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HIV-related stigma within communities of gay men: A literature review

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While stigma associated with HIV infection is well recognised, there is limited information on the impact of HIV-related stigma between men who have sex with men and within communities of gay men. The consequences of HIV-related stigma can be personal and community-wide, including impacts on mood and emotional well-being, prevention, testing behaviour, and mental and general health. This review of the literature reports a growing division between HIV-positive and HIV-negative gay men, and a fragmentation of gay communities based along lines of perceived or actual HIV status. The literature includes multiple references to HIV stigma and discrimination between gay men, men who have sex with men, and among and between many gay communities. This HIV stigma takes diverse forms and can incorporate aspects of social exclusion, ageism, discrimination based on physical appearance and health status, rejection and violence. By compiling the available information on this understudied form of HIV-related discrimination, we hope to better understand and target research and countermeasures aimed at reducing its impact at multiple levels.

Keywords: Stigma; HIV/AIDS; gay men; men who have sex with men; mental health; emotional well-being

Introduction

Stigma has been defined as any characteristic, real or perceived, that conveys a negative social identity (Crocker, Major, & Steele, 1998; Goffman, 1963). With regard to human immunodeficiency virus (HIV) infection, the Joint United Nations Programme on HIV/acquired immunodeficiency syndrome (UNAIDS) describes stigma as: "a process of devaluation of people either living with, or associated with, HIV and AIDS". Discrimination follows stigma and is the "unfair and unjust treatment of an individual based on his or her real or perceived HIV status" (UNAIDS, 2003).

Negative attitudes towards people with HIV have been recognised since the beginning of the epidemic. Despite public education programmes and equal rights legislation, stigmatisation continues to be widespread and can affect many aspects of life (Center for AIDS Prevention Studies [CAPS], 2006).

Most published reports on HIV-related stigma have assessed the attitudes of the general population. However, stigmatisation of HIV-positive individuals also occurs specifically within communities of gay men (Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008; Dowshen, Binns, & Garofalo, 2009). Indeed, a growing division has been documented (Botnick, 2000a), whereby HIV-negative gay men associate mainly or exclusively with other HIV-negative gay men, and vice versa. Botnick has linked this with observations that HIV-positive gay men have an increased tendency to withdraw from both their usual social scenes and wider society (Botnick, 2000b). This polarisation may negatively impact relationships and other aspects of physical and emotional health, social life, HIV testing behaviour, disclosure, disease prevention, and medication and therapy adherence (Botnick, 2000a; UNAIDS, 2009). Such effects, coupled with the fact that HIV prevalence and transmission rates in many developed nations are high, and increasing among gay men (UNAIDS, 2009), highlight the need for interventions to actively counter stigmatisation aimed specifically at HIV-positive gay men. This article reviews the fragmented and largely anecdotal literature on HIV-related stigma among men who have sex with men (MSM), and within communities of gay men, in order to inform future research and the development of more effective interventions.

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Methods

A PubMed search was undertaken to identify English language peer-reviewed articles using the search terms "AIDS" or "HIV" and "stigma", "discrimination", "rejection" or "isolation" for the period 1991–2010 inclusive. The literature search was then filtered by searching with keywords including "gay community", "gay men", "men who have sex with men (MSM)", "serosorting" and "disclosure". A total of 987 articles were found, reviewed for relevance and included where relevant.

A broader internet search, using the same terms, was also conducted using the Google search engine. The most relevant of the 15,400,000 hits were assessed for accuracy and authenticity (as far as possible) and included as appropriate.

Results

Forms of HIV-related stigma

Stigmatisation of HIV-positive gay men appears to be extensive and wide-ranging. For example, in a survey by the Dutch HIV Association of 667 people living with HIV/AIDS, the majority of whom identified as gay men (79.5%), participants all reported experiencing one or more forms of stigma. In particular, 70.2% of the gay respondents had experienced stigma in the gay scene, this was second only to stigma originating from the general media (82.3%) (Stutterheim, Bos, & Schaalma, 2008). Stigma included discrimination and rejection by HIV-negative gay men, stigma related to ageing, changes in physical appearance, race/ethnicity and self-stigma.

