

**Sexuality and considering motherhood after an
HIV diagnosis - An IPA exploration of the
experiences of European, childless women**

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by

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Declaration

I hereby declare that the work submitted in this dissertation is fully the result of my own investigation, except where otherwise stated.

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Abstract

Research in the field of HIV acknowledges the existence of social constructs, including the incongruity between HIV, motherhood and sexuality, which may add to the psychosocial burden of an HIV diagnosis (Blystad and Moland, 2009; Long, 2006; Stinson & Myer, 2012). However the research is fragmented, and addresses the concepts of motherhood and sexuality in the presence of HIV independently. There has been little consideration of how the opposing constructs may be simultaneously experienced and negotiated by positive woman. Additionally existing research focuses on pregnant women or mothers, it does not explore the impact of an HIV diagnosis before entering into motherhood. Despite adopting a philosophy of holism and valuing the creation of environments that sustain mental well-being, Counselling Psychology literature is relatively silent on women's adaptation to HIV. This qualitative study explores how European, childless women who have been historically underrepresented in the literature experience sexuality, and feelings of motherhood following an HIV-diagnosis. Interpretative phenomenological analysis of five women's experiences produced superordinate themes of, 'The even worse than undateable woman', 'Nothing can spark my sexuality' and 'You have to adapt...I owe it something'. The women speak of experiencing a continued psychological impact of an HIV-diagnosis, despite the advances in medication, which precipitates multiple psychosocial crises related to sexuality, identity, femininity and concepts of motherhood. There is a dominant experience of distress, confirming previous research on HIV-trauma. However there are also experiences of resistance, successful negotiation, and personal growth. Clinical implications are discussed in light of counselling psychology's multidisciplinary approach, including therapeutic recommendations to explore and challenge women's definitions of sexuality, femininity and motherhood.

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Glossary

Abbreviations:

HIV: Human Immunodeficiency Virus

AIDS: Auto Immune Deficiency Syndrome

Definition of terms:

Auto Immune Deficiency Syndrome (AIDS): is a condition diagnosed when an individual's CD4 count is low (less than 200 cells/mm³) indicating a weakened immune system as a consequence of end-stage HIV, and is characterised by the increased susceptibility to infectious diseases, such as pneumonia, certain cancers and neurological disorders.

CD4 (Cluster of differentiation 4): is a glycoprotein found on the surface of immune cells such as T helper cells. HIV attacks and kills T-cells. The body does replace the cells, however if the viral load, (the level of HIV in the bloodstream), is high, the body struggles to keep up with the production of T-cells to replace those killed by HIV and the person's immune system is compromised. Thus a low CD4 count represents a weak immune system and thus is more susceptible to developing AIDS.

Human Immunodeficiency Virus (HIV): is a retro virus that causes AIDS by infecting T helper cells of the immune system.

HIV-positive: diagnosis used to indicate that an individual has been found to have HIV within their bloodstream. Although they may not have AIDS or develop it for a long time, the presence of the virus increases the individual's risk to infections as a result of a lowered immune system, which may lead to AIDS.

Motherhood: is the state of being a mother. The participants were not given any definition of motherhood but were allowed to speak of motherhood or being a mother in the way they understood and related to it. All of the women spoke of motherhood as conceiving a child themselves (i.e. not being a mother through adoption/fostering or by any other means).

Positive women: describes women who are HIV-positive, in a way that seeks to promote more empowering discourses around seropositive women.

Seropositivity: a noun indicating a positive reaction to a blood test, which denotes the presence of HIV within the bloodstream.

Sexuality: within this literature review, will be based on the World Health Organisations (2006) definition of sexuality, where it describes it as more than just sexual identity and practice (although these may be central to its expression), “sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices roles and relationships” (p. 5), and will be considered to be bound up within the above mentioned notions. The participants were not given this definition of sexuality but were allowed to speak of their sexuality in the way they understood and related to it, however most of the women made reference to the elements described here.

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Finally and most importantly, I would like to thank the women who participated in my study. Not only have they made this project possible, but I have also learnt so much about strength and determination from them. I hope that I have been able to show this in my study. I am truly grateful for the opportunity they have given me.

1.0 Personal statement

Four years ago whilst working for an Australian government initiative offering support for people living with HIV, I met an HIV-positive client, to whom I became very close. He spoke of a life fraught with guilt, blame and ostracisation from his family, yet inspirationally a positive self-transformation. The extent of the impact of HIV to a person's psyche, their relationship with themselves and others was a stark revelation to me. I developed a strong sense of admiration of this client's ability to adapt, learn and reflect on positive experiences of an HIV diagnosis. From the many conversations we had about the challenges he had faced since his diagnosis, the most difficult challenge for him was getting to know and accept himself with HIV, with particular reference to his sexuality. Working with this client further fuelled my interest in HIV, and particularly the impact of HIV to one's sexuality.

The concept of sexuality has been a dominant part of my life from a relatively early age, being brought up in an extremely open and liberal family, where I was encouraged to question and discuss sexuality and sexual experiences; thus my own sexuality was apparent to me early on. Such a liberal parental outlook had its advantages, but as a teenage girl, talking of personal matters with parents became increasingly difficult and I felt guilt and shame towards my own sexuality when I did not open up my experiences for family discussion. Thus I now cherish my sexual identity as a very personal aspect of who I am. I believe that my own understanding of how my sexuality is key to my identity brings me closer to and enables me to empathise with individuals who are facing possible challenges to their identity.

Having only worked with positive men, and understanding some of the challenges they face as a result of their diagnosis, provoked my thinking and questioning about women living with HIV and the difficulties they face – are they the same or different to men? I would describe myself as a feminist, always eager to defend the female cause, thus when exploring possible research areas within the HIV literature I was drawn to the potential challenges faced

specifically by positive women. I was aware that my biases of gender differences and power, such as my belief that in most situations women face greater challenges than men, had the potential to affect my research with a feminist prejudice. I was aware of such biases during my literature searching and selection that I could possibly be drawn to research providing empowering accounts for HIV-positive women. However I consider that the awareness of my potential prejudices enabled me to minimise them throughout the study, through careful consideration and reflection.

Being a woman in her thirties I am feeling the societal pressure of thinking about entering into motherhood. However, not knowing whether I want children, yet feeling that I should, poses challenges for me, and as a result I have been questioning myself as a woman. Thus when deciding where to focus my research I began to wonder, if I was presented with a potential difficulty to have children, such as an HIV diagnosis, how would this change my relationship towards motherhood? These are questions that I cannot answer, but it highlighted to me that a woman diagnosed with HIV might face a plethora of challenges, including to her sexual as well as maternal self. Perhaps my focus on European women served as way of helping me to understand my identity questions and challenges as a thirty something, childless, European woman.

2.0 Introduction

HIV has become a metaphor for aberrant sexuality, and as a result is perceived as part of the identity of an HIV-positive person (Sontag, 1988). Subsequently, due to its associated stigma, it has been argued that understanding HIV outside the context of social constructs and influences is not possible (Long 2006; Sontag, 1988). Treichler (1988) describes HIV as an “epidemic of signification” (p. 236), meaning that HIV has provoked a plethora of meanings, which in turn have further incited the evolution of the epidemic. As a result of the multitude of meanings and stigmas associated with HIV, the psychosocial burden placed on the individual accompanying the HIV diagnosis is like no other chronic illness (Nightingale, Sherr & Hansen, 2010).

With the success of antiretroviral drugs and prophylactic medication, enabling positive women to become pregnant, with significantly reduced risks of transmission, living a long, healthy life and being able to become a biological mother are realistic options. Thus understanding the psychological challenges faced by positive women are both relevant and imperative.

HIV and motherhood are both produced from sexual intercourse, and sit uneasily within the concept of sexuality (Blystad and Moland, 2009; Long, 2006; Stinson & Myer, 2012). When a positive woman enters into motherhood, she is potentially exposed to two opposing identity constructs simultaneously: the aberrant HIV-positive identity and the mother identity, historically associated with goodness and virtue (Long, 2006). This may be a challenging position for positive women.

This chapter will critically review the relevant literature on socio-psychological research in HIV, with an emphasis on female sexuality and motherhood. By critically examining current literature, on understanding the interplay between HIV, sexuality and motherhood, I hope to more clearly define the literature gap I hope to address.

2.1 Focussing on European women

Approximately half of the world's population of people living with HIV are women (World Health Organisation, 2014). Despite this, the majority of the research is carried out with Caucasian, homosexual men (e.g. Stolte et al. 2004), possibly due to the historical relationship between men and HIV. As such the growing incidence of heterosexual positive women has been largely overlooked. Heterosexual transmission is now the highest reported mode of contracting HIV in Western Europe, and women have been found to be physiologically more vulnerable to contracting HIV than men (Iobst & Ghandi, 2009). Considering these findings, research into positive women is increasingly important.

The majority of studies with female participants include women of African origin or of mixed ethnicity (e.g. Long, 2002; Blystad & Moland, 2009). Thus European women are underrepresented, and potentially the experiences of this sub-group are overlooked. Little is known about the experiences of positive European women, as a Counselling Psychologist this gap in knowledge presents an interesting challenge to the multicultural commitment of the profession. Through focussing on this sub-group the study aims to widen the reach of working with such a population that may appear as a majority in society, yet in the world of HIV lives as a minority.

3.0 Literature Review

The following literature review explores the current psychosocial research in HIV, with a focus on positive women, sexuality and motherhood (for the current study's literature search strategy see Appendix A). The review initially explores the psychological significance of sexuality and motherhood in turn, followed by a review of the psychological significance of their interaction. The review then explores the psychological impact of HIV on women's sexuality and motherhood in turn, and culminates in exploring literature on the psychological impact of their combined interaction.

3.1 Psychological significance of sexuality

Sexuality, also referred to as sexual subjectivity, is defined as “the perceptions of pleasure from the body and the experiences of being sexual” (Horne & Zimmer-Gembeck, 2005, p.127). Martin (1996) suggests that sexual subjectivity arises from an individual's relationship with their body as well as through thoughts, feelings and reflections of their experiences.

According to the World Health Organisation (2006):

Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors. (World Health Organisation, p.5)

This definition proposes that sexuality is experienced through a personalised combination of expressions, and is a fundamental element of being human. Research has suggested that sexuality is modelled by interrelating elements; our own subjective beliefs about who and what we are, and societal and cultural influences (Saldanha de Almeida, Silveria, Ferreira da Silva, Araujo &

Guimaraes, 2010). Thus it can be argued that sexuality is not simply biologically explainable but constructed through individual experiences.

Much of the research over the last 20 years places heavy emphasis on the importance of sexuality in psychosocial development (Dunn, Croft & Hackett, 1999; Satcher, 2001; Foley, Kope & Sugrue, 2002). Therefore regardless of the differing perspectives on the forces of sexuality, such as biological, psychological and social influencers, there is a general consensus that sexuality is an essential feature that defines who we are as human beings (Parker and Gagnon, 1995).

3.2 Psychological significance of motherhood

Motherhood is filled with social meaning; reproduction is considered to be both an internal (to the woman) and an external (to society) validation of a woman's social identity (Harrison & Montgomery, 2001; Kitzinger, 1992; Mullin, 2005). Motherhood is entwined with notions of femininity (Chodorow, 1989), and mothering can reinforce a woman's gender identity (McMahon, 1995). Some research has suggested that women themselves consider having a child as essential to their own identity as a woman. Babies have been proposed to represent acceptance, love and the future, possibly especially important for women who have an uncertain future (Shayne & Kaplan, 1991).

Studies have reported benefits of motherhood to a woman's identity, including an increased sense of self-worth and fulfilment (Bailey 1999; Phoenix & Woollett, 1991; Smith, 2010). Nelson (2003) proposes that a primary process when entering into motherhood is the expansion of the woman's sense of who she is. This mirrors the findings of Sethi (1995), suggesting that entering into motherhood results in a transformation of the self. Weaver and Usher (1997) propose that motherhood can result in women experiencing a loss of identity, yet this loss is outweighed by the love felt for the child. Additionally research has described the transition to motherhood as an opportunity for growth and maturation (Bailey, 1999; Pancer et al., 2000; Parens, 1975; Rogan et al., 1997).

