EXPLORING GAY MEN'S EXPERIENCES OF SHAME IN RELATION TO SEXUALITY AND HIV AND THE IMPLICATIONS FOR SENSE OF SELF AND RELATIONSHIPS

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A thesis submitted in partial fulfilment of the
requirements of the
University of East London for the Doctoral Degree in
Clinical
Psychology

May 2018

Word Count: 27,536

ACKNOWLEDGEMENTS

First and foremost, I would like to dedicate this thesis to the ten participants who shared both their time and their stories with me. This thesis is a testament to your strength, determination and perseverance in seeking to change the world around you for the better. I have been truly inspired by your stories and hope that others reading this will also be inspired to keep challenging injustice.

I would also like to extend my most sincere thanks to Dr. Poul Rohleder for his support, expertise and guidance throughout the research process. His encouragement and reassurance was invaluable. Special thanks also goes out to the generous support of the clinicians across both NHS trusts who tirelessly helped me with recruitment, particularly Dr. Alexander Margetts, Dr. Tristan Barber and Chris Sandford.

Finally, a heartfelt thank you to goes to my family and friends for their support and encouragement throughout all my endeavours, in particular my mum, uncle Alan, and of course, Marco.

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List of Abbreviations

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
HAART	Highly Active Anti-Retroviral Therapy
MSM	Men who have Sex with MEN
LGB	Lesbian, Gay, Bisexual
LGBT	Lesbian, Gay, Bisexual, Transgender
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
IH	Internalised Homophobia
UAI	Unprotected Anal Intercourse
IPA	Interpretative Phenomenological Analysis
PrEP	Pre-Exposure Prophylaxis
PEP	Post-Exposure Prophylaxis
HCV	Hepatitis C

ABSTRACT

Background: For many researchers, the focus of their work exploring the negative consequences of identifying as a gay man living with HIV has centred around stigma. Yet, over the past few years many have questioned whether the broad definition of stigma alone is able to explain the negative implications of identifying both as a sexual minority but also the impacts living with HIV. More recently, some authors have begun to question whether the emotion of shame is of more central concern. However, there has been little investigative research into shame in relation to sexuality or HIV status.

Aims: Given the gaps within the literature, the study sought to explore whether shame was something experienced by gay men, and if so how they understood and experienced it in relation to both sexuality and HIV. The study also sought to investigate the impacts on both sense of self and relationships with others.

Methods: Drawing on a hermeneutic phenomenological epistemology, this study adopted a qualitative, interpretative phenomenological approach to exploring the shame experiences of 10 gay men living with HIV. The men were all recruited from central London NHS HIV community services and participated in semi-structured interviews.

Results: Five master themes were found across participant interviews 1) Sexuality: An Unacceptable Difference, 2) Managing an Unacceptable Self, 3) HIV: Rejection of the “Dirty” Self, 4) Negotiating a “Dirty” Identity, 5) Moving to a More Meaningful Self.

Conclusion: Despite arguments of the increasing acceptance of alternative sexual identities and the normalisation of HIV, the participants in the study reported experiencing shame as a distressing, layered emotion in response to living with two highly stigmatising identities. These layered experiences of shame often resulted in a sense of the self as inferior in comparison to heteronormative ideals and a number of unwanted difficulties within interpersonal relationships. However, participants also reported their HIV diagnosis as providing some meaning but after several years of difficulty. Implications for clinical practice, policy and research are discussed.

1.0 INTRODUCTION

1.1 Overview of the Chapter

This study sought to investigate the experiences of shame in gay men living with Human Immunodeficiency Virus (HIV) and its implications for sense of self and relationships. In seeking to explore this, this chapter will first provide an overview of the literature outlining the difficulties facing gay men living with HIV, before seeking to critically explore dominant theoretical explanations. It will then move on to examine the concept of shame before examining more specifically its implication for gay men living with HIV. Finally, the key aims and rationale for the current research study will be presented, including the study's research questions.

1.1.1 A Note on Terminology

In this chapter and throughout the study, the term 'gay' is used to denote men who are sexually attracted and have sex with other men. Whilst it is acknowledged that there have been numerous critique's around the use of this and associated terms (i.e. 'gay community') (notably Butler (2011); Holt (2011); Andersen et al. (1999)) for their negation of other aspects of identity, it was felt that using the term gay would allow for a homogenous sample of men in line with the methodology (See methods chapter for further detail, pg. 33). Specifically, the term MSM or men-who-have-sex-with-men is often used to acknowledge men who have sex with men but do not define as gay (Holt, 2011) however it was felt that this may invite a different shame profile as this may cover men who are still in relationships with women and consequently one would hypothesise experience heightened levels of shame (Young & Meyer, 2005). However, the term MSM will still be referred to where it is specifically referenced within the literature.

1.2 Health Disparities in Gay Men's Health

Despite arguments of the increasing moves towards acceptance of alternative sexual identities within society (Savin-Williams, 2005; Weeks, 2007), there remains an ever-growing body of research highlighting the numerous health disparities among lesbian, gay and bisexual populations (LGB), particularly within mental health (Bostwick et al., 2014; Grov et al., 2013; Hottes et al., 2016; Plöderl et al., 2013). For example, a recent systematic review looking at 12 UK population health surveys found that adults identifying as LGB were twice as likely as heterosexual adults to suffer from anxiety, depression and suicidality (Semlyen et al., 2016). For gay men specifically, there has been research highlighting the heightened risk of depression and suicide (Hottes et al., 2016; Lee et al., 2017; Plöderl & Tremblay, 2015; Plöderl et al., 2013). King et al. (2008), for example in their landmark review, found that gay men were more than six times as likely to have attempted suicide in their lifetime than heterosexual men.

Alongside mental health, concerns around drug and alcohol use have been consistently reported within the literature, and both UK and international studies have consistently demonstrated a high prevalence of drug use within LGB populations and MSM (Abdulrahim et al., 2016; Measham et al., 2011). More recently, there has been particular concern expressed by healthcare providers, as well as the gay and mainstream media around the use of drugs within the context of 'high risk' sex or so-called 'chemsex' (Bourne et al., 2015b; McCall et al., 2015; Sewell et al., 2017; Weatherburn et al., 2016). Chemsex has become a catch-all term to describe the use of drugs such as Crystal Methamphetamine and GBL/GHB during sex parties which often involve multiple partners and last for several days (Giorgetti et al., 2017; Hegazi et al., 2017). Although it is a minority of gay men and MSM that are thought to use drugs and participate in chemsex, there have been numerous concerns documented around the potential risks to health including high rates of shared injecting behavior (Bourne et al., 2015a), sexually transmitted infections (STI's)(Gilbart et al., 2015), HIV and Hepatitis C (HCV) transmission (McFaul et al., 2015; Pufall et al., 2018), mucosal trauma (Hegazi et al., 2017), sexual assault/rape (Bourne et al., 2013) and drug-related causalities (Wood et al., 2013). Consequently, there has been an increasing drive to understand the motives and reasons for participation in chemsex, alongside continuing discussions of wider health disparities within gay male populations.

1.2.1 Gay Men and HIV

Alongside the above difficulties, gay men have been one of the populations affected most greatly by HIV (see glossary for further explanation, Appendix A, pg. 126) (Reidpath & Chan, 2005; Skinta et al., 2014; Smit et al., 2012). As of 2016, a total of 101,200 people were living with HIV in the UK and 47,000 of those identified as gay or bisexual men (Kirwan et al., 2016). Whilst the rate of HIV diagnosis had been steadily increasing amongst gay and bisexual men over the last few years, 2016 saw a significant decrease in new HIV diagnoses (Kirwan et al., 2016). This reduction has been particularly poignant given the introduction of pre-exposure prophlaxis (PrEP) in the NHS which involves the pre-emptive use of highly active antiretroviral therapies (HAART) to those presenting with a higher than average risk for contracting HIV (i.e. those engaging in chemsex) (see glossary for further explanation, Appendix A, pg. 126) (Cohen et al., 2015). The prescribing of PrEP and the overall development of HAART in the mid-1990s highlights the significant medical advances that have taken place since the recognition of HIV in 1981 (Rohleder, 2016). Individuals living with HIV in western societies can now expect a normal life expectancy (Wandeler et al., 2016) thus the virus is now considered to be a chronic medical condition rather than the fatal illness it once was (Rohleder et al., 2013). Significantly, this change in the perceived position of HIV has been used by some as evidence of its ‘normalisation’ (Persson, 2013; Squire, 2013).

However, despite these normalisation arguments, there is a wealth of research highlighting the significant psychosocial sequalae reported by those living with HIV (Edmiston et al., 2015; Jallow et al., 2017; Kendall et al., 2014). For example, in their study reviewing a specialist HIV psychological medicine unit in the UK, Adams et al. (2016) found that the service had seen constant increases in referrals since 1990 with steady increases in the diagnoses of depression and anxiety disorders. For gay men living with HIV specifically, there is also research indicating higher rates of mental health difficulties including suicide risks above those of HIV negative gay men (Badiee et al., 2012; Capron et al., 2012; Catalan et al., 2011) . There is also evidence of increased substance use (Forrest et al., 2010) including engagement in chemsex, as well as indicators of high risk drug using behaviours such as increased injecting (Bourne et al., 2014).

1.3 Existing Theoretical Explanations

1.3.1 Stigma and the Development of a Spoiled Identity

In seeking to explain the above health disparities researcher have predominately utilised theories around stigma (Earnshaw & Chaudoir, 2009; McCall et al., 2015). Specifically, several have taken the work of Goffman (1968) as their conceptual starting point (Herek, 2009b). Goffman (1968, p. 3) defines stigma as “an attribute that is significantly discrediting and which in the eyes of society serves to reduce the person who possesses it” ultimately resulting in a “spoiled identity”. Certainly for HIV specifically, several authors have described the power of an HIV diagnosis in being able to spoil an identity in the eyes of others (Fife & Wright, 2000; Rohleder et al., 2015; Skinta et al., 2014) through its association with what Sontag (1991) describes as metaphors of plague, sin and death. Indeed, as highlighted by the responses of gay and bisexual men in the The People Living with HIV Stigma Survey UK (2015) the power of stigma surrounding the virus is still very present, with over half of the respondents experiencing discriminatory treatment in the last 12 months. This continuation of stigma and discrimination has also been indicated in research (Bogart et al., 2017; Courtenay–Quirk et al., 2006; Kalichman et al., 2017; Rendina et al., 2017b) and has been associated with increased difficulties with mental health (Bogart et al., 2017; Dowshen et al., 2009).

Yet, the utility of Goffman (1968)’s conceptualisation has often been questioned (Link & Phelan, 2001; Parker & Aggleton, 2003; Scambler, 2009). Although Goffman (1968) recognised stigma as fundamentally relational, his conceptualisation of a “discredited attribute” has led to stigma being seen as something possessed by the person rather than as a designation by others (Link & Phelan, 2001). It also has an over emphasis on dyadic social interactions as opposed to systematic structural discrimination (Weiss et al., 2006). This consideration of structural discrimination and power is critical when considering the stigmatisation of gay men generally and those living with HIV (Parker & Aggleton, 2003). As Link and Phelan (2001, p. 363) argue "for stigmatisation to occur power must be exercised*"* and ultimately what gets labelled as a stigma reflects the interests of dominant social groups. Hence, stigmatisation becomes "inherently linked to the production and reproduction of structural inequalities" (Parker & Aggleton, 2003, p. 19).

1.3.1.1 Layered Stigma and Heteronormativity

However, as already alluded to stigma related to HIV is not a singular entity but is layered or interacts with other aspects of identity (Swendeman et al., 2006). Indeed, since it's recognition HIV has been a virus associated with populations already denigrated by society including drug users, Black African populations and gay men (Joffe, 1999; Rohleder, 2007). For gay men specifically, HIV was initially named Gay-related Immune Deficiency (GRID) by the mainstream media (Epstein & Johnson, 1994), as well as a "gay disease" (Rohleder, 2016, p. 65), "gay cancer" and a "gay plague" (Fee & Parry, 2008, p. 54). As Sontag (1991) has extensively written HIV is a virus heavily associated with death, sickness and risk and has been seen both as a product and punishment of the immorality surrounding gay sexual behaviour (Herek & Capitanio, 1999). Indeed, research as indicated that blame, increased anger, and decreased sympathy towards someone living with HIV occurred more frequently if that person was a gay or bisexual man (Herek & Capitanio, 1999).

In thinking about the connection to gay sexual stigma, many have pointed to the deeply entrenched position of heterosexuality as the dominant and normative orientation or so called 'heteronormativity' (Epstein & Johnson, 1994; Flowers & Buston, 2001; Szymanski & Mikorski, 2016). Heteronormativity has been defined as the assumption that all human experience is unquestionably and automatically heterosexual (Kitzinger, 2005) and as Yep (2002, p. 168) writes its power as an ideology is its invisibility within social institutions as "natural, normal and universal"

(Epstein & Johnson, 1994; Rich, 1980). This unspoken presumption within our social and political systems exposes those who do not conform creating a sense of denigrated difference (Wittig, 1992). In evidence of this, many have highlighted the long history of abuse, violence and harassment that gay men and others have experienced throughout recent history (Guasp et al., 2013; Herek, 2009a). Consequently, in relation to HIV, heteronormative discourses enacted through such forums as the mainstream media have constructed HIV as a punishment for homosexuality and ultimately a punishment for failing to achieve the heteronormative expectation (Rohleder, 2007; Sontag, 1991).

1.3.2 Minority Stress

Alongside Goffman (1968)'s outline of stigma there have also been other conceptualisations that have sought to take into account structural context more specifically. For example, many break stigma down into three interacting levels including social (also referred to as enacted stigma), structural, and internalised (also referred to as felt or self-stigma) (Corrigan et al., 2005; Herek, 2009b). Whilst these have also been used in literature pertaining to distress related to sexuality (Herek, 2009b; Szymanski et al., 2001)and HIV (Herek et al., 2003), the predominate model used is that of Meyer (1995)'s minority stress which overlaps significantly with the above.

Although based primarily on social stress theory, Meyer (2003)'s minority stress framework draws on a variety of insights from social psychological research in positing that "gay people, like members of other minority groups, are subjected to chronic stress related to stigmatization" (Meyer, 1995, p. 38). As such, Meyer (2003) argues that the stress resulting from living in hostile and often homophobic cultures can explain the health disparities found in sexual minority populations as previously outlined. Specifically, Meyer (2003) included two main types of stressor (distal and proximal) within the model which he argued were chronic, socially based and unique to stigmatised populations. Distal stressors were thought to include direct experiences of discrimination, prejudice and violence, whereas proximal stressors were defined as the internal processes thought to occur following exposure to distal stressors. Proximal stressors were further described as expectations of rejection (known as rejection sensitivity – (Pachankis et al., 2008), experiences of rumination on past experiences of prejudice, hiding one's sexual minority status and the internalisation of negative attitudes towards one's own sexual orientation (also referred to as internalised homophobia – (Newcomb & Mustanski, 2010)). Meyer (2003) also argued that the negative impact of these stressors can be negated through more positive channels of social support and coping abilities and can be influenced by multiple contextual factors including the prominence or integration of the minority status (Meyer, 2003).

Across studies utilising a diverse range of methodologies, researchers have consistently found that exposure to both distal and proximal stressors outlined above largely explains the disparity in mental health outcomes including depression, suicidality and sexual compulsivity in relation to sexual minorities more generally (Plöderl & Tremblay, 2015) and gay men specifically (Pachankis et al., 2015; Rendina et al., 2017a). Some research has also indicated that it might contribute to HIV risk behaviours in gay and bisexual men such as lack of condom use and avoidance of disclosure around HIV status (Wang & Pachankis, 2016) However, despite HIV positive gay and bisexual men often being included within studies investigating minority stress, there has been little research examining the stressors facing them more specifically. One exception to this, is a study by Rendina et al. (2017b) who showed in a longitudinal study of 138 US HIV positive gay men, internalised stigma (both in relation to IH and internalised HIV stigma) was significantly associated with poorer mental health and increased sexual transmission risk behaviour (i.e. unprotected anal intercourse (UAI))

1.3.2.1 Internalised Homophobia

The concept of internalised homophobia (IH) is one aspect of Meyer (2003)'s minority stress model that has received significant attention in relation to gay men's health outcomes (Newcomb & Mustanski, 2010; Williamson, 2000).The term is often credited to both Weinberg (1972) and Malyon (1982) who both used it to describe how LGB people can come to internalise the repeated negative messages regarding their sexuality perpetuated by society. The concept is based in several schools of psychological thought including object-relations whereby through the process of introjection the negative views of society are incorporated into the self-representation (Malyon, 1982). This focus on the negative sexual self has been subsequently argued to impact on the development of a positive gay identity and has been included in a number of sexual identity models (Cass, 1979; Troiden, 1989). It has also been implicated, cross-sectionally, in explaining the mental health disparities in gay and bi-sexual men including depression, anxiety (Feinstein et al., 2012; Newcomb & Mustanski, 2010; Szymanski & Ikizler, 2013), and suicidality (Plöderl et al., 2013).

However, whilst there has been a considerable amount of evidence in support of IH, there has also been inconsistent research findings and criticism. Farnsworth (2003) examined the relationship between IH and UAI in a sample of gay and bisexual men and found no significant relationship. Similarly, Dudley et al. (2004) found no significant relationship between UAI and IH in a sample of young MSM. These inconsistencies with research findings have often been attributed to the multiple difficulties surrounding the validity, reliability and overall inconsistent operationalisation of the construct (Williamson, 2000). Research looking specifically at IH has also been criticised for failing to adequately recognise the fundamentally social nature of the construct and instead has focused on the individual, internal attributes surrounding it (Rohleder, 2016). Consequently, some researchers have advocated for the use of the term internalised heterosexism to more accurately account for context (Szymanski et al., 2008).

1.3.3 Critique of Existing Theoretical Explanations

Although theories of minority stress and IH have done much to broadly explain the difficulties and health disparities faced by gay men living with HIV, there has often been criticism aimed at their failure to explain how specifically “stigma gets under the skin” (Hatzenbuehler et al., 2009, p. 2). One attempt to readdress this was Hatzenbuehler et al. (2009)’s extension to the minority stress model in which he incorporated more general psychological (i.e. cognitive, affective, and interpersonal) factors, alongside the proximal and distal stressors already included in Meyer (2003)'s model. However there have been few other attempts. Whilst it is beyond the scope of this study to outline a full analysis of the concepts relating to stigma, minority stress and IH, this study looks more closely at the concept of shame which has been alluded to by some researchers to have an important role in mediating distress more specifically in relation to sexuality and HIV status (Bennett et al., 2016; Hutchinson & Dhairyawan, 2018). Whilst there is evidence that shame and aspects pertaining to stigma are related (see section 1.5.2.2 below on shame and internalized homophobia for further detail, pg. 26), to date there has been significant variability in how the two constructs overlap with little overall literature attending to shame specifically (Bennett et al., 2016).

1.4 The Concept of Shame

1.4.1 The Psychology of Shame

The concept of shame has seen a surge of interest from psychology and related disciplines over the last several years (del Rosario & White, 2006; Leeming & Boyle, 2004) and has subsequently been implicated in the development and maintenance of a wide range of psychopathology (Goss & Allan, 2009; Grabhorn et al., 2006) including depression (Cheung et al., 2004), anxiety (Pinto-Gouveia & Matos, 2011), eating disorders (Grabhorn et al., 2006) and sexual abuse and trauma (Feinauer, 2003). However, matching this popularity has been the wide theoretical variation by which it has been explored and operationalised (Gilbert, 1998) with theoretical positions ranging from the cognitive behavioural (Klass, 1990) and cognitive attributional (Lewis, 2000) through to the psychoanalytic (Jacoby, 2016; Wurmser, 1987) and developmental (Thompson & Newton, 2010). It has also been investigated as a cognition, emotion, behaviour and interpersonal dynamic (Tangney et al., 1996) and as such has provoked significant debate across the multitude of theorists and researchers investigating it, particularly in its differentiation from other emotions such as guilt (see Covert et al. (2003) for further discussion). Indeed, studies investigating shame more generally have been blighted by difficulties operationalising the construct including poor reliability and validity which often relate to back to the variation with definition and approach (Andrews, 1998; Blum, 2008).

However, despite these differing positions, theories often converge on an understanding of shame as a deeply painful, self-conscious emotion related to the negative evaluation of the self (Gilbert, 2000; Kaufman, 1989; Lindsay-Hartz, 1984; Tangney, 1995). Alongside the emphasis on the self, some researchers have also sought to emphasise the importance of the other with shame being conceptualised as not only an exposure of the self to the self but also the self to others (Gilbert, 2000).This negative evaluation of the self is often associated with a powerful sense of inferiority and a desperate desire to hide, escape or deflect the attention of others away from the ‘flawed’ self (Dolezal & Lyons, 2017; Johnson & Yarhouse, 2013). Some theories, in particular, have sought to emphasise these more relational components of shame including Gilbert (1998)’s evolutionary and biopsychosocial model and Kaufman (1989)’s shame theory. The later builds heavily on the work of Tomkins (1963) and affect theory and is particularly notable due to its application to sexual minorities (Kaufman & Raphael, 1996).

1.4.1.1 Gilbert’s (1998) Evolutionary and Biopsychosocial Model of Shame

Gilbert (1998)’s evolutionary and biopsychosocial model of shame argues that shame derives from the innate human motives for attachment and group belonging. All humans desire from birth a need to create positive feelings in the minds of others (Bowlby, 1969; Cassidy & Shaver, 2002). Consequently, the way a child experiences interpersonal relationships (i.e. caring or neglectful/abusive) has a significant impact on how they see themselves in the mind of others (Gilbert, 1998). Indeed, our survival is based around the early needs to be part of and thereby protected by a group and so responses such as self-monitoring, self-blaming and submission (Matos et al., 2013)   are crucial in preventing exclusion from the group, and ultimately death (Gilbert, 2003; Gilbert & Woodyatt, 2017).

For individuals who have experienced devaluation, criticism or abuse growing up, Gilbert (1998) argues that this can lead to feelings of external shame whereby their attention is attuned outward to seeing the self as negative in the mind of the other in either real or imagined social interactions (Goss et al., 1994). This, it was hypothesised, can lead to individuals managing shame in two ways – by internalising or externalising. Externalising of shame leads to external attributions involving anger and aggression towards others (da Silva et al., 2015). Alternatively, internalising of shame can lead to internal attributions that involve submissive behaviours and a sense of self as flawed, inadequate and undesirable (Harper, 2011; Pinto-Gouveia & Matos, 2011). Shame experiences often involve both types fuelling each other (Kim et al., 2011) but can also be mediated by earlier developmental experiences (Cunha et al., 2012) and also the social environment of the individual (Vagos et al., 2016). However, both internalising and externalising of shame can lead to cycles which reinforce shame for example, submissive behaviours may evoke domineering behaviours from others. Consequently, both types of shame have been associated with mental health difficulties for example depression (Cunha et al., 2012; Matos & Pinto Gouveia, 2014), eating difficulties (Ferreira et al., 2013), anxiety (Pinto-Gouveia & Matos, 2011) and anger (Matos et al., 2015). Furthermore, Gilbert (1998) argued that although shame is often a temporary experience, through repeated experiences of external shame (through the use of both externalising and internalising responses), it can lead to what he described as shame-proneness which incorporates a pervasive, chronic and global sense of sense as unwanted, inferior and defective (Gilbert, 2000; Tangney & Tracy, 2012).

1.4.1.2 Affect Theories of Shame

Like Gilbert (1998)'s evolutionary and biopsychosocial model, affect theories have sought to emphasise the biological and evolutionary functions of emotions such as shame in protecting the self (Tomkins, 1963). For Tomkins (1963), affects are the innate biological responses that bring salience to an event or situation and are the underpinning structure for cognition, emotion and action that cause an individual to focus their attention. For Tomkins (1963) shame acts as an "affect auxiliary" within this affect system and its role is to modulate the intensity of other positive affects notably “interest-excitement” - in essence bringing boundaries to our positive emotions (Tomkins, 1963).