Causes of HIV-related stigma within gay communities

Discrimination and rejection by non-HIV infected gay men

Some HIV-negative gay men feel that HIV-positive men threaten gay communities, either in terms of health or general perceptions of gay men (Flowers, Duncan, & Franks, 2000). For example, in a survey of HIV-negative gay Latino men, over 50% believed HIV-positive gay men were personally responsible for their HIV status and were more promiscuous than themselves (Courtenay-Quirk, Wolitski, Parsons, & Gomez, 2006; Díaz, 2006). Additionally, in this study 64% and 82% of respondents respectively stated that their HIV status made it more difficult for them to trust people or worried that sexual partners would reject them (Courtenay-Quirk et al., 2006).

Age-related stigma and stigma due to physical changes

Several studies have documented HIV-related discrimination and marginalisation based on age (Dodds & Keogh, 2006; Schrimshaw & Siegel, 2003; Siegel, Raveis, & Karus, 1998). These studies found that older HIV-positive men (aged ≥ 50 years) felt undervalued and believed that they received less empathy, sympathy and compassion than younger men with HIV.

Conversely, younger HIV-positive gay men have reported antipathy from older gay men (both HIV-positive and HIV-negative) who feel that since the younger generation have access to better HIV education and services than they did, younger gay men should be more responsible in avoiding infection.

A division also exists between men with HIV based upon the timing of diagnosis. According to reports from focus groups of HIV-positive gay and bisexual men in the UK, older HIV-positive men are often considered to be at the "lowest rung" of the "gay social hierarchy" (Dodds & Keogh, 2006). They are resented and rejected as being "dependent on the state", living on social benefits that are no longer available to younger HIV-positive men. Additionally, older men with HIV, who have not had the benefit of early effective treatment, are more likely than younger men to suffer physical manifestations of the illness, such as lipodystrophy, that generate further stigma (Monvoisin et al., 2008).

Changes in body shape and other physical characteristics that can occur due to HIV or its treatment are typically regarded as unattractive and a reminder of a person's HIV-positive status. Visible physical changes, such as lipoatrophy and lipodystrophy, are especially stigmatising (National Centre in HIV Social Research, 2003; Persson, 2005).

HIV-related stigma due to race or ethnicity

Racial and ethnic differences are well documented causes of stigma and discrimination in most populations, irrespective of sexual orientation. Data on race-based stigma specifically among HIV-positive men are limited and primarily focus on issues surrounding black gay men. For example, in a study of sexual partner selection in the USA (Raymond & McFarland, 2009), black gay men were perceived to be at higher risk of being HIV-positive compared to other ethnicities, which may lead men of other races to avoid black men as sexual partners. Furthermore, the study suggested that the attitudes of non-black gay men, and social networks and environments found in gay venues can also separate black gay men from their peers.

Self-stigma

In addition to the perceived stigma from external sources, "internal stigma" or "self-stigma" is a confounding issue among HIV-positive gay men and can be the result of ongoing external stigma. A US-based study found that MSM who "self-stigmatised" homosexuality were less likely to undertake HIV testing, with black MSM twice as likely as white MSM to have internalised homophobia (Glick & Golden, 2010).

Consequences and impact of stigma on HIV-positive men

Mental and emotional well-being

Among HIV-positive gay men, stigma has a considerable impact on mental and emotional well-being, causing significantly increased levels of anxiety, loneliness, depressive symptoms, suicidal ideation and engagement in avoidant strategies such as social withdrawal (Courtenay-Quirk et al., 2006; Grov et al., 2010). In addition, physical symptoms of HIV and side effects of its treatment can also have a negative psychological and emotional impact (Pence, 2009).