In the changing demographic of western societies, whilst motherhood remains central to a woman's identity, motherhood alone may no longer be the sole driver providing direction in women's lives as it once was, resulting in a change in the pressures women may face. Hays (1996) spoke of the more recent contradictory cultural pressures on women to, on the one hand, dedicate themselves to raising children, and, on the other hand, to pursue personal success through getting ahead in a career. When women deviate from the standard model (such as from being married and heterosexual) a variety of deviancy discourses emerge - even in today's modern, westernised societies, a woman can be at risk for being identified as a defective or bad mother (Arendell, 2000). Thus mothers remain subject to close social regulation and the 'good mother' ideal appears to still be present (Porter and Kelso, 2006).

Stereotypes of the "good mother" are further upheld by discourses, including the medical and natural childbirth discourses (Cosslett, 1994). These discourses have also been acknowledged in research exploring the experiences of those who apparently do not "conform" to conventional stereotypes of the "good mother" (Baker and Carson 1999; Bobel 2002; Garcia, Surrey & Weingarten, 1998; Hays 1996). The contrasting, overlapping, and ambiguous strands within these frameworks focus to varying degrees on a woman's biological tie to her child (both pre and post partum) and predisposition to instinctively be able to care for her child. For those becoming mothers, these include an expectation that their bodies are designed to reproduce, that (until perhaps shown otherwise) they will be able to achieve this (naturally), and that they will be able to (instinctively) meet their child's needs, as such be a *natural* mother in every way (Miller, 2005).

Within medicalised discourses, breastfeeding has assumed the status of moral imperative, inseparable from the conception of 'good mothering' (Carter, 1995; Murphy, 1999). The act of breastfeeding is not simply about meeting the nutritional needs of babies; it is also imbued with social, emotional, sexual and cultural meaning for mothers (Vincent, 1999). Breastfeeding could be understood as an empowering and gratifying experience for women, and one that "confirms a woman's power to control her own body and challenges medical hegemony"

(Penny Van Esterik, 1989, p. 70). The notion of a natural woman has been at the heart of infant feeding discourses for many years. Breastfeeding not only provides health benefits but is also understood to contribute to the bonding and attachment process and as such breastfeeding has become the “measure of the mother” (Carter, 1995). As such failure to breastfeed can be considered as deviant (Murphy, 1999).

Good mother (or *ideal* mother) discourses require that mothers “act responsibly” and present themselves in “culturally recognizable and acceptable ways” (Miller 2005, p. 86). Thus the literature on prevailing good mother discourses has been concerned with elaborating what is regarded as culturally desirable and socially acceptable for mothers. Thus the *good mother* appears to be formidable social construct that may place pressure on women to conform to particular standards and ideals, against which they are possibly judged and also judge themselves.

3.3 Motherhood and sexuality

A link between motherhood and female sexuality has been suggested in the literature, proposing that birthing, breastfeeding, and nurturing a child are experiences that impact a woman’s sense of herself as a sexual person (Daniluk, 1998). However the concepts of female sexuality and motherhood have a long history of being considered separate, and at times even opposing, constructs. The duality between the two concepts can be evidenced as far back as early religious writings, when a sexual woman was considered deviant and sinful, as represented by Lilith in Jewish interpretations (Kvam, Scheering & Ziegler, 1999), or motherly and virginal, such as Mary and Eve in Christian and Jewish writings and Yazoda, in Hindu tradition (Lott, 1987).

Horney (1967) suggests that there are two main roots to the existence of the divide between women’s sexuality and motherhood. The first originates from historical writings where women were portrayed as sexual deviants or as pure and nurturing (Lott, 1987). Secondly Horney argues that men possess an inherent

envy towards women, due to their biological ability to give birth, described as “womb envy.” As a result of reaction formation, this envy is converted into contempt for women, and as a consequence women’s sexuality is suppressed and focused into motherhood. Thus some feminist writers view the polarisation of sexuality and motherhood result from the social norms and stereotypes created by a patriarchal society (Chorodow, 1978; Rich, 1976). In a study by Allport (1958) asking men and women to describe the sexual behavior characterizing women, two opposing clusters emerged; the virginal, child-loving, sexually inexperienced woman and the seductive, manipulative, sexually experienced woman.

One may question if the Madonna-whore complex exists in its extreme in today’s westernised societies. Research suggests that depictions of women as mothers and as sexual people are rare, and it is only in more recent decades that the presentation of mothers as sexual has occurred, mainly through media images (Dobscha, 2006). The covers of popular magazines, initiated by the front-cover pose of a pregnant and naked Demi Moore (in 1991), simultaneously representing female sexuality and motherhood. According to O’Malley (2006), prior to this, pregnant women were rarely shown in fashion magazines, or were shown in desexualized ways. This bold image caused other magazines to follow suit, displaying similar images of pregnant, naked celebrities (such as Britney Spears, Christina Aguilera, Claudia Schiffer, Kim Kardashian, Mariah Carey, Tia Mowry, and Nia Long), perhaps paving the way for new discourses concerning women as both sexual and mother beings to emerge in what has previously appeared to be an inflexible arena. However the findings from subsequent studies suggest that what is on the inside of these magazines is a sharp contrast to what has appeared on the outside cover, where inside the duality between female sexuality and motherhood is still presented. Thus suggesting that the acknowledgement of mothers as sexual is only superficial. Johnston and Swanson (2003a) analysed the content of women’s magazines. Their analysis revealed that mothers are depicted as separate from their sexuality. In a second article by the same authors (Johnston & Swanson, 2003b), their analysis of women’s magazines revealed that whilst these magazines are full of advice for mothers, there is little recognition of the influence mothers have in

other areas of life, and with no recognition of them as sexual beings. More recent content analysis of current parenting magazines further suggests the portrayal of women as mothers and sexual beings as remaining mutually exclusive (Shipps & Caron, 2013). Thus it appears that in more recent years the duality between female sexuality and motherhood has been challenged, yet still appears to be present in society's constructions of women. What is apparent from the current literature is the absence of exploring how women experience and negotiate the concepts of motherhood and sexuality, including any duality, in today's westernised societies.

3.4 Women in HIV research

Positive women have been underrepresented in HIV research (Gurevich et al., 2007). Existing studies of positive women have mainly focussed on non-sexual issues such as stigma (Lawless, Kippax & Crawford, 1996), coping strategies (Vyavaharkar et al., 2007) and role transformation (Hackl, Samlai, Kelly & Kalichmar, 1997). Literature that has explored sexuality has mostly explored sexual practices, paying particular attention to prevention and promotion of safer sexual practices (Zablotsky & Kennedy, 2003). A less significant share of the research has explored sexuality and the psychological implications of an HIV diagnosis, including the challenges of a spoiled identity (Rohleder & Gibson, 2006) and sexuality (Gurevich et al., 2007).

Historically positive women have been portrayed negatively in the literature. Squire (1993) highlights the existing negative social constructs of positive women as dangerous and helpless. AIDS discourses have depicted positive women as "dirty, diseased and undeserving" (Lawless, Kippax & Crawford, 1996). At times research has over exaggerated women's infectiousness (Long, 2002; Squire, 1993).

Research further suggests that the combination of HIV and womanhood results in a whore versus mother contradiction, where women are considered to be infectious to their own children and to men (Sacks, 1996). Social constructions appear to characterize women as either a "good mother" or a "bad whore," which

in the presence of HIV turns women into both a bad mother and whore, thus a positive woman can represent womanhood at its extreme (Sacks, 1996).

3.5 HIV and women's sexuality

Some mixed gender studies have explored sexuality in the context of HIV, concentrating on, individuals' sexual practices (Maticka- Tyndale, Adam & Cohen, 2002), sexual relationships (Cranson & Caron, 1998) and issues of safe sex (Cusick & Rhodes, 2000). However due to the low proportion of women in the samples, women's voices and experiences were not prominent.

Research is varied regarding women's levels of sexual activity following an HIV diagnosis. Some women feel a lack of desire, other women feel a sense of sexual power and liberation, resulting in being able to take charge of her own sexuality (Lambert, Keegan & Petrak, 2005). Bova and Durante (2003) suggest that most women continue to be sexually active post diagnosis, and argue that it is not HIV itself that causes sexual dysfunction but the meanings that women attribute to their HIV status.

Subsequent research considers the psychological impact of HIV in relation to women's identity, with a strong emphasis on the loss of women's sexuality (e.g. Gurevich at al., 2007). Few studies have explored the opportunity for positive transformations following an HIV diagnosis, although an innovative study by Hankins, Gendron, Tran, Lamping and Lapointe (1997) explored the sexual satisfaction of Canadian, HIV-positive women, reporting that sexual satisfaction increased post diagnosis. A new-found outlook and appreciation for one's sexual life post diagnosis was suggested to account for the increase in sexual satisfaction.

A small number of studies have explored the conflicts that positive women experience between their identities, sexuality and relationships (Gurevich, Mathieson, Bower & Dhayanandhan, 2007; Jarman, Walsh & De Lacey, 2005; Rohleder & Gibson, 2006; Squire, 1993). Gurevich at al. (2007) interviewed positive women to explore how sexuality is experienced differently post diagnosis. The study reports that women feel a reduced sense of spontaneity and

a lack of sexual freedom post diagnosis, and thus experienced negative transformations in sexuality. Concurrent with previous sexuality related studies Gurevich et al. (2007) does not acknowledge the opportunity for positive sexual transformation post diagnosis.

A qualitative study by Rohleder and Gibson (2006), interviewing HIV-positive women in South Africa, suggests that positive women internalise feelings of having a ruined identity, relating to the social perceptions of HIV. Additionally Long (2009) proposes that being positive holds powerful personal meanings, including damage and guilt associated with the diagnosis, attributed to the social stigma of HIV.

A recent qualitative study exploring sexuality, through interviewing positive women, suggests that HIV blocks women's sexual desire and pleasure, lessening feelings of intimacy towards their partner; the study fails to explore how HIV blocks sexual desire and pleasure. (Saldanha de Almeida et al., 2010). Reflective of previous findings the study attends to the vulnerability of sexuality to varying social and cultural determinants, and the need to understand women's experiences to aid in support. Disappointingly much of the current research does not provide any clinical applicability for supporting positive women.

Overall current research suggests that an HIV diagnosis can mostly have a negative impact to a woman's sexuality, resulting in a lack of sexual desire, reduced sense of sense worth due a perceived spoiled identity, and a loss of freedom, to speak of a few. There are few stories of positive transformations, painting a bleak picture for positive women's sexuality.

3.6 HIV and motherhood

3.6.1 Decision making process

A significant proportion of the research into HIV and motherhood focuses on the process of deciding whether or not to have a child (Barnes & Murphy, 2009; Hutchinson & Kurth, 1991). Kirshenbaum et al. (2004) identified the risk of

vertical transmission, (transmission of HIV directly from mother to child), as a major factor in the pregnancy decision-making process, mirroring the findings of Sowell et al. (2002), where the perceived risk to the child is a key deciding factor. Both studies suggest that women's attitudes to pregnancy are associated with personal beliefs about the risk of vertical transmission. However the majority of Kirshenbaum et al.'s (2004) participants were pregnant prior to being diagnosed with HIV, thus had not faced their pregnancy with the psychosocial burden of the diagnosis, therefore the study is misleading in its aim to investigate positive women's experiences of the reproductive decision-making process. However an interesting finding suggested that positive women who had another child post diagnosis, reported a different experience to an HIV-negative pregnancy.

3.6.2 Incongruity between motherhood and HIV

On one hand motherhood is considered to be social norm, potentially elevating a woman's status and validating their social identity (Mullin, 2005). In contrast HIV infection is a stigma provoking condition that results in a castigatory social reaction (Ingram & Hutchinson, 2000; Long, 2009). Yet even in cases where circumstances determine whether or not a woman conforms to this norm, such as HIV infection, not having a child can be considered to be a norm defilement (Miall, 1998).

Ingram and Hutchinson's (2000) grounded theory study attempts to explore the reproductive and mothering experiences of HIV-positive women. The key psychological issue identified was a double bind; participants feeling inadequate if they don't have children, however feeling like bad mothers if they do. It is suggested that the social stigma of being pregnant when HIV-positive is internalised by the woman and becomes a source of conflict in the pregnancy decision-making process. Despite being a grounded theory study, no theory for the experience of motherhood in the presence of an HIV diagnosis is proposed.

Consistent with the findings of Ingram and Hutchinson (2000), Stinson and Myer (2012) suggest that a *good mother*, not burdened with an HIV diagnosis, is able

to enjoy guilt-free motherhood. Associations of being a *good mother* elicited further anxiety and incongruity; such as the social pressure to breastfeed the child, juxtaposed to the mother's perceived risk of vertical transmission during feeding. Reflective of previous findings, the study suggests that positive mothers have to work hard at maintaining their maternal identity compared with HIV-negative mothers (Giles, Hellard Lewin & O'Brien, 2009; Sandelowski & Barroso, 2003).