This understanding of shame was further developed by Kaufman (1989) who highlighted, like Gilbert (1998), the long term, developmental implications of children experiencing repeated shame affect. More specifically, he argued that through repeated experiences of children having their needs rejected or ignored by a caregiver, the child begins to develop strong associations between distress and shame whereby whenever a child experiences distress, shame will occur alongside. Kaufman (1989) argued that this association is stored in a child’s memory as an image or scene and that these scenes form the fundamental components of identity. Consequently, through a clustering of shame scenes, Kaufman and Raphael (1996, p. 108) suggests that “one’s identity becomes based on shame”. This internalised or dispositional shame is similar to Gilbert (1998)’s ideas of shame-proneness whereby the individual is characterised by a chronic tendency to feel shame and thereby believing the self to be “unlovable, deficient, defective, or a failure” (Kaufman & Raphael, 1996, p. 93).

Like Gilbert (1998)’s concepts of internalising and externalising shame and in expanding further upon the work of both Tomkins (1963) and Kaufman (1989), Nathanson (1992) discusses specifically how this internalisation of shame can lead to the development of specific, patterned ways for predicting and coping with situations that induce shame called defence scripts. These scripts allow the individual to manage shame, however he also recognised that the utilisation of them can also lead to problematic outcomes through the creation of vicious cycles (Elison et al., 2006). Consequently, Nathanson (1992) proposed a model of shame scripts called the Compass of shame. This model describes four families of script including withdrawal from social situations, avoidance (e.g. through skills, attributes that evoke pride), attacking the self (i.e. thereby avoiding the other doing it first), and attacking others (i.e. preventing shame in the self by inducing it in others). Nathanson (1992) hypothesised that individuals dealing with internalised or dispositional shame will utilise defensive scripts more frequently and the repeated use of these strategies will perpetuate feelings of shame ((Elison et al., 2006; Nathanson, 1992). This model of shame has been supported in several studies (Elison et al., 2006). For example, Elison et al. (2006) in their study which encompassed 90 white male and female undergraduates found that individuals consistently employed each of the shame defence scripts across different types of shame inducing situations and that these ratings were stable over time. This study also highlighted the frequent use of these defence scripts to a number of psychological difficulties including depression and anger thus supporting the wider literature of shame's impacts upon mental health (Ang & Khoo, 2004; Tangney & Dearing, 2002).

1.4.1.3 Kaufman and Raphael's (1996) Shame Theory in Relation to Sexual Minorities

These theoretical positions of repeated experiences of abuse leading to chronic feelings of shame and inferiority, alongside the exposure to repeated distal stressors within minority stress models (Meyer, 1995) would indicate a strong argument for shame to be one of the mechanisms leading to psychological distress for LGB youth (and its cross over with concepts of IH – (Allen & Oleson, 1999)). Indeed, Nathanson (1992) and Kaufman and Raphael (1996) expanded the above theoretical positions to incorporate shame experiences within LGB populations. They suggest that the repeated experiences of judgement, rejection and abuse from both parents, peers and the wider society can elicit chronic experiences of shame that can ultimately become internalised. Further they argue that the social monitoring and self-evaluative processes characterising shame would make clear the difference between gay youth and the heteronormative ideals perpetuated daily within the home and wider society (Kaufman & Raphael, 1996). Consequently, Kaufman and Raphael (1996, p. 88) argue that "the lesson is clear: being gay is shameful, an inherent flaw". This sense of the self as flawed can have significant impacts for relationships. For example, they argued that "when shame is the principle affect governing your affective life, then relationships can be marked by hiding and avoidance of intimacy" (Kaufman & Raphael, 1996, p. 196). In essence, shame can prevent intimacy in relationships through a feeling of increased exposure. Indeed, there has been some evidence to support this position amongst lesbian women and the subsequent impacts of shame on psychological health (Tigert, 2001; Wells, 2004; Wells &

Hansen, 2003). Importantly, Kaufman and Raphael (1996) discuss how shame can be further magnified by an HIV diagnosis. They argue that the disgust and shame of HIV has been transferred to gay men, and similarly the disgust and shame of gay men has been transferred to HIV thus creating the potential for a fundamentally flawed self (Kaufman & Raphael, 1996).

However, whilst there has been tentative support for these arguments, Leeming and Boyle (2004) have argued that current research to date has often focused on shame more as an internal, dispositional trait, rather than as an emotional state resulting from specific social contexts (i.e. stigma). Consequently, they feel that labelling those as ‘shame-prone’ or experiencing ‘internalised shame’ often gives little focus to the contexts that give rise to these experiences (Andrews, 1998). With this in mind, the position taken within the present study seeks to understand shame as an emotion that bridges the gap between the personal and the interpersonal, thus while it can be an emotion that is internalised in line with the theoretical positions of Gilbert (1998) and Kaufman and Raphael (1996), it is ultimately and emotion that for LGB people is set within specific social and interpersonal contexts of stigma.

1.5 Shame Implications for Identifying as a Gay Man with HIV

1.5.1 Identifying Relevant Literature

Given the strong theoretical basis for shame outlined above, and tentative empirical support coming from studies looking specifically at the shame experiences of lesbian women (Tigert, 2001; Wells, 2004; Wells & Hansen, 2003), a literature search was undertaken to explore research pertaining to gay men living with HIV specifically in order to assess its viability as an explanation for the significant psychological health disparities experienced by this population.

After an initial scoping review in March 2017, it was felt two separate narrative literature reviews looking at 1) shame in relation to identifying as a gay man and 2) shame in relation to HIV would help to comprehensively cover the literature across the two aspects of focus in the present study. The literature search approach adopted included a systematic database search using psychology, medicine and science-based academic electronic databases including PsycINFO, PsychARTICLES, Science Direct, PubMed, Cinnall Plus, SCOPUS and Academic Search Complete using the search term “shame” and a range of terms relating to identifying as a gay man, and HIV. Google scholar and open source repositories including Research Gate, CORE and Academia were also searched. The abstracts of studies were reviewed and the full text of articles that were deemed to be relevant obtained. Forwards and backwards citation tracking was also used on full text articles. Further details of the literature search process for both searches, including a full list of the search terms, limiters and inclusion and exclusion criteria can be found in Appendix B, pg. 129.

1.5.2 Literature Review I: Shame in Relation to Identifying as a Gay Man

In searching the literature, whilst there was some evidence of either qualitative or quantitative research (17 articles) looking specifically at shame in regard to the lives of gay men, it was not comprehensive and overwhelmingly dominated by US quantitative studies leaving little understanding of how gay men themselves experience feelings of shame in regard to their sexuality.

1.5.2.1 Mental Health and Psychological Consequences of Shame

Much of the research highlighted during the literature search focused upon mental health in relation to shame and sexuality (seven of the studies - (Greene & Britton, 2013; Hillier & Harrison, 2004; Matos et al., 2017; McDermott et al., 2008; Mereish et al., 2018; Mereish & Poteat, 2015) and thus supported more general shame literature of its significant impacts on mental health (Bennett et al., 2010; Fergus et al., 2010; Stuewig & Tangney, 2007) .

Four of the studies looked at depression or behaviours relating to self-harm and suicide. Three of these studies were quantitative in nature with two utilising online survey methods (Matos et al., 2017; Mereish et al., 2018). Matos et al. (2017) looked at differences between a small sample of 53 gay men and 52 heterosexual men in regard to shame events, self-compassion, psychological flexibility and depressive symptoms during childhood and adolescence. The findings indicated that the association between shame events in childhood (defined as experiences where one is criticised, put down or ignored) and gay men was stronger than for heterosexual men. The authors also concluded that gay men reported less self-compassion and psychological flexibility than the heterosexual men and that this was linked to stronger correlations with depression and internal shame (Matos et al., 2017). However, given the small sample size and the fact that the study did not seek to explore the nature nor the theme of shame experiences reported it is unclear what motivated the experience of shame (i.e. shame related to sexuality/gender non-conformity)(Matos et al., 2017).

The link, however, between depression and shame was supported by Bybee et al. (2009)'s quantitative study that indicated that chronic experiences of shame were associated with higher levels of depression among 81 adult gay men compared to 86 heterosexual men. Interestingly, they found that shame was correlated with concealment of gay identity which Meyer (2003) also highlighted. They also found that chronic levels of shame apparent in early adulthood fell as the men got older and that the reduction in shame accounts in part for the age-related improvements in depressive symptoms. These findings echo that of Savin-Williams (2006) who notes that many studies utilise adolescent samples in looking at gay men's mental health and that this is problematic as adolescence and young adulthood can be tumultuous time periods and are often characterised by periods of identity confusion.

Utilising a similar online survey methodology to that of Matos et al. (2017) but with a much larger sample (719 sexual minority adults (324 gay men)), Mereish et al. (2018) investigated suicide risk including specifically looking at the relational mechanisms of shame and rejection sensitivity as risk factors. Their study found that 68/324 gay men in the study were identified as having a suicidal risk. They also found that among the gay men in the study LGB-victimisation was positively associated with more shame, rejection sensitivity and suicidality, particularly within bisexual populations.

McDermott et al. (2008)'s study was one of only two qualitative studies within the search. This study utilised a Foucauldian discourse analytic approach looking to explore the relationships between sexual identities and self-destructive behaviours (defined as suicide, self-harm) in 69 LGBT young people (16-25yrs). However, the study did not explicitly differentiate between the sexual orientation of the participants within their study and so in application to the current study should be interpreted with caution. However, their results included those from both individual interviews and focus groups and hypothesised the use of shame-avoidance strategies such as routinisation and minimising homophobia, maintaining adult responsibility and constructing ‘proud’ identities as a way of managing shame resulting from homophobic experiences. The authors concluded however that the use of shame-avoidance strategies made the young people vulnerable to self-destructive behaviours through isolation, alienation and negation of support from others (McDermott et al., 2008).

Similarly, Hillier and Harrison (2004)’s mixed-methods, Australian, study investigated the autobiographical stories from 200 “same-sexed” participants aged between 14-21 years with most still in education. Again, the study provided limited data on the experiences of gay or MSM specifically. However, the main themes elicited through their stories had a pervasive sense of shame often described as inferiority in comparison to heteronormative ideals and repeated experiences of rejection coming from parents, peers and the wider society. The authors concluded that there were no dominant discourses within the young people’ narratives that described same-sex attractions as good, healthy or natural (Hillier & Harrison, 2004). However, as described above both Hillier and Harrison (2004)’s and McDermott et al. (2008)’s studies utilised adolescent/young adult samples and thus shame experiences may have been more poignant than those in comparison to older LGB (Savin-Williams, 2006).

Greene and Britton (2013)’s study utilised a quantitative research design in looking at the relationships between self-esteem, shame-proneness and forgiveness in a sample of 657 LGBTQ (184 gay men). Findings indicated that self-esteem was largely predicted by higher self-forgiveness and lower shame proneness across the whole sample. However, the study did not differentiate between different sexual identities and like most of the studies they utilised a predominately white sample who were well-educated (36% with a graduate degree) thus limiting generalizability (Greene & Britton, 2013).

Finally, Mereish and Poteat (2015) quantitative study looked at the associations between shame, poor relationships with peers, and loneliness in relation to minority stressors and psychological and physical distress in 719 sexual minority adults (324 gay men). Although the study found that the effects of proximal and distal stressors on psychological and physical were mediated through feelings of shame thereby giving support to such theories as Kaufman and Raphael (1996), the sample was not defined specifically by sexual identity again making it unclear as to whether these findings were specific to gay men.

1.5.2.2 Internalised Homophobia and Shame

Another theme within the literature was a focus on quantitatively defining shame's relationship with IH (Allen & Oleson, 1999; Brown et al., 2016; Brown & Trevethan, 2010; Greene & Britton, 2012; Hequembourg & Dearing, 2013). This was perhaps understandable given the conceptual overlaps particularly in considering the interplay between chronic experiences of minority stress and the devaluation of the sexual self (Meyer & Dean, 1998). A number of studies have incorporated shame either explicitly or implicitly in measures of IH (Hequembourg & Dearing, 2013) and many have concluded that shame is a substantial component of IH (Allen & Oleson, 1999; Brown & Trevethan, 2010; Greene & Britton, 2012). For example, a study by Allen & Oleson (1999) examined the relationship between the two in a sample of 100 gay men and found a positive relationship between levels of IH and levels of internalised shame and thus concluded that shame is the principle pathogenic factor in IH. However, the link between IH and shame was noted to still be comparatively understudied and the existing literature blighted by the lack of psychometrically valid and reliable instruments of both IH and shame (Allen & Oleson, 1999; Hequembourg & Dearing, 2013).

Brown et al. (2016) in their study felt that internalised shame and IH whilst connected had significant differences and measured them separately in their quantitative study comparing Malaysian (n=234) and Australian (n=123) gay men. Specifically, they looked at the impact of religion on experiences of shame and found that Malaysian gay men reported higher levels of internalised shame and IH than Australian men. The authors felt this was primarily due to Malaysia being a more religious country with increased discrimination enacted towards gay populations consequently supporting arguments of minority stress (Meyer, 2003). However, the cross-cultural nature of the research means that a significant number of variables could have impacted on the findings. There was also little further exploration of the relationship between IH and shame (Brown et al., 2016).

1.5.2.3 Impact of Shame on Identity Formation

Another area that was touched on by research was the impact of shame on identity formation (Brown & Trevethan, 2010; Greene & Britton, 2012). Given the previous evidence of constructs of IH being linked to difficulties in self-acceptance growing up in LGB youth, this link is perhaps unsurprising. For example, Greene and Britton (2012) in their study of 855 US LGBQ (355 gay men) participating in an online study investigating shame, IH and ambivalence on emotional expression across stages of development found that shame was negatively correlated with early stages of identity formation as hypothesised by Kaufman and Raphael (1996). Specifically, they found that shame demonstrated a large positive correlation with ambivalence over emotional expression and a large negative correlation with personal mastery indicating that shame is marked by emotional ambivalence and feelings of self-defeat (Greene & Britton, 2012). However again findings were not defined by sexual orientation and thus implications for gay men specifically were unclear. Similarly, Brown and Trevethan (2010) study found a relationship between shame, IH and attachment style in the 166 gay men included in their study. Specifically, their study found that shame was predicted by both an anxious and avoidant attachment style and IH. This is perhaps unsurprising given the high levels of reported parental rejection experienced by LGB populations (Goldfried & Goldfried, 2001; Lutwak & Ferrari, 1997).

1.5.2.4 Shame and Risk Behaviour

Five of the studies quantitatively sought to investigate the impacts of shame upon sexual compulsivity (Rendina et al., 2018) or sexual risk behaviours (Christensen et al., 2013; Clemson, 2010; Park et al., 2014; Wiswell, 2015) and again supports evidence within more general shame literature of the impacts of shame on sexual risk taking (Tangney, 1995). In their study investigating sexual compulsivity (defined as “frequent, difficult to control sexual fantasies, urges or behaviours which cause distress or impairment” – (Rendina et al., 2018, p. 2) Rendina et al. (2018) found in a US sample of 260 “highly sexually active” gay and bisexual men that shame in relation to sexual identity strongly predicted sexual compulsivity and this was maintained at three months. It was also positively associated with negative outcomes including depression, anxiety, and IH.

Four of the studies (Christensen et al., 2013; Clemson, 2010; Park et al., 2014; Wiswell, 2015) looked more specifically at sexual risk which was defined as UAI with a partner of unknown status. For example, Christensen et al. (2013) identified higher levels of shame predicted UAI amongst 921 MSM. Their study utilised the Positive and Negative Affect Schedule (PANAS-X; (Watson et al., 1988) however Park et al. (2014) have argued that the PANAS-X subscales are broad and therefore fail to give specific insight into the shame experiences affected MSM. For example, whether it is shame related to sexual desire or engaging in certain sexual behaviour or both (Park et al., 2014). In seeking to address this, Park et al. (2014) utilised an online national survey of 1177 young adult MSM (18-24 years) to test the hypothesis that shame in relation to desire and not sexual behaviour was positively associated with UAI and would moderate the relationship between knowledge and self-efficacy. Consequently, they found that sexual desire shame was negatively correlated with knowledge and self-efficacy and positively correlated with UAI. These findings indicated that there may be significant differences in where the focus on shame lies and its impacts upon behaviour (Park et al., 2014).

Two of the studies (Clemson, 2010; Wiswell, 2015) were unpublished PhD studies and again utilised quantitative methods to investigate sexual risk. In Clemson (2010)’s study, high risk sexual behaviour was defined as UAI with a partner of unknown HIV status. Through an online survey of 759 gay men, the research indicated that overall (77%) of the men participating in the study reported low levels of internalised shame and highlighted that gay men who did not know their HIV status had higher levels of internalised shame when compared to those who felt they knew their status. It also showed a predictive relationship between internalised shame scores and likelihood of engaging in “high-risk” sex. However, Wiswell

(2015)'s unpublished research showed no significant results for the 158 MSM defined as "shame-prone" to engage in substance use in the context of UAI.

Finally, one study looked at substance use. Hequembourg and Dearing (2013)'s quantitative study looked at the interrelationships between shame-proneness, guilt-proneness, IH and problematic substance among 239 LGB (97 gay men) and found that problematic drug and alcohol use was associated positively with shame-proneness and negatively associated with guilt-proneness across all sexual minority groups.

1.5.3 Literature Review II: Shame in Relation to HIV

In relation to HIV, there was again a dearth of exploration into the importance of shame with only five studies looking specifically at HIV shame (DeMarco, 1999; Neufeld et al., 2012; Persons et al., 2010; Rohleder, 2016; Skinta et al., 2014) and again a focus upon quantitative rather than qualitative experiences, and mixed samples.

1.5.3.1 Psychological Impacts of HIV Shame

In relation to the impacts of HIV-related shame there were some studies that investigated the psychological consequences (DeMarco, 1999; Persons et al., 2010; Rohleder, 2016; Skinta et al., 2014). For example, Persons et al. (2010) found that HIV-related shame was negatively associated with a reduced quality of life in 247 HIV positive men and women (n= 118 gay and bisexual men) with histories of childhood sexual abuse, even when controlling for HIV-related symptoms, psychological distress and shame associated with childhood sexual abuse. Similarly, DeMarco (1999) in his unpublished thesis quantitatively highlighted that being HIV positive was associated with increased levels of shame, increased use of detachment and avoidance coping strategies and increased levels of depression. His sample included 50 gay men with HIV/AIDS and 57 HIV negative gay men, as well as a comparison sample of 112 heterosexual male college students. However, it is noted that within this sample of 50 HIV positive gay men that 31 had a diagnosis of AIDS and thus it is very likely that shame maybe increased with a worsened state of health (Dolezal & Lyons, 2017).

Importantly, there were also two qualitative studies investigating the impacts of HIV-shame. Skinta et al. (2014) utilised an interpretative phenomenological analysis (IPA) methodology to investigate the impact of both stigma and shame in relation to HIV. The sample included eight US gay men recruited from a community HIV clinic who participated in open ended interviews around their thoughts and experiences of living with HIV. Three superordinate themes were identified including social support and the disclosure of serostatus, stigma associated with serosorting and the attempts to negotiate a spoiled identity. All through each of the men's accounts was an attention to shame around a sense of being inferior, and surprisingly feelings of both shame and stigma originating from the gay community and the negotiation of relationships, specifically the practice of serosorting (see glossary for further explanation, Appendix A, pg. 126) that sets those with HIV part from others and from acceptable social belonging. However, the focus on shame within the paper was often negated at the expense of stigma and consequently the themes and narratives attended more explicitly to stigma than to shame. However, a paper that sort to give more emphasis to shame was that of Rohleder (2016). This paper reanalysed using a psychoanalytic framework data gained from another qualitative study of a small sample of five gay men living with HIV (See Rohleder et al. (2015)). In the re-analysing of this paper, Rohleder (2016) highlighted how experiences of shame are mediated through discourses that seek to other and blame those living with HIV. Importantly, this paper also highlights the implications for the men of living with two stigmatising identities and specifically how HIV can perpetuate feelings of shame that originated earlier the men's lives around sexuality. However, this was a small sample, and again the original focus was not on shame specifically.

1.5.4 Shame in Relation to HIV and Identifying as a Gay Man

Given the strong historical associations between HIV and gay men (Rohleder, 2016; Sontag, 1991) it was surprising that only a few studies explicitly acknowledged the shame implications of living with two potentially shame-inducing identities (Skinta et al., 2014). Whilst the stigma research has spoken of the “double” (Grossman, 1991) or “layered” (Herek & Capitanio, 1999) implications of two stigmatised identities – this has been overwhelmingly missing from the shame specific literature. Whilst qualitative, IPA studies such as that Skinta et al. (2014) and Rohleder (2016) have touched briefly through their analyses of HIV the sense of shame in relation to both identities, there has been no study to date that has looked specifically at the shame experiences in relation to both HIV and identifying as a gay man.

1.6 Rationale for the Present Study

Consequently, as the above literature search has indicated there is a paucity of research exploring the pertinence of shame for gay men living with HIV, and importantly a dearth of qualitative studies giving voice to the specific experiences of this group. Given the importance of stigma within the literature and the multiple and significant negative consequences arising from it for this population, understanding mechanisms (i.e. shame) by which it affects individuals is important in being able to accurately target psychological treatments (Rohleder, 2016). Similarly, the tentative research highlighting shame’s links to substance use and sexual risk warrants further exploration given the concerning contexts of chemsex (Bourne et al., 2015b). Consequently, the present study seeks to address this gap in the literature by qualitatively exploring the shame experiences of gay men in relation to both HIV and sexuality, and following the implications from the wider shame literature, the impacts for both sense of self and relationships with others (Kaufman, 2004; Lewis, 1971).

1.6.1 Research Questions for the Present Study

In seeking to address the above aims, this study sought to answer the following research questions:

1. What are the experiences of shame among gay men living with HIV?
2. How is shame experienced in relation to HIV and sexuality?
3. What are the impacts of shame for sense of self, and for relationships with others?

2.0 METHOD AND METHODOLOGY

2.1 Overview of Chapter

The following chapter provides an account of both the methodology and methods used in the study. It will begin with an explanation of the epistemological underpinnings of the research before introducing Interpretative Phenomenological Analysis (IPA). Sections will take you through the sampling and data collection procedures before considering the specific application of IPA to data analysis. Finally, the chapter will conclude with ethical considerations, maintaining quality within the study and reflexivity issues.

2.2 Epistemological Position

All research is “bound up with particular sets of assumptions about the bases or possibilities for knowledge, in other words, epistemology” (Coyle, 2007, p. 11). Consequently, the present study utilised a hermeneutic or interpretative phenomenological epistemology. Such an epistemological position holds that “while experience is always the product of interpretation and, therefore, constructed (and flexible) rather than determined (and fixed), it is nevertheless ‘real’ to the person who is having the experience” (Willig, 2008, p. 13). More explicitly, philosophers such as Heidegger (1962) emphasised that people make sense of the world through social, historical and cultural contexts to which the research cannot be stripped or the researcher detach themselves. As such, exploration implicates the researcher’s own view of the world, as well as the nature of the interaction between researcher and participant. This means that any analysis produced is always an interpretation of the participant’s experience (Larkin et al., 2006; Smith, 2004). Consequently, the researcher is engaged in a “double hermeneutic” whereby the researcher “is trying to make sense of the participant trying to make sense of what is happening to them” (Smith et al., 2009, p. 3).

This phenomenological position is important within the context of the present study as the study sought to give voice to the shame experiences of gay men living with two identities – in essence what is it like to experience shame in relation these two identities and how can we make sense of it? (Larkin, 2015) – an understanding that has been fundamentally missing from the literature to date.

2.3 Methodological Approach

In line with the epistemological position set out above, the present study takes a qualitative approach to understanding the shame experiences of gay men living with HIV. Qualitative research is concerned with how people make sense of the world and allows for a deeper exploration and understanding of behaviour alongside the meaning and context of complex phenomena (Snape & Spencer, 2003). Consequently, it is an appropriate approach for studying the wide range of social dimensions needed to explore gay men living with HIV's experiences whilst also maintaining a contextual focus (Mason, 2002).

