to optimising prevention and treatment efforts.

## The science and epidemiology of HIV

HIV is a virus which attacks CD4 lymphocytes, an important type of white blood cell which is central to healthy immune functioning. The virus hijacks CD4 cells and replicates within them, ultimately destroying the original cells. This process continues until the infected individual's CD4 cells are entirely depleted, leading to the onset of opportunistic diseases and infections which can be fatal. HIV is the virus that causes autoimmune deficiency syndrome

(AIDS), which is the end stage of the disease. Since the first clinical observations of AIDS in 1981, 78 million people have been infected with HIV and 35 million have died of AIDS (UNAIDS, 2017). There is no known vaccine or cure. However, the illness is now treatable with ART, which can inhibit disease progression. Therefore, in countries in which ART is widely available, HIV is now considered to be a life-altering, rather than life-limiting, chronic condition.

HIV prevalence in the UK is approximately 0.16% of the population - according to a recent HIV epidemiology report (Kirwan et al., 2016), some 101,200 people are currently living with the chronic condition in the UK. Approximately 47,000 gay men were living with HIV in 2015, and in London it is estimated that 1 in 11 gay men is HIV-positive. In 2015, there were 6,095 new diagnosed cases of (sexually transmitted) HIV, of which 57% were among gay men. In addition to the biological risk factors, there are several psychosocial factors that increase HIV vulnerability among gay men. Theories from social psychology can enable us to understand increased HIV vulnerability in this population.

### The role of social psychology in HIV research

Two social psychological frameworks - social representations theory (Moscovici, 1988) and identity process theory (Jaspal & Breakwell, 2014) - are especially useful for describing and predicting how gay men understand, and behave in relation to, HIV and associated risk factors.

## Social representations theory

Social representations theory (Moscovici, 1988) provides a useful framework for understanding the development of perceptions of HIV and its associated risk factors. The theory was 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, HIV has been linked to immorality,

- contagion and death, all of which contribute to the perennial stigma surrounding the condition (Joffe, 1995).
- 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 pre-exposure prophylaxis (PrEP), the daily pill taken to prevent HIV infection, as a 'weapon' in the 'battle' against HIV. This can encourage the perception that PrEP can defeat HIV in the way that an army defeats its military adversary.

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 HIV. 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 seems opportune therefore to examine the multitude of social contexts in which discussions about HIV take place in order to discern more accurately its social representations.

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.
- 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 having an undetectable HIV viral load means that one is uninfectious (often referred as 'U=U'), though scientifically accurate, is not yet consensually shared by everyone in the gay community (Wilkinson et al., 2018). Some people are unaware of this scientific fact, while others simply doubt its veracity. This is, however, a social representation that is championed especially by HIV 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, Papaloukas, Jaspal & Lond, 2018).

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 HIV, social representations disseminated by HIV physicians, researchers and the scientific community are more likely to become hegemonic than those disseminated by other stakeholders.

Breakwell (2014) has outlined the processes that underpin the individual's relationship with a social representation. This can be referred to as 'personalising' social representations. After all, 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 not necessarily understand how it functions. This may limit their ability to appreciate the effectiveness of PrEP, which can in turn engender uncertainties about it. Thus, personalising social representations is an important process with ramifications for both perception and behaviour at an individual level. It has been shown that people personalise social representations in accordance with identity processes (Breakwell, 2014), which demonstrates the utility of identity process theory.

## Identity process theory

Identity process theory provides an integrative model of identity construction, threat and coping (see figure 1). 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 identity characteristics or social representations) into identity and the creation of space for it within the identity structure. For instance, HIV diagnosis requires the absorption of new information about oneself, that is, one's new HIV status (assimilation). The assimilation of this novel information may lead some gay men to feel ashamed of their sexual identity, leading to avoidance of sexual relations (accommodation) (Bernier et al., 2016).
- Evaluation refers to the process of attributing meaning and value to the components of identity. For example, an HIV diagnosis may be construed as reflecting a flaw in one's identity, which can induce feelings of shame and self-deprecation (Bennet et al., 2016).

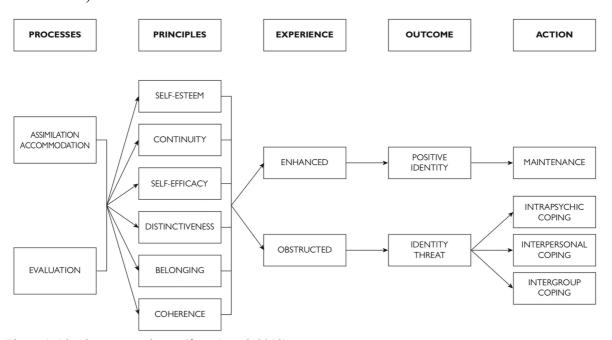


Figure 1: Identity process theory (from Jaspal, 2018)

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. For instance, body image concerns can lead some gay men to derive a negative self-conception on the basis of their appearance.
- Self-efficacy can be defined as the belief in one's competence and control. Even in the pre-ART era when HIV infection was a terminal illness, it was found that those gay men who perceive decreased control over their sexual behaviour were more likely to engage in sexual risk practices (Exner et al., 1992).