3.6.3 Portrayal of HIV-positive mothers

Ladd-Taylor and Umansky (1998) suggest the existence of the stereotype of HIV-positive mothers as deviants from the norm, considered to be bad mothers who are unable to protect their child from harm. Similarly Long (2009) suggests that social representations of positive women are depicted as bad and threatening even when considered within the positive concept of motherhood. Such polarising concepts highlight the possible psychosocial burden that a positive woman faces when thinking about motherhood, torn between being a *good* or a *bad* mother. Pierret (2000) suggests that HIV-positive women experience the stigma associated with their pregnancies to a high degree and do so for a long period post birth.

Sandelowski and Barroso (2003) conducted a meta-analysis of published and unpublished qualitative studies on positive women in the US. The study suggests the difficulty in escaping the idea of positive women not being good mothers, and even bad for entering into motherhood. Due to the incongruity of being a mother and having HIV, the study suggests that the women have to renegotiate their identities in order to be able to portray themselves as good mothers.

A study by Black, Nair and Harrington (1994) threatening to break the mould of previous negatively constructed research towards positive motherhood, suggested that amongst women who used illegal drugs, positive mothers displayed superior parenting behaviours and attitudes than HIV-negative mothers. However the study's conclusion is contradictory to its findings, initially claiming that positive mothers are more nurturing towards their children, yet then

goes on to suggest that many HIV-positive parents do not recognise the emotional needs of their children.

Overall research suggests that positive women face a double bind when thinking about motherhood, they are not *real* women if they don't enter into motherhood, yet are potentially *bad* mothers (and women) if they do, thus this conundrum adds to the psychological burden of negotiating a life with HIV.

3.7 HIV, motherhood and sexuality

The dichotomy between female sexuality and motherhood is dominant in the HIV literature focusing on women, with earlier research exploring positive women in the sex industry and more recently positive mothers. However with the recent advent of prophylactic medication (from 2010) making it a realistic possibility for positive women to become biological mothers, with a greatly reduced risk of transmission of HIV, potentially exposes positive women to requiring to negotiate these constructs in unison, in addition to negotiating being a woman living with HIV and any additional pressures that may add. Current research is limiting in exploring positive women's experiences of being a sexual woman, as well as being mother or when considering motherhood.

Long (2006) explores the conflicting identities experienced by positive mothers, and justifies the focus of research based on the existence of the two contradictory identities that HIV-positive mothers can find themselves in; the feared and depreciated identity of an HIV-positive woman and the idealised identity of motherhood. The study sample consisted of 50 South African mothers recently diagnosed with HIV, and through conducting semi-structured interviews and employing discursive and psychodynamic analysis, explored the experience of being an HIV-positive mother and the contradictory subjective positions held.

Four subjective positions were introduced from the study's findings, a woman with HIV; a person with HIV; HIV-positive mother-of-baby (baby being the primary focus); and mother-herself (experiences of motherhood from the

woman's perspective). Long proposes that the mother-herself position is elusive in the existing literature, yet is apparent through this study's data and argues that it is central to the identities of positive mothers.

The position of an HIV-positive woman was characterised by the study's findings of gendered relationships, in which women questioned their origin of infection, and faced complications in their relationships due to their status. Ideas of motherhood and the women's own bodies were excluded from this position which Long (2006) explains may be due to HIV arousing their sexual bodies in such a way that they needed to perceive their maternal and HIV bodies to be separate.

The position of an HIV-positive person in this study was seen as asexual and non-maternal. In the position of HIV-positive mother-of-baby, maternal subjectivity is influenced by concepts of the good or bad mother, and the nurturing or damaging mother. Long concluded that positive motherhood is experienced as a collision of opposites, illustrated by the four proposed subject positions that are difficult to maintain and reconcile. The HIV-positive mother intensifies the social constructs and fantasies around HIV, motherhood and sexuality, and being diagnosed as HIV-positive means making sense of these social fantasies.

Despite Long (2006) conducting interviews with 50 participants, however only four participants are used to illustrate the subjective positions presented in the analysis; although no justification is given for this. Equally the study does not attend to the possibility that this challenging contradiction could be experienced before pregnancy or before entering into motherhood.

Blystad and Moland (2009) conducted a study in East Africa focussing on the identity transformations of positive mothers. The study proposes that the incongruity between the concepts of being a mother (such as being nurturing and loving) and the concepts of sexuality, HIV and death pose challenges for the success of prevention of mother-to-child transmission of HIV programmes. Following an HIV diagnosis, women experienced transformations around their

beliefs about breastfeeding. In this study the women associated their milk with the virus, and changing it from a nourishing substance to something that could cause death. Women in the study felt confused, torn and even less of a mother if monetary reasons resulted in the mother having no choice but to feed the child with the “dangerous” milk. Thus breast-feeding for the HIV-positive women in this study became a non-mothering, even a dangerous act that challenged their maternal and female identities. Given that Rich (1976) suggests the link between sexuality and motherhood in the act of feeding, the study raises questions about the link between challenges to maternal identity and in turn challenges sexual identity. However exploring sexual identity is not an aim for this study, thus it is not addressed.

The study also suggests that as breastfeeding for HIV-positive women resulted into potential danger to another, relationships towards their bodies were transformed, with the women considering themselves as having failed bodies. Research into the sexuality of women considers a woman’s body and her relationship with her body as essential in developing and maintaining one’s sexuality (Martin, 1996). This raises questions around how women’s relationships with their bodies transform, before and during motherhood in the presence of an HIV diagnosis, and how that may interact with sexuality. Again attending to this question was not an aim of the study.

The study concludes that HIV-positive mothers experience having to carry the burden of the discordant concepts of motherly love and nourishment on one hand and the threats of immoral sexuality leading to a deadly infection on the other. During motherhood these opposing concepts are visibly manifested in the bodies of HIV-positive women, such as the growing womb where vertical transmission is a risk, or in the act of breast-feeding. As such some women on the PMCT programmes developed an aversion towards their bodies and considered themselves as failed women.

Stinson and Myer (2012) also explore the experiences of positive women, who are grappling with the contrasting concepts of the nourishing, nurturing mother and the sexually immoral woman. The narrative study focuses on breast-feeding

promoted by the prevention of mother to child transmission of HIV (PMTCT) programmes in East Africa. The study suggests that positive women have a diminished sense of pride with regards to motherhood. For these women feeding their babies formula created an additional burden, namely guilt around past sexual behaviour, and reduced their status as a mother. Thus the study proposes that HIV can act as a threat to women's mother identities.

A study by Saldanha de Almeida et al. (2010) interviewed nine women living with HIV in Brazil, and reported that the women's sexuality was present across several dimensions including appearing in sex, in understanding and knowing one's body, in feelings such as love and desire, in professional success and in feelings of freedom and choice as well as in relation to motherhood. The study also suggests that women find the issue between sexuality and motherhood difficult to navigate. The women report that pregnancy is shrouded in fear, doubt and uncertainties and a sense of blame and bitterness towards the father who infected the woman, who does not have to deal with the possibility of infecting a baby. Life and death are perceived to coincide paradoxically, which causes great anguish and fear for the women.

Overall research suggests that HIV, sexuality and motherhood do not sit well together. As a result positive women carry the psychological burden of the discordant concepts, and negotiating their sexualities and feelings about motherhood poses an additional challenge to living with HIV.

3.8 Counselling psychology and HIV-positive women

Counselling Psychologists have a quiet voice in the current HIV literature, yet the profession has the potential to offer useful contributions to the field. Long (2009) argues that due to the conscious and unconscious perceptions of badness, damage and guilt associated with the diagnosis, it is important to understand both the social and psychological experiences of being a woman living with HIV. Counselling Psychology has traditionally perceived the individual and mental health holistically (Kensit, 2000). As HIV is a chronic illness that carries a large psychosocial burden that can hold different meanings for individuals,

Counselling Psychologists can support individuals with a holistic view of the challenges they face and their effect on the individual. Similarly Counselling Psychologists can apply such a balanced view to research that is currently, and perhaps disproportionately, weighted towards pathology and trauma; a Counselling Psychology contribution to such research may widen the scope towards hope, adaptation and well-being.

Counselling Psychologists, in particular feminist Counselling Psychologists, which I consider myself to be, are well placed to, and should be keen to, develop a stronger voice in the female HIV literature, as the profession remains committed to forwarding ways of working which place women at the centre and to understanding the role of power in people's experience of distress (Proctor, 2002; White, 2006). There has been very little output from the Counselling Psychology literature that deals with relevant practice issues of working with HIV-positive women. Feminist counselling psychology aims to facilitate equality in personal power between men and women, and help clients to challenge culturally prescribed sex roles, thus Counselling Psychologists, if necessary, can help positive women do just that (Taylor, 1994).

Despite some research highlighting the need for psychological interventions to help women negotiate the subjectivities and challenges they face post HIV diagnosis, there is very little research to inform healthcare professionals, and namely psychologists how this might be done in practice (Jarman, Walsh & De Lacey, 2005). Counselling Psychologists have the ability to contribute to the existing literature by offering perspectives and skills from practice and through research, as I hope to contribute to through the findings of this study.

3.9 Research gap and proposed research question

Bova and Durante (2003) argue that it is not having HIV itself that is the cause of sexual dysfunction but the meanings that women attributed to having the virus. Studies have described how such attributed meanings can affect an HIV-positive woman's psychological outlook. Blystad and Moland (2009) suggested that the women's perception of their body with HIV and the meanings they associate

with their “failed bodies” challenged a woman’s sense of who she is. Long (2006) suggested that HIV-positive women consider themselves to be asexual and non-maternal.

Current research has highlighted the existence of contradictory meanings associated with HIV, motherhood and sexuality (Blystad and Moland, 2009; Long, 2006; Stinson & Myer, 2012). Long (2006) provided an insight into the complexities of subjectivities of HIV-positive motherhood, that positive women must negotiate through varying subject positions. In addition Blystad and Moland (2009) acknowledge this incongruity; in that HIV mothers carry the burden of the discordant concepts of motherly love and nourishment on one hand, and the threats of immoral sexuality on the other. Stinson & Myer (2012) explore the contradictory relationship between HIV, motherhood and sexuality in the context of breast-feeding the child, where its existence places psychological challenges for HIV mothers. Research acknowledges the incongruity between the social concepts of HIV, motherhood and sexuality that HIV-positive women can be exposed to, and additionally recognises the psychological challenges this polarisation can pose for positive women.

Current research touches on the existence of incongruent concepts that can add to the psychosocial burden experienced by an HIV-positive woman, however the research is fragmented and addresses the concepts of motherhood and sexuality in the context of HIV independently. Even though there is acknowledgment of the opposing constructs of HIV, sexuality and motherhood there has been little consideration to how the opposing concepts may be simultaneously experienced and negotiated by positive women. Thus studies have not explored in what ways experiencing a polarisation between motherhood and sexuality may add to the psychosocial burden of a positive woman. As previously discussed this is of particular relevance and importance given the advent of prophylactic medication enabling positive women to bear and have children, thus they have the potential to be exposed to themes around female sexuality as well as motherhood.

Current research focuses on the experiences of African, HIV-positive women (Blystad and Moland, 2009; Long, 2006; Stinson & Myer, 2012). Research

suggests that cultural differences including socio-economic background, ethnicity and country of origin may pose different challenges and alter the experience of living with HIV (Ciambrone, 2003; Paxon, Myers, Hall & Javanbakht, 2004). The experiences of African women may therefore differ from those women of other ethnicities, such as European women. As European women are currently underrepresented in HIV research they may have specific needs that are currently unnoticed. The lack of attention to this minority group poses an important challenge for Counselling Psychologists who aim to represent marginalised groups (Werth, 1993).

The small existing body of research exploring the subjectivities between HIV, sexuality and motherhood focus on HIV women that are pregnant or have previously had children. Thus it appears that an assumption has been made that HIV women who are not entering into motherhood are not necessarily exposed to the social constructs of HIV, motherhood and sexuality that mothers, or pregnant women may face. However, despite not having children it does not mean that feelings about motherhood, as well as sexuality, would not impact positive women, and would not be clinically relevant to them; such issues may be very relevant. In light of this, my proposed study will explore how European, childless, women experience sexuality and feelings about motherhood in the presence of HIV. The study aims to investigate how European, childless, positive, women make sense of sexuality and motherhood post diagnosis, from hopefully a balanced position; acknowledging the potential trauma of an HIV diagnosis, but also recognising any experiences of potential hope and optimism. As such, the study aims to provide clinically relevant information for healthcare professionals working with positive women, including recommendations on what helps or possibly hinders healthy adaptation.