In seeking to operationalise its qualitative stance, the present study utilised an IPA methodology (Smith et al., 2009). IPA is one of a number of approaches to qualitative research (Langdridge, 2007) and, with its groundings in hermeneutic phenomenology and idiography, seeks to examine in detail the lived experiences and meaning making people make to particular phenomena, within certain contexts (Brocki & Wearden, 2006; Larkin, 2015).

2.3.1 Why IPA?

The choice of IPA over other phenomenological and qualitative research frameworks was made for several reasons. First, health is the area of psychology where IPA first became established (Brocki & Wearden, 2006) and subsequently there has been a considerable body of work utilising and refining IPA to explore issues in the personal experience of health and the powerful ways in which health problems and their treatments can undermine a person's sense of identity (Smith et al., 2009). More specifically, IPA has been widely adopted by psychological researchers in studying issues relating to topics that are complex, ambiguous and emotionally laden including sex, sexuality and HIV (see - Skinta et al. (2014) and Flowers et al. (2011) for examples) (Smith & Osborn, 2003). IPA is particularly suited to researching these sensitive areas in that it can challenge understandings which are based around ‘othering’ people, or medicalising and pathologising behaviours (Smith et al., 2009) by asking the participant (as an expert) to talk about the way they think about an issue, rather than making assumptions (Smith et al., 2009).

2.4 Sampling and Selection

Following Smith et al. (2009)’s recommendation, this study recruited a sample of 10 gay men living with HIV. The sample size was sought in line with the overall idiographic approach of IPA in seeking to understand particular phenomena within particular contexts (Smith et al., 2009) whilst also allowing the disentanglement of themes that are idiosyncratic from those that are shared. The sampling method employed by this research was purposeful in line with the overall qualitative paradigm of the study. Selecting the sample purposefully allowed for a fairly homogenous sample (See Section 2.5.2, pg. 37 for sample characteristics) in line with IPA’s closely defined perspective rather than population focus (Smith et al., 2009).

2.4.1 Inclusion Criteria

In thinking about the inclusion criteria several specific choices were made. As previously described (See Introduction, Section 1.1.1, pg. 9) the choice to focus on gay men as opposed to MSM allowed for the identification of a more homogenous participant group in line with the homogeneity demanded by IPA(Smith et al., 2009). Further, the focus on gay men was due to the high rate of HIV amongst this population in the UK (Yin et al., 2014) but also the historical focus of HIV being labelled a “gay disease” (Rohleder, 2016, p. 65).

The choice of recruiting men over the age of 18 reflects the demographic profile of those attending HIV and sexual health services in the UK (Ogaz et al., 2016) but also an adult sample would allow the advantage of having longer life histories from which to draw from. It also avoids the criticisms outlined by (Savin-Williams, 2006) around the use of adolescent samples. Further, seeking those who have been diagnosed for at least one year allowed for recruitment of individuals who have had time to adjust to the immediate emotions surrounding being newly diagnosed (Nightingale et al., 2010). Finally, recruiting through London NHS HIV and sexual health providers gave access to a large population of individuals seeking treatment and or support for HIV.

Being non−English speaking was set out as an exclusion criterion, due to financial constraints around use of interpreters. There has also been some debate within IPA literature as to whether an interpreter would add a further level of interpretation to the double hermeneutic already in place (Smith & Osborn, 2003). Further, it was planned to exclude individuals if they were unable to give informed consent to participate, however, this was not necessary during the study.

2.4.2 Participant Identification and Recruitment

Participants to the study were identified and recruited via referral from health care providers in HIV and sexual health services across two central London NHS trusts. I attended staff team meetings to describe the study and asked staff to identify and approach any potentially eligible service users on their caseloads. Eligible service users were then approached for participation by their health providers who judged the potential risks of participation and, if deemed safe, described the study aims and procedures, nature of informed consent and any queries/concerns service users had regarding their participation in the study. Service users interested in participating could then verbally consent to passing on their contact details (email addresses) to myself, and/or were provided with my contact details in which to make contact themselves to arrange the interview. All participants were given a £10 love2shop voucher to thank them for their time. Due to financial constraints, travel expenses were not reimbursed

2.4.3 Sample Characteristics

Alongside the socio-demographics detailed in Table 1 below, it was also noted that all participants except one received one or more treatment episodes of psychological therapy in regard to their HIV diagnosis, with seven still undergoing treatment.

Pseudonym	Age	Ethnicity	Year of Diagnosis	Length of Time Living with HIV	HAART	Relationship Status	Length of Relationship
Michael	54	Black Caribbean	1993	25 Years	Yes	Relationship	8 Year
James	38	White Other	2005	13 Years	Yes	Single	n/a
Joe	28	White British	2014	4 Years	Yes	Relationship	1 Year
Charlie	28	White British	2016	2 Years	Yes	Single	n/a
Alistair	23	White/Black African	2012	6 Years	Yes	Single	n/a
Richard	51	White British	2006	12 Years	Yes	Single	n/a
Peter	24	White Other	2013	5 Years	Yes	Single	n/a
George	25	White British	2010	8 Years	Yes	Single	n/a
Martin	59	White British	1997	21 Years	Yes	Widowed	36 Years
Alex	34	White Other	2010	8 Years	Yes	Relationship	7 Years

Table 1: Socio-demographics Details of Participants

2.5 Data Collection

2.5.1 Research Method: Semi-Structured Interviewing

In following the idiographic focus of IPA, the present study used semi-structured interviews to obtain data from participants. This method allows for a deep, but flexible, exploration of individual experience and how participants made sense of their personal and social worlds (Smith et al., 2009). Smith and Osborn (2003) describe semi-structured interviews as the exemplary method for IPA arguing that they facilitate greater rapport and empathy but also free the researcher to explore important, but unexpected, topics. Facilitating a participants' ability to tell their story in their own words is a central premise of IPA and therefore while an interview schedule was used (See Appendix C, pg. 134) it merely acted as a guide to facilitate a more natural and sensitive conversation (Pietkiewicz & Smith, 2012) and was designed in accordance with the stages outlined by (Smith et al., 2009). The interview schedule was then piloted with my thesis supervisor and peers also undertaking IPA studies as a quality control (Biggerstaff & Thompson, 2008). Questions focused on the meanings participants ascribe to identifying as gay men, receiving HIV diagnoses, as well as any specific shame memories and feelings in response to these events. The same interview schedule was used for each interview. All interviews were audio-taped and transcribed by myself.

2.5.2 Socio-Demographic Data

Alongside the interview, data was also collected on basic demographic factors including age, country of origin, time since diagnosis, relationship status, receipt of anti-retroviral information (see Table 1, pg. 37 for socio-demographic data collection). There was also a space for participants to write any further information that they felt the researcher would benefit from knowing (See Appendix D for Socio-Demographic Data Sheet, pg. 138). Gathering this information allowed us to see the extent of the homogeneity of the sample.

2.5.3 Interview Data and Procedure

Data was collected over a six-month period. Each participant followed the same interview procedure as outlined (See Appendix E for study protocol pg. 140).

1. Participants were provided with a participant information sheet (See Appendix F, pg. 148) to consider for a minimum of 48 hours prior to agreeing to participate. This was to enable the participant should they wish to consider the implications of being involved with the study and to discuss this with friends and family should they so wish.
2. Upon agreeing to participate in the study, the interview was arranged at the NHS site in which they received their treatment and/or support. Interviews were conducted in a private room which was deemed secure and in which

interviews could not be overheard. All interviews were conducted between working hours (9am – 5pm).

3. At the start of each interview, the participant was provided with the participant information, consent form (See Appendix G, pg. 152), and confirmation of voucher payment sheet (Appendix H, pg. 154). Any questions that the participant had were answered and confidentiality and consent explored before formal signatures were required.
4. Before the start of the interview, participants were also asked to fill in the Socio-demographic form.
5. Each participant then undertook an interview lasting between 60-90 minutes. All interviews were recorded using an encrypted digital Dictaphone.
6. At the end of the interview, participants were thanked for their participation, provided with an opportunity to ask any further questions and provided with a debriefing sheet outlining further avenues of support (Appendix I, pg. 156).

2.6 Data Analysis

Once transcribed by the researcher, the transcripts were analysed using IPA methodology and followed the detailed guidance described by (Smith et al., 2009).

2.6.1 Individual Case Analysis

The first stage of analysis involved close, iterative readings of each of the transcripts in order to immerse oneself in the data (Larkin & Thompson, 2012). As part of this, my own recollections of the interview experience itself along with the initial observations about the transcript were recorded in the reflective journal (See Appendix J, pg. 158). This was in order to “bracket off” or temporarily suspend my own assumptions and judgements in order to focus on what was actually presenting within the data (Biggerstaff & Thompson, 2008; Husserl, 1999, pp. 63-65). Following this, the next stage of analysis involved the exploratory examination of both semantic content and language use. Notes were written on the right-hand side of each transcript margin to summarise and describe what had been said (descriptive comments), comment on the use of language (linguistic comments) and make initial interpretations (conceptual comments) (See Appendix K, pg. 160) for example excerpt of annotated transcript).

2.6.2 Emergent Themes and Cross Case Analysis

Following this, the second stage of analysis involved re-reading the individual narratives and the interpretative comments to develop emergent themes that captured the links between descriptive, linguistic and conceptual comments. These themes were reviewed by myself and my academic supervisor to consider how they could be clustered to form super-ordinate themes which captured the patterns between themes. Superordinate themes were identified following the processes outlined by Smith et al. (2009) and included abstraction (putting like with like); subsumption (where an emergent theme itself becomes a super-ordinate theme as it draws other related themes towards it); polarisation (examining transcripts for oppositional relationships); contextualisation (identifying the contextual or narrative elements within an analysis); numeration (the frequency with which a theme is supported) and function (themes are examined for their function) (Smith et al., 2009). An audit trail of analytical processes was maintained to keep a transparent and explicit decision-making process which allowed themes to be directly traced to the participant (Biggerstaff & Thompson, 2008). An example for part of the audit trail for cross-case analysis can be found in Appendix L, pg.163. Once super-ordinate themes were developed, quotes were found to illustrate each theme and transcripts were re-read to consider how well the themes accounted for the participant's overall experience. This process was repeated with each transcript. The final stage involved looking for patterns across participants accounts in which the superordinate themes and corresponding emergent themes of all participants were collectively analysed. Shared experiences within the group of participants were carefully considered and a structured list of final master themes assembled. The master table of themes for the group is shown in Table 2, pg. 46 in the Results section.

2.7 Dissemination

Feedback in the form of a brief summary report of the findings presented here will be given to the eight participants that wished to see the results.

2.8 Ethical Considerations

Throughout the design and undertaking of the study ethical principles were considered. In doing so, this study utilised the British Psychological Society (2009) Code of Ethics and Conduct and Guidance of Conduct and Ethic for Students (HCPC, 2012). As the study required participation from NHS service users, the study was put forward to NHS ethics. The study subsequently received a favourable opinion by the London – Camberwell St Giles Research Committee (Ref: 17/LO/0785) (See Appendix M, pg. 165) and gained Health Research Authority approval (Appendix N, pg. 173).

The following ethical considerations were made:

1. The process of obtaining informed consent with adult service users with a diagnosis of HIV:

   In preparation for obtaining consent from participants, I undertook Good Clinical Practice training on obtaining informed consent in the conduct of research. During the recruitment stage, potential study participants were offered clear information, both verbally and in writing (i.e. Participant Information Sheet) about the purpose, subject and nature of the study and what would be required if they consented to participate. It was also explained to participants that they were free to withdraw their consent up until a month after the interview. Participants were also given a minimum of 48 hours to consider their participation in the study before consent was sought. During the formal consent process each participant was informed that their responses would be anonymous. For example, pseudonyms would be used and all identifying features removed from transcripts. It was also made clear to participants that I would not access clinical files and that minimal demographic information would be collected. Audio files were only available to myself and my academic supervisor and full written transcripts to the myself, academic supervisor and thesis examiners. Audio-files were given unique identifying numbers and will be disposed of once the viva voce has been completed. Consent forms have been kept in a locked filling cabinet at the University of East London and stored separately from individual transcripts which have been password-protected and kept on a password protected computer.

2. During the research, the limits of confidentiality, as made explicit in the British Psychological Society (2009) Code of Ethics and Conduct, were again made explicitly clear to participants both verbally and in writing (i.e. Participant Information Sheet). For example, disclosure of personal information without consent may be justified in the public interest where failure to do so may expose the participant or others to risk of death or others are exposed to a risk so serious that it outweighs the participants privacy interest. In preparation of the above, a senior clinical psychologist operating across both trusts and specialising in HIV and sexual health became a clinical point of contact alongside the academic supervisor for any clinical risk matters arising. Fortunately, no such events occurred during the study. As advised by Smith et al. (2009) specific oral consent was revisited for sensitive, unanticipated topics.
3. Discussing issues around shame, as well as aspects of HIV and sexual behaviour has the potential to be distressing for some participants (Grace et al., 2016). Thus, I was cautious throughout the interviews to be cognisant for signs of distress. All participants were debriefed at the end of the interview and given information about local and national support organisations (See Debriefing Sheet).

2.9 Quality and Validity

There are a number of available guidelines for assessing quality and validity in qualitative studies (e.g. (Spencer L., 2003; Yardley, 2000). Since Smith et al. (2009) particularly recommended the Yardley (2000) guidelines, and have described how they apply to an IPA study, I have chosen to present the quality issues for this study according to Yardley (2000)'s four principles: sensitivity to context, commitment and rigour; transparency and coherence; and impact and importance.

2.9.1 Yardley's (2000) Principles

2.9.1.1 Sensitivity to context

Sensitivity to context can be established by demonstrating sensitivity to the socio-cultural milieu in which the study is situated, the existing literature on the topic, and the material obtained from the participants (Smith et al. 2009). Within the present study, I endeavoured to attend to this through the review of existing literature and theory described throughout the introduction chapter (See pages 9 – 31) and details of the sample characteristics (see section 2.4.3, pg. 37). Furthermore, the rationale for adopting IPA as the methodology was centred upon a need for sensitivity to context through its close idiographic engagement with the participants experience. The researcher was also conscious of issues of power in the interaction between them and the participants, particularly around both sexual orientation and HIV status and thus was cognisant of this through data collection and analysis. Sensitivity to context was also demonstrated by utilising in-depth analysis and supporting arguments with verbatim extracts. Smith et al. (2009) argue that this gives participants a voice in the project and allows the reader to check the interpretations being made.

2.9.1.2 Commitment and rigour

Yardley (2000)'s second broad principle is that of commitment and rigour which involves in-depth engagement with the topic and the development of competence and skill in the method used. Smith et al. (2009) suggest that this may be demonstrated through attentiveness to participants during data collection and taking care over the analysis. Examples in the present study include the transcript example (See Appendix K, pg. 160) and the audit trail of analysis (See Appendix L, pg. 163). The researcher had previously undertaken qualitative research, however sought to further develop their skills through attending specific lectures on these methods, conducting private reading on these topics, and honing interview skills through role-play. Peer review was also carried out by my academic supervisor who has previous utilised IPA methodology and has a specialist clinical and research interest in HIV and sexual health. With regards to rigour, Yardley (2000) is referring to the thoroughness of the study. Whilst the rigour of the study may have been affected by my lack of previous IPA experience, I was cognisant to carry out the study in a thorough and careful way drawing on available training and supervision where possible.

2.9.1.3 Transparency and coherence

Yardley (2000)'s third broad principle is that of transparency and coherence. Smith et al. (2009) state that transparency refers to how clearly the stages of the research process are described in the write-up and that there should be coherence between the research that has been carried out and the underlying theoretical assumptions of the approach being utilised. To aid the transparency of the analysis of the present study an excerpt from an annotated transcript can be found in Appendix K, pg. 160. Yardley (2000) also includes consideration of reflexivity within the principle of transparency, and a discussion of this is presented below in section 2.10, pg. 45. In considering the coherence of the study, the thesis has been drafted and re-worked several times, as well as proof read by multiple readers to ensure a coherent argument has been made and that the analysis is not contradictory.

2.9.1.4 Impact and importance

Yardley (2000)'s final principle is that of impact and importance arguing that the real test of validity lies in whether the research tells the reader something interesting, important or useful. With this in mind, I have sought to consider clinical relevance of the present study repeatedly throughout the studies conception, design and completion. These discussions can be found both in the introduction (section 1.6, pg. 31) and discussion (Section 4.5, pg. 93).

2.10 Reflexivity

Reflexivity involves reflecting on my impact as the researcher on the research process (Yardley, 2000). Since it is acknowledged in qualitative research and specifically within the double hermeneutic emphasis in IPA that the beliefs and assumptions of the researcher will influence how they collect, analyse and interpret the data, it is important to be as clear as possible about what these beliefs and assumptions are, and to "own one's perspective" (Elliott et al., 1999).Brocki and Wearden (2006) point to a relative weakness in published IPA research, in that the interpretative role of the researcher is often not discussed, and point to the need for researchers to acknowledge their perspective, including research interests, theoretical groundings and why they undertook their research. As such, my own position is outlined here and further within the discussion (See section 4.5, pg. 93). I also kept a reflective journal throughout the research (see Appendix J, pg. 158) in which I have documented my thoughts throughout.

I am a 30-year-old, heterosexual, White British woman. I would describe myself as coming from a relatively working-class background and I am HIV and HCV negative. My clinical practice as a trainee clinical psychologist would be described as integrative drawing upon a number of theories within a broadly critical realist perspective.

My interest to understanding gay men living with HIV's experiences of shame and its impacts on sense of self and relationships started as an assistant psychologist, seven years ago. One of my first posts was in a specialist substance use clinic whose main client population was gay and bisexual men engaging in chemsex. The referrals the clinic received often described a similar picture of young to middle aged MSM and gay men engaging in chemsex parties which caused several significant difficulties in regard to HIV, physical health and psychological health. In my work with these men, engagement in chemsex was often described in the context of long histories of difficulties with self-acceptance and thus an interest was formed in trying to understand the wider context to behaviours such as chemsex. This understanding was carried through into a placement during my clinical psychology training in a specialist HIV psychological medicine unit.

3.0 ANALYSIS AND RESULTS

3.1 Overview of Chapter

Following on from the methodology, this chapter completes an interpretative, idiographic analysis of the 10 participant interviews. Due to limitations of space, only master themes and their constituent superordinate themes from across the 10 cases (See Table 2 below) will be presented here, illustrated by verbatim extracts. It is important to acknowledge that these themes are only one possible account of the participant's experiences of shame in relation to sexuality and HIV and have been selected due to their relevance to the research questions. Whilst the following themes were common to all 10 accounts, there were also areas of divergence some of which will be addressed here.

Master Themes	Superordinate Themes
Sexuality: An Unacceptable Difference	Defined by Difference Rejection of the Emerging Sexual Self
Managing an Unacceptable Self	Concealing of the Sexual Self Moments of Freedom and Escape
HIV: Rejection of the "Dirty" Self	The Self as "Dirty" Rejected from Within
Negotiating a "Dirty" Identity	Withdrawal and Escape Concealing the HIV Self
Moving to a More Meaningful Self	Support from Services Changing Times Finding Purpose

Table 2: Table of mater themes and corresponding superordinate themes from across the 10 interviews

3.1.1 A Note on Presentation

To improve readability, some minor changes have been made to participant extracts. For example, where they do not affect meaning, minor hesitations and utterances such as "*erm*" have been removed. Any missing material is indicated by dotted lines within brackets e.g. (…). Material added to explain a participant reference is presented within square brackets [e.g.]. Dotted lines at the beginning or end of a quote indicate the person was talking prior to and after.

3.1.2 A Note on Shame

Prior to looking at each of the themes it is worth acknowledging that within participant accounts shame was not always acknowledged explicitly. This fits with existing literature that argues that "shame itself is often repressed because to acknowledge shame is to unwillingly invoke shame" (Munt, 2000, p. 535). Indeed, participant behaviours within the interviews were often those closely associated with feelings of shame (head lowered, eye contact avoided (Lindsay-Hartz, 1984)) and content of their responses closely followed previously outlined indicators of shame (perceived flawed self, sense of wanting to hide and disappear - (Gilbert, 2003) – see chapter one for further details, section 1.4, pg. 17). Consequently, shame was interpreted as an, at times, unspoken or implied emotion through participant accounts.

3.2 Sexuality: An Unacceptable Difference

One of the master themes throughout the participant's interviews was the early perception that their sexuality was an unacceptable difference in the eyes of the other. This was developed through both a perceived difference in regard to conformity with hegemonic conceptions of masculinity, and through the rejecting and sometimes violent responses of others towards perceived or actual disclosures of sexuality.

3.2.1 Defined by Difference

All participants commented upon an early recognition of difference as central to their first understandings of identifying as gay as illustrated by Martin and Michael's excerpts:

> *"…I was quite young when I knew... [that I was gay]. I remember writing a poem about a wishing gate and if I was going through a wishing gate I wish I was straight or not gay (…) I just wanted to be the same as everybody else because it is easier, it is so much easier. I knew I was different."*
>
> Martin
>
> *"…. I did note that I somehow appeared different and this is my perception of what other people were displaying; "oh you are so mild, you are so calm, you are so wise, you act older than your age"- all of the verbiage that is attributed to a child growing up who perhaps was a mummy's boy and loved it (…) but then recognised that it wasn't the thing to do and you were meant to be doing other things"*
>
> Michael

For Michael, the difference he points to in being a "*mummy's boy*" is initially described in positive terms "*wise*", "*calm*", however the "*but then*" indicates a sense of time and change with a perception that as he got older, this difference was one that was one to be perceived negatively. Indeed, as seen in Martin's excerpt, there is a desire to eradicate the part of the self that identifies as gay and this sense of difference as negative was seen across all transcripts except Alistair's (see below, pg. 55 for further discussion of Alistair's divergence in this respect). The negativity surrounding sexuality was mainly talked about in regard to a perceived failure to adhere to heteronormativity and, in particular, hegemonic masculinity:

> *"…. I started getting old enough to go to the working man's type of environments. My dad was in the army for years and he used to go to the British Legion (…) I shrank…. hide…. sit here…. drink…. don't talk… don't anything…. I never felt that there was anything that we had in interest…. sports, darts, wrestling…. it was an alien world with aliens and I didn't fit…."*
>
> Richard

This excerpt shows the strength of the disparity between Richard's sense of self and the men around him as highlighted in the use of the alien analogy. It's not just that other men are aliens that cannot be understood and are something to fear, but also the entire context ("*alien world*") – it is a strong image of difference. The first half of this quote also alludes to the fear that this difference will be exposed, for example, from the use of self-imperatives ("*hide*", "*drink*", "*don't talk*") – anything that might expose him. Although not explicitly stated, the sense of being frozen in this painful self-conscious state and wanting to avoid the exposure of the self to others is in line with conceptions of shame (See Introduction, Section 1.4, pg 17 - (Gilbert & Woodyatt, 2017; Lindsay-Hartz, 1984). Later in the interview, Richard expands on his sense of sexuality as different by highlighting that to be gay is to be inferior due to a failure to achieve what he describes as the fundamental heterosexual objective of the human species:

> *"…I do tend to question why I am here and what I am doing here and the inferiority complex that I carry…. because it's all about procreation…and evolution (…) and there has to be a runt I think every so often to almost temper things…"*
>
> *Richard*

This sense of inferiority in relation to heterosexual men and associated environments was also echoed in Alex's transcript:

> *"**Interviewer**: That sense of being an outcast…where did it come from?*
> ***Alex**: I was in the Boy Scouts for years (…) it was very regimental, and it was all about men being men and doing all these tough things and challenges and running and being really tough guys (…) it was a very lads' environment and still to this day I don't like lads' environments and with hindsight it wasn't the right environment for me… I stayed but again I was an outcast…. I was a weakling…. a weak person…"*
>
> Alex

Alex's sense of himself as a "*weakling*" mirrors Richard's sense of being a "*runt*" and projects a powerful sense of the self as inferior in comparison to the heterosexual male other. These feelings of inferior difference in comparison to expected masculine norms were often perpetuated and heightened by the rejecting reactions of others as outlined below.