- Distinctiveness refers to feelings of uniqueness and differentiation from others.
   Upon diagnosis with HIV, one may attempt to differentiate oneself from other people living with HIV in order to reduce exposure to stigma associated with the condition (Jaspal, 2018).
- Continuity is essentially the psychological thread between past, present and future. Diagnosis with a stigmatised chronic condition can disrupt the thread between past and present, and introduce an uncertain future, as this constitutes an example of undesirable change in one's life narrative.
- Coherence refers to the perception that relevant aspects of identity are coherent and compatible. It has been shown that gay men of religious faith may perceive their sexual and religious identities to be incompatible, which can induce psychological stress (Jaspal & Cinnirella, 2010).

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. However, the degree to which one's wellbeing is compromised is determined by the nature of the threat, the number of principles curtailed by the threat, and one's ability to cope effectively. HIV is incurable and thus occupancy of this threatening position is chronic – much like the physical condition itself. The chronicity of HIV – both as a physical condition and psychological stressor – can render it particularly threatening for identity. Many individuals diagnosed with HIV lack the social and psychological resources to cope effectively, leading to the onset of poor mental health (Jaspal & Dhairyawan, 2018).

People attempt to cope in response to identity threat. 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 men 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.
- 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.
- 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. Some gay men diagnosed with HIV report significant benefits of joining a support group in order to manage the psychosocial challenges of their diagnosis (Jaspal, 2018).

In the remainder of this article, it is shown how tenets of social representations theory and identity process theory can enhance HIV prevention and care.

## **HIV** prevention strategies

In the absence of an HIV vaccine or cure, prevention remains the most effective strategy against HIV. Although condoms remain a highly effective prevention tool, both for HIV and other sexually transmitted infections (STIs), rising HIV incidence suggests that not everybody uses them consistently or correctly. Condom fatigue among gay men, despite the risk of HIV, has been studied in several contexts (Shernoff, 2006). Some individuals may not use condoms because they believe that it interrupts the flow of sex or that it reduces physical sensation and pleasure. Some feel unable to negotiate condom use with their sexual partners, indicating low condom self-efficacy. Moreover, some gay men perceive condomless sex as a means of demonstrating their trust of, and commitment to, their sexual partners because condomless sex can increase feelings of intimacy and closeness (Flowers et al., 1997). In her research into sexual risk-taking among young people, Breakwell and Millward (1997) found that identity concerns might override risk - if a sexual risk practice such as condomless sex is central to, say, self-esteem, the individual may continue to engage in this practice despite the risk associated with it. There has also been some research into the alternative prevention techniques used by gay men – sometimes instead of condoms.

In recent years, treatment as prevention (TasP) has emerged as an effective strategy for preventing HIV, given that ART suppresses the HIV-infected individual's viral load to 'undetectable' levels<sup>2</sup>. Most experts agree that an HIV-infected individual who has had an undetectable viral load for 6 months cannot transmit HIV to their sexual partners. However, many new infections occur as a result of sexual intercourse with an undiagnosed and, thus, untreated HIV-infected individual. Yet, the HIV-infected individual may not feel ready to engage with HIV care, or they may be unable to adhere to ART due to their social and

psychological circumstances. They may, for instance, be in a state of denial in response to their recent HIV diagnosis or perceive ART as a threat to their sense of continuity. All of these factors can undermine TasP as a means of decreasing one's HIV risk.

Some gay men engage in 'serosorting', that is, they may have condomless sex with individuals believed to share their HIV status (Golden et al., 2008). However, almost one fifth of HIV-infected individuals in the UK are unaware of their HIV status and, due to the social stigma, some may choose not to disclose it. HIV stigma poses hyper-threats to identity, sometimes precluding HIV status disclosure (Jaspal & Daramilas, 2016). Incidentally, those with acute HIV infection are perhaps less likely to be aware of their infection but will present a high viral load. Similarly, some HIV-positive individuals assume that a sexual partner who does not raise the issue of condom use 'probably' has HIV. Individuals who 'serosort' in this way are relying on the social representations that people with HIV disclose their status to their partners, on the one hand, and that those gay men who do not use condoms are already infected with HIV, on the other hand. Individuals may not wish to broach the stigmatised topic of HIV. They may make assumptions about their partner's status in the absence of explicit HIV status disclosure.

In recent years, PrEP has emerged as an effective biomedical approach to HIV prevention. Various clinical studies attest to its effectiveness if adherence is satisfactory. There is no straightforward correlation between awareness of and intention to use PrEP – gay men who are aware of PrEP do not automatically endorse it as a prevention tool. Barriers to using PrEP include inter alia HIV-related stigma, and concerns over side-effects and that it might not be reliably protective against HIV (Jaspal & Daramilas, 2016). Risk perception plays an important role in determining use intentions – in one study, 78% of the gay men who met the behavioural criteria for PrEP did not perceive their risk to be significant enough to warrant PrEP use (Gallagher et al., 2014).

All of the prevention options described above have limited effectiveness. Their effectiveness depends on the ability of gay man to have an awareness and understanding of risk representations, and to discuss risk and HIV prevention options with their sexual partners. There are clearly significant psychosocial barriers to uptake of some prevention methods.