3.10 Research question

The study focuses on European, childless, positive women, exploring their experiences of the subjectivity between HIV, sexuality and motherhood. The guiding research question of the study is: How do European, childless, positive

women experience their sexuality and their feelings about motherhood post diagnosis?

4.0 Methodology

This section describes the rationale behind choosing the qualitative method Interpretative Phenomenological Analysis (IPA) for the current study's analysis, and details the process of participant recruitment, and the collection and analysis of data.

4.1 A qualitative approach

As previously discussed very few studies have explored the experiences of European, childless, positive women in relation to their sexuality or feelings around motherhood, and even fewer studies have explored the two concepts simultaneously. Qualitative research aims “to understand and represent the experiences and actions of people as they encounter, engage and live through situations” (Elliot, Fischer & Rennie, 1999, p.216). Additionally a qualitative approach aligns with the principles of Counselling Psychology; as a field that emphasises subjective experience, dialogue and a relational view of the human being. As Van Manen (1990) proposes:

“One needs to be as perceptive, insightful, and discerning as one can be in order to show or disclose the phenomenon in its full richness and in its greatest depth. Subjectivity means that we are strong on our orientation to the object of study in a unique and personal way.” (Van Manen, 1990, p. 20)

This indicates that subjectivity is a double practice of social interpretation by the participant and the researcher; ultimately a joint construction of reality is achieved. Thus a qualitative approach aims to capture a detailed experience, or understanding, of phenomena, and in this case to produce an in-depth account of European, childless, women's experiences of sexuality and feelings about motherhood post an HIV diagnosis. Therefore a qualitative research design was deemed most suitable for the current study.

4.1.1 Ontology and Epistemology

The current study's ontological position is rooted in constructivism; 'truth' or 'reality' can never be truly 'known' in a subjective world (Pring, 2004). 'Reality' is constructed from the perceptions of the individual, therefore cannot be considered as absolute (Bryman, 2001). Thus a constructionist approach to research aims to explore patterns and meanings between individual's interactions in the world, which are influenced by social, cultural and historical factors (Gergen, 1985; Madhill, Jordan & Shirley, 2000). The ontological position of the current study aligns with the idiographic nature of phenomenology.

The current study adopts an interpretive and relativist approach; as such the research adopts an inductive stance, and reality is considered subjective (Blaikie, 1993). Thus when exploring an individual's experience, reality is constructed in the moment, and is negotiated between both participant and researcher subjectivities (the double hermeneutic). Interpretative phenomenology acknowledges that the researcher's involvement with the participant, their interview and textual data, are essentially interpretative acts, and through careful interpretation, some kind of access to the inner cognitive world of the individual is possible (Smith, 1996).

4.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis was chosen as the preferred qualitative method (Smith, 1996; Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009). IPA is derived from three philosophical underpinnings: phenomenology, hermeneutics and idiography. Phenomenology is the study of an observable event and thus, as a research approach, it focuses on the consciousness of the experience in order to understand the meaning of the lived experience for the person (Smith, Flowers & Larkin, 2009). Secondly, hermeneutics is the study of interpretation, with the understanding of text, and the interpretation of its meaning a key component (Gadamer, 1996). Thirdly, IPA is a strongly idiographic approach, it is concerned with the detailed analysis of a single case or multiple cases (Smith & Eatough, 2006).

IPA was created by Smith (1996), and its approach attempted to resolve the then current debate between social cognitive and discourse analytic paradigms. Social cognition is based on the premise that one's verbal communication contains underlying cognitions. However the discourse analysis community argued that verbal reports are dependent on context, yet structured by discourse (Potter & Wetherell 1987). Therefore IPA offered a compromise, with its roots in phenomenology, the meanings that individuals gave to experience was of utmost importance, whilst remembering that perception, structured by discourse and meanings (which involve social interactions), is only available through interpretation (Smith, 1996). Through attempting to access the participants understanding, the researchers own understandings and preconceptions come into play; thus interpretation of the participant's world must be understood through an inter-subjective meaning making process (Smith, 1996).

IPA was chosen as the preferred qualitative method for a number of reasons. Firstly, its aim of conducting a detailed exploration to capture an insider perspective on individuals' lived experiences (Smith & Osborn, 2003) corresponds with the aim of the current research. Secondly, IPA's emphasis on saying something in detail about the perceptions and understanding of a small group of people, that can have relevance in the wider context also fits with the intention of this study (Smith, 1996; Smith, Flowers & Larkin, 2009). Smith et al. (2009) suggest that focusing on the particular takes us closer to the universal, as it gives us insight into the 'essence' of a human being. As such idiography can refer to a process that moves from the examination of a single case, or small sample, to more general claims; thus can prescribe a different way, from a nomothetic approach, to establishing generalisations (Smith & Osborn, 2003).

I also found the process of conducting IPA appealing due to its inductive nature, the way it lends itself to exploring the complexity in people's experiences, and the freedom to not limit the focus on existing knowledge, in order that, unanticipated themes may emerge. This aligns with Counselling Psychology's idiographic and subjective approach to clinical practice and research.

Furthermore, I felt that IPA was a more suitable approach than other qualitative approaches for the purposes of this research. For instance, Discourse Analysis emphasises the role of language in construing social reality, in contrast to focusing on understanding personal experience (Willig, 2003). While IPA subscribes to social constructionism, and thus acknowledges the action-orientated nature of language, it argues that people not only act as discursive agents, but also give meaning to their lived experiences (Eatough & Smith, 2006). With the aims of this study it was considered that the meanings the women gave to their experience may be important to their wellbeing. IPA was favoured over Grounded Theory, which aims to produce theoretical explanations of psychological phenomena as opposed to capturing personal experience - the current study was not concerned with challenging or developing new theories. In addition, with IPA's idiographic philosophy, it is concerned with the particular and the micro-analysis of an individual's experiences, while grounded theory is more concerned with macro-level, theoretical accounts of experience and tends to utilise a larger sample (Smith et al., 2009). The current research question is concerned with the particular lived experiences of European, childless, positive women, rather than aiming for a theoretical account of their experience. However, it is possible - and even desirable - within IPA to aim for sufficient analysis that allows for the development of group-level themes to emerge, thus moving beyond a mere description of the data (Smith et al.).

4.3 Participants

4.3.1 Recruitment

Purposive criterion procedures (Patton, 1990) were employed in order to select the sample, facilitating the recruitment of a homogenous sample, and thus enabling idiosyncratic experiences to be explored (Smith & Eatough, 2006). In line with Smith et al. (2009) recommendations, five women were recruited.

Recruitment consisted of aiming to reach the desired population through communicating with organisations having potential access to them; the list of organisations contacted is located in the appendices (Appendix B). Organisations

were initially contacted using a standardised email template (see Appendix C) in order to ascertain if they could assist in the recruitment, either by displaying a recruitment poster (see Appendix D) or by distributing an information pack (see Appendix E) to service users. Responses were slow, however some organisations responded, willing to display the recruitment poster in organisational buildings or on their websites, a list of said organisations is located in Appendix F.

After eight weeks, given the limited number of positive responses from organisations, those who had not responded were telephoned, with the aim to speak to the decision maker, to further explain the research and to establish a relationship. This approach was more successful with several organisations offering to disperse the information pack directly to service users (see Appendix G for such organisations).

After a further six weeks of no response from any service users, adhering to the proposed recruitment strategy approved by the ethics committee, the initial inclusion criteria 'British' was expanded to 'European'. The aim of this expansion in the recruitment criteria was to aid in recruiting participants without compromising the homogeneity of the sample and the ability of the study to answer the research questions. Organisations previously contacted were sent amended recruitment materials and were informed via email of the change in recruitment criteria.

Five participants got in contact to register their interest of participating in the study. Three potential participants made contact by phone, and two emailed. Those who emailed were then phoned in response to their email by the researcher. Over the phone, following introductions and an assurance of confidentiality, the researcher explained the research and participation, and answered the participants' questions. Individuals were then asked if they were still interested in participating, if so, in order to meet the inclusion and exclusion criteria for the study, they were asked to complete a short demographic questionnaire (see Appendix H) and the GAD7 and PHQ9 (reasoning explained in ethics section) (see Appendix I). All potential participants agreed to potential participation, and selected email as the mode for subsequent communication,

having been made aware of the potential risks of emails and having been offered other modes of communication (such as post). The researcher emailed the above-mentioned questionnaires, along with a comprehensive information sheet (see Appendix K). Individuals were asked to read the information sheet and complete the questionnaires, and to then email their responses back to the researcher, as well as encouraged to ask any further questions. Once the researcher received the completed information from participants, all individuals were deemed suitable for participation, the researcher then phoned in order to make arrangements for the interview. The participants were offered their choice of venue for the interview, which aided power sharing. However the organisations that assisted with recruitment offered rooms in their buildings to conduct the interviews, participants were informed of this and all five participants chose to be interviewed at their affiliated organisation. This had several main advantages; locations were convenient to participants, participants were familiar and thus more likely to be comfortable in their surroundings, and rooms were private, thus ensuring anonymity.

4.3.2. Inclusion and exclusion criteria

For the purposes of this research a diagnosis of HIV was a necessary requirement for inclusion in the study, as well as being female, currently without any children (and not currently pregnant). As previously discussed research into experiences of childless, positive women is lacking. Furthermore as the majority of existing research into positive women focuses on African populations, as research suggests western women may have different experiences to that of African women, exploring westernised, positive women's experiences was considered important (Ciambrone, 2003; Paxon, Myers, Hall & Javanbakht, 2004). Being European was considered to be a suitable measure of being westernised (i.e. person who has a westernised culture) and thus deemed to be an important inclusion criterion; in the current study this inclusion criteria was defined and fulfilled by people who consider themselves to be European.

Additionally participants were required to be of childbearing age, defined within this study as being an adult within an age range enabling the potential bearing of

a child (i.e. over 18 years of age and pre-menopausal). Only adults (over 18 years) were included in the study, to avoid any ethical age-related issues. It was considered that post potential child-bearing age (i.e. post-menopausal) should be excluded, as it was considered that other stage of life experiences, such as ageing issues, may come into play, possibly interfering with addressing the study's research aims around motherhood and sexuality.

Due to the sensitive and emotive topics being discussed at interview, it was considered that suicidal individuals should not participate in order to ensure their safety. The GAD7 and PHQ9 (Appendix I) were used as an indicator of vulnerability of potential participants (Kroenke, Spitzer & Williams, 2001; Spitzer et al., 2006). The tools are not direct measures of risk of suicide, however it was deemed that they provided information around their potential risks that could inform a conversation, during the screening telephone call, about their safety.

4.3.3. The Sample

Five childless, European, positive women, aged between 32 and 43 years were each interviewed once. At the time of the interview all women were childless, were not pregnant and were currently living in the UK. All five participants believed they contracted HIV through sexual intercourse. The participants' anonymity and confidentiality is protected throughout the current study by identifying the women as numbers. For further demographic information about the participants see Table 1.

Table 1

Demographic information for the five study participants

Participant	Age (yrs)	Ethnicity	Place of birth	Country of residence	Relationship status	Taking HAART	Time since diagnosis (years)
Participant 1	38	White British	UK	UK	Single	Yes	2
Participant 2	43	White Spanish	Spain	UK	Single	Yes	20
Participant 3	37	Black British	UK	UK	Single	No	2
Participant 4	42	White British	UK	UK	In a relationship	Yes	11
Participant 5	32	White Spanish	Spain	UK	Single	No	5

4.4 Ethical Issues

4.4.1 Ethical considerations

Ethical approval for the study was granted by London Metropolitan University's Research Ethics Committee (see Appendix J). The research also complies with The British Psychological Society's *Code of Human Research Ethics* (2010). The study also adhered to guidelines protecting the personal safety of researchers (Craig, Corden & Thornton, 2000).

4.4.2. Informed Consent

Participants were asked to give their written consent (see consent form in Appendix L) if they wished to participate in the study. A consent form was provided prior to interview, detailing key information about the study; including the purpose of the study, the intended method and confidentiality. Participants

were informed that they had the right to withdraw from the study at any time without penalty and without giving a reason. An official university contact for reporting any queries or concerns was also provided on the form. Participants were made aware that they had six weeks to withdraw post interview, if they no longer wished to participate, again without penalty and without giving a reason. Written consent was gained before interviews commenced.

