

**Othering, blame and shame when working with people living with HIV**

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### **Abstract**

Significant advances in HIV treatment has meant that for the majority of patients with HIV they are able to live a normal lifespan. However, HIV remains a highly stigmatizing disease with the potential to significantly impact on ones social identity and sense of self. This paper draws on data from a qualitative study of interviews with five gay men, to explore the experiences of shame in relation to living with HIV. The paper adopts a psychoanalytic lens to highlight the mechanisms of splitting that may be involved at both a social and individual level, and the experience of shame among the participants. The paper aims to use this research data to supplement our understanding of what may be occurring 'on the couch' with patients who are living with HIV.

**Key words:** HIV, stigma, othering, shame, sexuality.

### **Introduction**

We are now in to the fourth decade of the HIV epidemic and advances in treatment and care has meant that HIV is now considered to be a manageable chronic illness, rather than the fatal illness that it once was. We are more likely to be seeing patients

who are HIV-positive who are able to live a full lifespan, but now have to face and come to terms with living with an illness that continues to be highly stigmatizing. Surprisingly little has been written in the psychoanalytic literature about HIV, yet psychoanalytic psychotherapy has much to offer in terms of helping clients living with HIV understand and work through the significant psychic trauma associated with having an HIV diagnosis.

In the early years of the epidemic, when HIV in most cases led to AIDS and subsequent death, what little psychoanalytic writing there was tended to focus on HIV as a symptom partly related to what was referred to as the perverse pathology of 'the homosexual patient'; a consequence and symptom of his disordered and perverse self-concept (see for example Burgner, 1994 and Hildebrand, 1992). While these patients might well have had serious psychological issues, and were facing a terminal illness in early adulthood, the attention given by such psychoanalytic writers to the meaning of their HIV focuses on understanding HIV almost solely as an expression of their homosexual 'pathology'. For the analyst it was the patient's homosexuality that was the real sickness. For example, Limentani (1994), in a conclusion to his paper on the "treatment" of homosexuality, writes about gay patients with HIV:

These people represent the most serious challenge to psychotherapists all over the world, as they often present themselves with strong features of manic denial and defiance. In some respects they are no different from the true homosexuals of twenty years ago who might have been depressed, in a background of inability to relate to their fellow human-beings. At the first

interview of a patient, we quickly notice his anxiety that the analyst may be interested only in changing his sexual orientation. But we soon notice a lack of genuine contact with a best friend; or anger and resentment that a good friend who had been the victim of AIDS should have exposed the patient to it. It is then that we become aware that the main source of the nearly-conscious problem is disillusionment with the homosexual solution. (pg. 60)

Such perspectives place the 'problem' firmly within the mind of the patient – they are distressed and angry because they cannot relate to others and their perverse solution has failed. The goal of therapy (as seems to be suggested in the cases described by Burgner) was to try and get the patient to take responsibility for their perverse behaviours that led them to become infected with HIV. While the patients with HIV who were coming for help from psychoanalysts might well have had difficulties in their relationships, it may have become easy for such psychotherapeutic work with patients who have HIV to become *moral work* around the 'facts of life' (Chasseguet-Smirgel, 1983). Such a perspective ignores the complex interaction between social attitudes, personal lived experience and the construction of internal schemas of the self. As Akhtar (2014) points out, those who are labelled as 'minorities' (such as sexual minorities) are defined as such in part by the "distorted gaze of the so-called majority on it" (pg. 138). Thus psychotherapy work that does not take cognizance of the social in interaction with the individual, runs the risk of replicating such socially-mediated shame, rather than seeking to reduce it.

In contrast to these pathologizing perspectives, other authors offer a more compassionate and humane stance, highlighting the benefits of psychotherapy for assisting patients with the impact that HIV and AIDS had on the sense of self. For example, Blechner (1993) considered HIV as “psychologically threatening” (pg. 64), and pointed to the importance of helping patients manage the overwhelming anxieties associated with ‘not knowing’ about their disease progression, as well as the fears (or denial) associated with risk. Similarly, Cartwright and Cassidy (2002) regarded HIV as an “insidious traumatizing process” (p. 150), and argued on the importance of acknowledging the external reality of HIV (the stigma, the medical, the physical) when working psychotherapeutically with patients who have HIV.