## Social representations of HIV risk and prevention

There is a need to explore awareness and understanding of HIV and its associated risk factors in gay men at risk of infection and in the general population. In interview research conducted with a sample of 13 ethnically diverse HIV-negative gay men in the East Midlands,

perceptions of HIV appeared to converge around social representations of personal responsibility and culpability, on the one hand, and risk and fear of infection, on the other hand, as exemplified by the following extracts:

If you end up getting HIV, it's basically down to something that you've done. It's stupidity. You can just use a condom, can't you?

If you've got HIV, I feel sorry for you but you got yourself to blame really.

There was an attribution of personal responsibility and culpability to gay men living with HIV who were positioned as able, but unwilling, to use condoms. Furthermore, although people living with HIV were represented as worthy of sympathy due to the gravity of their condition (see below), their culpability was reiterated. The continuity principle requires individuals to construct meaningful theories that can explain and rationalise the occurrence of adverse events, such as HIV infection. Accordingly, interviewees held a social representation that gay men living with HIV are themselves responsible for their infection. By emphasising the culpability of those infected, interviewees were able to construct a 'just world' in which they, as 'responsible' people, remain free of infection. The following extracts demonstrate why HIV was 'othered' in this way, that is, represented as affecting only those whose behaviour is 'irresponsible':

It's a big killer. It can kill a person in a few years so I'm really careful about it.. I'd die if I got infected.

It's highly contagious. One person gets it and then the whole community basically has it. Everyone... so it's really dangerous and deadly, and it's sex.

Interviewees clearly held the hegemonic social representation that HIV is a serious illness but the condition was also anchored to death and contagion despite the availability of ART and the reality of TasP. It was personified in terms of a 'big killer'. This also increases HIV stigma. The social representation of HIV was imbued with imagery of danger and destruction, thereby inducing fear and avoidance. These social representations might accentuate fear not only of HIV but also of those living with the condition. Indeed, interviewees anticipated deeply negative psychological consequences of infection.

This fear of the 'infected Other' is consistent with research that shows that people tend to 'other' illness, including HIV, and thus view it as affecting outgroups or people unlike themselves (Joffe, 2007). Understanding HIV risk representations among gay men is important. In their interview study of 13 HIV-negative gay and bisexual men, Goldenberg et al. (2016) found that participants perceived sex with partners who were not gay-identified, not out about being gay or having sex with men as being low risk. These identity characteristics led some interviewees to believe that their partners were not frequently having sex with other men, which in turn paved the way for engaging in condomless sex with them. In short, interviewees held the social representation that bisexual men are 'low risk' compared to gay men. The authors conclude that HIV prevention messages and policies should focus on challenging this social representation, which can lead to the perception that non-gay identity is protective of HIV.

Some gay men may appraise the risk of infection from partners who do not disclose a positive HIV status or who claim to be HIV-negative as low. A survey conducted among gay and bisexual men in Australia revealed that over 75% of respondents held the social representation that individuals living with HIV should disclose their HIV status before sex, that is, they had this expectation of their sexual partners (Murphy et al., 2015). This social representation may lead to inaccurate risk perceptions among gay men, and to engagement in serosorting behaviours, which, as outlined earlier in this article, has only limited effectiveness.

Bourne et al. (2016) have studied social representations of HIV transmission risk among virally suppressed gay men living with HIV. They found that there was a consensually held social representation that condoms constitute the most effective HIV prevention method and a weaker endorsement of undetectable viral load as an HIV prevention method. Despite scientific evidence of 'U=U', this social representation was not pervasive in the sample and, thus, could plausibly affect sexual behaviour. For instance, some HIV-infected gay men may feel uneasy about engaging in condomless sex with their primary partner. This in turn could reduce feelings of intimacy, which some gay men do associate with condomless sex. Conversely, HIV-negative partners of people living with HIV may be fearful of having condomless sex due to fear of infection, which could undermine the quality of the relationship. In their interview study of perceptions of PrEP, another biomedical approach to HIV prevention, Jaspal and Daramilas (2016) described two major social representations among the gay men who were interviewed. HIV-negative gay men generally held a social representation of PrEP as a risky solution for 'high-risk' individuals, while those living with

HIV held the competing social representation that PrEP might enhance interpersonal relations between serodiscordant gay men.

Social representations vary in accordance with group membership - individuals are exposed to particular social representations through their group memberships. In a study of Latino and Black gay men in the US (Murray et al., 2018), it was found that perceived stigma in relation to being gay and a racial minority was associated with engagement in sexual risk-taking behaviours, possibly via the threats to self-esteem generated by stigmatising social representations of these group memberships. Perceived stigma might also decrease the effectiveness of interventions to prevent HIV and to promote sexual health. Similarly, hegemonic social representations that stigmatise HIV and those living with the condition can give rise to anticipated stigma among those MSM who perceive themselves to be at risk of infection (Starks et al., 2013). On the one hand, this can exacerbate the risk of poor sexual health as individuals may deflect and deny their risk of infection and refrain from testing regularly for HIV. On the other hand, this can seriously compromise mental health and wellbeing. Thus, exposure to negative, stigmatising social representations of important group memberships, such as one's sexuality and ethnicity, can lead to threats to identity and, thus, engagement in maladaptive coping behaviours to buffer the threat.