4.4.3 Confidentiality

Participants were informed verbally, and on the consent form (see Appendix L), about confidentiality and its limits. Participants' names and other identifying information were removed from the write-up of the study and replaced with a number or alternative description. Identifying information was stored separately from audio-recordings and the subsequent data-analysis at my home address. All research materials were kept securely and confidentially at my home address. Participants were made aware that audio recordings would be destroyed as soon as my doctoral qualification has been conferred, and any anonymised data would be kept for five years post research project submission (until September 2020), according to the London Metropolitan University's Code of Good Research Practice (2014), after which it would be destroyed. The researcher transcribed all interviews and was the only person who had access to the voice recorder and software involved.

4.4.4 Potential Distress

Participants were assured, both verbally, prior to the interview and on the consent form (see Appendix L), that they were not obliged to answer interview questions, and that the interview could be terminated at any time.

As participants were asked to discuss potentially emotive and distressing experiences during the interviews, a distress protocol (Appendix M), intended to minimise risk and ensure the wellbeing of participants, was adhered to during each interview. This involved the researcher being attuned to verbal and non-verbal cues of distress, and in such an event being able to practise the distress protocol.

On completion of the interview participants were provided with a debriefing sheet, which included the researcher's and supervisor's contact details, as well as contact details for support organisations (Appendix N). Additionally, at the end of the interview participants were encouraged to ask questions or discuss any concerns or feelings that were evoked during the interview, aimed to minimise levels of distress.

4.5 Data Collection

4.5.1 Interviews

A semi-structured interview schedule was developed (Appendix O), which was based on relevant literature, discussions with IPA-experienced research supervisors, discussions with the London IPA group and guidance on interview schedule development (Smith & Osborn, 2008; Smith et al, 2009). The schedule was used flexibly to facilitate further probing of any areas of interest that might emerge, and to encourage detailed descriptive accounts (Smith & Eatough, 2006).

The interview was trialled using a Counselling Psychology colleague, and further developed through points learnt from the mock interview. Following several draft schedules, the questions and their order were modified until it was deemed adequate in its ability to address the study's research questions, as well as enabling participants to assume the role as experiential experts in the phenomenon being studied (Smith & Osborn, 2008).

4.5.2 Interview Process

The information sheet and consent form were discussed in detail before commencing the interview. Participants were encouraged to ask any questions or voice concerns before signing their consent. Once consent was obtained and the participants were ready, the researcher engaged the recording equipment; two voice recorders, to allow for back-up should one device fail. Interviews lasted between 45 minutes to just over one hour. During the interview the researcher adhered to the distress protocol (see Appendix M). On conclusion of each

interview the participant was provided with a debriefing sheet (see Appendix N). Participants were given a further opportunity to raise questions, concerns or comments. Once any queries were addressed the researcher thanked each participant for their participation in the study. Further contact with participant by the researcher was limited to email contact; with the promise of the final version of the thesis to be provided if the participant confirmed interest at the interview.

Following each interview the researcher noted down non-verbal cues and any process information in a reflective diary that was referred to during the analysis of the data (Smith et al., 2009) (see extracts from the reflective diary in Appendix P).

4.6 Data analysis

Data was analysed using IPA, as detailed by (Smith et al, 2009). The research supervisor was consulted throughout the analysis, by presenting and discussing sections of analysis at various stages. The process also conformed to guidelines for ensuring quality in qualitative research (Brocki & Wearden, 2006; Elliot et al., 1999; Sandelowski, 2004).

4.6.1 Transcription process

Each interview recording was transcribed by the researcher, and included all that was audible from the recording, as well as pausing (identified in the transcript as 'dots,' one dot per second). During this initial transcription phase any content that required anonymising was highlighted, such as names and geographical locations. The second phase involved fully anonymising the transcripts, through altering the previously highlighted items. All participants names were given a number, dependent on the chronological order of their interview; thus participant 1 through to participant 5. Any other highlighted identifying information was changed to an alternative description. Thirdly the transcript layouts were altered to meet IPA requirements for data analysis, including margins on the left and right for notes to be made, and line and page numbers (for an example of the transcript layout see Appendix Q).

4.6.2 Analytic process

The principles set down by Smith & Osbourne, (2003) and Smith et al. (2009) have been closely followed throughout, and have thus resulted in idiosyncratic data analysis.

Data was manually analysed, as it was considered that no matter how proficient the computer software, there was a possibility of an interference in the phenomenological process; by using the software it is no longer solely between the participant and the researcher.

Firstly the chapter on analysis in Smith et al. (2009) data was read several times, paying particular attention to their examples of data analysis. Secondly, all five transcripts were read individually several times, to enhance engagement with the text. For each individual transcript the left hermeneutic was achieved, (noted in the left margin), by making exploratory annotations when reading each transcripts bearing in mind linguistic, descriptive and conceptual commentary. The notes indicated anything that seemed interesting or significant in relation to descriptions and language used, including initial associations that came to mind, similarities and contradictions (Smith & Osbourne, 2003).

The right hermeneutic was achieved by re-reading each transcript and the initial noting in the left hand-column. Then by noting emerging themes in the right margin, developed through interpretation of the initial left hand notes, and drawing on psychological terminology, whilst remaining grounded in the words of the transcript (Smith & Osbourne, 2003; Smith et al. 2009). This required moving to a more interpretive level of abstraction, general enough to allow theoretical connections to be made. The practice of constant checking between interpretations and the text ensured that the themes remained grounded in the text. In keeping with the phenomenological nature of IPA, words or phrases used by the participants themselves were used, where relevant, as labels for the emerging themes. The noted emergent themes were aimed at reducing the data set whilst maintaining the complexity of the initial note taking (for an annotated

transcript example see Appendix Q). From the transcript a list of emergent themes was created for a participant (for an example see Appendix R).

The third stage involved organising the emergent themes into clusters, based on connections related to associations; making connections between emergent themes. Any themes that emerged where associations in the text were no longer obvious were dismissed. Each of the clusters was labelled to represent a shared meaning, and these themes were presented in a table of super-ordinate themes (for an example of a participant table of themes see Appendix S). This process was repeated for each transcript, resulting in a table of super-ordinate themes and subordinate-themes, with quotation references, for each of the five participants (see Appendix T). After all interviews had been analysed, individual theme tables for the participants were examined, and clusterings of their superordinate themes were constructed which transcended all participants. This involved looking for patterns across the sample, and was achieved through redefining and reconfiguring some of the superordinate themes, as well as consistently returning to the transcripts. As a result of this process super-ordinate themes and subordinate themes for the group were created from the themes that consistently emerged across the sample. Thus a master table of themes for the group was created (Appendix U).

4.7 Writing up

The master theme table developed in the final stage of analysis was used as the basis for writing up the analysis. Verbatim extracts from the transcripts were used to illustrate and explain the themes derived from the analysis. The analysis section provides a narrative account of the themes that emerged from the group.

4.7.1 Quality and Validity in qualitative research

The quality and validity guidelines proposed by Elliot et al. (1999) were adhered to in the current study. These include; “owning one’s perspective, situating the sample, grounding in examples, providing credibility checks, coherence, accomplishing general vs.. specific research tasks and resonating with readers” (Elliot et al., 1999, p.220).

Triangulation is considered to be an important way of establishing credibility in IPA research (Smith and Osborn, 2003). Triangulation proposes that convergence of data from multiple perspectives is an indication of the validity of research findings. Although triangulation often refers to the convergences of data across different data sources or methods, it can also be used to describe convergences across perspectives (Breitmayer, Ayres & Knafl, 2007). Triangulation occurred through the use of supervision and peer review.

Emerging themes were also discussed in supervision as the analytic process developed, and the coherence and comprehensibility of the analysis was reflected on. Additionally through the audit of analysis sections in group supervision, it was agreed that the themes elicited could be justified, and appeared grounded in the text, thus demonstrating credibility and trustworthiness of the data. Further auditing of sections of analysis were presented and discussed at the London IPA group (a group consisting of experienced researchers and other doctoral trainees). There was agreement with the themes derived from the transcripts, and therefore the analyses appeared to be an acceptable reflection of the interviews.

Triangulation has been criticised as relying on the positivist assumption that there is a singular, fixed truth to which results can be compared (Angen, 2000). However, from a social constructionist perspective, which proposes that there are multiple realities and understanding is co-created, the multiple perspectives that might emerge through triangulation can lead to a richer understanding and are hence welcomed (Smith, 1996).

Finally, throughout the research process a reflective diary was kept (Smith, 1996), in which I wrote about my ideas, influences, interests, biases, personal development, concerns and emotions that the research evoked (see Appendix P). Supervision was also used to reflect on the process notes to aid reflexivity and interpretations.

5.0 Analysis

Participants were asked to talk as best they could about the different ways in which living with HIV has potentially affected or influenced their feelings, attitudes or beliefs about themselves, with a specific focus on sexuality and their feelings around motherhood. From the interviews, using the method detailed above, a master table of super-ordinate and sub-ordinate themes was developed for the group (see Table 2 below, and for a more detailed version, including participant quotes, see Appendix U).

Table 2

Master table of themes for the group

THE EVEN WORSE THAN UN-DATEABLE WOMAN

Sub-ordinate themes

- **The promiscuous woman**
- The bad, HIV-positive mother
- You have to tell

NOTHING CAN SPARK MY SEXUALITY

Sub-ordinate themes

- Loss of femininity
- Not bothered by sex
- You stupid cow

YOU HAVE TO ADAPT...I OWE IT SOMETHING

Sub-ordinate themes

- Why can't you just go away?
 - The fight
 - I owe it something
-

In this analysis section each super-ordinate and sub-ordinate theme is interpreted in turn, using examples of individual participant experiences from their transcripts.

5.1 Super-ordinate theme: The even worse than undateable woman

All participants related how, as a consequence of living with HIV, they had experienced a deterioration in who they felt they were as women, whether it be sexually, as a partner, as a potential mother, or the way they saw or felt about themselves as person. All participants reported a current or past engagement in a struggle with some part of that process, thus in most cases attempting to negotiate a spoiled identity.

5.1.1 The promiscuous woman

All participants shared a similar experience of feeling that they were labelled as an irresponsible, wrong-doing and promiscuous woman.

Participant 4: “We’re given all kinds of labels, of being promiscuous, or um you know junkies or um whatever and it’s shaming and um not liberating” (101-103)

Participant 4 speaks of experiencing derogatory labels, being imprisoned by their connotations, feeding into the notion of the spoiled identity of a positive woman. She experiences her HIV as an indicator of indiscriminate sexual ways to others and possibly to herself. Similarly HIV being synonymous with other forms of socially perceived immoral acts, such as drug taking. Her sexual self, due to the sexual nature of the prejudice, could feel damaged by the HIV, which in turn could negatively impact her overall sense of who she is.

In participant 1’s case, she tries to justify to herself and the researcher how she does not fit in with the societal misconceptions of positive women.

Participant 1: “I’m, you know, not an ex sex worker. I didn’t use to do intravenous drugs.” (120)

A battle against societal labels is apparent. The women’s perceptions of societal stigma are that they are now considered fringe members of society and can be grouped together with other social wrong doers, including prostitutes and drug takers. When speaking about this the participant appeared angry, possibly representing anger at having HIV; she did not deserve to get HIV - she was good, not a bad prostitute or drug taker. Prior to diagnosis she may have considered that others got HIV, not her, and thus as a result she then struggled to understand and accept her diagnosis.

Similarly participant 2 struggles with the labels assigned to women living with HIV.

Participant 2: “It’s a dirty one, because it means you’ve done something wrong or you have poor judgement, or you have something hiding in your history, or you are up to something naughty or you’ve been naught....that there’s something wrong with you, or your choices, or quality of life or something, you know. So they think there’s something wrong about you as a person.” (592-607)

Participant 2: “I still feel that shame and guilt... .feeling shitty and guilty and shame and you know undeserving and unworthy.” (195-304)

This woman refers to the notion of positive women potentially being considered as societal wrong doers. This could also represent her perception of her sexuality and female identity, as now dirty and tainted, identifying with societal misconceptions, thus causing her shame and self blame. Her use of “still” feeling shame implies such feelings have been plaguing her for some time, they seem hard to shift.