Gay men and, in particular, those with HIV, are more likely to suffer from mental health problems than the general population (King et al., 2003, 2008). From self-completed surveys of major depressive disorder (MDD) in sexually active gay men attending general practices in urban Australia (Mao et al., 2009), it appeared that the rate of MDD among the 195 HIV-positive gay men was significantly higher than that among the 314 HIV-negative gay men (31.8 vs. 20.1%, respectively). MDD was also independently associated with denial and isolation coping strategies, and with less social support. Furthermore, in a study of HIV-positive MSM in New York and San Francisco, participants perceived a "rift" based on HIV status within their gay community that was linked to depression, anxiety and loneliness (Wolitski, Dey, Parsons, & Gomez, 2002).

Social segregation based on HIV status

Studies of "serosorting" have emerged in the literature, whereby gay men and MSM associate predominately with others of the same HIV status (Barber, 1991; Johnson, 1995; Yi, Shidlo, & Koegel, 2004). Serosorting extends to individual relationships and communities, whereby both HIV-positive and HIV-negative men screen prospective social or sexual partners for concordance in HIV status before associating with them socially or sexually. Some authors report positive aspects of serosorting for both HIV-negative and HIV-positive gay men, while others have likened it to an "AIDS apartheid"[1] based on internal or outwardly perceived stigma (Barber, 1991).

Some studies have suggested that serosorting may reduce transmission among high-risk HIV-negative gay men (Eaton, Kalichman, O'Connell, & Karchner, 2009; Philip, Yu, Donnell, Vittinghoff, & Buchbinder, 2010; Wilson et al., 2010). However, Eaton et al. (2009) found that HIV-negative MSM who serosort were inadvertently placing themselves at risk for HIV through infrequent HIV testing, lack of HIV status disclosure, acute HIV infection as well as co-occurring sexually transmitted infections. Moreover, true serosorting is only possible for diagnosed HIV-positive men outside of clinical settings (Cairns, 2007). It has been suggested that most HIV-negative and HIV-positive men may more accurately be described as practising "seroguessing" selection based on perceived rather than actual HIV status (Zablotska et al., 2009).

Social withdrawal due to changes in physical appearance

A series of interviews in Australia with HIV-positive gay men linked the presence of lipodystrophy with feelings of isolation (Persson, 2005). Specifically, participants reported a loss of intimacy and avoidance of particular social spaces and activities because they felt self-conscious about their appearance and/or feared rejection. Furthermore, individuals with physical manifestations associated with HIV may participate in increased risk-taking behaviour and other potentially health-compromising behaviours that have been associated with low self-esteem (Collins, Wagner, & Walmsley, 2000; Duran et al., 2001).

Testing and disease prevention

Studies have specifically shown a correlation between HIV-related stigma and lower rates of counselling and testing, poorer knowledge about transmission and a greater reluctance to disclose HIV status and test results (Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010). Some men avoid taking HIV tests or seeking treatment through fear of the negative social consequences, stigma and discrimination associated with a positive test result (CAPS, 2006; Feng, Wu, & Detels, 2010; Nanin et al., 2009).

A qualitative study by Flowers et al. (2000) on the attitudes of Scottish gay men to HIV testing explored the importance of community within gay men's HIV risk-management belief framework. Flowers et al. found that HIV testing policies and attitudes to the

visible effects of HIV or its treatment can contribute to the social exclusion experienced by HIV-positive gay men. However, we could find no studies on whether medications with fewer stigmatising side-effects or universal HIV-testing policies can change attitudes or reduce stigma.

More studies are needed to determine whether the adoption of medications with fewer stigmatising side-effects and universal HIV testing policies that focus on normalisation can help change attitudes as well as provide public health benefits.

Disclosure of HIV status

In a qualitative study in the USA (Courtenay-Quirk et al., 2006), participants described how social isolation within gay communities often occurred when people chose not to disclose their HIV status to anyone outside their immediate support network. Conversely, participants reported "externally imposed" social isolation when they disclosed their status, strongly reinforcing avoidance of disclosure.