## Psychosocial stressors, identity threat and risk

Among gay men, there appears to be a high prevalence of specific psychosocial stressors, which can pose significant threats to identity. Examples include childhood sexual abuse (CSA), homophobia, and HIV stigma. CSA is up to four times more prevalent among gay men than heterosexual men and HIV-positive gay men are more likely than HIV-negative gay men to report a history of CSA (Lloyd & Operario, 2012). History of CSA is in turn associated with engagement in sexual risk behaviours and, in the case of HIV patients, with disengagement from care. In their study of ethnic minority gay and bisexual men, Jaspal et al. (2017) found that the relationship between CSA and HIV risk was mediated by the maladaptive coping strategy of substance misuse. It is possible that individuals self-medicate against psychological adversity associated with CSA by engaging in the 'escapist' strategy of substance misuse. This can offer temporary psychological respite in the way that other deflection strategies (e.g. denial) do. Furthermore, it has been suggested that CSA can have long-term adverse effects for the individual's self-esteem, leading to decreased self-care, and for self-efficacy, undermining their ability to negotiate condom use and sexual practices (Rosario, Schrimshaw & Hunter, 2006).

Life-long exposure to heteronormativity and homophobia is prevalent among gay men (Stonewall, 2017). This can make it difficult for some to derive a positive self-conception on the basis of their sexual identity and thus some may come to regard it as a source of shame and guilt. They may attempt to conceal their sexual identity from significant others due to the fear that self-disclosure could expose them to stigma, thereby challenging their self-esteem. Homophobia from significant others, such as family members and close friends, can result in the internalised homophobia, that is, the uncritical acceptance and internalisation of the stigma that one encounters. In short, the individual may accept, internalise and assimilate to their thinking and self-conception the negative and stigmatising social representations of their sexual identity. Due to the increased risk of threats to identity, life-long exposure to homophobia, and especially internalised homophobia, is associated with poor mental health outcomes, including anxiety, depression and, in some cases, suicidal ideation (Walch et al., 2016).

An HIV diagnosis itself is often experienced as a threat to identity given the associated social stigma. In the 2015/16 Stigma Survey, it was found that around half of HIVpositive gay men reported negative emotions, such as shame and guilt (Stigma Survey UK, 2015). Moreover, HIV stigma can affect several aspects of identity among gay men living with HIV, such as their sexual, family, and occupational identities (Jaspal & Daramilas, 2016). Partly due to the associated social stigma, HIV diagnosis and the experience of living with HIV can give rise to post-traumatic stress disorder (PTSD). In a systematic review of HIV infection associated with PTSD and post-traumatic growth (Sherr et al., 2011), it was found that there was a 5-74% prevalence of PTSD in HIV patients compared to 7-10% in the general population. There was also evidence of a link between HIV-related trauma and PTSD. This can have significant implications for health behaviours, such as decreased adherence to ART and low engagement with HIV care (LeGrand et al., 2015). Similarly, Carrico et al. (2014) indicated that positive affect of individuals living with HIV was associated with entry into HIV care three months after diagnosis and adherence to ART over the 18-month follow-up period. The social stigma that links HIV diagnosis to promiscuity and immorality could threaten self-esteem in the newly diagnosed individual, leading to feelings of self-disgust and shame. Threats to self-esteem, and the negative affective experiences associated with them, may serve as a barrier to HIV care, thereby undermining physical health outcomes. Indeed, low self-esteem can reduce the level of confidence required to seek HIV care (Castrighini et al., 2010).

In response to psychological adversity, some gay men resort to maladaptive coping strategies, such as sexual compulsivity, engagement in chemsex, and unprotected anal

intercourse. All of these behaviours are intended to buffer the negative effects of threat, but they are maladaptive in that they can actually undermine sexual health outcomes. It has been found that emotion dysregulation, internalised homophobia and problematic attachment styles, all of which can threaten identity, are associated with sexual compulsivity among gay men (Pachankis et al., 2015). Various studies indicate a high prevalence of 'chemsex' (drug use in sexualised settings) in gay men, and particularly in those living with HIV, which is associated with diagnosed depression or anxiety and the desire for escapism (Bourne et al., 2014). Unprotected anal intercourse may reflect a desire for intimacy and acceptance from others, especially in response to long-standing lack of intimacy, and to rejection and exclusion (Starks et al., 2014). All of these practices can increase the risk of HIV infection in HIV-negative gay men and lead to poor sexual health outcomes in HIV-infected gay men. Homophobia and HIV stigma, in particular, may contribute to disengagement from HIV prevention, such as PrEP, and HIV care, namely ART.

## **Engagement with care & ART adherence**

Linkage into HIV care is associated with a better prognosis as disease progression can be monitored and patients can initiate ART. Moreover, ART adherence reduces the risk of onward HIV transmission. However, numerous studies have found that HIV patients can experience difficulties in continuing to engage with care and in adhering to their medication (e.g. Cambiano et al., 2010). A meta-anaysis of 569 studies revealed that patients with a variety of illnesses manifested a non-adherence rate of approximately 25% (DiMatteo, 2004). This might be more acute for HIV patients in view of the side effects associated with some drug regimens and the mental health issues that frequently accompany HIV infection (Jaspal & Dhairyawan, 2018).