Several participants speak of experiencing a “double stigma.” Initially the stigma of living with HIV and then further exacerbated by being a *woman* with HIV.

Participant 4: “I think because women, um, because of the stigma with HIV and women, it can be very oppressive.” (98-99)

She is insinuating that there is something extra challenging about being a positive woman; the two feel mismatched. One may question what it is that is oppressive, is it the presence of the label of HIV, her perceptions of the label, others perceptions, her perceptions of others? Participant 1 similarly experiences the mismatch of being a woman and being HIV-positive.

Participant 1: “That’s the last thing he’s going to necessarily expect me to say, you know, I’m HIV-positive. Whereas you know with two gay guys, *I’ve got something I need to tell you*, it would be the first thing that the guy would think he’s going to be told.” (440-442)

She perceives that no man would think of a woman as having HIV, as perhaps women should not be promiscuous. Positive women are possibly stigmatised as they are not the women they *should* be, HIV represents them not being the ideal sexually reserved woman, despite only potentially one sexual partner required to get HIV. The gendered experience could be explained by the existence of societal norms of women as pure, non-sexual and thus good. Women living with HIV explicitly break this social ideal due to the sexual nature of the disease.

For some participants living with HIV appears to impact their sense of self-worth and viability as women, partners and mothers; it’s appears so far away from what is expected of a woman. Participant 3 perceives herself as undesirable due to her HIV status.

Participant 3: “I’ve got this disease and no-one will want me.” (194)

Her desire or need to be loved and wanted is apparent but it seems as though HIV has taken away her perceived desirability. For her possibly being wanted is important to defining what being a woman is. For her it appears that basic needs of love and belonging can no longer be met now that she is positive.

Participant 3: “You know I watched the undateables....my god even they are managing to get dates, even they’re managing to have a partner...why can’t I have something simple that other people have?” (146-156)

She compares herself to the “undateable” individuals featured in a television programme; even “they” who are considered to be undateable are able to find love and companionship. HIV makes her more undesirable than even “them,” despite its invisibility. She now belongs to another group of *them*, even worse than the undateables, women with HIV. HIV appears to have taken away the possibility of experiencing fundamental human needs of love and being with another. There was a sense of huge sadness and loss when she spoke.

Participant 1 shares a similar perception; that due to her HIV status she is no longer a desirable partner.

Participant 1: “Even if I do physically fancy them the likelihood of that guy wanting an HIV girlfriend is pretty low.” (428-9)

She seems to consider herself as an undesirable “HIV girlfriend.” Not only does HIV appear to deny this woman of love and a partnership, but also from being physically and sexually desired by another. HIV is perceived as destroying her sexual attractiveness and overall girlfriend credibility; HIV, being a woman, sex (with another) and having a partner appear to be mismatched.

In some cases others reactions have provided an opportunity for some of the women to possibly create, reinforce or exacerbate beliefs of being tainted and undesirable due to their HIV status.

Participant 3: “So I told him. He was gone like a shot.” (221-2)

With participant 3 having disclosed her status to a lover, it seems that this man could not get away quick enough. Being an HIV-positive woman appears so bad, that despite knowing the participant previous to her diagnosis, the HIV changed

who she was to him (or even who he was, someone with a positive girlfriend) into something he had to get away from.

Participant 1 has also experienced negative reactions from others. She spoke of the behaviour of an intimate partner that she disclosed to.

Participant 1: “And then a week later his *serious ex-girlfriend* came back on the scene and umm he *was not able to see me anymore.*” (492-3)

The HIV appears just too serious and damaging for the other to withstand. The way the partner veils his excuse may be internalised by her that she less desirable than the HIV-negative, ex-girlfriend.

Participant 2 speaks of similar experiences of others reactions to her HIV status.

Participant 2: “When you tell somebody, ah their faces you, it’s not like oh you know I have a heart problem, *oh poor you or oh how well you are doing.* But when you say *I am positive or I have...HIV.* Oh you know the impact that you have on others.” (571-4)

There is a sense that participant 2 blames herself for others’ reactions, and feels responsible for the impact that she feels she has on others. There appears to be a perception that she, with HIV, is hurting another. Self-blame appears as an underlying tone through many of the themes and contributes to this theme in terms of the women’s perceptions of themselves, contributed by others, as wrong-doers and therefore bad.

Participant 4: “I had to invite in a lot of forgiveness.....I had to learn about compassion for myself and forgiveness towards myself.” (52-423)

This woman has adopted the position of the wrong-doing, positive woman. It appears that she blames herself for her HIV status, as such experienced shame and guilt that required a conscious effort to forgive. One may question what it was that she felt she needed to forgive herself for, for her past sexual behaviour,

for having unprotected sex, for enjoying sex, for damaging herself? Internalised societal norms around women's sexual behaviour may be a contributory factor to the women's self-blame and in turn need to seek self-forgiveness; she has possibly had to do this for the first time, and has possibly had to learn this capacity.

5.1.2 The bad, HIV-positive mother

Some participants shared the experience of perceiving that HIV does not sit well with motherhood; thus felt that being a positive mother was unobtainable or undesirable to them, (and to others), and because being a bad, positive mother was a potential reality. Consequently the capacity to be a bad, positive mother added significantly to their concept of being an undesirable partner.

Some participants referred to the process of becoming pregnant whilst living with HIV as being unnatural.

Participant 1: "...now I have HIV, it won't really be a natural method"
(267)

Positive women in the UK are strongly advised to take antiretroviral medication during and post pregnancy, to feed the baby formula rather than breast milk and to give the baby antiretroviral therapy for four weeks post birth; all to significantly lower the risk of transmission of HIV to the baby. It appears that for participant 1 a fantasy exists where a "natural" pregnancy is defined as one without intervention, but one may question if this fantasy even exists without the presence of HIV. The use of the word "method" has clinical and experimental implications, further emphasising "non-natural," HIV-positive motherhood. Overall there appears to be the perception of the lost potential of a natural, and what this participant appears to consider as a normal, pregnancy as a result of HIV. It may be that the participant is experiencing shame as she feels she is no longer able to have a *normal* pregnancy and birth, therefore no longer considers herself as a natural or *normal* woman. The identity of a normal woman appears

to be tied up to a particular type of birth; one without intervention, despite lots of women requiring drugs and other procedures.

Participant 5 also refers to the non-natural aspects of HIV positive motherhood.

Participant 5: “On the other hand you have to take drugs and give drugs to your child and you cannot breastfeed...I would not feel I would want to bring up a child if I had to give drugs to a little baby... and I think breast feeding is so important for babies.” (310-315)

Again there is a sense of discomfort for this participant about the necessities of giving birth, such a having to breastfeed, when living with HIV. There was a sense of sadness when she spoke about this matter, which may be in response to the loss she feels about not being able to have a *normal* pregnancy that she perceives she would have been able to if she did not have HIV. The loss might also be experienced in relation to her capabilities as a woman, the HIV has tarnished some unique assets of womanhood, including giving birth and breastfeeding; a *normal* woman would be able to do this.

Additionally the thought of having to take drugs herself may be experienced as detrimental to her sense of womanliness; possibly that she is an inadequate woman requiring pharmacological input for a *natural* process. She also appears to feel guilt that she would have to inflict drugs on a vulnerable baby, she could be concerned that her own destructiveness in getting HIV will be transferred to the baby. Some of the women also experience this fear of their own destructiveness in relation to others when in a relationship; which will be discussed further in subsequent themes. Participant 5 would rather forgo her needs and desires as a woman, through acts she perceives as unnatural and thus inadequate, rather than to give life to another, through acts which could be perceived as caring, such as not breastfeeding to ensure the child’s good health. Perhaps her need to feel *normal* appears to trump any needs that the other might have.

She also refers to breast-feeding, another natural process that is hampered by HIV, and the subsequent drug taking. Being advised not to breast-feed is potentially detrimental to her definition of being a good mother. Being a bad mother for her is defined in two ways; giving too many drugs and no breast milk. For her the perception of being a good mother seems confined to bodily processes and functions, rather than what she does as a mother, positive or not, may represent. For example feeding of any kind could be perceived as nurturing, but not in this case.

Two other participants appear to experience feelings of guilt and badness if they were to pursue HIV-positive motherhood.

Participant 4: “Now I remember feeling quite strongly that I wouldn’t want to put that onto my unborn child.” (*speaking about being an HIV-positive mother*) (251-2)

Participant 2: “So I felt it was too much of a burden to pass it onto somebody.” (*talking about motherhood*) (198-9)

There is a sense of concreteness here for both of these women – drugs, burden, put – it all feels very solid and rigid. Both speak of potential feelings of guilt about having a child when living with HIV and talk of burdening the child with their (the mothers) HIV status; that it would be unfair, or bad of them to want to meet their desires of becoming a mother, and have a child that would have to contend with having a positive mother. This is a similar process discussed in the previous subtheme in relation to partners; there is a perception that HIV is too destructive or potentially hurtful for another to bear. Both participants appear to project their feelings that HIV is too difficult and hurtful for them, thus defend against these feelings and project them onto the unborn child. It’s interesting that the women possibly feel that their HIV status would be the most important aspect of them to their child, not the possibility that their child would love their mother despite their status. HIV appears so destructive and devastating to the women that they feel the need to protect others from their potential to hurt, thus some withdraw motherhood (and relationships). Most of the women seem to deny

themselves of being a potentially bad, HIV-positive mother through withdrawing from sexual relationships, thus any opportunity is lost; this is discussed further in the second super-ordinate theme.

Despite advancements in prophylactic medication, enabling women to conceive and give birth with greatly reduced risk of transmission, most of the participants seem to experience a need, or pressure, to deny themselves the experience of motherhood, potentially as a means of punishing themselves for being a bad, promiscuous woman.

One participant implies a possible questioning of her abilities as a mother post diagnosis.

Participant 1: “comments from Anne like, *you know, you’d be a good Mum* and like that.....And me going, *would I, would I?*” (295-297)

It could be interpreted that by simply being a positive woman one has the potential to be a bad mother, perhaps the shame of her HIV impacts her perception of herself as a mother. A later subtheme ‘you stupid cow’ could be being spoken to here, how could a stupid cow that gets HIV possibly be a good, responsible mother? Being positive and being a mother does not appear to sit well together, which could be related to the sexual nature of HIV.

5.1.3 You have to tell

There appeared to be a shared experience amongst four of the women in relation to feeling a pressure to disclose their HIV status to potential intimate partners. Thus consequently they all perceived their disclosure as lowering their credibility as a desirable partner, and in most cases feeling as if they have rendered themselves undateable women in doing so.

Participant 3 speaks of feeling an overwhelming pressure to disclose her status to a potentially intimate partner.

Participant 3: *“I’ve got to tell him. I’ve got to tell him. I’ve got to tell him. That was all that was in my mind.”* (219-221)

It appears that the weight of an HIV label is so overwhelming that it is all consuming when she is with him, and she feels no choice but to disclose. Disclosure could serve as a means of disconnecting with the other, as she is now undeserving (through having HIV) she pushes the other away, thus disclosure could be a self-sabotaging act. Alternatively it could also be used as a reason to keep people away, just as it may be used as a reason not to have children. Possibly one discourse is being used to escape from the other; HIV potentially allows the women to refuse to be good partners as it does to be good mothers.

Similarly in participant 2’s case she described that not disclosing is too difficult to bear.

Participant 2: *“I feel like as a woman, you have to tell. You cannot just say nothing because it’s very difficult. Very difficult.”* (107-110)

She emphasises how hard it is to tolerate withholding her HIV status in a potentially intimate situation. She implies that there is a difference in being a woman living with HIV, in terms of disclosure, compared to a man; a woman “has” to tell, she has a duty to. It appears that a woman with HIV experiences an extra responsibility towards others.

Participant 5 experiences what appears to be the extra pressure and responsibility to disclose being a positive woman.

Participant 5: *“We are women so there’s a double stigma.....I think that we women have to disclose more, disclose more.”* (41-45)

She speaks of a gendered experience for positive women; there seems to be something even worse about a woman having HIV than a man. This gender difference is experienced and plays out for these participants in the pressure to disclose. Participant 5 explains why she feels the need to share her status.