However, there is counter-evidence that disclosure in carefully selected settings may act as a coping strategy against stigma, particularly in situations when the individual believes disclosure might encourage social support, or reduce gossip and rumours (Makoae et al., 2008). Poindexter and Shippy (2010) identified three overarching themes relating to HIV disclosure: (1) hiding or selectively disclosing (i.e., stigma management); (2) partial disclosure to help control spread of the information; and (3) widespread or complete voluntary disclosure (i.e., stigma resistance). Where physical manifestations of HIV infection are present these can mitigate towards (forced) disclosure (National Centre in HIV Social Research, 2003; Persson, 2005).

Rejection in relationships

In a study of HIV-positive gay men in the UK (Bourne, Dodds, Keogh, Weatherburn, & Hammond, 2009), the greatest concern, shared by nearly all of the men in the study regardless of local HIV prevalence, was the possibility of rejection by sexual partners following disclosure of status. Indeed, nearly every participant had experienced rejection by potential sexual partners due to HIV status. The harm this caused to their self-esteem and self-confidence was often serious and long-lasting. Some men reported subsequently developing significant social and sexual distance from other men with HIV, whom they frequently characterised as morally inferior. In this example of self-stigmatisation imposed from external perceptions, also known as meta-stereotyping (Klein & Azzi, 2001), the respondents felt strongly that being associated with HIV-positive sexual spaces, either online or offline, would compound stigma directed towards them.

In one qualitative study of relationships between HIV-positive and HIV-negative men in Toronto, Canada, many HIV-positive gay men reported rejection and lack of empathy from HIV-negative friends and/or partners (Maxwell, 1998). In addition, a survey in the UK reported anecdotal evidence from gay men who faced rejection and violence by potential partners upon disclosure of their HIV status, while others were surprised that HIV-negative gay men were not more supportive (Weatherburn et al., 2009).

High-risk behaviour

HIV-positive gay men may participate in high-risk behaviours, such as drug use and unprotected anal intercourse (UAI), as a means of coping with living with HIV (Kelly, Bimbi, Izienicki, & Parsons 2009). Men with HIV participating in high-risk behaviours, including UAI, tend to report increased stigma, gay-related stress, self-blame-related coping and substance abuse (Kelly et al., 2009; Radcliffe et al., 2010).

In a review of the sociology of "barebacking" (UAI), numerous theories are proposed for why gay men engage in unprotected sex, including the fact that many HIV-positive men feel socially alienated from HIV-negative men (Shernoff, 2005). In a series of interviews on disclosure practices, risk taking and attitudes about HIV infection conducted among 150 gay men in the USA who had participated in UAI, respondents cited a community-wide shift towards non-disclosure and UAI since the advent of effective anti-retroviral therapy (ART) (Sheon & Crosby, 2004). Shifts in attitudes to HIV and risk taking since the advent of effective ART are complex and wide-ranging. Persson (2005) reports that normalisation can lead some individuals to engage in higher-risk behaviours, including increased UAI. Stigma associated with a fear of physical changes due to side effects of treatment may also cause some individuals in certain situations to delay seeking and initiating treatment (Abaynew, Deribew, & Deribe, 2011).

Alcohol consumption and recreational drug use

Research into the link between stigma, and alcohol and drug use is inconclusive. While some studies found no evidence of a link (Courtenay-Quirk et al., 2006), others reported that young men with HIV who experienced greater amounts of stigma were more

likely to use illicit drugs than their counterparts who experienced less stigma (Swendeman, Comulada, Lee, & Rotheram-Borus, 2002).