In this paper, I draw on recent qualitative research data of a small sample of people living with HIV, to explore the experiences of shame that may often be central to work with HIV-positive patients. I explore this in relation to prevailing social discourses that ‘other’ HIV and those infected, and how this links with internal experiences of shame and not being good enough. My focus is not on psychotherapeutic material, but rather I use research data to highlight the reported emotional and interpersonal struggles associated with living with HIV, and in particular, how the experience of shame is mediated through social discourses that other and blame. I focus on the social moralising that takes place when it comes to HIV and sexual behaviours, and the importance of a psychotherapeutic practice that is compassionate, supportive and curious. In doing so I aim to highlight the importance of psychotherapeutic work that is concerned with understanding the meaning of their distress for the patient, rather than a policing kind of therapy akin to moral work concerned with ‘curing’ the ‘illness’ of their homosexuality.

## **The context of the HIV epidemic**

Before proceeding it is important to have a picture of the context. It is estimated that up to 120 000 people were living with HIV in the United Kingdom, and an estimated 35.3 million people were living with HIV worldwide by the end of 2012 (UNAIDS, 2013). Globally, HIV is an infection which has been transmitted largely through heterosexual transmission (a majority of the people living with HIV globally are women). However, there are different epidemics in different parts of the world, with different 'vulnerable groups'. In countries like the USA and countries of Europe, the mode of transmission has predominantly been through unprotected sex among men who have sex with men and infection via the use of contaminated needles among intravenous drug users. In the UK, the HIV epidemic has for the most part been confined to men who have sex with men as a vulnerable group. However, over the past decade, the prevalence among male and female African migrants in the UK has increased.

There has been an enormous global public health response to the HIV epidemic, focusing on prevention as well as treatment and care. With the development of highly active anti-retroviral therapy (HAART) in 1997, the number of AIDS deaths has seen a steady decline, with more and more people being able to lead a full lifespan with HIV as a manageable chronic illness. There is of course a different picture across countries. In a well-resourced country such as the UK, effective treatment and care is readily available. In the less-resourced countries of sub-Saharan Africa (the epicentre of the global HIV epidemic) access to effective treatment has been poor, but has gotten significantly better as a result of pressure on governments and pharmaceutical companies. Thus, the rate of AIDS deaths and the rates of new

infections worldwide are declining. This is a good news story. But this 'normalization' of HIV has not diminished the huge stigma that HIV has, which has the potential to "spoil" a person's identity (Goffman, 1963).

### **HIV and social othering**

The South African supreme court judge, Justice Edwin Cameron, who writes about his experience of living with HIV in his book *Witness to AIDS* (2005), describes AIDS as such:

It is a threat a tragedy a blight a blot a scar a stain a plague a scourge a pestilence a demon killer rampant rampaging murderer. It is made moral. It is condemnation deterrence retribution punishment, a sin a lesson a curse rebuke judgement. It is a disease. (p. 42).

HIV (and AIDS) as a *disease* comes last; so many metaphors are piled on before this. Susan Sontag (1991) observed the metaphors that HIV and AIDS attracted from when AIDS was first identified in 1981 in San Francisco, USA. From the start, HIV was associated with deviance, with disgust, with shame. It was a "gay" disease, it was a moral punishment, there were "victims" of the disease (those infected via blood transfusion) versus those that got it because of their 'bad', 'immoral' behaviour; the perverts, the promiscuous, the drug addicts. These were also related to the many irrational beliefs about contagion, blame and cures which were prevalent at the time, which to a large extent rested on ignorance and homophobia, including among the psychotherapists and psychoanalysts (see Clarke & Blechner, 2011 for a discussion on this). Sontag wrote *AIDS and its Metaphors* (1991) following on from her work

*Illness as Metaphor* (1978), where she presented an angry critique of the notion that illness (in that case Cancer) is an expression of one's character; that it is a symptom of one's psychology. Sontag wrote this shortly after being diagnosed with cancer, as a way of ridding herself of the 'blame the victim' metaphors. In *AIDS and its Metaphors*, Sontag writes that she had written her earlier book to "calm the imagination" (pg. 14), and to deprive her illness of an unwanted metaphorical meaning that would make matters worse and hamper her efforts towards recovery.

Our understanding of the disease has advanced considerably, and since it became evident that HIV was not just a "gay" disease, as the epidemic mushroomed in sub-Saharan Africa and other regions of the world, some of the metaphors associated with HIV have been challenged. Yet, the stigma continues, and in the minds of most (in countries like the UK), HIV is a disease of *others* – gays, Africans, drug addicts.