3.2.2 Rejection of the Emerging Sexual Self

Alongside their self-perceived difference as negative, all of the participants recalled experiences of their sexuality being rejected by others. This rejection took many forms including others seeing their sexuality as disgusting, to more overt experiences of exclusion, abuse and humiliation for failing to perform hegemonic masculine expectations. This rejection from others laid the groundwork for ongoing difficulties with mental health, and shame through a sense of confirmed inferiority (Goss et al., 1994).

For Joe and Charlie, observations of their parent's reactions gave early messages that to identify as gay provoked disgust:

“…. we would be watching EastEnders with my mum as a kid and there was a gay couple on it (…) and every time they kissed on screen my mum would go “Uuuuuuurrrrrrrrggggghhhhhh” [disgusted noise] *and look away and that made me feel shit for years because I was like (…) my sexual orientation was wrong…”*

Joe

“…my mum made quite a few comments growing up like about bum sex and who sticks it up who’s bum and how gross that must be and that has definitely stayed with me…”

Charlie

These messages of disgust were heightened as Joe states by the fact that it was a reaction and ultimately a rejection from “*my own mother*” and those deemed closest. For Joe, this rejection became an overt reality when his mother kicked him out of the house for coming out as gay, aged 17. For others such as Richard, Michael, Peter and George messages from parents were that sexuality was “*something unspeakable*” and “*something to be repressed*” ultimately confirming their perceived difference as one as wrong in the eyes of the other. Although not explicitly mentioned by participants, one could imagine that these messages of disgust at images of gay relationships were heightened against the backdrop of the family, a pinnacle of the heteronormative imperative (Flowers & Buston, 2001).

Alongside experiences at home, all of the participants spoke of receiving some degree of abuse, hostility or rejection from peers growing up due to a perceived or disclosed gay sexual identity. This was often in response to a perceived failure to adhere to heteronormativity and hegemonic masculinity:

“I remember people trying to make me feel bad about who I was…. things they’d say, “Why do you talk like that?”, “Why do you do things like that?” …. “Why are you interested in those things?” “Isn’t that girls stuff?!” …. “Aren’t they all gay?!” …. I would have sixteen-year-old kids teasing me calling me “faggot” and I was six….”

James

"…..there was a whole period from when I was maybe 15…16 in GCSE (…) where the popular, straight boys would come up to me and start talking with a stereotypically camp gay voice and then it became more physical where they would come up and start grabbing my arse and stuff and laughing (…) and they were making fun of me…you know ….. "He'll enjoy it cuz he's gay" and I never told anyone I was gay….it was just because my friends were girls and I didn't really enjoy football…."

Joe

*"**Interviewer**: Did you ever experience homophobia?*
***George:** (…) I came out at school…. I remember getting called a gay prick all the time or "turn around and don't let him see your bum" as if I would want to shag everyone….so yeah at school it wasn't very nice…."*

George

These excerpts create a perception of the messages provided by peers in relation to the self and sexuality- the gay self as inferior, emasculated and warranting of abuse. The association between being gay and gay sex ("*grabbing my arse*", "*don't let him see your bum*") is also alluded to here in the quotes by Joe and George and indicated the wider narratives of a gay identity as one associated with promiscuity (Rohleder, 2016; Sontag, 1991).

Alternatively, for Richard, a key moment of rejection by his peers was through his early sexual explorations with a neighbour where he was avoided after engaging in masturbation and oral sex:

"…. suddenly just to be blanked…not that I wanted it to continue but even that it would be acknowledged between us…that this had happened and that we might talk about it and we certainly wouldn't adopt a behaviour that was one where you couldn't even be associated…. and I think that then started my examination of myself…of how I might be perceived by others…"

Richard

For Richard, these experiences hold a significant meaning in terms of the examination of the self– alluding to an internalisation of the other. It is not just a case that the sexual activity is denied and avoided but him as a person. This focus on the negative self in the eyes of the other clearly echoes the more relational conceptualisations of shame previously described (Gilbert, 1998; Kaufman & Raphael, 1996). Later in the interview, Richard describes the long-standing implications of these events as feelings of low self-esteem, depression and suicidality. Similarly, seven of the participants all describe feelings of low self-esteem, low confidence, depression and anxiety originating from these types of experiences:

> ***"Interviewer:*** *What impact did that [abuse at school] have?*
> ***George:*** *I think that's where my anxiety came from originally it just…. it's not nice….it makes you feel shit…I don't understand why people do it….it makes you feel less of a human because you are gay"*
>
> George

> "…. *if you are hearing from either from your parents or from society or from the media or from school friends or teachers or whoever that being gay is less than good (…) you grow up with that and it stays with you and you know I was in the generation of "you're so gay", "that's so gay" (…) like that was so part of my vocabulary that when I discovered that I was in fact gay it was so intrinsically trenched in in less than good…"*
>
> Charlie

Both excerpts highlight feelings of inferiority and in George's case dehumanising messages that originate from the rejection of others. Whilst many of the participants described rejection within adolescence, these experiences continued into adulthood ultimately perpetuating feelings of inferiority and wrongness:

“…. I remember me hugging a colleague and a guy went past and said “That’s a bit gay isn’t it?!” …. I mean it’s not extreme homophobia but it’s clear that he didn’t like what he was seeing…. there was another where I was holding hands with someone…. I don’t think we were holding hands actually…I think we were laughing and joking (…) and this guy was like “Uurrgghhh [disgusted noise] *there are gays everywhere””*

George

Again, the focus on the other is clear in George’s excerpt “*he didn’t like what he was seeing*” but a sense of minimisation is also present in “*it’s not extreme homophobia*” which perhaps allows George to deflect the shameful feelings associated with homophobia. Richard also described difficulties in the workplace and a perception that the predominately male heterosexual environment he worked in prompted sniggering and mockery from others due to his sexuality:

“…..the thing around shame is….it is a big knot….in the tummy…it really is an “oh god….I feel inferior to these people” or that they don’t respect me or that I’m there in a position of authority to you know…..to tell people what they are doing (…) it doesn’t matter what position or where you are if you are queer then you are nothing because you are not expressing your masculinity….you don’t count….”

Richard

As Richard articulates here, shame experiences relating to feelings of inferiority are still present and undermine any alternative identity he may possess e.g. a manager. For Richard in a mirroring of experiences at school and in the home, expressing masculinity is the foundation upon which all else rests and to which deviation is unacceptable.

For Alistair, however, identifying as gay was not problematic as he felt he had the support of a predominately heterosexual male friendship group at school:

> *"…. I was lucky some people are so unlucky…. some people in my own school in my year were unlucky but yeah I think because I was so cocky and confident about it…it sort of paved a way to success in school which you know a lot of gay guys would say they hated school but I absolutely loved it...."*
>
> Alistair

Whilst this may have been the case, there are also parts of Alistair's transcript that allude to some underlying difficulty associated with his sexuality. For example, he talks about having experienced emotional difficulties including depression and impulsivity from a young age and the use of sex to escape these difficulties (from the age of 13). Similarly, why is it that he feels the need to be "so cocky and confident" when peers around him are so unlucky? More specifically, through the interview Alistair's behaviour was one that was felt to typify the behavioural characteristics of shame (Gilbert, 2003). For example, he avoided eye contact, lowered his head and drew a repeated pattern on a piece of paper whilst he spoke. Whilst this behaviour was not specific to Alistair, the contrast between his behaviour and the content of his words was noticeable and is a theme that will be given specific consideration within the discussion (see section 4.2.3, pg, 85). Consequently for men in the study, sexuality as a gay man provided strong feelings of inferiority and unacceptable difference against a backdrop of heteronormativity and hegemonic masculinity.

3.3 Managing an Unacceptable Self

This second master theme aims to capture the various ways participants described managing this painful sense of inferiority, and difference around their sexuality. This included a sense of concealing the sexual self through hiding and pretence but also moments of freedom and escape where at least superficially they experienced feeling liberated from shame.

3.3.1 Concealing the Sexual Self

In seeking to manage sexuality in the face of others, several of the participants described having to manage their outward behaviour to either avoid being outed as gay or moderating the perceived impact on others of being too out or "*too effeminate*" thereby encapsulating what Goffman (1968) refers to as "impression management". For Michael, who spent his childhood and young adulthood in Jamaica, hypervigilance and moderation to the self was even more important given his awareness that others could be killed for coming out as gay. Consequently, his interview was littered with a pervasive sense of having to constantly self-monitor and evaluate the self in the eyes of others:

> *"…. I wasn't acting upon any of these responses* [early sexual desires] *… I don't think there was any outward physical displays that would give me away…."*
>
> Michael

Shame here is conveyed powerfully through the phrase "*give me away*" which indicates a concealed self, a self that has the potential to be exposed by the omnipotent gaze of the other. Both he, Richard and Peter also spoke about keeping their sexual experiences "*in the shadows*" or in dark, discrete places in response to this:

> *"….so everything was under covers…it was dark… I guess* [we] *met and mingled and partied in the shadows… …in secluded places…not unlike many other societies…but particularly with a background knowing that we have to be extra careful because if caught what the consequences could be….*"
>
> Michael

*“**Interviewer:** Growing up not being able to say who you were…. what impact do you think that had? If any?*
***Peter:** …. I did loads of sex in terms of men who were older than me and we used to have sex in cars or in a discrete places because everybody plays in discrete back alleys because they don’t want anybody to know and that creates the feelings that I really don’t want to share who I am, I didn’t want to tell people and it makes you feel like that is normal….”*

Peter

As Peter states here, this sense of having to stay in the dark creates a feeling of having to withhold parts of the self and that this compartmentalising becomes normal. This sense of having to separate the sexual self from the self portrayed to others was mirrored through other interviews where participants talked about putting on more acceptable fronts:

*“**Richard**: .... I’ve always been very, very self-conscious not to be too camp for example and not to allow my guard down and say anything that might be considered a little bit effeminate or too much in somebody’s face….*
***Interviewer:** Why?*
***Richard:** Well just not to offend but also to try and keep the peace with people and in business one needs harmony (…) what I have been very hyper-conscious of is not endorsing everything that they’ve got your stereotypical you know…. coming in and being very camp….and so what I have done is that I started staging and being somebody else…and acting….and becoming a little bit of a farce….”*

Richard

For Richard, experiences of shame although not explicitly said are clear through his perception that an effeminate gay man would cause offence thus in response he “*suppresses*” his sexuality to convey a more acceptable self. The strength of his hypervigilance to his own behaviour is pervasive – “*very, very self-conscious*”, “*very hyper-conscious*”. The performance (“*acting*”) he describes, however, as a “*farce*” – one that is absurd and one that is ultimately fake.

Others also spoke of pretence or hiding parts of the self:

"…. I was growing up with quite frankly becoming a gay in a straight body (…) like I wanted to be someone else who I couldn't be and because of what people were telling me was the normal… I was really just killing the part inside of me which was me…."

Peter

"….I got asked a lot if I was gay and I denied it every single time for at least four years (…) you get so good at lying and so convinced that it's not true in you, like I used to fool around with a boy or have gay sex or suck someone off or be sucked off by a boy and the minute it was finished be like that's not me and this compartmentalising of who you are is so damaging….it's really, really fracturing…."

Charlie

As each of the three excerpts demonstrate, the consequences of experiencing shame and inferiority, led to feelings which in themselves also had consequences thus creating further problems:

"……I will still find it extremely difficult if I were out and there was a very flamboyant gay man sitting at my table and drawing attention…I would want to dissociate myself from that….is so engrained is that…that I can't let myself be associated with it….and I find it quite abhorrent….and its inhibiting in that it never allows me to celebrate…. truly to be excited…and I rarely feel that and that's one of the issues around my low moods is that you know…I've so constrained myself that I have tied my hands…."

Richard

"…. I've often not trusted myself in the past or felt like I'm not good enough for my friends or felt like I'm actually like a horrible person a lot because you don't trust yourself growing up…."

Charlie

In sum, together these excerpts demonstrate not only that participants concealed aspects of the sexual self from the stigmatisation and hatred from others but also a sense of conflict within them for example, Charlie immediately disavows the sexual desires he just felt, Peter “*kills*” the sexual part of himself and Richard feels abhorrence at being associated with effeminacy and flamboyancy.

3.3.2 Moments of Freedom and Escape

Alongside aspects of concealing the sexual self, the participants were also able to share aspects of their lives where they felt comparatively free to express themselves, for example, by participating in interests and areas of skill and positive reward. For both Michael and James, their skills provided an area of pride and one in which for Michael at least, felt others could take pride in:

> *“I think it was something I wanted to celebrate…. this new discovery of self and things that I found interesting and I became good at and I wanted to celebrate that and I wanted to make my family proud and my parents, my colleagues proud (…) I just think I wanted to make me proud and I was proud…”*
>
> Michael

> *“…the only thing that ever made me happy was my career or my abilities….so that’s why I threw myself into my career even more so being in the studio and dancing and getting work and going here and going there…it was the only way I could get away from any of it….”*
>
> James

In both cases, skills, abilities and careers provided a sense of positivity, yet they also provided an escape in which as James described they could get away from the difficulties they experienced. Yet, their narratives also suggest some conflict about this as both experienced abuse from others regarding their choice of activities:

"…. the discrimination was set in place…it was almost institutionalised…if you gonna go into theatre you ought to be gay…you should be gay…you must be gay if you are doing theatre…music…art…."

Michael

"….. "oh yeah but you're a dancer" …. "you're a typical gay" … "oh you're quite skinny as well you know" …. "all skinny gay guys are dancers…they're all camp" and you know "you give us gays a bad name"

James

The imperatives listed by Michael "*you should, you ought, you must*" suggest an internalising of the other's voice commanding a sense of exposure. Interestingly, the responses James lists are those from other gay men. Although James mentioned a sense of low-self-esteem, like Alistair and Martin, he often did not expand upon topics aligned to shame regarding his sexuality (and HIV) even when probed. However, throughout his interview he often expressed extremely negative language and sentiment towards other gay men e.g. "*dirty queers*" perhaps indicating ongoing issues towards acceptance of the sexual self.

Alongside careers, skills and abilities, Richard, Alistair and Charlie also expressed using sex (including chemsex) as ways of expressing oneself but similarly feelings of escape:

*"**Interviewer:** Are there any opportunities to be yourself?*
***Richard:** I think I've been grappling through it through sexual encounters in areas where you can do absolutely anything without repercussion…. it is very liberating and if its anonymous so much the better of course because there is no…. you can do something quite outlandish, walk away and never be seen again…. I don't know whether it is conditioning rather than anything else but the only way I knew as an outlet or as a way to be amongst others where I felt comfortable and where I felt that what I wanted to do or what I said or how I reacted to something wasn't unacceptable…"*

Richard

> *"… sex on drugs is a totally different thing from other sex for me…. it's not even comparable (…) it's like so much better…and its annoying because that means it's hard to quit…so in that moment in that chemsex moment I escape through both those things…. get super high and then have hours of sex…"*
>
> Charlie

Again, whilst these areas allowed a sense of being free, they also come with consequences. For Richard, sex is free but it is also hidden, anonymous, in certain places and with very little potential for intimacy and relating. A similar picture arises for both Charlie and Alistair yet through their narratives both also draw attention to a sense of layered shame resulting from these forums of expression (e.g. shame in relation to the use of drugs themselves). Consequently, in trying to manage a sense of inferiority and shame the men were further pulled into difficulties which in themselves had implications.

3.4 HIV: Rejection of the "Dirty" Self

The third master theme involved the diagnosis of HIV which many described as a gaining of a "*dirty*" sense of self. This was primarily due to its association with gay sexuality creating a sense of layered stigma and shame. This theme also encapsulates the significant experiences of rejection and the exposure the men faced primarily from within the gay community around their diagnosis.

3.4.1 The "Dirty" Self

All participants within the study commented on an HIV diagnosis as representing something fundamentally negative about the self at least in the first few years following diagnosis. For most of the participants, this negativity centred around being "*dirty*":

"…. quite frankly I thought that I was dirty…you know…that I wasn't like normal people…."

Peter

"….. just thinking that it's something dirty…like the only way I can describe it is like a colouring like when you found out someone was HIV their whole pigmentation gets really greenified and it's quite dramatic…."

Charlie

The imagery contained in Charlie's excerpt is notable here in conveying a sense of illness and a consuming of HIV of the self - "*their whole pigmentation*". The use of the word "*greenified*" suggests connotations of pestilence, and even disgust. These feelings of dirtiness and disgust have been persistent features within HIV qualitative studies (Rohleder et al., 2015) however the fact that Charlie was diagnosed just over year prior to the participation in the current study implies that they are still very much present as George also suggests in his quote below. For George, the word dirty was mentioned 15 times over his interview and as he alludes to in his quote, "*being dirty*" suggests that this was something embodied:

"…. the association is that only gay men get it and it is known as a dirty disease and I think it still is now as well…. I kinda think about that sometimes…. about being dirty..."

George

The association made here between HIV as a "*dirty disease*", and a "*gay disease*" was one that was made in every interview and suggests a layered sense of shame and stigma regarding both identities. For many, HIV was dirty because it was a disease seen as one associated with gay sexual activity either by the self or by the perception of what others thought. The focus on what others may perceive of an HIV diagnosis can be seen clearly in Richard’s excerpt and again alludes to the presence of shame in the denigrated sense of self in the eyes of the other:

*“**Interviewer**: You talked about these really difficult experiences and that was disclosing HIV, or sexuality or…?*
***Richard:** I’d say shame, I think in the early days of HIV…after diagnosis….because of the stigma and because of the publicity that had been surrounding gay behaviours around promiscuity and all of the things that that might conjure up which would be cottaging….which would be going to dirty places to have random, anonymous sex with literally anybody or going to a gay club in London….what would people think of that?(…) I think that’s where the shame came…that I didn’t want my friends or family to associate me with that behaviour…..because I thought that they might think that it was kind of dirty or that you know that you are deviant….”*

Richard

For Richard, the difficulty in accepting his HIV diagnosis was primarily centred around what it meant as a gay man and what that ultimately meant to others, and it was striking that following this section of the interview he elaborated on the sense of himself as a “*deviant*” by making a comparison between his sense of sexuality and paedophilia. The comparison with paedophilia highlights the extent of his perceived stigma and has clear links with the heteronormative, historical conflation of homosexuality, perversion and paedophilia (Igartua et al., 2009):

“…. I am going to say paedophile just because it’s in my head but it’s that kind of associational stigma that tilts you to this day you think…. pervert…”

Richard

Consequently, the discussions surrounding HIV as one associated with dirtiness, disgust and perversion echoed those of how sexuality was initially spoken about by the men and indeed many described it as “*getting back into the closet*” and ultimately undoing any progress they felt they had achieved in relation to acceptance around sexuality. The power of holding in mind the view of others, and the subsequent impact of that on the self had clear similarities with the shame experiences documented around sexuality. The association by the men of HIV as a gay disease and one associated with deviancy and promiscuity indicates a layered shame with HIV strengthening the view of the self as abhorrent in the eyes of the other.

3.4.2 Rejected from Within

Unlike conversations around sexuality where participants reported rejection arising predominately from heterosexual individuals and environments, a theme across the participants HIV discussions was one of the pervasiveness of hostility and rejection coming from within the gay community. This was often due to disclosure to potential sexual partners on dating apps, or through face-to-face dating which left the men often feeling "*expose*d" and "*humiliated*". All of the participants described at least one experience of being rejected by an actual or potential sexual partner. Some of these responses were described as being "*blanked*", "*ignored*" or "*blocked*". For others such as Joe and Alistair reactions were stronger:

> *"…. the first thing he said to me was "wow, I'd kill myself if I had that" and I was just like…. "so basically, you think I should just die? …should I go and kill myself?" … that's how I took it…. that "people like you shouldn't exist…. you shouldn't be alive…and you don't deserve to be" (…) I felt really humiliated….it put me off dating for quite a while…."*
>
> Joe

> *"…. he was calling me "AIDS ridden" …he was like "you are deliberately gonna infect me" and I was fucking livid to the point where my heart just sank and I was like I feel sick and then he threatened to tell people…he was like "I'm gonna go to the police and I've got your details" (…) you know I was genuinely petrified..."*
>
> Alistair

The accusation of intentional transmission as outlined by Alistair was one described through five of the participants accounts, and like Alistair's was often linked to an accusation of having AIDS as opposed to HIV. The interpretation here was that AIDS represented the ultimate feared state and the accusation of intentional transmission, to use the metaphors commonly associated, was a “weapon” of this ultimate pathologized and stigmatised self (Sontag, 1991). This sense of demonization was one articulated by James:

> *“….. I think sometimes the way I felt….sometimes that I was demonised….mainly by other gay people…that if they found out I was positive they were like “oh my god” it was all of a sudden I was like a vampire or something like I was there like at home with a cauldron you know….on the stove……brewing up batches of HIV thinking “Who am I going to give it to next?””*
>
> James

The descriptors used in James’s excerpt are striking particularly in the use of the horror imagery. It is a strong sense of the self as pathologized in the eyes of others and one that provides a fundamental threat to the safety of others. What is interesting is that in both of these accounts, James and Alistair respond with predominately feelings of anger and fear e.g. “*fucking livid*”. Anger has often been associated with shame experiences (Gilbert, 2003) and is often argued to present itself when shame is unacknowledged (Scheff, 2003). Certainty, through Alistair’s interview it was hard for him to verbalise shame directly and often other emotions such as anger were more present:

> *“…. if I ever see him again* [Sexual partner who accused him of intentional transmission] *(…) I am probably going to lash out at him and would knock ten shades of shit out of him…”*
>
> Alistair

Although not acknowledged directly, one can imagine that these experiences caused a significant sense of shame as indicated by Joe’s sense of “*humiliation*”– a sense of an inferior, exposed self in comparison to others. For Alistair, however the abuse coming from within the gay community is ultimately a consequence of the abuse faced by gay men more generally:

“…. yeah it’s only ever been from within the community because you know us gays we can be cruel because we have had to defend ourselves for so long that we are now defending against our own….”

Alistair

Whilst experiences of rejection were predominately framed from within the gay community in relation to HIV, it is important to acknowledge that experiences of rejection also came from outside. For George and Joe this painfully came from those closest as George describes:

“...I remember her [mother] saying “no son of mine is gay…. “my son is an AIDS cunt” … “you’re a gay prick” just stuff like that and every time she said it she slapped me or punched me so yeah it made me feel worthless….my own mum is like disowning me kind of thing (…)I beat myself up a lot so having someone else do it was horrendous and just calling me all these names…I just didn’t want to be here anymore…I didn’t want to be alive….”

George

This excerpt is extremely powerful, and George’s transcript unsurprisingly was dominated by this violent altercation with his mother and sisters. There are strong connotations of the connection between HIV and gay sexuality, and the echoes of the rejection coming much more painfully from those closest. The power of receiving these types of rejection is clearly marked in George’s suicidal feelings and feelings of worthlessness. Understandably experiencing repeated experiences of rejection from both family, friends, and within the gay community had significant consequences on the men’s mental health and self-esteem. Sadly, for some of the men this resulted in feelings of suicidality. For others, feelings of low self-esteem and worthlessness were also present as Martin describes:

"…. just how worthless you are…. that you are not even a third-class person (…) confidence is a bugger….it takes years and years to build up but it can be pulled from under your feet really quickly….and then to build it up again takes longer than the first time…."

Martin

Consequently, whilst the participants were able to describe both positive experiences of HIV disclosure, overwhelmingly their interviews were dominated by the recollection of painful experiences of rejection which resulted in a heightened sense of self as pathologized, exposed and inferior to others particularly from within the gay community but also from outside. In a similar way to sexuality, this resulted in a collection of shame-based strategies to manage such a denigrated sense of self.

3.5 Negotiating a "Dirty" Self

Mirroring the strategies used to manage the sexual unacceptable self, participants described a number of ways to manage the consequences of an HIV identity which felt both "dirty", exposed and provoked rejection and hostility from others. This included a sense of withdrawing and escaping the gaze of others through social isolation, and use of drugs, alcohol and sex. It also included a sense of concealing the self through perceived more acceptable selves such as pretence of negative and undetectable identities.