Access to care and adherence to HIV medication

Individuals experiencing high levels of stigma are over twice as likely to have suboptimal adherence to their HIV treatment and are five times as likely to report poor access to medical care (Sayles et al., 2009). One study found that stigma and poor medication adherence were more common among people who disclosed their HIV status to a broad range of social contacts (Vanable, Carey, Blair, & Littlewood, 2006). An earlier study found that men reporting discrimination from their sexual partners were less likely to be adherent to medication, with a significant relationship existing between involuntary disclosure and non-adherence (Peretti-Watel, Spire, Pierret, Lert, & Obadia, 2006).

Conclusions and discussion

Gay men may confront multiple layers of stigmatisation and discrimination based on their sexuality, behaviour and their HIV status from other HIV-negative and HIV-positive gay men. The consequences of this are wide-ranging and can negatively impact many aspects of an individual's daily life, social and sexual relationships, emotional and physical health. HIV-related stigma and discrimination have been associated with increased risk-taking behaviours in both HIV-positive and HIV-negative men, and a decrease in successful HIV prevention and testing in these men. When compounded by self-stigma, HIV stigma has been noted in a growing number of reports as a significant divisive influence between and among gay men at both a community and individual level.

Divergence is evolving between community and individual approaches to HIV prevention. For instance, studies have reported a reduction in condom use due to individual risk-assessment strategies, such as serosorting and viral load sorting (Prestage et al., 2009), and changes in attitudes towards testing. These may in part be associated with HIV-related stigma and a wish to avoid discovery or disclosure of HIV status and the associated threat of rejection and reduced social support (Imrie & Macdonald, 2009). Indeed, the issue of serosorting is complex. While some HIV-positive men may view serosorting as a means to cope with their anxiety about transmission, it has also been argued that men are more comfortable in relationships with men of the same status due to HIV-related stigma. Additionally, the practice of seroguessing conflates the issue; HIV risk-reduction messages should highlight the limitations of relying on assumed HIV status when making sexual risk decisions (Eaton et al., 2009; Truong et al., 2006).

In some countries, transmitting or exposing another person to HIV can be considered a criminal or unlawful act (UNAIDS, 2008). This is a contentious topic and one that may be influenced by stigmatising attitudes (Dodds et al., 2009). According to UNAIDS, criminalisation of HIV transmission may reinforce HIV-related stigma, spread misinformation about HIV, hinder HIV testing and counselling support and, importantly, create a false sense of security by encouraging HIV-negative men to indulge in risky behaviours, believing themselves legally protected from transmission (UNAIDS, 2008).

More research is required to fully assess the extent, consequences and potential countermeasures in relation to HIV-related stigma within gay communities. In particular, much of the available literature is anecdotal, highlighting the need for empirical evaluations. The consequences of such missing data negatively affects individuals living with HIV, and may also threaten to further divide communities of gay men and present a significant barrier to efforts aimed at addressing the overall HIV epidemic.

While stigma-reduction programmes have been identified and shown to be effective in small-scale, short-term trials, none have been conducted specifically among gay men, and many gaps remain, especially in relation to the size, duration and impact of these initiatives (Brown, Macintyre, & Trujillo, 2003). Increased efforts to raise awareness and to develop validated strategies to help reduce stigmatisation of HIV-positive gay men are urgently needed. Social cohesion in target groups of care and prevention are, from our understanding, important for mental and emotional well-being. Reducing the gaps between HIV-positive and HIV-negative men is therefore important not just for the well-being of HIV-positive men. Improving knowledge about HIV transmission and HIV prevention, and understanding about living with HIV, we believe, should help reduce the stigma that currently exists due to misunderstanding and lack of awareness, and hopefully increase the uptake of HIV testing and prevention measures. Indeed, UNAIDS has identified the reduction of stigma and discrimination as a central part of national HIV programmes (UNAIDS, 2007). Such initiatives should foster a renewed dialogue about living with HIV as a gay man, create opportunities to share understanding and experience among HIV-positive and HIV-negative men, and aim to reunite

gay communities by reducing stigma and offering integrated medical and social support.

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Note

1. A reference to the policy of race segregation and discrimination in twentieth century South Africa.

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