There are multifarious reasons underpinning non-adherence to ART. ART initiation represents a major lifestyle change for patients who are required to take daily medication for an indefinite period of time. Both actual and perceived side effects of ART can impede satisfactory adherence. The fear of negative side effects after an initial poor experience can hinder re-engagement. All of these factors can challenge the continuity principle of identity, thereby inhibiting engagement with care.

Concerns about body image can play an important role in considerations about side effects. Although uncommon with newer anti-HIV agents, ART can sometimes cause lipodystrophy and lipoatrophy in patients, which in turn can induce body change distress (Peterson, Martins, & Cofrancesco, 2008). Moreover, some patients may not be aware of, or

understand, the social representation that HIV is a serious condition that requires treatment. Lack of clarity regarding the necessity of ART and concerns about a variety of side effects can interfere with adherence (Nieuwkerk, 2008).

There appears to be a high prevalence of mental health disorders in HIV patients, which can complicate engagement with and retention in HIV care and, by extension, uptake of and adherence to ART (Jaspal & Dhairyawan, 2018). Decreased quality of life, depressive symptoms and higher levels of HIV stigma are significant risk factors for non-adherence (Protopopescu et al., 2009). Depression is one of the most common comorbidities to HIV infection, and is associated with decreased energy, inconsistent memory, and pessimism.

Stigmatising social representations of HIV can interfere with ART adherence. One of the insidious consequences of HIV stigma is indeed the negative health outcomes among HIV patients themselves. HIV stigma affects willingness to disclose one's positive serostatus to others as one may experience fear and anxiety about how others will react to this information. Previous experiences of rejection from sexual partners, for instance, may lead individuals to be fearful of HIV status disclosure. Non-adherence to ART is likely to be prevalent among those patients who are particularly concerned about, and sensitive to, HIV stigma. However, this will vary as some individuals are less exposed to HIV stigma than others and have greater social and psychological resources for buffering the negative psychosocial effects of stigma. One such resource is social support, which is also a known predictor of increased retention in HIV care and adherence to ART (DiIorio et al., 2009). Social support decreases negative affect, thereby enhancing self-efficacy to adhere to ART (Simoni, Frick and Huang 2006). Positive interpersonal relationships appear to enhance engagement with care and indeed adherence to ART. This can be manifested in terms of being reminded to take one's medication or feeling the need to engage in self-care behaviours due to the presence of significant others in one's life.

## A model for enhancing HIV prevention and care among gay men

In this article, various psychosocial stressors and their potential impact for identity processes have been described. Effective coping is key to both psychological and physical wellbeing. Jaspal (2018) has proposed a multi-level model that can enable practitioners to predict, and to intervene in order to mitigate, poor sexual health outcomes (see figure 2).

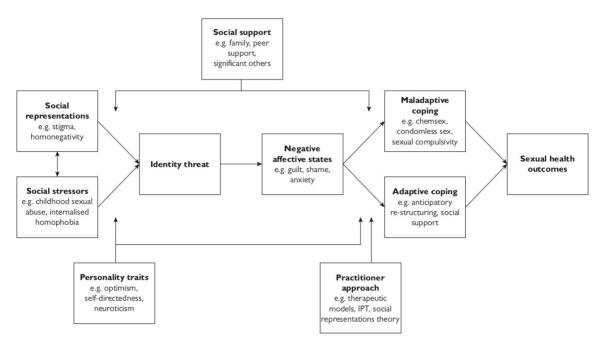


Figure 2: A framework for understanding self-identity, wellbeing and sexual health among MSM (from Jaspal, 2018)

Unfortunately, human beings all experience what can be loosely described as 'adverse events'. These are essentially social representations, events and situations which can cause psychological stress. As highlighted in this article, gay men have been, and continue to be, exposed to negative social representations of their sexual identity as a result of their socialisation in heteronormative contexts, on the one hand, and due to exposure to overt homophobia, on the other hand. Some may come to internalise the homophobia that they encounter, leading to internalised stigma. In addition to these negative social representations of their identity, there is a higher prevalence of particular social stressors among gay men, such as CSA, homophobic abuse and increased HIV risk.

Both these negative social representations and the adverse stressors have the potential to undermine the principles of self-esteem, continuity, self-efficacy and so on, leading to identity threat. Yet, not everyone exposed to negative social representations or social stressors will necessarily experience identity threat. The relationship between the adverse event and identity threat is likely to be mediated by personality traits, on the one hand, and by the availability of social support, on the other. For instance, an individual with high levels of neuroticism might be more prone to identity threat than an individual who has high levels of optimism. Moreover, the gay man who possesses a social support network is likely to draw on that network in order to mitigate the negative psychological consequences of the adverse event, thereby initiating effective coping before the onset of the threat.

If the adverse event does threaten identity, the individual will experience a negative affective state, such as guilt, shame, or anxiety. Negative affect is likely to be accentuated if the adverse event challenges more than one principle. Indeed, as demonstrated in this article, an HIV diagnosis can pose 'hyper-threats' to identity because it simultaneously undermines various, if not all of, the identity principles which habitually guide identity processes. Furthermore, people tend to favour some identity principles over others and that this is contingent partly on value orientations (a personality trait). An adverse event that threatens a favoured identity principle is likely to induce a more protracted state of negative affect. For instance, an individual who values conservation (such as tradition and conformity) may append greater importance to the continuity principle of identity than somebody who values openness to change (such as self-directedness and stimulation) who may, conversely, be more concerned about maintaining a sense of distinctiveness. The individual who values conservation and is faced with an adverse event that challenges continuity may also experience a heightened state of negative affect in response to that adverse event.