3.5.1 Withdrawal and Escape

The similarities between managing shame resulting from sexuality and the shame resulting from HIV were extremely similar and were associated with a strong sense of wanting to "*hide*", "*disappear*" and "*escape*" from the rejecting gaze of others. At the interpersonal level, the tendency to want to socially withdraw has been highlighted in much of the shame research to date (De Hooge et al., 2018; Haidt, 2003; Lewis, 1995). Consequently, participants spoke of withdrawing from social circles and isolating the self from others as Martin, George and Michael explain:

"…. absolutely shamed to the point of not going out…."

Martin

"…. I used to just shy away, and I mean it got really bad last year and I used to stay in and on my annual leave I wouldn't leave the house (…) I would be too nervous and too anxious, so I used to think I would rather not face the world…."

George

"……of course you feel like there is HIV written across your forehead and that they're reading that and there is no way to hide from it… you run….you hide….you runaway….you hide…you smoke some weed and you escape from that….you disappear….you become a recluse…isolate yourself….keep your social contacts to a minimum…"

Michael

The sense of shame arising from the exposure of HIV is clearly articulated by all. There is a sense that the self is so exposed to others that one needs to remove themselves completely however there may also be a protective strategy involved in order to prevent further hostility. In response to the prolonged use of social withdraw strategies, the participants spoke of feelings of isolation and loneliness. Given the discussions above around the stigma lying within as well as outside gay communities then it is perhaps unsurprising that participants acknowledged feelings of isolation. For some of the participants gay peer groups had formed a protective function where they could be themselves yet with HIV this was also under question and as such the men described feelings of alienation and loneliness.

Alongside social withdrawal, nine out of the 10 participants described using either drugs, alcohol and/or sex to manage the difficulties arising from shame such as low self-esteem and low mood. Although Martin did not specify the use of drugs or sex for managing difficulties arising from HIV, he did acknowledge that he "*was a drinker*" but did not associate this with either shame around sexuality or HIV. However, given the difficult experiences he grew with (significant physical violence from peers and others around sexuality) one could imagine alcohol being used to manage such difficult experiences as was described by both George and Alex:

"…. I did drink a lot…. a hell of a lot….to drown it out …. cuz I just felt better when I was drunk as opposed to being sober…. I was hiding it all and it was easier to deal with…"

George

*"**Interviewer:** What does alcohol allow you to do or not do?*
***Alex:** It just makes you stop….it just makes you stop worrying…. it just stops that voice…. this nervousness…this anxiety…. this social anxiety…. what do other people think of me? what do other people want me to do? and it becomes this loop that I get completely stuck in……."*

Alex

The social anxiety that both describe in their interviews alludes to the interpersonal nature of shame (Kaufman, 1989). Whilst George describes alcohol as allowing him to hide from others and escape the difficult feelings he experiences, Alex articulates a sense of alcohol releasing him from the ruminative loop associated with the perception of himself in the eyes of others. For Alex, this sense of wanting to please others was also apparent during the interview itself and he acknowledged that it provided a barrier to therapy where he had sought to please the therapist:

> *“**Alex:** I mean shame…. I’m trying to think cuz I don’t know if that is what you want me to say or not…. I don’t know what* [Name of Psychologist] *told you about me…I’ve started stressing out slightly because I am starting to think about what I think you want me to say rather than what I want to say….*
> ***Interviewer:** I understand….* [Name of Psychologist] *hasn’t told me anything just so you know that……I think you should go with what you want to say, rather than what you think I want to hear….*
> ***Alex:** I have a lot of anxiety about what other people think about me…”*
>
> Alex

Similarly, Michael, Charlie, Joe, Alistair, Richard, and George all used drugs and sex or a combination of the two to manage similar feelings. For Peter, engagement in chemsex initially allowed him to feel connected to his HIV through the emotional regulation effects of drugs and sex. It also allowed him to be surrounded by people who were either positive themselves or disinhibited enough not to care thus negating any difficulty:

> *“…it was through the chems that I started to feel connected to my HIV and the sex and the drugs and everything and then soon after I just, I just thought that this is the way forward so and I was getting even more lost in my life….”*
>
> Peter

As Peter alludes to with “*getting lost*”, whilst seeking release and escape through alcohol, drugs and sex allowed the men moments of relative freedom (similar to conversations around sexuality), it also bought other challenges in the form of further shame around the use of drugs, HCV diagnoses, hospitalisation as a result of alcohol dependency and broken relationships. For some of the participants such as George, James and Alistair, although they used either sex or drugs to manage emotions, each described a sense of wanting to separate themselves from those engaging in chemsex as typified by Alistair:

*“**Alistair:** I would never now meet someone on chems…because I fucking hate them…*
***Interviewer:** Why do you hate them?*
***Alistair:** (…) I know it’s bad but I take inspiration from them and use them as examples of what I don’t want to become (…) like “wow…Alistair you have done well” (…) its scarring our community and you know it’s taking us back to the 80s cuz we are throwing ourselves into these dark corners….”*

Alistair

Alistair’s comparison here with others is interesting. Although he discusses a strong dislike of chems and those who attend them, a large part of his interview was the description of his own attendance at chemsex parties, although he was sober. We could hypothesise that the view of those attending chemsex parties as typifying the worst of the gay community (“*scarring*”, “*taking back to the 80s*”) is a projection and splitting perhaps of the shame that Alistair feels to his own diagnosis and sexual behaviour. This was also seen in James and George’s accounts and perhaps indicates a separating of the self from the ‘bad’ others in order to protect against the painful feelings of shame towards the self. Indeed, this may go some way to explaining the wider rejection of HIV from the gay community, particularly in light of the backdrop of heteronormativity.

3.5.2 Concealing the HIV Self

For Michael, James, George, Joe, Charlie, Richard and Alex managing an exposed self involved either not disclosing a positive status or pretending to have a more acceptable identity – again as seen through experiences of sexuality and the pretence of a “*straight or suppressed*” self. For James and Alex this involved either stating that they were negative with sexual partners or more recently that they were negative on PrEP:

"Oh yeah I stopped telling anybody about my status…and if anyone asked…I was like "Yeah I'm negative" ….I didn't want to deal with it…..but I felt horrendous……I felt like a liar….I felt like a fraud….a phoney…I didn't feel good about myself for doing that to someone cuz I wanted to tell them and if I did kinda get involved with a guy …I ended it after a couple of months because I was like….I'm gonna have to tell him and I don't want to so I just stopped it….."

James

"…. last weekend…there was a guy who very openly [on social apps] said "Positive Undetected" and I thought to myself "good for you for saying that" …. because if anyone asks me I'll say "I'm on PrEP"

Alex

Whilst these strategies allowed them to continue having sex particularly with the development of HAART, and the discovery of gaining an undetectable identity, as James describes, these behaviours also came with feelings of being a "*fraud*" and again a sense of having to conceal and compartmentalise parts of the self. As James goes onto to state this often became a barrier for the men in terms of developing more longer term, intimate, relationships. One can imagine that if the self is seen in such negatives terms (such as those seen above), even despite an outward portrayal of a more acceptable identity, intimate sexual relationships may prove problematic as seen more closely in the Rohleder et al. (2015) paper. Having not disclosed for several months, several of men recalled being rejected once the partner found out – again providing further forums for the exposure and ultimately confirmation of the self as unacceptable.

For all participants except Michael and Martin the obtainment of an undetectable identity (see glossary for further explanation, Appendix A, pg. 126) became a notable marker in their narratives of shame as something to defend the self with. Given the strong perceptions outlined above that those with HIV were a physical and as well as psychological threat to others, becoming undetectable was an important change in the perception that they were no longer physically risky to others and therefore no longer needed to share their status:

"……because I am undetectable, and I really hold on to that as a thing that was a really huge thing for me...if it wasn't for being undetectable I would be a bit more lost at sea…. because that's what I am scared about passing it on…"

Charlie

However as described above whilst this eased more casual encounters, the disclosure of an HIV status was still unavoidable within longer-term relationships and still brought episodes of shame. However, three of the participants were in serodiscordant relationships (see glossary for further explanation, Appendix A, pg. 126) at the time of the interview indicating a sense of hope for change. The recent introduction of PrEP as alluded to by Alex is an interesting recent development, and further work will need to assess its impact on shame more specifically. Consequently, whilst many spoke of their experiences of shame around HIV, their experiences were not all negative and many spoke about how over time, HIV helped them to develop a sense of meaning.

3.6 Moving to a More Meaningful Self

The movement to a more meaningful self was usually a slow process and took several years. Whilst for some of the participants difficulties with shame in relation to sexuality and/or HIV were still very present, many of the participants described feeling more hopeful and developing a sense of meaning through their HIV. This was often the result of support from services including engagement in newly diagnosed groups, and psychological therapy. It was also the consequence of a perceived change in times with increased dialogue and visibly of HIV. Finally, participants also discussed finding purpose by actively challenging stigma and giving back to the community through volunteering and educating others.

3.6.1 Support from Services

All of the participants had received some level of psychosocial support from the HIV clinics they attended. Nine of the participants had received individual psychological therapy and six had completed a newly diagnosed course. Whilst for some this was several years after their diagnosis, for Joe, Charlie and Alex it was a matter of weeks. These courses were felt to be significant in bringing people into contact with others and providing accurate facts about HIV- thus "*arming*" the participants with facts in which to protect the self, and challenge others. For Alistair, Charlie, James and Joe it was a powerful experience being able to sit with others and relate to their stories as Joe describes:

> *"…. I had a simpatico with everybody in that room…we all could relate to each other's experiences and talk about each other's fears and stuff and there was people there who were younger than me…. people there that were older than me…. some that were the same age …."*
>
> Joe

The "*simpatico*" Joe talks about felt important in counteracting the individualised sense of isolation and loneliness that pursued an HIV diagnosis. The group also provided an opportunity for one to be honest and open about what has happened as seen through *"talk about each other's fears"* – which as indicated through the other themes was rare for the participants to be able to acknowledge and express. Joe's comparisons between him and the people attending the group was also significant and was one spoken about by James also:

"…..I remember in my group there was a white, ginger, heterosexual, attractive white male and then there was your middle class, typical girl from Surrey hills….the blonde and like mid 20's and there was a whole different mix of people in the group and I kinda went "oh my gosh….it's not just a bunch of screaming faggots"

James

The comparison made by James of the heterosexual members of the group is noticeable. The fact that there were heterosexual people with HIV appears to normalise HIV in James's eyes (he later describes them as "*normal people*") and moves it away from being a "gay disease" – "*it's not just a bunch of screaming faggots".* James's use of language has been previously discussed yet, despite the differences in language, the presence of a wide range of people within these groups allowed the men to begin to counteract the ties between gay sexuality and HIV.

Another area of support from services that felt helpful in counteracting feelings of shame was the pursuit of psychological therapy although this was not explored fully due to the time constraints of the interview. Whilst many found it helpful in beginning to evaluate the impacts of a diagnosis, there was a sense that it was too short to be able to fully explore the intersectional impacts surrounding shame in regard to both sexuality and HIV as Charlie explains:

"….I mean I started therapy after my diagnosis here and that was great but it was very much about my diagnosis and what I discovered actually was that I was very ok with my diagnosis quite early on but didn't get to the root of a lot of other stuff and so now I am on a psychodynamic course of therapy just to like unpack childhood stuff…."

Charlie

3.6.2 Changing Times

Alongside specific areas of support, all participants recognised a sense of change in how HIV in particular was perceived in comparison to when they were first diagnosed subsequently leading to less feelings of stigma and shame. Many pointed to the impacts of medication in facilitating dialogue (by reducing the risk of transmission to others) but there was also a perception of increased visibility both within the gay community and more generally. For Martin, the overall visibility of HIV clinics was in stark contrast to when he was diagnosed in 1997:

> *"I was in [Name of HIV/Sexual Health Clinic] …. it was just mad….it was like going to a disco…. it's got a neon sign outside…. music…. it's so bloody trendy…… I could see where it was coming from…rather than sitting in a dark room with one copy of the woman's world…. which was from 1966 on the coffee table and everyone sitting in silence….it is way better than that…."*
>
> Martin

> *"…. there has been a lot of change in the last couple of years I've noticed a lot more people are familiar with the undetectable thing… with antiretrovirals….with PrEP….PEP….people seem to be really familiar with it now so there's a lot more serious and open discussion about it (…) there are a lot more campaigns…even on the underground…"*
>
> Joe

Both quotes highlight the move from HIV being seen as something unspeakable and in the shadows to something spoken about and visible to all (even on the "*underground*"). For all participants these developments highlighted something extremely positive and increased feelings of inclusivity. Whilst some still felt that there was a long way to go before HIV was normalised, there was a perception of increasing community and strength as explained by Charlie:

"…. if you start chatting shit about HIV it's me but it's also hundreds of thousands, millions of people today and in the last 30/40 years…..it's the same if you started chatting shit about gay people you are taking on me and the whole of the community (…) if you are going to have some warped vision about HIV then you have misunderstood something far bigger than me…"

Charlie

3.6.3 Finding Purpose

A final theme through eight of the participants accounts was about wanting to give back either through education or through helping others through volunteering, charity work or participating in research and thereby indicating a sense of finding purpose. This was an important marker for participants as it allowed them to engage directly and often publicly with their diagnosis, ultimately increasingly their visibility and thereby indicating a sense of acceptance as described by Michael and Charlie below:

"….I did a lot of volunteering….I was volunteering every day of the week (…) and that opened the flood gates and there I was sat right on the bridge and looking at this sea of opportunity (…) and at that point I accepted myself, it felt good and all of those things helped to diminish the fact that I was a gay man living with HIV.."

Michael

"…I have changed my career and ambitions a little bit and I'm looking more to work in HIV outreach and stuff and that really excites me (…) that feels right at the moment and it feels more honest and I'm doing something that I am being truthful about myself, and in being gay…"

Charlie

As can be seen in both accounts the active pursuit of volunteering and outreach allows a feeling of "*acceptance*" and "*honesty*" which again was felt to be missing in their previous discussions that were more associated with "*concealing*", "*escaping*" and “*hiding*”. The helping of others is perhaps also a way of continuing to heal the self, for example, both reference this honesty and acceptance being associated with both identities of HIV and sexuality, and Michael’s use of the word “*diminish*” creates a sense of aspects of shame remaining – they are “*diminished*” not gone.

For others including Charlie, educating others and challenging stigma was felt to be an important aspect of finding meaning in their diagnosis and in finding renewed purpose in challenging the perceived causes of their shame. For Joe specifically, the role of educator was a significant theme and he mentioned the idea of education or to be educated 28 times through his interview:

“…. I feel like such a duty now to be part of that….to be part of that crowd of people that are educating people…. I feel now that that’s my responsibility to stop the stigma…. you know…and help prevent it….”

Joe

His sense of “*duty*” and “*responsibility*” here highlights a strong sense of obligation to challenge the stigma which he described previously as being one of the more difficult aspects of his diagnosis. It is an active role, which again counteracts the narratives of passivity in “*hiding*” from one’s diagnosis. This sense of visibly and actively challenging stigma alludes to a shift from shame to pride and was one again seen through several accounts such as Alistair’s:

“….in a way it gives you a sense of pride…you know…especially what I have learnt in the patient groups I’ve participated in, the research I’ve done and been a part of…everyone’s virus is unique which gives you that little sense of “I’m one in seven billion here hun…”

Alistair

For Alistair the combination of the support of clinics and in actively participating in research has led to a sense of uniqueness and a sense of pride – these are stark contrasts to his early difficulties when first diagnosed. However, one wonders whether, as previous research has suggested (McDermott et al., 2008; Munt, 2000) these overt expressions of pride also mask residual feelings of shame that were hypothesised to continue to affect the men.

4.0 DISCUSSION

4.1 Overview of Chapter

This chapter will begin by outlining the themes from this study both in relation to the initial research questions and existing literature. Implications of these findings will then be discussed in regard to recommendations for clinical practice and policy, as well as future directions for research. Limitations of the study are then reviewed before the researchers own reflections are finally considered.

4.2 Summary of Key Findings

The purpose of this study was to explore and to understand gay men living with HIV's experiences of shame in relation to both sexuality and HIV status, and its implications for sense of self and relationships with others. The initial research questions set out at the beginning of this study were as follows:

1. What are the experiences of shame among gay men living with HIV?
2. How is shame experienced in relation to both HIV and sexuality?
3. What are the impacts of shame for sense of self, and for relationships with others?

In answering these questions, overall the findings from this study suggest that, despite arguments of increasing acceptance of differing sexual identities (Savin-Williams, 2005) and the perceived 'normalisation' of HIV (Squire, 2013), many gay men still experience shame as a layered emotion in response to living with two highly stigmatised identities. In line with previous research and theory (Kaufman & Raphael, 1996; Rohleder, 2016; Skinta et al., 2014), these layered experiences of shame often resulted in a sense of the self as inferior and had numerous undesirable implications for interpersonal relationships including difficulties with intimacy.

4.2.1 Shame in Relation to Sexuality

For many of the men, experiences of shame in relation to their sexuality were present from an early age. These experiences often manifested as the result of early awareness of an inferior difference against a backdrop of heteronormativity and hegemonic masculinity. Indeed, the pervasiveness of rejection and discriminatory experiences across the home, peer and work environments has been repeatedly acknowledged throughout the literature (Allen & Oleson, 1999; Flowers & Buston, 2001; Goldfried & Goldfried, 2001; Ryan et al., 2010; Skidmore et al., 2006). However more importantly for this study, these experiences of rejection were reported by the men to induce painful moments of self-consciousness, in which the self felt both inferior and exposed to others. Although this was rarely explicitly acknowledged by participants as shame, these descriptions are in line with those previously outlined (Gilbert, 2003; Kaufman, 1989; Lindsay-Hartz, 1984). Similarly, the unspoken nature of shame has also previously been acknowledged by past research (Scheff, 2003) and is discussed in further detail in section 4.3, pg 86 below.

Importantly, this repeated experience of shame had led some of the men to talk about difficult feelings of self-hatred, self-disgust and self-loathing that were in line with conceptions of internalised homophobia (IH) (Malyon, 1982) and theory indicating the potential for repeated experiences of shame to be internalised (Gilbert, 2003; Kaufman & Raphael, 1996; Nathanson, 1992). It is important, however, to emphasise that these experiences of IH were as (Russell & Bohan, 2006, p. 346) argue “grounded not in interior experience but in an intersection between interiority and social and political contexts”. Indeed, in response to this sense of self as fundamentally unacceptable to others, many strategies were used to avoid further hostility and rejection. These strategies often encompassed Goffman (1968)’s ideas of impression management including pervasive self-monitoring and the concealment of one’s sexual identity. In line with Nathanson (1992)’s compass of shame these strategies appeared to increase feelings of shame and had notable impacts upon interpersonal relationships (Lutwak et al., 2003). For example, many spoke of increased feelings of withdrawal, isolation, mistrusting the intention of others and a difficultly with intimacy. As Kaufman and Raphael (1996) have argued this is perhaps unsurprising given that intimate relationships require individuals to expose themselves in some way thus potentially evoking further shame (Lansky, 2005; Skinta et al., 2014). Indeed, the use of sex, drugs and alcohol whilst used to escape difficulties, were interpreted as ways of keeping distance from intimate relationships (Skinta et al., 2014) and again brought with them further levels of shame and difficulty. Consequently, it was clear for many of the participants that shame experiences in regard to sexuality were both past and present difficulties and had significant implications for a sense of self as inferior, and consequently significant implications for relationships with others.

4.2.2 HIV: Echoing Past Shame Experiences

Alongside these difficulties, for all participants gaining a diagnosis of HIV was a "traumatising process" (Cartwright & Cassidy, 2002, p. 150) due to its association as a "dirty" disease and one associated with deviancy and perversion. This sense of "dirtiness" is one that has been discussed numerous times throughout the literature (Fife & Wright, 2000; Rohleder et al., 2015; Sontag, 1991) and is one that the men themselves overwhelming related to gay sexual behaviour. This finding of the closeness or intersection between HIV and a gay sexuality is one that has been highlighted in previous stigma research (Crandall & Coleman, 1992). Yet, the current research also expands upon this by highlighting that shame, alongside stigma, is also simultaneously felt in regard to both identities and thus indicates a layered and intersecting experience of shame (Bennett et al., 2010; Cochran & Mays, 2009; Rohleder, 2016).

Certainly, for the men in the study HIV represented a heightened repeat of feelings of an exposed inferiority in the eyes of others, as well as the self. Many repeated feelings of self-hatred, self-blame and self-disgust and some described it as going back into the closet, undoing the moves towards acceptance they felt they had gained around sexuality. Indeed, some authors have argued that a diagnosis of HIV may perpetuate existing internal conflicts around sexuality due to the intensively constructed relationship between the two (Rohleder, 2016). This experience of heightened negativity towards the self and the heightened image of how others may perceive their diagnosis created significant distress that was clearly still present for some of the participants. Whilst not examined explicitly in relation to shame, research has highlighted significant mental health distress arising from “internalised HIV stigma” (Fife & Wright, 2000; Kalichman et al., 2009). Subsequently, as Flowers et al. (2011, p. 1388) argue whilst “the initial distress around the potential for death has diminished, the psychological and social factors associated with HIV remain”.

Again, like sexuality, the men described pertinent experiences of rejection when disclosing their status to friends and family, however, much of their shame was attributed to the rejection experiences from the wider gay community, particularly actual or potential sexual partners. This finding is one that has been described in the literature already (Rohleder, 2016; Skinta et al., 2014). Previous research has indicated that some HIV negative gay men feel HIV positive gay men threaten gay communities, either in terms of health or general perceptions of gay men (Flowers et al., 2000). Although difficult for the men, it could be argued that the reactions of the wider gay community are directly attributable to the hostile, heteronormative discourse that has so closely linked HIV and AIDS as a “gay disease” (Rohleder, 2016, p. 65). For example, Joffe (1999) utilising a Kleinian psychoanalytical framework discusses how this splitting of gay men into ‘good’ (HIV negative) and ‘bad’ (HIV positive) can function as a defence against the anxiety generated through persistent exposure of one’s sexuality as ‘the bad other’. Interestingly, whilst all the men in the present study discussed being on the receiving end of hostile responses, there were also parts of the interview in which they denigrated other gay men (e.g. those engaging in chemsex). Again, Rohleder (2007, p. 408) building on Joffe (1999)’s work discusses how “the notion of oneself as deviant and bad may be split off and projected onto ‘others’ who come to represent ‘the deviant’”. It also echoes Nathanson (1992) defence script around attacking others to deflect painful self-feelings of shame.

Consequently, given the difficulties associated with living with a layered experience of shame, it was unsurprising that the men repeated the strategies used previously to manage such a powerful sense of the self as inferior in the eyes of the other. Many of the men, for example, described a heightened sense of wanting to “hide” or “disappear” following their diagnosis and initially withdrew from their social circles. At the interpersonal level, the tendency to want to socially withdraw has been highlighted in much of the shame research to-date (Haidt, 2003; Lewis, 1995) and mirrors that of HIV research which similarly highlights that gay men withdraw from their usual social scenes and wider society following an HIV diagnosis (Botnick, 2000; Skinta et al., 2014). Similarly, the use of alcohol, drugs, and sex were returned to in order to regulate difficult emotions and alternative identities such as a negative identity and PrEP were put forward to mitigate hostile responses. Again, whilst in the short-term the use of these strategies bought relief, and were useful in facilitating casual sex, they often caused significant problems in relation to HCV and other STI's as well as longer term relationships where they were accused of betraying others (Pachankis, 2007). Consequently feelings of shame and the methods used to predict and manage exposure of the inferior self can trap men in a vicious cycle in which it was difficult to escape and to which anxiety, depression, low self-esteem and even suicidality can follow.

4.2.3 Moving Forward

Importantly for most of the men, across their narratives there was a shift in their sense of self as inferior although this often came after many years of difficulty. One of the key issues in allowing men to be more open about their HIV status was a perceived change in the wider context in regard to increased visibility of HIV and a sense of developing community. Whilst the men still agreed that there were significant issues around acceptance of HIV, the increased visibly of those with HIV encouraged the men to begin to open up about their own experiences and start to become more active in challenging stigma. Given the emphasis on stigma, there has been a significant amount of focus on stigma-reduction programmes from large government and international agencies (UNAIDS, 2007). However, more importantly for the participants, anti-stigma initiatives have also come from the gay community itself and organisations such as ACT UP have been significant in increasing visibly and initiating dialogue (Shepard & Hayduk, 2002) – thus actively challenging the sense of having to hide.