Joffe (1999) adopts a psychoanalytic framework for understanding how the othering of HIV, and locating the risk for HIV in others serves as a defence against vulnerability. After all we are talking about a virus, which is transmitted through infected blood; a virus cannot choose the identity of the person whose body it infects. Joffe draws on Klein's (1959) concept of the paranoid-schizoid position to argue that society manages the intense fear and disgust associated with HIV and AIDS by creating a clear distinction between 'them' who are at risk for HIV and 'us' who are not. Vulnerability and risk are split off and located in others who are represented as the bad object. Rohleder (2007) also explores how those who are at increased risk themselves take a defensive subjective position by locating themselves as the 'good' ones, both pre- and post-infection. Similarly, Cartwright and Cassidy (2002)

observes the splitting of the “badness” associated with the infection on to the “bad” behaviours of others, in an attempt of “unburdening the self” (p.156) of this badness.

While some of the anxieties associated with a certain early death have mostly disappeared, the impact of living a lifespan with an illness that is deeply stigmatizing has the potential to continue to be a psychic trauma. Living with HIV also means living with medication, which may have some unpleasant side-effects, most common of which are diarrhoea, nausea, fatigue headaches, and in some cases Lipodystrophy. This may take a toll on the patient’s mood. As recent reviews have indicated, many people living with HIV have higher rates of depression, anxiety and suicidality (Catalan et al., 2011; Sherr et al., 2011). Poor psychological health (in the form of depression or stress, for example), in turn affects physical health, and research on psychoneuroimmunology has suggested that psychological therapy might improve endocrinological and immune functioning in health patients (Miller & Cohen, 2001;). For example, Antoni (2003) found that a cognitive-behavioural stress management intervention had a positive effect on psychoneuroimmunology in patients with HIV. One study (Euler, Schimpf, Henning & Brosig, 2005) found that psychoanalysis may have a positive effect on immunological and endocrinological functioning, although the findings were based on only two case studies, and so present considerable methodological limitations. Overall, research on psychoneuroimmunology has produced inconsistent results (Miller & Cohen, 2001), and knowledge in this field still needs to be advanced. The importance of finding and making available effective forms of psychotherapy that can alleviate the psychological distress that accompanies living with HIV seems a clear and urgent

task for psychoanalytic psychotherapists to turn to. They will need, however, to jettison some of their more unhelpful assumptions from the past.

### **Sources of data**

While I have experience of working therapeutically with people living with HIV in an NHS setting as well as in South Africa, I draw here on a secondary analysis of data from a qualitative study which originally aimed to explore the sexual self-esteem experiences of seven men living with HIV in the UK (Rohleder et al., in press). For the purposes of this paper I focus specifically on experiences of shame in relation to living with HIV. I do so in the spirit of supplementing our knowledge informed from the couch with knowledge informed from research off the couch (Lemma, 2012).

The original study included 7 men: 5 of whom identified as gay and 2 of whom identified as heterosexual. Of the seven men, 3 were interviewed in a group. The intention for the study was to interview all participants individually, but 3 participants requested to be interviewed together, and we agreed to their request. For the purposes of this paper, I draw on data from the interviews with the 5 gay men, as my intention here is to explore issues of shame related to HIV as it intersects with a minority sexual identity. The men were recruited through two HIV-related support organisations. Interviews lasted approximately 1 hour and were audio recorded and transcribed. All participants gave their informed, signed consent to take part in the study. Ethical approval for the current research was provided by the author's home institution.

The interview transcripts were analysed by means of Interpretative Phenomenological Analysis (IPA) (Smith et al. 2009). IPA is an approach used in qualitative research which operates at a case study level of analysis, and allows for the exploration of subjective experience; what *matters* to a person, and what things *mean* to him or her (Larkin, 2015). The method of analysis involved a close reading of each transcript and identifying salient themes that captured participants' experiential ideas, views and concerns. The analysis was conducted to identify common themes within each case and across the sample. I present the results here in terms of these common themes, rather than an analysis of individual case vignettes. In this paper I have made a secondary analysis of the data, drawing on a psychoanalytic framework to deepen and extend my interpretation of the findings.

#### *Brief description of the five men*

Dave<sup>1</sup> was a 35-year old white gay man, and had been diagnosed with HIV 3 years previously. He had gone for an HIV test following a period of having had some mental health difficulties and knowing that he had sex without a condom. At the time of the interview he was employed full time, and was not in a relationship.