As a theory of identity threat and coping, identity process theory predicts that the threatened individual reacts to the threat by deploying coping strategies. Coping occurs at three distinct levels. The ways of coping can also be meaningfully differentiated into adaptive and maladaptive strategies. Examples of adaptive coping include anticipatory re-structuring, re-conceptualisation, and the derivation of social support. Examples of maladaptive coping include denial, engagement in chemsex, and sexual compulsivity. At least three variables will determine the choice of coping strategy: personality, the availability of social support and the practitioner.

First, personality traits will predispose an individual to cope in particular ways. For instance, the individual who values conservation may be less inclined to elect a coping strategy such as anticipatory re-structuring due to their desire to maintain a sense of continuity between past, present and future. They do not wish to entertain the idea of change because they strive to hold onto the past. On the other hand, the individual with a personality profile that favours sensation-seeking and hedonism may react to threat by engaging in risk behaviours, such as condomless sex or sexual compulsivity.

Second, the availability of social support is a significant determinant of coping strategy. Put simply, only those who actually possess a social support network can make use of it. The socially supported individual is more likely to engage in effective strategies, such as self-disclosure and to make use of the support offered by others than the individual who lacks a social support network.

Third, practitioners working with gay men at risk of poor sexual health outcomes have the potential to channel their clients and patients towards effective coping strategies. Tenets of social psychological theory, such as social representations theory and identity process theory, can enable the practitioner to gauge their patients' awareness, understanding and potential behaviour in any given context. This can also allow the practitioner to predict patterns of behaviour in their patients, allowing them to intervene to mitigate negative patterns of coping. For instance, a newly diagnosed gay man who has not disclosed his sexual identity to others due to anticipated homophobia is also likely to conceal his HIV status from others, precluding access to social support. The practitioner may intervene by facilitating access to social support networks. In short, the choice of coping strategy plays a fundamental role in sexual health outcomes among gay men facing identity threat.

#### **Conclusions**

Much of the biomedical and social sciences evidence converges in showing that HIV prevention and care are inextricably entwined. Yet, the presence and salience of psychosocial stressors in the lives of gay men can hinder HIV prevention and care efforts. The incorporation of social psychological theories, such as social representations theory and identity process theory, in clinical practice can greatly enhance prevention and care efforts. These theories can enable us to understand and, in some cases, to predict maladaptive strategies for coping with psychological adversity, which in turn can lead to poor sexual health outcomes. It is similarly possible to channel patients and clients towards more adaptive coping strategies. Indeed, as Breakwell (2018, p. 9) aptly notes, '[a] person's identity is a dynamic, evolving system – being created over a lifetime. Supporting and channelling that evolution is often a most valuable task of a practitioner.'

### References

Bennett, D. S., Traub, K., Mace, L., Juarascio, A. & O'Hayer, C.V. (2016). Shame among people living with HIV: a literature review. *AIDS Care*, 28(1), 87–91.

Bernier, A., Lefèvre, M., Henry, E., Verdes, L., Acosta, M.-E., Benmoussa, A., ... Préau, M. (2016). HIV seropositivity and sexuality: cessation of sexual relations among men and women living with HIV in five countries. *AIDS Care*, 28(Supplement 1), 26–31.

Bourne, A., Reid, D., Hickson, F., Torres Rueda, S. & Weatherburn, P. (2014). *The Chemsex study: drug use in sexual settings among gay & bisexual men in Lambeth, Southwark & Lewisham.* London: Sigma Research, London School of Hygiene & Tropical Medicine.

www.sigmaresearch.org.uk/chemsex Accessed on 11 July 2018.

Bourne, A., Dodds, C., Keogh, P. & Weatherburn, P. (2016). Non-condom related strategies to reduce the risk of HIV transmission: Perspectives and experiences of gay men with diagnosed HIV. *Journal of Health Psychology*, 21(11), 2562-2571.

Breakwell, G.M. (2014). Identity process theory: Clarifications and elaborations. In R. Jaspal and G.M. Breakwell (eds), *Identity Process Theory: Identity, Social Action and Social Change*. Cambridge: Cambridge University Press.

Breakwell, G.M. (2018). Foreword. In R. Jaspal (Ed.) *Enhancing Sexual Health, Self-Identity and Wellbeing among Men Who Have Sex With Men: A Guide for Practitioners* (pp.7-9). London: Jessica Kingsley.

Breakwell, G.M. & Millward, L.J. (1997). Sexual self-concept and sexual risk-taking. *Journal of Adolescence*, 20(1), 29-41.

Cambiano, V., Lampe, F.C., Rodger, A.J., Smith, C.J., Geretti, A.M., Lodwick, R.K., Puradiredja, D.I., Johnson, M., Swaden, L. & Phillips, A.N. (2010) Long-term trends in adherence to antiretroviral therapy from start of HAART. *AIDS*, *24*(8), 1153–62.