This shift to a more positive identity was also supported by HIV statutory and non-statutory services including attendance at newly diagnosed courses and individual psychological therapy. Whilst the implications for psychological therapy are discussed further in section 4.3, pg. 86, it was notable that although useful many described the short-term psychological interventions offered by statutory NHS HIV services as being insufficient to target the layered experiences of shame that incorporated both HIV, and sexuality. In relation to newly diagnosed courses, it was notable that the men described the importance of seeing others, particularly heterosexual others, living with HIV. Seeing heterosexual others with HIV allowed the men to counteract the associations that HIV was predominately a “gay disease” (Rohleder, 2016, p. 65) – thus again challenging the narratives the men themselves had been socialised to from society (Sontag, 1991). Indeed, courses also provided a forum for men to be “armed” with the facts of HIV and, like the participants in Smith et al. (2017)’s study, felt this allowed them to actively stand against others in challenging discourses of stigma. Indeed, both engaging in the community and taking on alternative roles such as that of educator and volunteer provided the men with forums of pride in relation to both their HIV and sexuality. Through their narratives there was indeed a sense of a dichotomy between shame and pride which has also been debated within the literature (McDermott et al., 2008). Whilst queer theorists have suggested that the shame/pride binary remains essential for LGBT people’s negotiation of heteronormative societies, they also suggest that arguments of gay pride are intrinsic to a community still dealing with shame (McDermott et al., 2008; Munt, 2000; Probyn, 2000). Specifically, often within pride discourses individuals “still in the closest” are positioned as hiding their sexuality, and therefore struggling with shame, whilst those who are “out” are accepting and prideful. Indeed, in the present study the discrepancy between the content of participant narratives and their behaviour in the room perhaps suggests that defences against shame are harder to maintain than perhaps the men wanted to present – mirroring findings found in McDermott et al. (2008). Consequently, this binary appears to allow for only two positions – out and proud or closeted and shameful (McDermott et al., 2008). In reality, however, and as most of the participant narratives highlight, this binary negates a more nuanced position where shame may still be felt in some forums, whilst also moving to more acceptance in others.

As such, whilst many of the men were able to move towards places of acceptance in relation to both sexuality, and HIV, it was clear from their accounts that shame stemming from society’s attitudes towards both gay men and those living with HIV is still an ongoing fight.

4.3 Implications for Clinical Practice, Research and Policy

4.3.1 Implications for Clinical Practice

4.3.1.1 Shame in the Therapy Room

The experiences of layered and intersecting shame recounted by those in the study have significant implications for the therapeutic relationship. The difficulty for some participants to talk openly about shame, and a desire to please the other (as seen pertinently in Alex’s account) may mean that shame experiences are often overlooked and ultimately neglected within therapeutic encounters, particularly if discourses of pride are put forward (Munt, 2000). This supports research within both psychological and sociological literature of shame as an unspoken emotion (McDermott et al., 2008; Probyn, 2000; Scheff, 2003) and one that is invoked through its discussion (Munt, 2000). Whilst engagement in activities such as chemsex or alcohol may alert the clinician to shame (Pakianathan et al., 2016), it is important for therapists to be cognisant to this unspoken nature and to be proactive in bringing the emotion into the therapy room when working with difficulties relating to sexuality and HIV. One interesting finding that may aid clinicians in saying the unsayable is a finding from McDermott et al. (2013)’s study investigating hard to reach young people engaging in self-harm. They found that when talking online with young people, shame was articulated as opposed to previous face-to-face studies where it was not. For those struggling to acknowledge shame, using methods slightly removed from directness of an interpersonal contact such as writing may help to articulate an emotion that feels unsayable (Pachankis & Goldfried, 2010).

4.3.1.2 Specific Therapeutic Modalities

There is a dearth of literature looking at psychological therapies in relation to HIV specifically (Catalan et al., 2011; Sherr et al., 2011) yet given shame's fundamental interpersonal nature (Gilbert, 2003; Kaufman, 1989; Rohleder, 2016), helpful work may be undertaken by utilising therapies that focus on interpersonal difficulties such as Dynamic Interpersonal Therapy (Lemma et al., 2011) and Cognitive Analytical Therapy [CAT] (Ryle & Kerr, 2003). Whilst neither have been explored specifically in relation to HIV, both offer short-term approaches that would suit the demands of NHS HIV settings. CAT may be particularly useful due to its exploratory rather than symptom-focused approach and its focus on mapping the relationships between difficult early experiences, and the use of damaging strategies to manage emotional regulation and interpersonal difficulties (Ryle & Kerr, 2003). Indeed Sacks et al. (2016) in their paper looking at the use of CAT within sexual health settings highlighted its promise as an intervention to high-risk sexual behaviours including chemsex.

Third wave approaches such as Compassion Focused therapy (CFT) and Acceptance and Commitment Therapy (ACT) may also be useful components of treatment given their more explicit focus on shame and the avoidance of unwanted emotions (Gilbert, 2017; Skinta et al., 2015). Indeed, Yadavaia and Hayes (2012) used an ACT intervention to target self-stigma related to sexuality across 6-10 sessions, and despite a small sample size showed significant improvements in distress related to sexuality. Skinta et al. (2015) also applied a combination of ACT and CFT to address self-stigma related to HIV status in a pilot study of five men and again results indicated improvement in increasing psychological flexibility and reducing difficulties related to HIV-related stigma. However, further research is needed to confirm the effectiveness of these interventions overtime. This is particularly pertinent given that many of the individuals felt that the short-term psychological work offered primarily at diagnosis was insufficient for them in being able to work with the longstanding and intersecting difficulties around sexuality and HIV.

Finally, and most importantly, whilst the recommendations above are provided in line with the provision of overwhelmingly individual therapy within HIV NHS settings

(Harding et al., 2011), one of the key findings within this study was the importance of acknowledging the impacts of living within contexts of pervasive heteronormativity and homophobia and Higa et al. (2013) argue that psychological interventions that do not acknowledge these more macro factors may struggle to create change. The ongoing stigma faced in relation to both identities is one that cannot be challenged from just addressing the intrapsychic, individual world (Cartwright & Cassidy, 2002). Utilising principles from community and liberation psychology approaches may therefore be helpful. Specifically, approaches such as those used by Holland (1991) may offer a way of supporting the community initiatives already long-established in regards to HIV (Shepard & Hayduk, 2002). These community-based initiatives facilitate connection to others and encourage dialogue and action around the structures and systems felt to be creating the backdrop to feelings of shame. Here the relative power of psychologists can support collective resistance in arguing for alternative discourses about sexuality, sex and HIV (Halperin, 2008). These approaches may also be important in relation to shame acting as deterrent to engaging in therapy which could be seen as a forum for exposing the self and therefore avoided (Kaufman & Raphael, 1996).

Narrative therapies may also be useful approaches in recognising the impacts of dominating problem-saturated stories stemming from structural inequality (Brown & Augusta-Scott, 2007). These approaches, instead, position individuals as experts of their experiences whilst externalising problems away from the individual (White & Epston, 1990). These types of intervention are particularly useful in intending to the reality that many gay men living with HIV may also face additional layers of stigma and shame due to further intersections of disadvantage such as ethnicity and class (McDermott, 2011; Veenstra, 2011). However, as with other forms of psychological intervention there is little research or evidence base developed to explore the effectiveness of these approaches (Catalan et al., 2011; Harding et al., 2011; Sherr et al., 2011).

4.3.2 Implications for Research and Policy

4.3.2.1 Implications for Policy and Society

Despite arguments of normalisation (Squire, 2013), the findings in this study clearly highlight ongoing issues relating to both sexuality, and HIV and the intersection between them. This has important considerations in the political climate of the NHS where specialist HIV services are currently under threat (Baylis et al., 2017). Many have argued that recent changes in NHS commissioning structures, have left HIV services fragmented and de-stabilised (Baylis et al., 2017; Kirby & Thornber-Dunwell, 2014). Whilst the threat of losing HIV specialist services may result in a loss of specialist knowledge and expertise, it may also have certain benefits in regard to shame. At the start of the epidemic the wider-socio-political response was to segregate HIV services off away from mainstream hospital services perpetuating a sense of 'the other' (Joffe, 1999; Walsh et al., 2016). The current specialist nature of HIV services could therefore be seen as continuation of this segregation of people living with HIV away from the main society, thus perpetuating feelings of difference, inferiority and disgust (Joffe, 1999). Whilst attendance at other more mainstream physical and mental health services may lead to feelings of increased exposure and visibility, it may also go some way to normalise HIV and issues relating to sexuality across more general health settings. However, it is also likely that GPs and other services would not have the knowledge or understanding to attend to experiences of shame in regards to HIV or sexuality (Madeleine et al., 2011). Consequently, further consultation is needed with both service users and staff of HIV services as to the best service design to meet their needs.

Further, one of the key forums highlighted within the findings was the early impact of school, alongside the home, of fostering a sense of unacceptable difference in the men growing up. Alongside experiences of abuse, harassment, bullying and violence an absence of sex education relating to gay sex and relationships created early feelings of shame, and the self as 'unspeakable'. Although much has been written in the literature arguing for change within schools (Buston & Hart, 2001; Flowers & Buston, 2001), clearly difficulties still remain. As Flowers and Buston (2001, p. 62) argued "the school is an obvious site in which heterosexism and homophobic behaviour can be challenged and where attitudes and behaviour of future generations can be shaped". For example, Russell et al. (2009) and Ryan et al. (2010) have both discussed the importance of visible gay-affirmative resources in schools which are consistently shown to be related to sexual minority health.

Finally, another area in which these findings are pertinent is the media. Recent court cases regarding the criminalisation of HIV transmission and the controversy over the prescribing of PrEP within the NHS have shone a light on how issues relating to sexuality and HIV are negatively portrayed and discussed within the media (Grov et al., 2015). Such negative portrayals and discussions can reinforce ideas of difference and pathology potentially reinforcing feelings of shame highlighted in this study (Persson & Newman, 2008). Although covering such stories is important, the use of language and stereotypes is problematic and thus further work is needed to challenge these portrayals given their impacts on men's wellbeing. Again, this is another forum for psychologists and others to counter-act the perpetuation of heteronormative ideals on more macro-system levels.

4.3.2.2 Future Research

When considering future research, the area of shame in relation to HIV and sexuality has been widely under-researched (Rendina et al., 2018) and thus provides a fertile area for further exploration, particularly in regard to the lack of research looking at interventions around shame (Catalan et al., 2011). Whilst the present study sought out in line with its IPA methodology a small, and comparatively homogenous sample (See Section 2.4, pg. 35), further work would need to be undertaken to assess a wider sample of gay men living with HIV. As previously mentioned differences in regard to shame are likely to be mediated by many aspects of intersecting identity (for example, class, ethnicity, age - (McDermott et al., 2008; McLaughlin, 2006) and thus to understand this complex emotion more fully further research is warranted in these areas.

A further interesting avenue of research is that of PrEP. Given this comparatively new development in the HIV field, further qualitative research is warranted in understanding the impact of PrEP on experiences of shame for those living with HIV and HIV negative individuals (Grov et al., 2015) particularly in light of the findings that PrEP provided an avenue of hiding the self. It maybe that PrEP builds on the undetectable status in reducing perceived threat and thus aiding shame and stigma within the gay community (Flowers et al., 2011; Grov et al., 2015), however further research is needed in this area to establish whether this is the case.

However, like with psychological interventions themselves, future research must similarly avoid the pitfalls of research that is “done to” and “not with” HIV affected communities (Elam & Fenton, 2003). Participatory action research (PAR) may be an option in this respect as it acknowledges the extent to which research can represent the interests of the powerful and service to reinforce dominant positions (Baum et al., 2006). Given the emphasis within the current study of the dominance of heteronormativity within these men’s lives, and the researcher ‘s own position of heterosexuality, future research within the shame must look towards incorporating gay men living with HIV themselves in order to improve overall research validity.

4.4 Study Strengths and Limitations

This study is only one of a handful of studies assessing experiences of shame in relation to HIV, and one of the first to look explicitly at the impacts of shame in regard to both HIV and sexuality. Whilst the small sample size does not permit more generalizable results, it has allowed a nuanced, rich and in-depth exploration of personal participant experiences which are theoretically transferable to others in similar contexts (Rohleder et al., 2015; Smith et al., 2009). As set out in the methodology, Yardley (2000) guidelines for the assessment of quality and validity were followed (see Section 2.9, pg. 42). The adherence to these principles can be seen as a considerable strength of the study.

In regard to limitations, the heterogeneity regarding the time of diagnosis undermined the required homogeneity of the sample demanded of IPA (Smith et al., 2009). Both Martin and Michael were diagnosed in the early/mid 1990’s and whilst HAART was available it was in its infancy and carried significant side effects, many of which were extremely distressing (e.g. weight-loss, lipodystrophy) (Brener et al., 2013). It was also a time when the likelihood of HIV progressing to AIDS was a stark reality (Shiels & Engels, 2017), and both Michael and Martin outlined their distressing experiences of opportunistic infections and hospitalisations as a result of HIV progression to AIDS. Understandably, the increased visibly through side effects, potential of death/grief and loss, and the general moral panic of the time surrounding HIV/AIDS (Labra & Thomas, 2017) provides a different shame context than the rest of the sample, many of whom were diagnosed nine/ten years later. With the importance afforded to HAART and an undetectable HIV status within this study, future studies may wish to separately explore the experiences of those diagnosed more recently to those diagnosed in the earlier stages of the epidemic. It must also be acknowledged that the sample also included gay men in London, a large, and comparatively gay-friendly metropolitan city and consequently shame experiences may differ significantly to those of rural areas (Flowers & Buston, 2001).

A further point of consideration for the study was that all participants except one were either engaged or had recently completed psychotherapy around HIV, HCV, and/or issues relating to sexuality. Consequently, it is acknowledged that this will have affected how participants interpreted their shame experiences and its impacts upon sense of self and relationships. One can imagine that having explored these issues within a therapeutic context had led to the development of healthier management strategies and techniques. However, it is likely that only men who have already made some progress in regard to managing experiences of shame were available to participate in research such as this. There may be many gay men living with HIV for whom shame continues to be very damaging and for whom exposing oneself though either therapy or research may feel impossible (Flowers & Buston, 2001). Indeed, even those that participated within this research sometimes struggled to articulate experiences directly. Methods such as those used by McDermott et al. (2013) may help to gain the views of hard to reach populations of gay men living with HIV.

Finally, a further limitation of the study was that the study did not use participatory methods. Engagement from the men themselves with the findings would have heightened the validity of the study and avoided an enforcement of my own ideas onto the data (Mays & Pope, 2000). This is an important limitation as although the men in the study reported experiences of shame, other areas of concern in their lives may have been more pertinent. One of the important considerations in undertaking this research was an awareness that to focus on shame, alongside HIV may also run the risk of further stigmatising, stereotyping, pathologizing and even sensationalising aspects of gay men's lives (Abdulrahim et al., 2016). Whilst focus upon HIV and aspects of sexual behaviour is crucial in being able to better understand and target areas of need, the prioritisation of this over other health and social concerns may reinforce a sex and diseased focused narrative that, as has been indicated, can ultimately contribute to feelings of shame and stigma. In response to this, the wider stigmatising contexts of heteronormativity and homophobia that give rise to these difficulties have been emphasised and future research must focus on the wider context that gives rise to such feelings and experiences lest we repeat what Kitzinger (1997, p. 213) states: "What political choices are they [psychologists] making in focusing on the problems of the oppressed rather than on the problem of the oppressor?*"*.

4.5 Researcher Reflections

Alongside earlier reflections on my personal context, political position and personal and work experiences more generally (see Section 2.10, pg, 45) several further reflections were felt to be important to include within the context of the findings. Importantly, a difficulty throughout the interviews and analysis were the questions I had over what constituted shame. As a clinician working within HIV, I had the time to build relationships with people and understand the subtle ways in which shame could individually present. Within the context of this research, answers and information had to be gathered quickly and I often questioned whether I had misinterpreted an action of shame, that was perhaps less pathologically related to the novelty of the research setting. More specifically, I was often struck by the way in which some participants would often be overtly positive about their experiences, and I often found myself questioning and reinterpreting these as ways of deflecting shame. Having noticed this through the use of the reflective journal (see Appendix J, pg. 158), I often utilised thesis supervision in order to check through the integrity of my interpretations, particularly around over-interpreting of shame.

Another important reflection was my position as a female, heterosexual, HIV negative researcher. I was initially aware that participants may feel the discrepancy in gender between us would prevent the amount and type of information shared, particularly in relation to sexual intimacy or sexual behaviour. Research by Elam and Fenton (2003) for example suggests that people are more likely to share information with those who are like themselves. However, more importantly I was aware that of my position as a heterosexual researcher investigating a negative emotion, could have affected their willingness to come forward with experiences of heterosexual abuse. For example, I was particularly aware of the focus on within-group stigma and the locating of further pathology towards this group.

In line with the above point, on reflection I have wondered whether a different epistemological approach and methodology would have allowed more scope to recognise the structural implications and relationship between heteronormativity, sexuality, HIV status and shame. Indeed, whilst IPA gave a focus upon personal experience in line with phenomenology, I have wondered whether more a social constructionist position would have allowed the study to draw more attention to the interpersonal and societal functions of shame experienced by gay men living with HIV as argued by Leeming and Boyle (2004). Whilst a phenomenological approach was important in adding to the literature the voices of gay men living with HIV, future studies would benefit from utilising epistemologies and methodologies that allow a more critical examination of participant experience through a lens investigating the impacts of culture and society (Leeming & Boyle, 2013).

4.6 Conclusion

In conclusion, this study used an interpretative phenomenological analysis methodology to explore gay men’s experiences of shame in relation to both sexuality and HIV, and the implications for sense of self and relationships. The main findings suggest that the men in the study experience compounded feelings of shame in relation to both identities predominately as a result of discrimination and prevailing discourses of heteronormativity and homophobia that provide the context to their lives. Indeed, the experiences of receiving a positive HIV diagnosis intersected with the earlier shame experiences described by the men in relation to their sexuality leading to a pervasive sense of self as inferior and “dirty”. Similarly, these feelings of shame were overwhelming set and perpetuated within interpersonal contexts and subsequently many of the men spoke of the difficulties forming intimate relationships, particularly on the gay scene. Consequently, despite the increasing moves towards acceptance of differing sexualities, and the improvements in medical treatments of HIV, gay men living with HIV continue to experience shame and an identity of ‘the other’.

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APPENDIX A

GLOSSARY

GLOSSARY

Terms	Definition
Acquired Immunodeficiency Syndrome (AIDS)	AIDS (Acquired Immune Deficiency Syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that can happen because the immune system has been significantly damaged by the HIV virus. AIDS cannot be transmitted between people, whereas the HIV virus can.
High Active Anti-Retroviral Therapy (HAART)	HIV is treated through the use of antiretroviral medication which work by stopping the HIV virus replicating, thus allowing the immune system time to repair. A combination of several (typically three or four) antiretroviral drugs are used and are known as Highly active anti-retroviral therapy. Several drugs are used because HIV can adapt quickly and become resistant.
CD4 Cells	The HIV virus attacks specific cells of the immune system, known as CD4 or T cells. These cells coordinate the immune system's response to micro-organisms such as viruses.
Human Immunodeficiency Virus (HIV)	HIV is a virus that attacks specific cells of the immune system, known as CD4 cells or T cells thus reducing the body's ability to fight infection and disease. HIV resides permanently within the body following infection and although there is no current cure, the advent of HAART has increased life expectancy, particularly in Western societies.
Lipodystrophy	The redistribution of body fat, often characterised by a distended stomach, a hump at the back of the neck and enlarged breasts, a side effect of some of the early anti-retroviral treatments.

Post-exposure Prophylaxis (PEP)	Post-exposure prophylaxis or PEP is a month-long course of anti-retroviral treatment that an individual can take if they think they have been exposed to HIV. The sooner this is started, the more likely it is to work in preventing HIV. After 72 hours it is unlikely to prevent transmission of HIV.
Pre-Exposure Prophylaxis (PrEP)	Pre-Exposure Prophylaxis or PrEP is a course of anti-retroviral treatment taken by HIV negative individuals before sex to reduce the chance of HIV transmission – in essence blocking HIV if it gets into the body before it has a chance to infect.
Serodisconcordant/Seroconcordant	A serodiscordant relationship is one in which one partner is infected by HIV and the other is not. When both partners have the same HIV status this is called a seroconcordant relationship.
Undetectable Viral Load/Status	When someone has been taking HAART for some time (up to 6 months) they can acquire an undetectable viral load meaning that they cannot transmit HIV. Whilst HIV is still present, its levels are too low to be detected.

APPENDIX B
LITERATURE SEARCH STRATEGIES

Literature Search 1) Shame Literature in Response to Identifying as a Gay Man

In undertaking the following search, the guiding question used was: how has shame in relation to identifying as a gay man been investigated in the literature to date?

Initially the following search terms were used together with the word “shame” using the Boolean operators ‘AND’ and ‘OR’:

- gay
- msm / men-who-have-sex-with-men
- homo-sex*
- homosex*

The term MSM was included due to its use within the literature.

Limiters included:

- Title and Abstract Only
- English Language Only

These search terms and limiters were applied in the following databases:

- PsycINFO
- PsychARTICLES
- Science Direct
- PubMed
- Cinnall Plus
- SCOPUS
- Academic Search
- Google scholar and open source repositories including Research Gate, CORE and Academia were also searched.

A total of 235 articles were initially found. All titles and abstracts were reviewed.
In addition to the limiters applied, all studies were considered regardless of:

Inclusion Criteria:

- Country of Origin
- Date of Publication
- Quantitative or Qualitative Methodology

Due to the limited breadth of literature, studies were also included even if they incorporated a mixed sample (i.e. LGBT).

Exclusion Criteria:

- Poetry, Fiction, Book Reviews, Artistic Literature
- If shame had been brought up but not as a direct focus or variable of investigation
- Book chapters or discussion papers were also excluded due to space constraints of the thesis.

Consequently, the search identified 28 suitable experimental studies reporting on either quantitative or qualitative studies of shame in relation to identifying as a gay or msm man. However, I was unable to gain 11 of the unpublished dissertations, leaving 17 articles discussed within the review.

Literature Search 2) Shame Literature in Response to Identifying as a Gay Man Living with HIV

In undertaking the following search, the guiding question used was: how has shame in relation to identifying as a gay man and living with HIV been investigated in the literature to date?

Initially the following search terms were used together with the word “shame” using the Boolean operators ‘AND’ and ‘OR’:

- gay
- msm / men-who-have-sex-with-men
- homo-sex*
- homosex*
- HIV or AIDS

The term MSM was again included due to its use within the literature.

Limiters included:

- Title and Abstract Only
- English Language Only
- 1980 Onwards (due to this being the year HIV was clinically identified)

These search terms and limiters were applied in the following databases:

- PsycINFO
- PsychARTICLES
- Science Direct
- PubMed
- Cinnall Plus
- SCOPUS

- Academic Search
- Google scholar and open source repositories including Research Gate, CORE and Academia were also searched.

A total of 90 articles were initially found. All titles and abstracts were reviewed. In addition to the limiters applied, all studies were considered regardless of:

Inclusion Criteria:

- Country of Origin
- Date of Publication
- Quantitative or Qualitative Methodology

Due to the limited breadth of literature, studies were also included even if they incorporated a mixed sample (i.e. LGBT).

Exclusion Criteria:

- Poetry, Fiction, Book Reviews, Artistic Literature
- If shame had been brought up but not as a direct focus or variable of investigation
- Book chapters or discussion papers were also excluded due to space constraints of the thesis.

Consequently, the search identified 6 suitable experimental studies reporting on either quantitative or qualitative studies of shame in relation to identifying as a gay or MSM man living with HIV. However, I was unable to gain 1 of the unpublished dissertations, leaving 5 articles discussed within the review.

APPENDIX C
INTERVIEW SCHEDULE

Interview Schedule

Study Title: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships.