James was a 50 year-old white gay man, in a committed relationship for the past 5 years. He was diagnosed in the late 1980s when symptomatic with AIDS-related illnesses. His health had deteriorated significantly at the time, but with the introduction of highly active anti-retroviral treatment (HAART), his health improved and he has been managing his HIV illness with medication since. He was employed full time and lived with his partner.

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<sup>1</sup> Pseudonyms have been used, and some details have been modified to ensure anonymity

Brian was a 46 year-old white gay man, who had been diagnosed HIV-positive less than one year previously. At the time of the interview he was employed and was living on his own. He had been single for some years, and reported having had few sexual partners.

Ken was a white gay man in his 30s (he did not report his age), who had been diagnosed with HIV 3 years previously, after being ill for some time. At the time of the interview he was in part-time employment and was in a recently-formed relationship with a man who was HIV-negative.

Tim was in his late 40s (he did not report his actual age), and had been diagnosed with HIV 25 years previously. He had been very ill in the past, but was currently managing his HIV effectively with treatment, although he struggled with various side-effects. At the time of the interview he was unemployed and receiving a disability allowance. He lived alone and was not in a relationship.

All five men had at first found it very difficult to disclose their status to others, but did so over time. Most have done so selectively to close friends, and some family, and in most cases these people had been supportive. Out of the five men, James was the most open about his HIV status socially.

### **HIV as an internalized object of shame**

All five men described feelings associated with shame (certainly initially when first diagnosed) about having HIV. They all at various points in their interviews referred to

themselves in strong terms as “dirty” or “hazardous” or “toxic”. James described having felt like a “danger” and a “threat”. Brian talked about this most strongly describing how he could not even contemplate the idea of having sex ever again:

*I'm dirty and I'll never be able to have sex again so I try wipe it from my head.*

His comment was that “I’m dirty” – “I *am* dirty”. In that sense the HIV had become a bad internal object which he had totally identified with. He went on to give a sense of how pervasive this sense of himself was asking himself “*who would ever want me?*”. The metaphors associated with HIV that have always been linked to deviant identities seem to be internalized here as a ‘spoiled identity’ (Goffman, 1963), and it is this social and cultural context that causes distress and this distorted sense of self. It was in references to sex and sexuality where the men referred to such feelings more acutely. All five men spoke about how soon after being diagnosed they thought of themselves as too dangerous to be having sex. James recalls how he first felt about sex soon after being diagnosed with HIV:

*I just kind of figured ‘Ok well that’s that then, I’ll never have sex again’ and I was terrified of the thought that I’d pass it on, and I just couldn’t imagine what that would be like, to do that. So I just thought ok, it is easier just to not have sex anymore.*

Over time, James thought in less restrictive terms:

*that changing and realising I'm not; that I can't cope with just not having sex at all and having no contact to thinking 'Ok, what, what I'll do is I'll, I'll have some sexual contact but I'll limit it to only completely risk free things'*

James was the only one who was now feeling more positive about his sexual self-esteem. The other four men still struggled with feeling too dangerous to be having sex. Brian struggled with this most acutely. While these four men spoke about this in terms of sex as dangerous, they also spoke about feeling less sexual. Some considered that their difficulty with sex was also due to a decrease in libido as a side-effect of the anti-retroviral medication that they were taking (for example Tim). However, those that spoke about such side-effects in the same breath acknowledged that it was not just that, it was also a psychological difficulty. For example, Ken talks about a decreased interest in sex as a kind of solution to dealing with his shame:

*In a strange reverse psychological way actually not getting an erection, not having an orgasm, not having sex I actually feel better. It is almost as if I'm blocking out the HIV as if it is not there, because as soon as that, as soon as something like that arises, pardon the pun, it reminds me of the HIV, so and that's why I was so dead against getting into relationships before*

He went on to explain how this was about his sense of shame:

*I no longer feel attractive myself, I, in terms of, of sex and even sexual thoughts, I, it all seems to relate to HIV and to me it's like HIV has made it seem ugly, dirty, unattractive.*

What is indicated here in Ken's account is that the feelings of shame and poor self-esteem is not entirely related to his 'original' internal self-concept, but rather to the social metaphors around HIV. He states "*I no longer feel attractive*" as he has to incorporate the metaphors of dirtiness and deviance. The result is a splitting in sexuality, where sex is seen as 'bad' and being desexualized functions as a kind of defensive solution to the internal conflict of feeling dirty and ashamed. Dave referred to this more explicitly. He spoke about feeling hazardous, and how he compartmentalised his sexuality as something that had to be kept safely split off:

*I just kind of I started to view my, my sexuality and my sex drive as a kind of problem, well not a problem, but a thing that needed managing cause it would kind of get in the way at times. When I started to kind of hide it off, as a kind of separate thing from the rest of me, which I think might be why, I haven't, you know, I kind of put it, put sex in the box and I kind of go into the box when I want to have sex but it's kind of all kept in a corner there*

### **HIV and internalized homophobia**

While talking about his difficulties with HIV, shame and sex, Dave started to link these feelings to his previous difficulties with his sexuality as a gay man:

*Although I was openly gay, I wasn't really, you know, I was kind of going away from the rest of my life. Do, you know, 'doing it', I kind of call it 'doing it', getting the you know, getting the horniness out of the way and then getting on with whatever else I've been doing, and that you know, and there wasn't, there wasn't so much a fit between you know, my sexuality and how it was playing out in my, in my life and the how my life was shaped. You know, it was very, I had very kind of, felt like a very kind of hetero, straight, heterosexual world and then there was this kind of other pocket of, you know, that was the gay bit and the sex bit*

Brian and James similarly made links with their struggles with feelings of shame about having HIV and past struggles with coming to terms with their homosexuality. For example, James reflected back on the journey he went through in coming to a point of acceptance of, not only being HIV-positive, but being a gay man too (which he linked all together):

*...the issues around my acceptance of my sexuality and being comfortable with myself as a gay man combined with my issue of the diagnosis and with my problem drinking and, I know it was one of those things. How much that was linked to my sexuality and feelings of discomfort about, about being gay and being not, how I felt that would affect people's acceptance of me, and my own self-acceptance I suppose. And HIV obviously, you know, magnified and contributed to some of that discomfort.*

Dave reflected how the whole process of being diagnosed with HIV and disclosing to others was “*like coming out as gay all over again*”. The current stigma and distress associated with HIV also becomes linked to internalized homophobia. Internalized homophobia is a term used to describe the internal self-loathing that some gay men (and lesbian women) may experience, which is understood as anti-homosexual societal attitudes being introjected and internalized by the individual resulting in an internal conflict involving feelings of shame, guilt, anger and hate (Malyon, 1982). HIV (the “gay plague”) stirs and adds fuel to a possible existing internal conflict around self-acceptance. The psychic trauma of HIV links to previously existing difficulties around sexuality, shame and self-acceptance. Thus, for gay men, it may not only be a matter of struggling with the shame associated with the ‘dirty’ disease HIV, but also about being gay and HIV-positive, confirming perhaps the ‘gay plague’ as ‘punishment’ metaphor.

### **HIV, blame and being the ‘bad’ citizen**

Part of the men’s reported difficulties of living with HIV was not only the impact that this had on their sense of self, but also on their sense of themselves as a social citizen. Shame in this sense was an interpersonal experience. All the men interviewed in some ways referred to feeling a little bit like a social outcast, or as Dave put it “*a leper*”.

This was partly linked to a sense of blame for having been a ‘bad’ citizen. Dave spoke about this most eloquently. He spoke about feeling like he had “*failed in my, you know, in my duties to kind of have safe sex*”. This reflects the social representations that prevail about HIV and who are the sorts of people that get

infected – the ‘others’ in society. As I have shown elsewhere (Rohleder, 2007), the risk of getting HIV, which is seen as a threat to the self, is likely at first to be projected on to ‘bad’ others who are the embodiment of that risk. Once diagnosed, these disavowed aspects need to be incorporated in to the self. Thus, for some of the men, the difficulties lie in how their identity becomes a spoiled social identity as they are associated (and they associate themselves) with the ‘bad’ other. Dave described this splitting of the ‘good’ and the ‘bad’ gay men on social networking dating sites (like Gaydar):

*the problem is that people, and I'm sure I was probably one of them as well, so I'm, I don't, I try not to kind of be too judgemental about it, but a lot of people don't know much about HIV and they kind of think you know, they think themselves around the problem and you get you know, people saying they are HIV negative when it turns out actually turns out they haven't had the HIV test like ever, or you know, in the last three years. And you know, there is a lot of rhetoric around meeting on terms: 'DDF' – 'drug and disease free'. So, it can be quite, people can be quite hostile to people, you know, and that's difficult. If anyone has kind of specifically said on their, on the profiles that they are not interested and that they only want to meet HIV negative guys then I will attempt to give them, you know, a wide berth*