Carrico, A.W. & Moskowitz, J.T. (2014). Positive affect promotes engagement in care after HIV diagnosis. *Health Psychology*, 33(7), 686-689.

Castrighini, C., Gir, E., Neves, L., Reis, R., Galvão, M. & Hayashido, M. (2010). Depression and self-esteem of patients positive for HIV/AIDS in an inland city of Brazil. *Retrovirology*, 7(Supplement 1), 66. https://dx.doi.org/10.1186%2F1742-4690-7-S1-P66

DiIorio, C., McCarty, F., DePadilla, L., Resnicow, K., Holstad, M.M., Yeager, K., Sharma, S.M., Morisky, D.E. & Lundberg, B. (2009). Adherence to antiretroviral medication regimens: A test of a psychosocial model. *AIDS and Behavior*, *13*(1), 10–22

DiMatteo, M.R. (2004). Variations in patients' adherence to medical recommendations: A quantitative review of 50 years of research. *Medical Care*, 42(3), 200-209.

Exner, T.M., Meyer-Bahlburg, H.F.L. & Ehrhardt, A.A. (1992). Sexual self-control as a mediator of high risk sexual behavior in a New York City cohort of HIV-positive and HIV-negative gay men. *Journal of Sex Research*, 29, 389–406.

Flowers, P., Smith, J., Sheeran, P. & Beail, N. (1997). Health and romance: Understanding unprotected sex in relationships between gay men. *British Journal of Health Psychology*, 2(1), 73-86.

Gallagher, T., Link, L., Ramos, M., Bottger, E., Aberg, J. & Daskalakis, D. (2014). Self-perception of HIV risk and candidacy for pre-exposure prophylaxis among men who have sex with men testing for HIV at commercial sex venues in New York City. *LGBT Health*, *1*, 218–224.

Golden, M.R., Stekler, J., Hughes, J.P. & Wood, R.W. (2008). HIV serosorting in men who have sex with men: is it safe? *Journal of Acquired Immune Deficiency Syndromes*, 49(2), 212–8.

Goldenberg, T., Finneran, C., Sullivan, S.P., Andes, K.L. & Stephenson, R. (2016). "I consider being gay a very high risk factor": How perceptions of a partner's sexual identity influence perceptions of HIV risk among gay and bisexual men. *Sexuality Research and Social Policy*, 14(1), 32–41.

Jaspal, R. & Breakwell, G.M. (eds) (2014). *Identity Process Theory: Identity, Social Action and Social Change*. Cambridge: Cambridge University Press.

Jaspal, R. & Cinnirella, M. (2010). Coping with potentially incompatible identities: Accounts of religious, ethnic and sexual identities from British Pakistani men who identify as Muslim and gay. *British Journal of Social Psychology*, 49, 849–870.

Jaspal, R. & Daramilas, C. (2016). Perceptions of pre-exposure prophylaxis (PrEP) among HIV-negative and HIV-positive men who have sex with men. *Cogent Medicine*. *3*: 1256850 DOI: 10.1080/2331205X.2016.1256850

Jaspal, R. & Dhairyawan, R. (2018). Sexual health, HIV & mental health in BAME communities in the UK. In R. Raghavan (ed), *Mental Health, Ethnicity and Cultural Diversity: Narratives for Transformative Services*. Bingley: Emerald Publishing Limited.

Jaspal, R. & Nerlich, B. (2017). Polarised Reporting about HIV Prevention: Social Representations of Pre-Exposure Prophylaxis (PrEP) in the UK Press. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 21(5), 478-497.

Jaspal, R., Lopes, B., Jamal, Z., Paccoud, I. & Sekhon, P. (2017). Sexual abuse and HIV risk behaviour among black and minority ethnic men who have sex with men in the UK. *Mental Health, Religion & Culture, 20*(8), 841-53.

Jaspal, R. (2018). Enhancing Sexual Health, Self-Identity and Wellbeing among Men Who Have Sex With Men: A Guide for Practitioners. London: Jessica Kingsley Publishers.

Joffe, H. (1995) Social representations of AIDS: towards encompassing issues of power. *Papers on Social Representations*, 4(1), 29-40.

Joffe, H. (2007) Identity, self-control, and risk. In G. Moloney & I. Walker (eds) *Social Representations and Identity*. New York: Palgrave Macmillan.

Kirwan, P.D., Chau, C., Brown, A.E., Gill, O.N., Delpech, V.C. & contributors. (2016). HIV in the UK - 2016 report. London: Public Health England. <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/602942/HIV\_in\_the\_UK\_report.pdf">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/602942/HIV\_in\_the\_UK\_report.pdf</a> Accessed 11 July 2018.

LeGrand, S., Reif, S., Sullivan, K., Murray, K., Barlow, M.L. & Whetten, K. (2015). A review of recent literature on trauma among individuals living with HIV. *Current HIV/AIDS Reports*, 12(4), 397–405.

Lloyd, S. & Operario, D. (2012). HIV risk among men who have sex with men who have experienced childhood sexual abuse: Systematic review and meta-analysis. *AIDS Education & Prevention*, 24, 228-241.

Moscovici, S. (1988). Notes towards a description of social representations. *European Journal of Social Psychology*, 18, 211–250.