**Audio-recorder Turned off

Introduction & Preamble: Thank you for agreeing to participate in this research study. As stated on the information sheet (dated 01.03.17, version 2) this study is looking to understand what it feels like to experience shame both in relation to sexuality and HIV, but to also explore how shame impacts upon the way individuals see themselves and their relationships with others. In doing so, it is hoped that findings from this research will help to shape future psychological interventions targeting shame.

The interview will last approximately 60 minutes and is confidential. As described in the participant information sheet (dated 01.03.17, version 2) the only time I would break your confidentiality would be if I was worried about either yours or someone's safety. If this is the case, I will seek to discuss this with you first.

All your responses will be anonymised (for example, pseudonyms will be used and all identifying features removed) and the audiotape destroyed after transcribing. Only myself and my supervisor will be able to listen to your audio-tape and look at your full transcript however I will be using word-for-word quotes in the thesis write up and any future publication. These quotes will however be completely anonymised.

You are free to leave the interview at any point without giving a reason. If you find a potential question upsetting or too difficult then we can either stop for a break, skip the question or terminate the interview. There are no right or wrong answers to these questions, I am interested in your experience. You can take your time in thinking and talking about your experiences. This interview may feel a bit like a one-sided conversation as I will say very little. I will also make brief notes to things I may want to come back to. Do you have any questions before we begin?

**Audio Recorder Turned On

Interview Questions: Note to Researcher: Questions are used as a general guide. Interviewer should probe issues raised by the participant in the interview. E.g. ask participant to elaborate on things, give examples, etc.

1. **Can you tell me about when you were diagnosed with HIV? When were you diagnosed?**

   Prompts: Do you recall your reaction to the diagnosis? Any thoughts? Any feelings? Any bodily responses? How did you manage hearing this news? Have these feelings/ thoughts changed since?

2. **Have you disclosed your diagnosis to anyone? (e.g. family, friends, colleagues, health professionals)**

Prompts: What has this been like? How did you feel disclosing this? How did the people you disclosed to react? How did their responses affect you e.g. feelings, thoughts about yourself? about them?

3. **How would you have described yourself prior to getting a diagnosis?**

Prompts: How did you feel about yourself? How did you feel about others? How would you have described others with a diagnosis prior to getting a diagnosis yourself?

4. **Some people have described feelings of shame in relation to identifying as a gay man – is this something you have ever experienced?**

Prompts: What thoughts, feelings do you experience in relation to identifying as a gay man? Can you think of any memories where you have felt this? How do you think others around you have responded to you being a gay man?

5. **What does it mean to you to have an HIV diagnosis as a gay man?**

Prompts: Has this changed how you see yourself? If so, in what ways? Any examples? Has it changed how you see others?

6. **Have you ever experienced any judgment or prejudice from others around you as a result of being a gay man with HIV?**

Prompts: Any specific memories or examples of discrimination? How did you feel in response? What impact did this have on your sense of self?

7. **How have you coped/managed with any negative feelings or experiences that have arisen?**

Prompts: Have you ever found yourself using drugs/alcohol/sex to manage these feelings/experiences? Would you describe engaging in risky sex since your diagnosis? What does that term mean to you? Have you ever had therapy to manage these issues?

8. **What support, if any, do you think is lacking, and may be useful to have more of?**

Prompts: Would you like the opportunity of more psychological support? Would you prefer individual or group support? Would peer mentorship be something of interest to you?

9. **Do you think any positive change has occurred because of your diagnosis?**

10. **Do you have any final points that you think we haven’t covered or anything you wish to add?**

Thank you for taking the time to participate in this research and share your experiences.

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APPENDIX D
PARTICIPANT SOCIO-DEMOGRAPHICS DATA SHEET

TRUST LOGO HERE

Demographics Questionnaire

Title of Project: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships

The following questions will help us to know more about the people we have interviewed and make sure that we have talked to people with different experiences. This information will be kept confidential and individual answers will not be disclosed to anyone else. Your answers will not be linked to you name. If you have any questions around the completion of this form, do not hesitate to speak with the researcher.

1. What is your age? ………………………………………….years

2. How would you describe your ethnicity? ………………………………………….

3. Where were you born? ………………………………………….

4. When were you diagnosed with HIV? ………………………………………….

5. Are you receiving HIV medication? ☐ Yes ☐ No

6. What is your relationship status? ………………………………………..

7. If yes to Q6, How long have you been in this relationship? ………………………………………..

8. Is there anything else you would like to tell the researcher? …………………………………….............

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APPENDIX E
STUDY PROTOCOL

Study Protocol

Study Title: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships.

Abstract

For many researchers, the focus of their work exploring the negative consequences of identifying as a gay man living with HIV has centred around stigma. Yet, over the past few years many have questioned whether the broad definition of stigma alone is able to explain the negative implications of identifying both as a sexual minority and as someone living with HIV. More recently, some authors have begun to question whether the emotion of shame is of more central concern. Therefore, the proposed study seeks to explore, using semi-structured interviews and Interpretative Phenomenological Analysis, the concept of shame in the lives of gay men living with HIV, giving specific attention to the implications for sense of self and relationships with others.

Background:

For many researchers, the focus of their work exploring the negative consequences of identifying as a gay man living with HIV has centred around stigma. Yet, many have questioned whether the broad definition of stigma alone is able to explain the negative consequences of identifying both as a sexual minority and someone living with HIV. More recently, some authors have begun to question whether the emotion of shame is of more central concern (Bennett et al., 2016; Hatzenbuehler et al., 2009). Shame has been defined through a multitude of different theoretical perspectives however many converge on the conceptualisation of shame as a painful, self-conscious emotion related to the imagined or real deficiencies of the self (Bybee et al., 2009; Gilbert, 1997; Kaufman, 2004; Lewis, 1971). Although often subsumed within definitions of stigma, shame can be argued as a related but distinct construct that has its own specific implications for an individual's mental wellbeing and behaviour (Covert et al., 2003; Johnson & Yarhouse, 2013). For example, experiencing elevated feelings of shame has been linked with increased feelings of depression, anxiety and suicide (Tangney & Dearing, 2002).

In relation to distress associated with both sexuality and HIV, many have begun to argue a case for shame believing it to be a consequence of gay men internalizing the messages from society that being gay, and being HIV positive are not acceptable (Bennett et al., 2016; Hallman, 2009; Johnson & Yarhouse, 2013; Kaufman & Raphael, 1996). However, there remains little research looking at whether gay men living with HIV themselves would affirm the focus on shame, and even less known about how they understand and experience this emotion in relation to both their sexuality and

HIV. The focus on shame within this specific population is of interest due to findings highlighting a role for shame in those engaging in risky sexual behaviour (Tangney, 1995), increased use of illicit substances (Malow et al., 2001) and poor mediation adherence in those living with HIV (Konkle-Parker et al., 2008). This is particularly pertinent given the current concerns raised around the use of illicit substances in the context of risky sex by gay and bisexual men, so called ‘ChemSex’, and its public health consequences in relation to HIV and other sexually transmitted infections (Bourne et al., 2015; McCall et al., 2015; Stuart et al., 2015). Research attempting to understand underlying mechanisms is also significant when considering the findings that gay men diagnosed with HIV show an elevated risk for suicide and deliberate self-harm (King et al., 2008; Meyer, 2003).

The proposed study therefore seeks to fill this gap by exploring the shame experiences of gay men, and how they understand and experience it in relation to both sexuality and HIV. The focus on gay men is due in part to the high rates of HIV amongst this particular population in the UK (Yin et al., 2014) but also the historical focus of HIV being labelled a ‘gay disease’ (Rohleder, 2016, p. 65). Further still, this study would like to build on findings within the shame literature of its impacts on both sense of self and relationships (Kaufman, 2004; Lewis, 1971). As such, the study will be recruiting gay men living with HIV, aged over 18, and seeking treatment through NHS HIV and sexual health providers. The choice of recruiting through an NHS provider allows greater access to those who are more recently diagnosed, engaging in continued risky sexual behaviour and those receiving anti-retroviral medication – all of which have been linked to shame (Konkle-Parker et al., 2008; Malow et al., 2001; Tangney & Dearing, 2002; Tangney, 1995). Finally, seeking a sample of gay men living with HIV over the age of 18 reflects the demographic profile of those attending HIV and sexual services in the UK (Ogaz et al., 2016). Similarly, seeking those who have been diagnosed for at least one year allows us to recruit individuals who have had time to digest the impact of the diagnosis and adjust to the immediate emotions surrounding being newly diagnosed (Nightingale et al., 2010). Once finished this study will form part of the completion criteria for the Professional Doctorate in Clinical Psychology and as such a detailed research proposal has already been reviewed and passed by the educational institution (University of East London) who will award the overall degree.

Study Research Questions:

1. What are the experiences of shame among gay men living with HIV?
2. How is shame experienced in relation to HIV and sexuality?
3. What are the impacts of shame for sense of self, and for relationships with others?

Methods:

Study Design: Qualitative

Study Population: Gay men living with HIV

Inclusion Criteria:

To be eligible for inclusion in this study, participants must be:

1. Identify as a gay man, aged 18 or over
2. Have a sufficient level of English in which to complete an hour long qualitative interview
3. Have a positive diagnosis of HIV and be receiving treatment and/or support from [Name of Trust] or [Name of Trust]
4. Have been diagnosed with HIV for at least one year.

Exclusion Criteria:

People will be excluded from the study if they:

1. Are not currently receiving treatment and/or support from [Name of Trust [Name of Trust] or [Name of Trust]
2.Are considered by their health provider or the researcher to be too unwell or distressed to participate in the study
3.Are unable to give informed consent to participate in the study

Identification of Study Population:

NHS professionals in [Name of Trust] and [Name of Trust] will be asked to identify and seek participation from service users attending HIV and sexual health services who meet the inclusion criteria. The researcher will regularly attend staff team meetings to describe the study and ask staff to identity any potentially eligible service users on their caseloads. Study adverts will be placed in Trust waiting rooms, on electronic noticeboards and toilet facilities so that potential participants can self-refer to the study.

Recruitment:

Service users will be recruited to the study via referral from health providers or self-referral from study adverts. Eligible service users may be approached for participation by their health providers who will judge the potential risks of participation for service users and, if deemed safe, will describe the study aims and procedures, nature of informed consent and any queries/concerns service users may have regarding their participation in the study. Service users interested in participating in the study will be asked to provide contact details (i.e. email address) so that the researcher can contact them to arrange the interview. Service users may also make a self-referral to the study via email from the study advertisements.

Remuneration:

All participants will be given a £10 love2shop voucher to thank them for their time. Due to financial constraints, travel expenses will not be reimbursed.

Sample Size:

Following Smith et al. (2009)'s recommendations, this study will seek to recruit a sample of ten gay men living with HIV. The sample size chosen will enable the researcher to disentangle themes that are individual from those which are shared.

Data Collection:

1. Socio-Demographic factors (including age, country of origin, time since HIV diagnosis, relationship status, receipt of anti-retroviral medication)
2. Qualitative Interview (approximately 60 minutes for each interview)

Qualitative Interview Procedure:

Research interviews will be conducted in a private room within the Trust, or at the University of East London during working hours (9am -5pm). The researcher will ensure that the location(s) where an interview takes place are secure and cannot be overheard. The interview will be conducted by the researcher who will be supervised by Dr. Poul Rohleder (Academic Tutor and Clinical Psychologist). The researcher has considerable clinical experience working with this population, and is experienced in conducting qualitative interviews. Consent will be sought from participants to audio-record responses to the qualitative interview.

Smith and Osborn (2003) describe semi-structured interviews as the exemplary method for IPA arguing that it facilitates greater rapport and empathy but also frees the researcher to explore important, but unexpected, topics. Facilitating a participant's ability to tell their story in their own words is a central premise of IPA and therefore while an interview schedule will be used it will merely act as a guide to facilitate a more natural conversation (Pietkiewicz & Smith, 2012). Questions will focus on the meanings participants ascribe to identifying as gay men, receiving HIV diagnoses, as well as any specific shame memories and feelings in response to these events. Questions will also look to the impact of shame surrounding HIV and sexuality and the impact this has had on their sense of self and also relationships.

Analysis:

Qualitative responses will be analysed following the detailed guidance set out in Smith et al. (2009). This involves close, iterative readings of each of the transcripts, treating them as discrete individual cases before pursuing shared across case interpretations (Larkin & Thompson, 2012). To ensure quality, Yardley (2000)'s four principles; sensitivity to context, commitment and rigour, transparency and coherence and impact and importance will be considered throughout.

Ethics:

Informed Consent:

The process of obtaining informed consent with adult service users with a diagnosis of HIV. The study researcher has undertaken Good Clinical Practice (GCP) training on obtaining informed consent in the conduct of research, supplemented by training on obtaining informed consent in the conduct of research with vulnerable populations. During the recruitment stage, potential study participants will be offered clear information, both verbally and in writing (i.e. Participant Information Sheet) about the purpose, subject and nature of the study and what would be required of them if they consented to participate. It will also be explained to them that they are free to withdraw their consent up to a month after the interview. This date was chosen as it allows for the minimum amount of time for the author to complete their analysis and overall completion of the study. Potential participants will be given a minimum of 48 hours to consider their participation in the study before consent is sought. During the formal consent process, each participant will be informed that their responses will be anonymous and confidential. For example, pseudonyms will be used and all identifying features removed from transcripts. It will also be made clear to participants that the researcher will not access clinical files and that minimal demographic information will be collected. Audio-files will only be available to the researcher and academic supervisor, and full written transcripts to the researcher, academic supervisor and thesis examiners. Audio-files will be disposed of once the viva voce has been completed by the researcher. Consent forms will be kept in a locked filling cabinet at the University of East London and stored separately from transcripts kept on a password protected computer. Each individual file will also be password-protected.

Confidentiality:

In some situations, it may be necessary to disclose personal information without an individual's consent if it is in the public interest. The British Psychological Society guidance on confidentiality will be followed (British Psychological Society, 2009). Disclosure of personal information without consent may be justified in the public interest where failure to do so may expose the participant or others to risk of death or serious harm. In cases where the participant or others are exposed to a risk so serious that it outweighs the participant's privacy interest, consent to disclosure will be sought. If it is not practical to seek consent the information will be disclosed to an appropriate person or authority. All participants will be made aware of the limits of confidentiality during the consenting process. Given the link between illicit drug use, risky sexual behaviour, shame and HIV, there may be a chance that disclosures of illicit behaviour are made during the interviews. During the recruitment stage and throughout the interviews, study participants will be made explicitly aware of the nature and limits of confidentiality. However, it must also be noted that whilst questions may focus on the possible use of illicit substances or sexual risk in terms of coping more broadly with feelings of shame, details and explicit questions will not be asked about illegal activity (for example, drug dealing). The researcher will contact their academic supervisor (Dr. Poul Rohelder, Academic Tutor and Clinical Psychologist) to discuss any situations when confidentiality may need to be broken. A senior clinical psychologist within one of the NHS trusts whom specialises in HIV and sexual health has also agreed to be a point of contact for any clinical risk matters arising.

Risks, Burdens and Benefits:

Discussing issues around shame, as well as aspects of HIV and sexual behaviour can be distressing for some participants (Grace et al., 2016). During the interview, the researcher will be cognisant for signs of distress, and if observed will take appropriate action including asking the participant if they would like a break, skipping questions that cause distress or terminating the interview. All participants will be debriefed at the end of the interview and given information about local and national support organisations. The researcher will ensure that the location(s) where an interview takes place are private and secure, and cannot be overheard. Interviews will be conducted either in a secure room at the NHS Trust or if non-available at a secure room at the University of East London. All interviews will be conducted between the working hours of 9am and 5pm to facilitate researcher safety. The researcher will have access to a mobile phone at all times during interviews and will give details of interview locations, start times and approximate end times to their supervisor (Dr. Poul Rohelder, Academic Tutor and Clinical Psychologist) at their academic institution.

Supervision:

Supervision will be provided from a UEL academic supervisor with experience in the field, Dr. Poul Rohleder. An onsite senior clinical psychologist will also act as a liaison, [Name of Psychologist] (CNWL).

Resources:

The study will require an audio-recorder, transcribing technology and a computer with password protection facilities. A locked filing cabinet at UEL will also be required. No resources will be required from the NHS, aside from rooms in which to conduct the interview. However, if rooms are not available, then interviews will be conducted at the University of East London.

Dissemination:

The study will be written as a doctoral thesis in the first instance, however subsequent publications will be pursued in peer-reviewed psychological journals.

Timetable:

April 2017	**Submit NHS application and register with local R&D.**
May – October 2017	**Data Collection**
November – May 2018	**Data Analysis and Write Up of Thesis**
May 2018	**Submit Thesis**
June/July 2018	**Viva Voce**
July – August 2018	**Dissemination and Publication**

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APPENDIX F
PARTICIPANT INFORMATION SHEET

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Information Sheet

My name is Stacey Hemmings and I am a Trainee Clinical Psychologist studying at the University of East London. I would like to invite you to take part in a research study which aims to investigate experiences of shame in gay men who are living with Human Immunodeficiency Virus (HIV) and how this has impacted the way they see themselves (their sense of self) and their relationship with others. The study is part of my Professional Doctorate in Clinical Psychology. Before you decide whether to take part, you need to understand why the research is being done and what it will involve. The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this research study. Please take time to read the following information carefully and discuss it with others if you wish. If you require any further information or have any unanswered questions after reading, please do not hesitate to ask or contact me using the details at the end of this letter.

Project Title: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships

What is the purpose of the study? We know that shame is a feeling we all experience at some point during our lives yet research has shown that some gay men and those living with HIV report feeling more intense and persistent feelings of shame. Experiencing such a distressing emotion more intensely and for longer can have a substantial impact on the way some individuals view themselves and also their relationships with others. Therefore, this study aims to understand what it feels like for an individual to experience shame both in relation to sexuality and HIV, but to also explore how this impacts upon the way they see themselves and their relationships. In doing so, it is hoped that findings from this research will help to shape future psychological interventions targeting shame.

Do I have to take part? No. It is up entirely up to you whether you decide to take part or not and you should not feel forced or pushed into participating if you do not want to. If you decide to take part you are still free to leave the study at any time and without giving a reason. Furthermore, if you choose to leave this would not affect the care you receive either now or at any time in the future.

What will happen if I do take part? I will ask you to participate in an individual interview that lasts approximately 60 minutes. The interview will take place either at the HIV clinic where you are receiving treatment or at a room at the University of East London. At the start of the interview I will ask you to sign a consent form to show you have agreed to take part. Questions asked during the interview will focus on how you have experienced shame both in relation to your sexuality but also HIV and what impacts this has had on how you see yourself and your relationships with others. With your permission, I will also audio-tape the interview, so that I can transcribe the interview at a later stage. Should you withdraw up to a month after the interview; the researcher reserves the right to use your anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher. As a thank you for taking part in the research, you will be given a £10 Love2Shop voucher.

What are the advantages of taking part? I cannot promise that the study will help you directly but your information will help to increase our understanding of shame and may help to develop further types of psychological support to those experiencing high levels of shame.

What are the disadvantages of taking part? Recalling your experiences and memories of shame may bring up some distressing thoughts and feelings for you both during and after the interview. During the interview, you can take your time answering, have a break or choose not to answer questions that cause you significant distress. You can also choose to end the interview. You will also be provided with sources of support during the study and have the option of discussing matters further with a clinical psychologist who specialises in this area should you wish to.

What if there is a problem? If you have any concerns or questions about the study, please contact the study's supervisor - Dr. Poul Rohleder, School of Psychology, University of East London, Water Lane, London, E15 4LZ (Telephone: 02082236674. Email: p.a.rohleder@uel.ac.uk). Alternatively, you can contact the chair of the school of psychology research ethics sub-committee: Dr. Mary Spiller, School of Psychology, University of East London, Water Lane, London E15 4LZ (Tel:02082234004 . Email: m.j.spiller@uel.ac.uk).

Will my information be confidential? The information you provide will be confidential and will only be shared with my supervisor, thesis examiners and I. The only exception to this is if you tell me information which suggests serious harm to either yourself or others. I will seek your permission to speak with your care team if this happens but may be required to break confidentiality without your consent if such an issue were to arise. Your personal details will be kept separately from your audio recording and your audio file assigned an identification number, so that your responses cannot be linked to you. Audio-tapes will be transcribed shortly after the interview and then destroyed after the work has been signed off by the University of East London. All identifying information will be removed during transcription. Each individual transcript will be password-protected and stored on a password-protected computer which only the researcher will have access to. Hard copies of any information collected will be stored in a locked filing cabinet. Data collected for the study may be looked at by the examiners of the thesis to check the study is being carried out correctly; all will have a duty of confidentiality to you as a research participant.

What will happen with the results of the study? The results of this study will be written up as a doctoral thesis and an article submitted to a psychological academic journal. All information you will provide will remain anonymous. Anonymised direct quotations from your interview may be used in the thesis write up and in publication. For example, pseudonyms will be used and all identifying features removed. Copies of all publications will be available from the researcher upon request. All data belonging to the study will be destroyed after 3 years.

Who has reviewed this study? All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by Camberwell St Giles Research Ethics Committee REF: 17/LO/0785.

Resources: If you are experiencing distress and would like to talk to someone about what help is available, speaking with your GP or HIV consultant is a good place to start. Also charities such as the Terence Higgins Trust (www.tht.org.uk / 0808 802 1221); London Friend (www.londonfriend.org.uk / 020 7833 1674) and Positively UK ((http://positivelyuk.org/ / 020 7713 0444) offer a variety of online and telephone counselling and information services for those struggling with issues around sex, sexuality and HIV.

Thank you for taking the time to read this information sheet and please feel free to ask me any questions. If you are happy to continue, you will be asked to sign a consent sheet prior to your participation. Please retain this information sheet for your reference.

Stacey Hemmings (Trainee Clinical Psychologist) University of East London, Water
Lane, London, E15 4LZ. Email: u1525463@uel.ac.uk

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APPENDIX G
PARTICIPANT CONSENT FORM

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Consent Form

Title of Project: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships

Please initial box

1. I have read and understood the Participant Information Sheet (dated 01.03.17, version 2) for the above study and have been given a copy to keep. I have had the opportunity to think about the information, ask questions, and have had my questions answered. I understand what is being proposed and the procedures in which I will be involved have been explained to me. ☐
2. I understand that taking part in the study is voluntary and that I can leave at any time, without giving any reason, without my medical care or my legal rights being affected. ☐
3. I also understand that should I withdraw a month after the interview; the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher ☐
4. I understand that my involvement in this study, and data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed. ☐
5. I understand that the interview will be audio-taped and that this audio recording will be destroyed after the work has been signed off by the University of East London. ☐
6. I agree to anonymised direct quotations from my interview being used in the write up of the thesis and in subsequent publications. ☐
7. I fully and freely consent to participate in the study. ☐

Name of Participant: Date: Signature:

Name of Person taking consent: Date: Signature:

When completed: one copy for participants, one copy for researcher site file.

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APPENDIX H
PARTICIPANT VOUCHER ACKNOWLEDGEMENT FORM

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Title of Project: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships

I have received a £10 Love to Shop Voucher for my participation in the above study

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

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APPENDIX I
PARTICIPANT DEBRIEFING SHEET

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Debriefing Sheet

Study Title: Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships

Thank you so much for taking the time to participate in the above study. The purpose of the study was to investigate shame experiences in gay men living with HIV, and its impact on sense of self and relationships with others. It is hoped that by further exploring shame and its relevance, we can begin to raise the importance of addressing shame experiences with healthcare professionals and develop psychological interventions targeting it.

If you have any questions relating to the study, please do not hesitate to contact the researcher [Stacey Hemmings, u1525463@uel.ac.uk] or the Study Supervisor [Dr. Poul Rohleder, p.a.rohleder@uel.ac.uk, 02082236674]. Alternatively, you can contact the chair of the school of psychology research ethics sub-committee: Dr.Mary Spiller, School of Psychology, University of East London, Water Lane, London E15 4LZ [Tel: 02082234004. Email: m.j.spiller@uel.ac.uk].