A little later in the interview he went on to expand on this further:

*it's not what people say to you, it's what people say about you; not knowing necessarily that they are saying that about you. But it's all the rhetoric, it's the,*

*it's the 'drug and disease free' bit, you know. I've never, I don't, I never take drugs, I've never been, apart from you know, alcohol and tobacco, you know I never really been into, but it's you know, that, they're all lumped into the same you know, I'm lumped into the same category as somebody who's off their head on, on, tina (crystal meth), and you know, it's that kind of thing erodes over time the way your, your self-esteem.*

Dave reflects on his struggle in being the 'bad' citizen. Earlier in his interview he spoke about how when diagnosed with HIV he immediately found himself reflecting on how it was that he became infected: *"it was a point in which I had to kind of reflect back on, well how did it, how did that happen?"* He thought about what "irresponsible" and "self-destructive" behaviour resulted in him acquiring HIV. His attempts to resist this (he does not take drugs) is futile when socially he is lumped together in to a category of deviant other. It is also important to note that the social metaphors around HIV also leads to othering and splitting within the so-called gay community; into 'good' and 'bad' gay citizens.

### **HIV, responsibility and impact on sexual relationships**

Tim, Dave and James all spoke about such feelings of guilt and shame being evoked by dynamics within a relationship context. For example, Tim spoke about how ultimately being HIV-positive (and in a relationship with a man who was HIV-negative) ended the sexual relationship with his partner of many years. Although Tim puts this down mostly to a reduced libido as a result of the side-effects of medication, he suggests that this was also psychological:

*We always was safe and took precaution. He said; 'I love you and it's you I want, not the problems, but unfortunately that's the package.' After about nine, ten years I literally couldn't take the demand for sex anymore. By that time I had gone on to drug trials and the inclination for sex was just not, not there. You know, I was still only thirty but it wasn't, the excitement had all been lost in the previous ten years so to speak and my worry also was about passing it on.*

James recalled his experience of being in a relationship with a man who was HIV-negative, where he felt that his partner was pushing the boundaries of safe/unsafe sex. He described how his partner would increasingly hesitate in putting a condom on, until a time occurred where he did not. James recalled his response:

*I had a terrible panic and was terrified, so we went into the doctors and they gave him a course of post-exposure prophylaxis, and he had terrible side effects and we ended up breaking up. A few months later we got back together; there was an incredible sexual tension between us and we really did love each other and we found it really difficult to be apart. But, I said; 'Ok at least that won't happen again' and sure enough in the next year it did and when it finally happened again and he kept pushing and pushing, I just ended up breaking it off because, because I felt like I was being- it made me feel toxic again. It made me feel like I was being used as some, as a way for him punishing himself and damaging himself and I wasn't prepared to be that weapon, you know.*

In the above quote, James draws on the metaphors of HIV as punishment and sin. Although James speaks of feeling a sense of responsibility for ensuring the 'safety' of his partner, we could interpret (in his ending the relationship) his anger at being made to feel guilty and ashamed at being used as a kind of biological 'weapon'. Dave similarly spoke of such experiences (with more casual sexual partners), and eventually summarized his various experiences of managing his social identity as HIV-positive as fuelling his "*internal rhetoric about not being good enough*". Such accounts reveal the inter-personal aspect of shame. While Tim, Dave and James may have had their own internal struggles with feeling dirty and hazardous, their internal shame was also mediated by the experience of being treated like a 'bad' object (a "weapon").

### **Mourning and hope**

The interview material reflected a sense of loss and sadness as the men struggled with coming to terms with the impact of living with HIV. In all the interviews, there was at first a sense of loss as participants spoke about how HIV had changed their sense of self as a sexual person, and a social citizen. A first reaction for all was that they would "never have sex again". Those who had been diagnosed more recently were struggling to come to terms with the impact that being HIV-positive was having on their lives and sense of self (and were being supported by the HIV-organisation from where they were recruited). Brian in particular was struggling to make sense of things, and spoke about feeling quite depressed and feeling very strongly the sense of shame of being HIV-positive. At one point in the interview he stated:

*I wished I had been diagnosed with cancer, cause I would rather have been given a disease I could die from than have; this to me is the worst disease you could get*