Participant 5: “I really think that we are women, we care more about it. Like I’m, *oh my god I’m going to transmit this to some other person*. I think that, I don’t know if I’m being too sexist here but I think that men don’t have that big concern.” (453-455)

It is interesting that she makes the assumption of what positive men might feel when she would not know; again a gendered experience is perceived. For her it appears that there is an innate, nurturing aspect to a woman that she feels a man does not possess, or perhaps that she has not seen. Thus the woman, as a result of their caring nature, is more concerned about the other than themselves, and the concern of transmitting HIV becomes apparent in an intimate situation. There is a fantasised other, through her own projections, that would see her as uncaring; the potential real other does not get a say. Interestingly, just like the bottle and drug giving to a baby, disclosure is unable to be viewed as an act of care towards the other. There is a huge amount of fear in potentially hurting the other, when in reality the transmission rate from a woman to man is much lower than the reverse.

What is also revealed here is how this woman defines an intimate relationship. There is no indication that an HIV-positive man exists to whom she would not have to worry about transmitting HIV, and she can’t consider herself as desirable to another; thus it appears that a relationship only involves two HIV-negative people.

For some of the women, sex appears to have been redefined as a result of the HIV diagnosis, for participant 5, sex and disclosure have become fused together.

Participant 5: “I said to myself that I would not have sex again, with a person without disclosing my HIV status.” (121-122)

It appears that it is not merely presence of the label that has created a barrier in intimate situations, but the participant’s perceptions and responses to the label. Participant 5 also reveals some of her understanding of what sex means to her;

she mentions that she would not have sex again “with a person.” What she might not be saying is that she can (or also cannot) engage in sexual acts alone, which contributes to sex and her sexual self, thus is potentially not denying (or further denying) herself all sexual pleasures.

Participant 3 reflects on her own traumatic experience of diagnosis, which appears to be a contributing factor in her decision to disclose prior to sexual relations.

Participant 3: “I’m thinking *my god you know I could never do that to somebody else*. And I think it need to be by permission almost....I would never want anyone to feel like I did that day I was diagnosed. Never. I would never do that to anybody else.” (209-263)

Somebody infecting her with HIV appears to be so traumatic that she can only indirectly refer to it; she is adamant that she would never inflict on somebody else what somebody did to her. She infers that anybody else would or must feel that same way as she does towards her HIV. There is also the assumption here that the other knew their status and did not disclose to her. However if the sex was unprotected and she had been unknowingly HIV-positive, she could be the one transmitting HIV to him; thus disclosure is being insisted upon, the disclosure that was never thought about before.

She speaks of needing permission to have sex, as though she feels that she is not worthy of such pleasure or intimacy, unless the other accepts her. Her need for others permission could reflect the impact of the HIV to her self worth, she possibly views herself as less of a woman compared to an HIV-negative woman.

Participant 3 speaks of imagining what sex without disclosing would be like, she fantasises that the burden would be too great for her to enjoy the sexual experience.

Participant 3: “So if the person has not consented to having sex with me, who has HIV, for me in my head it doesn’t work, I would be thinking about it, I couldn’t relax.” (249-251)

This is interesting as often consent is thought of with regards to sex, but in this case, for her, it is consent to sex with me who has HIV, that is thought about. Participant 3 speaks of disclosure as a means of protecting the other from the pain that she experienced due to another. She speaks as if her HIV status prevents her from freely enjoying sex as she might have before her diagnosis, potentially reducing the feeling of intimacy and pleasure. However one might consider that she is actually protecting herself, inferred by the repetitive use of “my” and “I.” In fact she may use her HIV status as a means of preventing sexual enjoyment as punishment for badness or as a means of seeking absolution, if someone knowingly agrees she is acceptable, however, in reality this is a frightening possibility.

Participant 5 demonstrates the difficult, and potentially self-sabotaging position that HIV, or their reaction to HIV, captures them in.

Participant 5: “also disclosing, because you think that the other person will be scared of you, they will treat you different. I think that’s why I don’t disclose more often...I am scared of telling them because perhaps they will treat me differently.” (175-423)

It seems as though there is a perceived inevitability that people will react negatively to her HIV status. One may question if the assumption of the fantasised other’s reaction is a projection of her new way of relating to herself post diagnosis, she treats herself differently, denying herself of sexual pleasure, intimacy and the potential of love from another. One may also consider if there is a hidden, and heavily defended, wish to be treated differently, to be a scary woman; however, responsibility for this cannot be accepted, as according to some social norms women should be caring and motherly.

5.2 Super-ordinate theme: Nothing can spark my sexuality

All of the women reported some change in how they relate to sex post diagnosis; how they practice sex, how they experience sex, how they view themselves as a sexual person. It became apparent through the interviews that the nature of transmission (all of the women reported contracting HIV through sexual intercourse) is an integral part in not only their subsequent sexual practices but also to their perceived sexuality and femininity.

5.2.1 Loss of femininity

The participants shared a similar experience of feeling that HIV has impacted their sense of femininity and all have felt less of a woman at some point since diagnosis. Participant 2 speaks of having to remind herself that she is a woman.

Participant 2: "I said, *I am a woman*. And try to be more, do the best with what you have." (309)

She implies that she is feeling less of a woman; somehow HIV appears to overshadow femininity. Again the repulsion of being a woman and being HIV-positive appears to be experienced; effort is required to maintain her sense of womanliness. There is a sense of hope when she speaks, there appears to be aspects of her "woman" that she can hold onto, though perhaps with effort; something of her "woman" still exists.

She speaks of ways she attempts to preserve her femininity.

Participant 2: "One of the nice things about being so thin is that you can get away with lots of lovely dresses. And I think *why not?* It's the only thing I have left you know, so why not." (281-2)

She connects and displays her womanliness through her clothing; thus her sense of being a woman is related to her clothing and her body. There was a sense of loss and sadness when she spoke of only being left with her thin body as a way

of expressing herself, and being close to her sense of womanliness. The control over her sense of who she is, and particularly how she relates to her womanly sense of self, has been taken away from her; the only way she can express it appears superficial and external. She also appears unsure as to whether or not she can *use* her HIV to enjoy her figure and nice dresses. This is interesting considering the existing female trends towards thinness; this woman appears conflicted to use her slimness and her body in the presence of HIV.

Participant 4 similarly speaks of the impact of HIV to her sense of femininity.

Participant 4: “rediscovering my body, rediscovering my femininity.” (48)

She implies that due to becoming positive something was taken away from her which resulted in her having to search and get to know herself again. One may consider that HIV resulted in a breakdown of her old self, and a new self is now being built. She also suggests that the relationship she has with her body has changed as a result of the HIV and somehow this is related to her sense of femininity. Perhaps HIV created a sense of disconnection between her body that contracted and harbours the virus, which in turn was closely connected to her womanliness; thus a rift was created between the two.

Participant 4 recalls an incident, where as a result of the HIV, her sense of femininity diminished.

Participant 4: “I had an experience a couple of years ago with an interaction with medication and I lost loads and loads of hair. My hair is a massive part of my identity and femininity....so when that’s taken away you could really see the impact on my self-esteem and confidence.” (149-153)

She describes her hair as an attribute that she measures her sense of identity and womanliness by, which was once lost due to HIV. There is also a sense of loss of control experienced by the woman; HIV appears indiscriminate in what it takes away. It seems that so much of the feminine identity of these women is in their

bodies and there appears to be a struggle to connect with this identity. This is related to other discussed themes, where the women struggle adopting previous or new identities; their sexual, female and mother identities are suppressed, denied or lost in some way. It is within the bodies of the women that the virus lives and consequently femininity cannot be accessed, sex not had and babies not born.

Participant 1 speaks of behavioural changes relating to flirting since becoming positive.

Participant 1: “Sometimes I probably would have done, flirted. I might have had a little more confidence about it.” (*talking about flirting*) (511-512)

It appears that since being diagnosed she feels less confident to engage in behaviours that she used to. The loss of confidence may be related to her perceptions of HIV, and herself with HIV, she possibly no longer feels desirable to another, thus flirting appears inane. Alternatively post diagnosis flirting may represent danger, perhaps her flirting lead her to sexual intercourse and ultimately to HIV. The flirting may also represent her past promiscuity, that resulted in her HIV, thus as a means of punishment she denies herself of anything sexual.

Participant 1 appears to question the point of sexually related behaviours.

Participant 1: “There’s not many men that would take me on anymore now.” (528-529)

Again, and a shared experience with other participants, HIV has resulted in her being a less desirable woman. She appears to be implying that as a positive woman she assumes she is a burden. Thus it appears that not only is femininity wrapped up in the bodies of the women, there is also some association between womanhood and being taken on (and loved) by a man; as this is not happening femininity is compromised. This may also relate to the previously discussed

theme around loss of mother identity, and in some way femininity and womanhood is about being loved by a child.

5.2.2 Not bothered by sex

HIV appeared to challenge the legitimacy of the sexuality of the five participants and for most, post-diagnosis, their sexual desires appear denied.

Participant 3: “They say, *are you sexually active?* And I say, *what the fuck!...god how can you even ask that question!*” (192-193)

The notion of having sex when positive appears horrifying, even ridiculous, to this woman. It is interesting though that the other, by asking the question, can perceive her as a sexual person, but in her eyes how dare they! She cannot perceive herself as a sexual person now that she has HIV. Later in the interview she further stresses the unthinkable nature of having sex when positive.

Participant 3: “But for me I can’t imagine having sex with anybody.” (215)

For this woman there is a sense of imagining what sex would be like now, post-diagnosis, potentially without consideration of the possible reality. It seems like she has rejected her sexual needs, thus rejecting her sexual self, along with rejecting the other. When asked about her sexuality, she describes the effect of HIV on her sexual self.

Participant 3: “And then you have HIV, it’s just another, well for me, it’s just like a coffin nailed.” [talking about her sexuality] (231)

HIV appears to kill her sexual self, “nailed” shut, no opportunity for resurrection. There is a sense of sadness, as well as acceptance, that as a positive woman, this is just the way it is; perhaps this is easier to consider than the messy alternative of negotiating sex with HIV. Any sexual desires that she may have appear suppressed and are buried. One may question what or who has nailed the coffin,

HIV, others, herself? The thought of fulfilling those desires is too difficult to bear; perhaps she protects herself from the pain by repressing her sexual needs.

Participant 5 speaks of feeling sexually constrained by her HIV.

Participant 5: “before I was more free.” [talking about sexuality] (153)

HIV seems to have placed limitations on the woman’s sexuality, she feels no longer able or “free” to be and express herself, including her sexual self, in the way she used to.

Participants 1 and 3 both speak of feeling sexual desires, whilst simultaneously disengaging with them.

Participant 1: “I am as horny as hell, but not really bothered about sex.” (617)

Participant 5: “We all think about that. But I am not doing it.”[talking about sex] (143-144)

Participant 1 contradicts her needs by possibly convincing herself that her sexual needs are not important. She speaks of sexual arousal as “hell,” one may question whether she considers her arousal as bad or evil like hell. She appears to split her arousal, which is in the body, between the act of sex, which is currently outside of her body. By supressing her sexual desires, which are perhaps bad (which also lead her to get HIV), she perhaps has the potential to be a good and desirable woman. Participant 1 is possibly implying that sexuality for her is more than what she feels and connects with in her body, it is also related to the connection with another body. One may consider if the women masturbate to fulfil their own sexual needs. Even so the women considered their sexuality to be compromised post diagnosis, as such their relationship to their own sexuality seems to be connected to expressing this through having sex with another.

For Participant 2, since diagnosis, she has not been involved with another on an intimate level.

Participant 2: "I have not had a partner for so long...well it's been such a long time that not had this [sex] and somehow I'm not bothered by it."
(248-268)

Again sex appears to be defined as sex when there is a partner, and by not having a partner the sexual self is dormant. Additionally, as sex is deemed no longer obtainable perhaps the desire is killed off. Possibly in some way the women nail their own sexual selves ("*coffins*") shut.

Participant 1 thinks about sex, it is not spoken about as something repulsive as it is for participant 3, yet it appears unobtainable.

Participant 1: "There's that little period of time where you are still a bit, Oh I'm missing sex, that goes away quite quickly for me, and then i'm kind of, you know, I don't really think about that anymore." (346)

She appears to minimise the importance of sex in her life post diagnosis. Since diagnosis it appears that sex was deemed unobtainable for her and she missed it, but over time she has learnt to deal with the loss, through supressing her sexual needs and sexual self. This suppression is also inferred when she speaks of her non-operational sexuality.

Participant 1: "nothing can spark my sexuality to come to the surface."
(326)

The spark that once was there seems to have gone out, it appears to be within her but is unable to be expressed. Perhaps this is not surprising given that sexuality seems to be closely linked to sex with another, she won't engage in a sexual way with another, thus the spark has no chance of ignition. Her sexual self appears to be buried, possibly in some way by herself. Her buried sexual self, unable, or not allowed to be activated, plays out in her life.