Talking about shame can understandably leave us feeling a sense of distress or discomfort. If you are experiencing distress and would like to talk to someone about what help is available there are a number of available options:

1. Your General Practitioner (GP) or HIV Care Team
2. Terence Higgins Trust (www.tht.org.uk / 0808 802 1221)
3. London Friend (www.londonfriend.org.uk / 020 7833 1674)
4. Positively UK (http://positivelyuk.org/ /020 7713 0444)

All of the above charities offer a range of online and telephone counselling and information services for those struggling with issues around sex, sexuality and HIV.

If you would like to receive a summary of the results once the study is completed, please email the researcher [U1525463@uel.ac.uk]. In the email, simply write 'Request summary of results' in the subject bar. It is not necessary to add any further information.

Thank you again for your time, it is greatly appreciated.

V2 01 03 2017

APPENDIX J
REFLECTIVE JOURNAL ENTRY

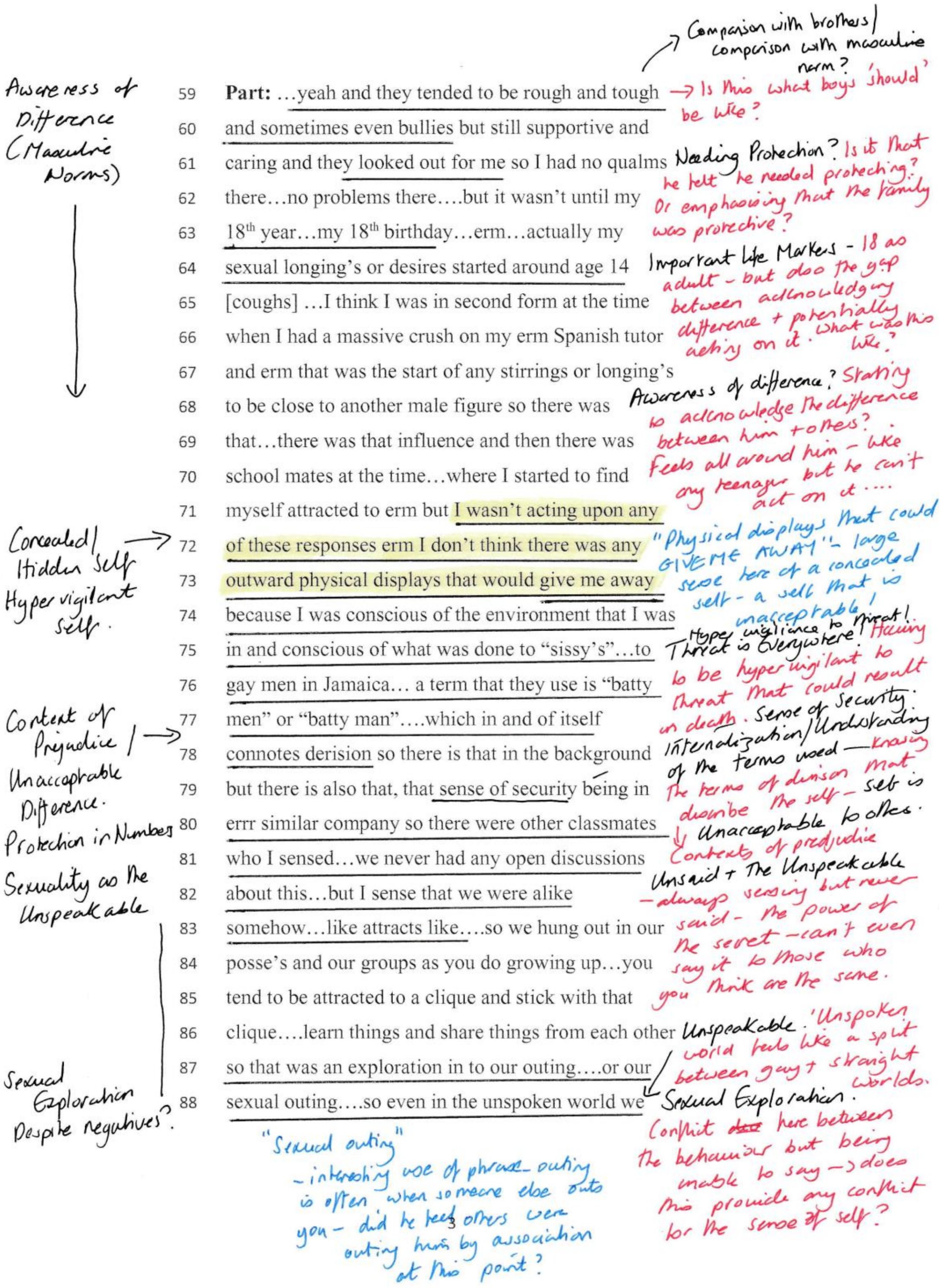
Reflections - Post Interview 5

- Interesting interview - participant often denied shame in relation to sexuality - yet in the room I felt like he was displaying quite strong body language that would fit with shame - ie. no eye contact, he sat drawing a repetitive pattern on a piece of paper as he spoke - still able to build relationship with him but felt like he was hiding something / trying to keep me from probing certain parts - maybe too difficult for him.
  - Is the above really shame or was it just nervousness about being in a strange context with an interviewer asking very personal questions.
- Was it that I (or he) presumed that I was a heterosexual, straight interviewer asking questions about how he felt identifying as gay - Am I interpreting his denial of difficulty around sexuality because of the repeated messages that I am exposed to - putting gay men into the sick, pathologised role? Why was it so difficult for me to accept his denial of difficulty around sexuality - mainly behaviours in the room but then early experiences of difficulty - see therapists from young age; early sexual explorations (13yrs) - children do explore sexually but this felt like he was engaging in more substantial behaviours.
  - Lots of humour used - defence against shame? Talk to PR about this.
  - Interpersonal nature of shame - research interview itself is an interpersonal context - hard to expose oneself / be exposed by questions
- Hard to describe how I felt - frustrated in some ways that I am either not asking the right questions or the nature of shame means that it isn't obvious. Also hard to see / hear people displaying such behaviours and not be able to respond clinically. Feeling a significant push to ask people about behaviour but would that be too exposing / too clinical?
- Quite young age - also my age - maybe hard to expose oneself to someone who might think is a relative peer? Age certainly important factor for him - perhaps feelings of judgement coming from me in

APPENDIX K
EXAMPLE OF CODED TRANSCRIPT EXCERPT

Example of Coded Transcript Excerpt.

Of note - red writing indicates conceptual comments, black writing indicates descriptive comments and blue writing indicates linguistic comments



Awareness of Difference (Masculine Norms)

Concealed/ Hidden Self Hypervigilant Self.

Content of Prejudice / Unacceptable Difference.

Protection in Numbers

Sexuality as the Unspeakable

Sexual Exploration Despite negatives?

Part: …yeah and they tended to be rough and tough and sometimes even bullies but still supportive and caring and they looked out for me so I had no qualms there…no problems there….but it wasn't until my 18th year…my 18th birthday…erm…actually my sexual longing's or desires started around age 14 [coughs] …I think I was in second form at the time when I had a massive crush on my erm Spanish tutor and erm that was the start of any stirrings or longing's to be close to another male figure so there was that…there was that influence and then there was school mates at the time…where I started to find myself attracted to erm but I wasn't acting upon any of these responses erm I don't think there was any outward physical displays that would give me away because I was conscious of the environment that I was in and conscious of what was done to "sissy's"…to gay men in Jamaica… a term that they use is "batty men" or "batty man"….which in and of itself connotes derision so there is that in the background but there is also that, that sense of security being in errr similar company so there were other classmates who I sensed…we never had any open discussions about this…but I sense that we were alike somehow…like attracts like….so we hung out in our posse's and our groups as you do growing up…you tend to be attracted to a clique and stick with that clique….learn things and share things from each other so that was an exploration in to our outing….or our sexual outing….so even in the unspoken world we

Comparison with brothers/ comparison with masculine norm?

→ Is this what boys 'should' be like?

Needing Protection? Is it that he felt he needed protecting? Or emphasising that the family was protective?

Important Life Markers - 18 as adult - but also the gap between acknowledging difference + potentially acting on it. What was this like?

Awareness of difference? Starting to acknowledge the difference between him + others? - like feels all around him - like any teenager but he can't act on it….

"Physical displays that could GIVE ME AWAY" - large sense here of a concealed self - a self that is unacceptable!

Hypervigilance to threat! Threat is Everywhere! Having to be hypervigilant to threat that could result in death. Sense of Security.

Internalization/Understanding of the terms used — knowing the terms of derision that describe the self - self is ↓ Unacceptable to others.

Contexts of prejudice

Unsaid + The Unspeakable - always sensing but never said - the power of the secret - can't even say it to those who you think are the same.

Unspeakable. 'Unspoken world feels like a split between gay + straight worlds.

Sexual Exploration.

Conflict ~~due~~ here between the behaviour but being unable to say -> does this provide any conflict for the sense of self?

"Sexual outing" - interesting use of phrase - outing is often when someone else outs you - did he feel others were outing him by association at this point?

knew we were one of a kind and that we belonged so errrrmmmm [short pause]…schooling was a massive part of that and the influences from that and the activities that we chose to engage in…. also another particular influence that helped to support our coming out erm or blossoming into what could have been erm a very arid dessert with very little resource or support to enable a full coming out as it were so everything was under covers…it was dark weeee….errr…I guess met and mingled and partied in ermmm in the shadows…in the dark…in secluded places…not unlike many other societies…but particularly with a background knowing that erm we have to be extra careful because erm if caught what the consequences could be…potentially…and death is one of the consequences…disinheritance being disowned by family members…erm being erm humiliated.. totally publicly errr there was no hold back about actually laying full on errr the repercussions of, of our sin in a so-called Christian society and err what the impact was gonna be on judgment day…so growing up with that background...I grew up in a Christian family…my dad was Roman Catholic and we were brought up in the church and we attended every Sunday so errmm so it was drummed into us…but strangely enough one of my first encounters of a sexual nature that was indirect was in my church and it was from a local parish priest and I was a youngster at the time…I must have been about 13, 14 and errrmm I sensed what was happening…it didn't get

Unspoken Belonging

In the Shadows/ Hiding Self.

Hiding the Self/ Consequences of being out.

Unacceptable Difference./ Gay Sexuality as Immoral

Unspoken Belonging - what was it that he felt was similar? What kind? Again a sense of splitting here - them + us.
- Outed by association through activities?

"Use of natural metaphors here - sense of the context drying up his sexuality - being unable to explore/ blossom. Contradiction here though.

Not Fully Out - again pervasive sense of concealing the self.

The dark/The Shadows - powerful images of being pushed into the darkness/ Going into the darkness to avoid exposure - connotations of secrecy, hiding. Exhilarating though maybe?

- Do the 'erms' etc indicate not wanting to tell me - exposure to the interviewer.

Consequences of being out/ Unacceptable/ sense of tremendous anxiety and risk - how can we develop a sexual identity in a context like this?

Humiliation of Others. - stigma/shame so powerful that others are contaminated by association. Humiliation → exposure.

Awareness of Difference - the difference of the context + his but also that this is ↓ Unacceptable difference

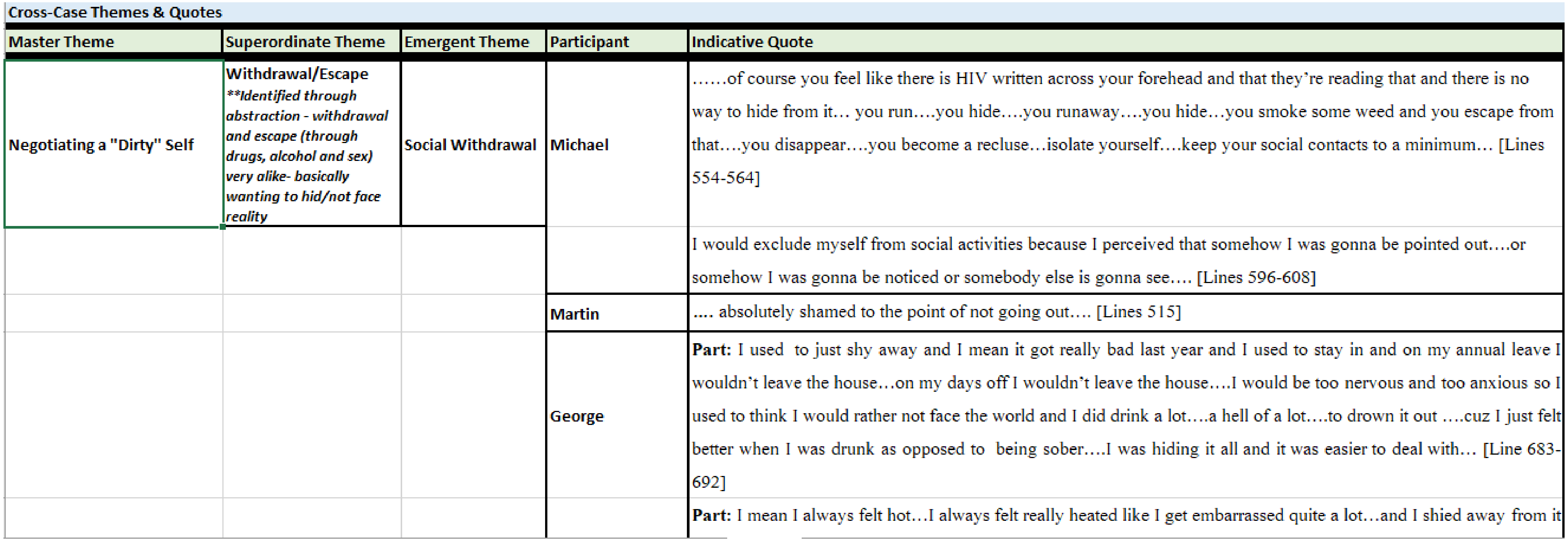
Religious Sin/Immorality of Sexuality - conflict here - family religious, drummed into him - messages all around him - almost like he is being drummed by the frequency.
- Overlap with early sexual formative experiences.
- Negative connotations of sin.

↓ 'sensed' - nothing is ever said/acted.

↓ Hypocrisy - again unspeakable.

APPENDIX L

EXAMPLE OF AUDIT TRAIL FOR GROUP CROSS-CASE ANALYSIS



Cross-Case Themes & Quotes

Master Theme	Superordinate Theme	Emergent Theme	Participant	Indicative Quote
Negotiating a "Dirty" Self	**Withdrawal/Escape** *****Identified through abstraction - withdrawal and escape (through drugs, alcohol and sex) very alike- basically wanting to hid/not face reality***	**Social Withdrawal**	**Michael**	……of course you feel like there is HIV written across your forehead and that they're reading that and there is no way to hide from it… you run….you hide….you runaway….you hide…you smoke some weed and you escape from that….you disappear….you become a recluse…isolate yourself….keep your social contacts to a minimum… [Lines 554-564]
				I would exclude myself from social activities because I perceived that somehow I was gonna be pointed out….or somehow I was gonna be noticed or somebody else is gonna see…. [Lines 596-608]
			Martin	**….** absolutely shamed to the point of not going out…. [Lines 515]
			George	**Part:** I used to just shy away and I mean it got really bad last year and I used to stay in and on my annual leave I wouldn't leave the house…on my days off I wouldn't leave the house….I would be too nervous and too anxious so I used to think I would rather not face the world and I did drink a lot….a hell of a lot….to drown it out ….cuz I just felt better when I was drunk as opposed to being sober….I was hiding it all and it was easier to deal with… [Line 683-692]
				Part: I mean I always felt hot…I always felt really heated like I get embarrassed quite a lot…and I shied away from it

APPENDIX M
NHS ETHICS FAVOURABLE OPINION LETTER

Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02070148044

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

02 June 2017

Miss Stacey Joanne Hemmings
Trainee Clinical Psychologist
University of East London & Camden and Islington NHS Foundation Trust
School of Psychology, Stratford Campus,
The University of East London
London
E15 4LZ

Dear Miss Hemmings

Study title:	**Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships**
REC reference:	**17/LO/0785**
IRAS project ID:	**218531**

The Research Ethics Committee reviewed the above application at the meeting held on 19 May 2017. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Recommendation

a) Please include the involvement of the patients and their relatives, the public and service users in the study design, conduct and management of the study for future studies.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

The Committee welcomed you to the meeting and thanked you for submitting your application for REC review.

Social or scientific value; scientific design and conduct of the study

This is a worthwhile study and an important research question.

The Committee noted that the study is not compliant with HRA Approvals. The HRA Initial Assessment referenced the transportation of personal data to university staff and the process of obtaining the contact details. The funding arrangements for the study was also raised by the HRA Assessor and noted by the REC to have no material ethical concerns.

The study design, conduct and management had not been reviewed by the public, patients or service group users. The answers given in the IRAS REC application for the justification for this is not adequate. The Committee stated that the protocol should be reviewed by a patient support group.

The justification for using IPA analysis in not clear and may not be useful given the small recruitment sample size of 10 participants.

You were asked to define the meaning of shame and stigma.

You replied to say that the concept of shame can be broken down into different meanings and it is society that causes this concept as a whole. Social construction is the idea of shame being a thing in someone, not necessarily dialectal.

The Committee accepted this explanation.

Recruitment arrangements and access to health information, and fair participant selection

The process for recruiting participants is fairly standardised. There will be posters put up in clinics to recruit gay patients diagnosed with HIV. The Committee queried how private this form of recruitment would be if a patient is seen by others to be writing the study's contact details and thereby disclosing that he is gay and is HIV positive. The Committee agreed that this is an ethical concern to consider and agreed that patients attending clinic appointments would be expected to exercise their discretion.

The Committee stated it is unclear why only gay men are included in the study as not all men who have sex with men are gay, they could be bisexual or people who do not wish to identify themselves by sexual orientation.

The rationale for selecting the sample population was unclear to the Committee. You were advised that it cannot be presumed that only gay men have sex with men and that it is becoming more commonplace for a person's sexual orientation, in particular the younger generation not to be categorised or labelled in this way. As a result their sexual orientation is not known and it would be difficult for the researchers to include them into the study.

You agreed with the Committee and replied to say that the aim of this study is to better understand the experiences of shame in gay men only before thinking more broadly about other sample populations.

The Committee accepted this justification.

You were advised of the likelihood of accidental identification of gay HIV patients who are observed writing down the study details from a poster in the clinic. The Committee acknowledged that the decision to respond to an advert in this way is the choice of the individual alone.

You replied that there are many posters used in clinics to recruit to HIV studies and there are many studies on a wide range of sexual transmitted diseases. This is not considered to be an issue for the clinic or for the participant taking part.

The Committee accepted this response and asked Mss Hemmings to clarify if the study is solely aimed at participants who have HIV through having sex with gay men using illicit substances. The Committee queried whether there could be significant differences in the experiences of shame dependent on the means in which the HIV virus was acquired.

You acknowledged that different circumstances exists, however there is an increasing concern regarding the use of illicit drug use in relation to risky sex with gay and bisexual men, also known in society as 'Chemsex'.

The Committee asked for your rationale for using IPA (Interpretative Phenomenological Analysis) and how meaningful IPA would be in a small sample group of 10 participants.

You explained that IPA is a qualitative approach to research which seeks to examine the lived experiences and the unique routes of HIV acquisition. It has gained significant popularity in clinical health psychology and explores the nature of major life experiences. You added that IPA was designed to be used on a much smaller sample group of patients and works better on a personal level on small samples.

The Committee accepted this response and asked if IPA would distinguish between shame and the relationship between shame and risk taking behaviour.

You explained that IPA would be able to distinguish between the two as it adopts a flexible approach and explores the journey of shame and what it means to the individual. IPA looks at iterative themes.

The Committee thanked you for your explanation.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

There is a risk that the participant may become distressed as highlighted in the application form. The participants are asked to explore their experiences of shame. The Committee were assured that the appropriate arrangements are in place to safeguard the participant in the event they become distressed. However, it was unclear what support will be available at the research sites; the hospital and the university.

You were asked by the Committee to explain what would happen if the participant became distressed during the interviews and Miss Hemmings replied to say that she is a trainee clinical psychologist and experienced in dealing with distressed patients. The interview would be stopped immediately if the participant becomes uncomfortable. If there are any major concerns with the participant's health and wellbeing then the participant will be referred to a supervisor and the appropriate clinical support that are available at the hospital and university.

It was noted that the participants will have access to the study results.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee asked how the participant's contact details will be transferred to you.

You advised the Committee that you are in the process of obtaining an honorary contract with the University of East London. The Committee responded to advise you that all information sent about the study via email is to be treated in strictest confidence and that the subject heading in the email referencing the study title should not include the word 'HIV'.

You agreed to take this forward. Miss Hemmings informed the Committee that all personal data will be transcribed by her and destroyed after the study has ended. The transcripts will be kept and anonymised.

Informed consent process and the adequacy and completeness of participant information

You were advised by the Committee that the PIS mentions that the interviews will take 90 minutes, however in the REC application form it states they will take 60 minutes. The Committee did not request an amendment to the study documentation as part of the ethical opinion letter.

The consent form states what will happen to the participant's data if they withdraw from the study after October 2018, but this is not mentioned in the PIS. The Committee did not request an amendment to the study documentation as part of the ethical opinion letter.

Participants will be reimbursed with a £10 voucher for taking part in the study.

The Committee asked you if you had any questions for the Committee and you replied that you did not have any questions for the Committee.

You were thanked for attending the meeting and you left the room.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [redacted] Study Advertisement]	V2	01 March 2017
Copies of advertisement materials for research participants [redacted] Study Advertisement]	V2	01 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Indemnity Policy]	V1	09 March 2017
Interview schedules or topic guides for participants [Interview Schedule]	V2	01 March 2017
IRAS Application Form [IRAS_Form_21042017]		21 April 2017
IRAS Application Form XML file [IRAS_Form_21042017]		21 April 2017
IRAS Checklist XML [Checklist_21042017]		21 April 2017
Non-validated questionnaire [[redacted] Socio-Demographic Sheet]	V2	01 March 2017
Non-validated questionnaire [[redacted] Socio-Demographic Sheet]	V2	01 March 2017
Other [[redacted] Debriefing Sheet]	V2	01 March 2017
Other [redacted] Debriefing Sheet]	V2	01 March 2017
Other [Good Clinical Practice Certificate]	V1	05 March 2017
Other [UEL Research Integrity Module Certificate]	V1	26 September 2016
Other [HRA Statement of Activities]	V1	09 March 2017
Other [HRA Schedule of Events]	V1	09 March 2017
Other [Response from applicant re validation query]		03 May 2017
Participant consent form [[redacted] Participant Consent Form]	V2	01 March 2017
Participant consent form [redacted]Participant Consent Form]	V2	01 March 2017
Participant information sheet (PIS) [redacted] Participant Information Sheet]	V2	01 March 2017
Participant information sheet (PIS) [redacted] Participant Information Sheet]	V2	01 March 2017
Referee's report or other scientific critique report [UEL Proceed Letter for Thesis Proposal]	V1	10 January 2017
Referee's report or other scientific critique report [UEL Thesis Proposal Feedback/Peer Review]	V1	09 January 2017
Research protocol or project proposal [Study Protocol]	V2	01 March 2017
Summary CV for Chief Investigator (CI) [Curriculum Vitae SJ Hemmings]	V1	03 March 2017
Summary CV for supervisor (student research) [Curriculum Vitae Dr. Poul Rohleder]	V1	09 March 2017

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/0785	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

[redacted]

[redacted]

E-mail: nrescommittee.london-camberwellstgiles@nhs.net

APPENDIX N
HRA FAVOURABLE OPINION LETTER

NHS
Health Research Authority

Miss Stacey Joanne Hemmings
Trainee Clinical Psychologist
University of East London & Camden and Islington NHS
Foundation Trust
School of Psychology, Stratford Campus,
The University of East London
London
E15 4LZ

Email: hra.approval@nhs.net

15 June 2017

Dear Stacey

Letter of HRA Approval

Study title:	**Exploring Gay Men's Experiences of Shame in Relation to Sexuality and HIV and the Implications for Sense of Self and Relationships**
IRAS project ID:	**218531**
REC reference:	**17/LO/0785**
Sponsor	**University of East London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **218531**. Please quote this on all correspondence.

[redacted]

Copy to: [redacted]