Brian is suggesting here the insidious trauma of the social shame about HIV. His interview was quite depressing, and he spoke repeatedly about feeling dirty and ashamed. He was receiving some support from an HIV community organisation, which was starting to help him reclaim his sense of self-esteem. For example, he states:

*Counselling really helped me get my head around getting this dirty, oh I've got this dirty, take the dirty thing out of it. Cause I am not dirty and I never was but I've always viewed HIV as a dirty disease.*

Those who were diagnosed some year back, spoke about their initial struggles, but reflected currently being in a happier, or otherwise more hopeful and optimistic place. James reported feeling like he was at a particularly good moment in his life, and was in a happy committed relationship. His sense of self-esteem began to improve as a result of improved health (due to effective HIV treatment) and feeling more confident about talking about his HIV status to others. He reported that with time, this not only helped improve his self-esteem, but also his experience and enjoyment of sex:

*it was not just about the sex but about the connection and it was about intimacy rather than just being about sex as well. And a lot of that was*

*because of disclosure and my desire to talk about some of those things when I met people*

For most of the other participants, there was a sense of hope for a better interpersonal future. However, they could only imagine this with someone who was also living with HIV. Given the anxieties and feelings of guilt and shame that they sometimes associated with HIV (as a result of considerable stigma), most could not foresee a happy and comfortable life with someone who was HIV-negative. For example, Dave referred to this as the one possibility where he could be in a relationship or amongst friends where he felt psychologically 'safe':

*it kind of led me on to meet other kind of men, more, other HIV-positive guys because that was kind of the one group of people where it felt entirely safe in all senses of the word*

Even Brian, despite his overwhelming despair, spoke about the potential to fall in love with someone who was HIV-positive, even though he regarded this as a "*day-dream*").

## **Discussion**

HIV can result in a disruption to the individual's life-narrative, impacting not only on their sense of self-identity, but also on their interpersonal relationships. The above interview data show how much of what underlies the struggles of living with HIV is the internal experience of socially-mediated shame, of being the 'other' that is feared and denigrated. Of course this is not the only experience or narrative for people

living with HIV. For many men and women who have been living with HIV, their diagnosis has resulted in a re-evaluation of one's sense of self, and has led to an empowering, and transformative life experience. Certainly for James, his coming to terms with living with HIV and what this means for who he is as a person, has been transformative, but this was the culmination of many years of struggle.

For these men, some of their struggles with shame also involved past (or present) struggles with their sexuality, expressed in internalized homophobia. While the concept of internalized homophobia is useful to understand such internal struggles, it is important to note that critiques of the term 'internalized homophobia' highlight the suggestion that it is primarily a (pathological) experience residing *within* the individual, which partly ignores the reality of a prejudiced and hostile context. Rather, 'internalized homophobia' is argued to be "grounded not in interior experience but in an intersection between interiority and social and political contexts" (Russell & Bohan, 2006; 346). One just needs to refer to the rampant anti-gay discourses that have prevailed recently around the issues of same-sex marriage and parenting. Lynch (2015) argues how the young gay boy learns from an early age how some of their sexual desires are "unsanctioned by others" (pg. 140), resulting in experiences of shame. Gay men may have experienced their sexuality as "an outlaw" (pg. 151) when younger, and so HIV as an 'outlaw' links to these earlier struggles. This is indicated in the data when many of the men interviewed split off their sexuality, denying sex which was equated with badness and harm. This is also observed by Cartwright and Cassidy (2002) who provide a case study of a patient who spoke about himself in an increasingly desexualized way. While such splitting may be an internal defence mechanism, it would be inappropriate for psychotherapists to ignore

the social and cultural factors at play here. For example, were Ken and Dave (see results section) to seek psychotherapy to help them with these difficulties, they may be vulnerable to be harmed by therapy were analysts to interpret their splitting off of their sexuality as a perverse solution (along with their homosexuality) to conflicts about love and hatred (as may be the case in a Kleinian approach), rather than conflicts essentially about identity and self-worth. It is a response to the psychic trauma brought on by the othering associated with HIV.

HIV was initially equated with homosexuality (the “gay plague”) and the social othering associated with HIV was layered with prejudice against homosexuality. However this form of splitting and othering also occurs within the so-called gay community. As some of the men report, they could only feel comfortable with other HIV-positive men. Sero-sorting (choosing partners deliberately on the basis of their HIV-status) is used as a ‘safe sex’ practice among the so-called gay community. As Skinta and colleagues (2014) highlight, the practice of sero-sorting perpetuates HIV-stigma and shame, with those living with HIV perceived as unacceptable to HIV-negative people. This has recently been referred to by some gay men living with HIV as “gay-on-gay shaming” (Staley, 2014).