Murphy, D.A., de Wit, J.B., Donohoe, S. & Adam, P.C. (2015). The need to know: HIV status disclosure expectations and practices among non-HIV-positive gay and bisexual men in Australia. *AIDS Care: Psychology and Socio-Medical Aspects of AIDS/HIV*, 27, 90-98.

Murray, A., Gaul, Z., Sutton, M.Y. & Nanin, J. (2017) "We hide ...": Perceptions of HIV risk among Black and Latino MSM in New York City. *American Journal of Men's Health*, 12(2), 180-188.

Nieuwkerk PT. (2008). Lower perceived necessity of HAART predicts lower treatment adherence and worse virological response in the ATHENA cohort. *Journal of Acquired Immune Deficiency Syndromes*, 49(4), 460–2.

Pachankis, J.E., Rendina, H.J., Restar, A., Ventuneac, A. & Parsons, J.T. (2015) A minority stress—emotion regulation model of sexual compulsivity among highly sexually active gay and bisexual men. *Health Psychology*, *34*(8), 829-40.

Peterson, S., Martins, C.R. & Cofrancesco, J. (2008). Lipodystrophy in the patient with HIV: Social, psychological, and treatment considerations. *Aesthetic Surgery Journal*, 28(4), 443–451.

Protopopescu, C., Raffi, F., Roux, P., Reynes, J., Dellamonica, P., Spire, B., Leport, C. & ANRS CO8 APROCO- COPILOTE Study Group. (2009). Factors associated with non-adherence to long-term highly active antiretroviral therapy: A 10 year follow-up analysis with correction for the bias induced by missing data. *Journal of Antimicrobial Chemotherapy*, 64(3), 599–606.

Rosario, M., Schrimshaw, E. W. & Hunter, J. (2006). A model of sexual risk behaviors among young gay and bisexual men: Longitudinal associations of mental health, substance abuse, sexual abuse, and the coming-out process. *AIDS Education and Prevention*, 18(5), 444–460.

Shernoff, M. (2006) Without Condoms: Unprotected Sex, Gay Men and Barebacking. New

York: Routledge.

Sherr, L., Nagra, N., Kulubya, G., Catalan, J., Clucas, C. & Harding, R. (2011). HIV infection associated post-traumatic stress disorder and post-traumatic growth - A systematic review. *Psychology, Health & Medicine*, *16*(5), 612-629.

Simoni, J.M., Frick, P.A. & Huang, B. (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychology*, 25(1), 74-81.

Starks, T.J., Rendina, H.J., Breslow, A.S., Parsons, J.T. & Golub, S.A. (2013) The psychological cost of anticipating HIV stigma for HIV-negative gay and bisexual men. *AIDS and Behavior*, 17, 2732-2741.

Starks, T.J., Payton, G., Golub, S.A., Weinberger, C.L., & Parsons, J.T. (2014). Contextualizing condom use: Intimacy Interference, stigma, and unprotected sex. *Journal of Health Psychology*, 19(6), 711-720.

Stigma Survey UK (2015). HIV in the UK: Changes and Challenges; Actions and Answers The People Living With HIV Stigma Survey UK 2015, Men Who Have Sex With Men (MSM). <a href="http://stigmaindexuk.org/reports/2016/MSM.pdf">http://stigmaindexuk.org/reports/2016/MSM.pdf</a> Accessed on 11 July 2018

Stonewall (2017). LGBT in Britain: Hate Crime and Discrimination. <a href="https://www.stonewall.org.uk/sites/default/files/lgbt\_in\_britain\_hate\_crime.pdf">https://www.stonewall.org.uk/sites/default/files/lgbt\_in\_britain\_hate\_crime.pdf</a> Accessed 11 July 2018.

UNAIDS, (2017) Ending AIDS: Progress towards the 90-90-90 Targets. Joint United Nations Programme on HIV/AIDS (UNAIDS). Available at http://www.unaids.org/sites/default/files/media\_asset/Global\_AIDS\_update\_2017\_en. pdf Accessed 13 September 2017

Walch, S.E., Ngamake, S.T., Bovornusvakool, W. & Walker, S.V. (2016). Discrimination, internalized homophobia, and concealment in sexual minority physical and mental health. *Psychology of Sexual Orientation and Gender Diversity*, *3*, 37-48.

Wilkinson, A.L., Draper, B.L., Pedrana, A.E., Holt, M., Hellard, M.E. & Stoové, M. (2018). Measuring and understanding the attitudes of Australian gay and bisexual men towards biomedical HIV prevention using cross-sectional data and factor analyses. *Sexually Transmitted Infections*, 94, 309-314.

Williamson, I., Papaloukas, P., Jaspal, R. & Lund, B. (in press). 'Here's this glorious pill': Gay and bisexual men in the English Midlands navigate risk and responsibility in the age of pre-exposure prophylaxis. *Critical Public Health*.

# **Author biography**

Rusi Jaspal is Professor of Psychology and Sexual Health, and Pro Vice-Chancellor for Research at De Montfort University, Leicester, UK. He is the author of *Enhancing Sexual Health, Self-Identity and Wellbeing among Men Who Have Sex With Men: A Guide for Practitioners* (Jessica Kingsley, 2018). E-mail: rusi.jaspal@cantab.net