It is important to bear in mind the limitations of this study in that it is not a generalizable or representative sample. The five men were all white, British gay men, and it must be acknowledged that the experience of being HIV-positive is also affected by other socially- and culturally-mediated experiences. For example, in my work in South Africa, I observed how the experiences of shame of some people living with HIV in South Africa needed to be understood within the context of the

racial politics associated with HIV and HIV treatment at the time (Rohleder, 2007). For the psychoanalytically minded, this article is also drawing on material that is about experience which is consciously reported. However, as Lemma (2012) argues, such material is of relevance for broadening “our understanding of the phenomena we observe ‘on the couch’” (p. 278). It is also more generalizable than the sort of theorizing that is based on one or two case studies (such as Burgner), and draws on the experiences of people that do not have the sorts of pathologies that might usually be seen in the clinic. The research interview also allows the participants to speak freely without (it is hoped) judgement, and can provide readers with an example of the sort of phenomenological exploration that can be done in psychotherapy.

### **Implications for psychotherapy practice**

Psychodynamic and psychoanalytic psychotherapy has much to offer in supporting people living with HIV, by working at containing anxieties and split off aspects of the self, and giving meaning to experiences through interpretation (Cartwright & Cassidy, 2002). Blechner (1993) observes how, in the early years of the HIV epidemic, psychotherapy work with patients who were diagnosed with HIV involved overwhelming feelings of loss and pain associated with a forthcoming early death. A challenge was to encourage some hope in the therapy, whilst facing the dread of death. The realities of HIV and AIDS have changed, but HIV also encompasses a ‘social death’. The goal for psychotherapy in this context is to assist in the formation of a more integrated social identity, and the renegotiating of a sexual self-esteem and sense of self damaged by HIV. A particular focus of work can be in working through the experience of shame. But, while psychotherapists are concerned with the intrapsychic world, it is important to focus on the social realities too. Cartwright

and Cassidy (2002) argued how the realities of HIV disease and HIV stigma requires that psychoanalytic psychotherapy move outside of the traditional “good enough” therapeutic frame, needing instead to be prepared for flexibility out of a need to deal with various disease-related realities. They go on to state that the therapists may be required to extend themselves beyond their usual therapist role, acquainting themselves with HIV and AIDS related medical knowledge, so as to have an understanding of medical treatment, their effects and side-effects (and not confuse them as psychosomatic symptoms). With regards interpretation, they caution against the sort of moralising interpretations that link their HIV status to their character behaviours, emotions and fantasies, which, “if not accurate, run the risk of replaying stigmatization” (pg. 163). The emphasis here is on taking cognizance of social realities in understanding the individual’s psychic experience. The work of current cotemporary psychoanalysts is moving in this direction. For example contemporary psychoanalytic work on body and mind and sexuality (for example Lemma, 2015; Lemma & Lynch, 2015) is aiming to apply principles of socially-mediated experiences on clinical work, moving away from the sort of moral work of earlier theorists.

However, as readers know, the availability of psychoanalytic psychotherapy in the NHS is very limited, and psychological support for NHS patients who are living with HIV tends to draw on short-term evidence-based models of therapy. Given that so much of the participants’ experiences in this study occurred within the interpersonal context, helpful work can be done by focusing on current interpersonal difficulties, using the model of Dynamic Interpersonal Therapy (Lemma, Target & Fonagy, 2011). As Purnell (1996) notes, getting a diagnosis of HIV has the potential not only

to damage one's sense of self, but also, because of the significant stigma, it may "undermine securely attached relationships" (Purnell, 1996; 523), and thus impact on psychological wellbeing. Dynamic Interpersonal Therapy, as an evidence-based therapy offered in the NHS, may be a very helpful approach.

## **Conclusion**

I have used data from a recent qualitative study on sexual self-esteem experiences of men living with HIV to illustrate that, despite significant medical advances having been made in the treatment of HIV, it remains a significantly stigmatized disease, with the potential to impact deeply on an individual's social identity as well as internal psychic health. Psychoanalytic and psychodynamic therapy has much to offer in helping the patient with HIV work through the socially-mediated shame and its impact on their sense of self. Above all else, it is society's attitudes that denigrate and 'other' people living with HIV that need to be challenged.

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