Participant 1: “*You must remember to look at men tonight, you must remember to look around.....I just forget to look!*” (371-380)

In reality there is no reason why she could not look for men, maybe she does not want to look, and HIV gives a reason not to. One may question if it is as simple as “I just forget” or if she has buried her sexual self beyond memory.

The apparent insignificance of participant 1’s sexual needs may reflect a hopelessness of not being able to have such needs met as a result of her perceived undesirability to another. Similarly participant 3’s sense of hopelessness is apparent.

Participant 3: “I can’t even think about that [sexuality] because all I can think is, I’ve got this disease and no one will want me.....Please don’t ask me if I am involved with somebody, because it’s like saying *have you won the lottery?* It’s not going to happen.” (193-200)

She perceives that being a positive woman is unfavourable to the other. However for this woman there is no room for the possibility of sex, or a relationship, because she has decided to opt out; you have no chance of winning the lottery if you don’t buy a ticket! This also further implies an association of sexuality as being related to another. As the other is assumed or decided as unobtainable sexuality becomes distanced and an inactive part of oneself.

5.2.3 You stupid cow

The majority of the women blamed themselves and spoke about feeling stupid for getting HIV. As analysis transpired there appeared to be a link between the women’s experienced loss of, or suppressed sexuality, and the self-blame and guilt they felt for contracting HIV.

Participant 1 self-blames and reprimands herself for her past sexual practices.

Participant 1: “*What a stupid cow you’ve been.....I should have used condoms more.*” (88-101)

She appears angry with herself, there is a sense that she feels she should have known better than to put herself in a vulnerable position; that she should have protected herself from HIV. Thus she may question if she was not responsible to look after herself, so how could she be responsible for another, a partner or a baby? There is also a sense of the weight of responsibility she directs solely towards herself, and not towards the other. She further emphasises the extent of self-blame.

Participant 1 “My initial thing was just so, I just felt so stupid.” (84-5)

It appears that the feelings of foolishness and self blame were overwhelming, the first thing she thought when diagnosed, which perhaps represents the internalised societal stigma of living with HIV, and possibly further exacerbated by being a ‘sexual’ woman. One may question what the stupidity is hiding, and to why a condom was not used. Perhaps she did not want to, and in fact enjoyed sex without one; but that notion is perhaps far from how a woman *should* behave, and thus potentially difficult to admit.

Participant 2 similarly shares the experience of self-blame.

Participant 2: “So there’s all that guilt and shame underneath.....It was my fault, you know, it was my poor decision....and I feel responsible for what happens to me...I protected myself to not get pregnant but not for everything else that happened.” (193-364)

She feels guilt and shame towards her previous sexual practices; avoidance of relationships and intimacy may serve to reduce such feelings. The guilt experienced may be associated with the failure to protect herself from HIV, which in turn may result in her questioning herself with a relationship or with a child, and her ability to keep them safe. She implies that her worst fear through having sex was getting pregnant, HIV appeared not to be a consideration.

Additionally participant 5 blames herself for getting HIV, due to her past sexual practices.

Participant 5: "I wish I was more respectful with that before." (234-5)

It appears that she is ashamed that she did not respect herself through engaging in the sexual practices that she did. Thus if she was not able to respect herself, which resulted in HIV, perhaps she perceives that she could not respect a partner or a child, or in fact that the other could not respect her.

For participant 2 it appears that she has done something so shameful, that is it hard to live with, and possibly difficult to like herself.

Participant 2: "But it's me who has to live with myself and with my body."
(646)

It appears that HIV represents something shaming. She contracted HIV through her body, where it continues to reside, thus she struggles having a relationship with HIV, her body, herself, and with others who might encounter her body. She also speaks of a self that is differentiated from her body; the two seem separated in some way. One may question is this separation is as a result of the HIV; the embodiment of the HIV within her body, and the need to expel it. This split may be a way of dealing with HIV; the HIV is in the body and not in the self (her mind).

Participants 1 and 5 both speak of the guilt associated with hurting another though being HIV-positive.

Participant 5: "hurting your mother, hurting your grandmother, what will they say, my god!" (187)

Not only are the women burdened with the guilt associated with self-blame, but also the guilt and shame of potentially hurting the other as a result of their diagnosis. The women appear to negotiate a new sense of personal

destructiveness, and again, given this potential to now hurt, how could they be with another, a partner or a child?

Participant 1 experienced a sense of relief that as her parents are dead she no longer has the potential to hurt them.

Participant 1: “I thought at least my parents are dead. I don’t need to tell them.” (694-702)

She seems to experience some comfort in her parents not being alive, perhaps as there is no longer any possibility of her and her HIV causing them pain.

5.3 Super-ordinate theme: You have to adapt...I owe it something

All participants relayed that living as positive women they faced a variety of struggles they had not contended with before diagnosis. However, even though they grappled living with HIV, and in most cases still do, some women attributed positive life experiences or self-growth, as a result of having HIV. This super-ordinate theme aims to highlight these contrasting experiences of negotiating living with HIV as a woman.

5.3.1 Why can’t you just go away?

Most of the women, regardless to whether or not they have reached a point of accepting their HIV status, have experienced, at some point post diagnosis, wishing that they were not HIV-positive, yet all of the women appear to have incorporated HIV in some way into the way they perceive and view themselves as women, partners or potential mothers.

Participant 4 appears to have a confused and complex relationship with HIV, she initially speaks of HIV being external to her sense of who she is.

Participant 4: “I am a woman with HIV.” (306-8)

“Woman” precedes “HIV,” perhaps suggesting that HIV does not consume her sense womanliness or how she views herself; first and foremost she is a woman. This maybe interpreted as resistance, or being in denial of the consumption of HIV to her identity as a woman, due to the interchangeable way she describes herself.

Participant 4: “because I’m HIV?....I do know that that is very specific to my experiences of people around my HIV.” (303-443)

Here the way she relates to HIV appears to have shifted. She has taken ownership of the HIV, describing it as “my HIV,” as though she experiences closeness with it. Similarly “I’m HIV,” suggests an intimate connection between the self and HIV; the HIV is the whole of her. The different ways she describes herself and HIV may reflect the point of her negotiation with HIV, perhaps she is still working out how to be, and to see herself as a positive woman.

Participant 2 appears to struggle defining her relationship with HIV.

Participant 2: “Even though I keep using I am positive, which means, implies, that’s who you are. You know and it’s not true, is it?” (522-3)

She appears to have consciously thought about how she relates to HIV. It appears that even though she verbalises being defined by HIV, there is a resistance, or possibly hope, that this is not the case. Perhaps the double meaning in being a *positive person*, (optimistic/confident or living with HIV), used here is an indication of her conundrum, one may question if she is confused as the whether or not she can be both.

In contrast Participant 3 appears to accept HIV as a part of her.

Participant 3: “Because HIV is a part of me, it’s not the whole of me.” (422-3)

This woman appears to define herself as a whole that is split into parts, a part being her HIV, one may wonder how large a part HIV takes up of herself. However there also appears to be a resistance to the HIV not taking up a greater part of herself, suggesting it could if allowed.

For the majority of the women HIV appears to be present in how they experience and relate to themselves as women, one woman speaks of experiencing this presence.

Participant 2: “You sometimes think, *oh shit, why can't you just go away.* But obviously it's not going to.... If you put it to the back of your mind, it's always there.” (353-529)

She seems to switch, and battle, between HIV being a part of her and not being a part of her; wanting “it,” (not me), to go away, yet on the other hand “it's who I am.” Perhaps she is struggling to be a woman with HIV. There is a sense that battling against her HIV is exhausting, however HIV is never going to go away, however much resisted; one may question what would happen if she just let the HIV be.

5.3.2 The fight

For the majority of participants a battle against HIV ensued post diagnosis. For some it appeared to be a battle of self-preservation, as though the HIV was a threat to the women's sense of whom they are, some women appeared defeated by HIV.

Participant 2 speaks of regret for a life that was not fully lived before her diagnosis.

Participant 2: “I don't even feel like I've lived at all.” (86)

There appears to be regret in relation to the opportunities that are now lost due to her HIV status, or perhaps HIV has put her in touch with opportunities that were

never experienced or not taken prior to diagnosis. It appears that a woman negotiating HIV may need to grieve for a past life. She is implying that she has never lived, one may question as to why it has taken an HIV diagnosis to realise this. Alternatively with that realisation, albeit through an HIV diagnosis, that one is not or was not living, one has been given a choice or opportunity to live (despite being present before diagnosis).

Similarly participant 3 speaks of regrets and a perception of life now being over.

Participant 3: "I know you should not regret things, but I would probably have lived differently..... I should have made the most of it." (38-462)

She speaks as though her life is now constrained by HIV, yet contrastingly her language implies that she did not live particularly freely pre-diagnosis. Again, why wasn't she "making the most of it" pre-diagnosis, why did it take HIV to realise this? There is also the assumption that HIV is automatically impacting on the way she was or wasn't living her life, a resignation to this, yet does not imply how it is interacting. HIV appears to have brought some of the women into contact with what they never had, or were not doing, which is a difficult realisation to bear.

However there appears to be a resilience that emerges in relation to their 'new' lives with HIV. There is a sense of strength and determination, as well as hope that a life with HIV is worth living. Perhaps this is the start of them taking the opportunity to now start to live their life that was not lived before HIV.

Participant 2: "You have to adapt." (258-9)

It seems that she now has to accommodate HIV in herself and her life. It also seems that she experiences no choice other than to construct herself or her life to suit the HIV; one may question what the alternative of not adapting to the HIV may be, neglecting herself, a rejection of HIV and herself?

Participant 5 is determined, perhaps to fight against HIV from consuming herself, or a fight to preserve the life she had before diagnosis.

Participant 5: “I try to deal with that. Cope with the challenge....I’m a fighter.” (449-486)

It appears that she experiences HIV as something to conquer, and a challenge that she is determined to succeed at. Since diagnosis it appears that she has been ensued in a battle with HIV, perhaps a war for self-preservation, and it appears that this fight is on-going, but one that she is determined to win. One may wonder if she would have described herself as a fighter before diagnosis or if the HIV has enabled her to unlock or access a part of herself that she could not, or did not need to before.

Participant 4 similarly experiences a fight against her HIV.

Participant 4: “I have never allowed HIV to stop me....it’s like *do I overcome that? Yes.*” (349-392)

It appears that, if “allowed,” HIV could prevent her from being who she is; perhaps consume or act as a threat to her identity, her womanliness, her sexuality. Strength, determination and conscious effort is required to prevent HIV from engulfing who she is. In comparison to participants 2 and 4, this woman does not imply that HIV has stopped her living, nor that her life that is now over. It appears that she holds the power in her life, not HIV, and she will live, or not live, her life through her choice, not HIV’s.

As a result post diagnosis she was able to identify the “warrior” in herself.

Participant 4: “there’s a real warrior.” (414)

One may question in this instance who or what has she has had to battle against which has enabled an appreciation of the warrior in herself; she spoke in the previous quote of not allowing herself to be stopped by her HIV, perhaps the

battle has been against herself (not specifically her HIV) and her negotiation of HIV. It also applies that possibly others do allow HIV to consume them. It appears that courage has been required to stand up to the potential threat of HIV, or the threat of herself with HIV. Perhaps the courage has been required for the process of self exploration that occurred for this woman post diagnosis, and such self-exploration has been required to prevent HIV or herself with HIV from restricting her life and perhaps her sense of who she is.

One woman spoke of another battle, a fight against others perceptions of women living with HIV.

Participant 5: “We have to fight to make it something common....we really have to fight against that.” (413-433)

She displays her resistance and desire to challenge the societal conceptions of HIV-positive women. There was a sense of great passion when she spoke; perhaps this woman needed something to fight against in order to come alive, and live the life not being lived before. One may question what it is in this instance that needs fighting against, society, others, herself?

5.3.3 I owe it something

Despite living with HIV being a continuous battle or source of hardship for most of the women, some of the women experienced their diagnosis as an opportunity to increase their self-awareness, and for one woman in particular, achieve personal growth.

Participant 2 appears to show some gratitude to having HIV.

Participant 2: “Being positive means so much negative stuff to my life, I owe something to it as well...It gave me to tools to explore myself, who I was.” (297- 308)

HIV appears to have enabled self-exploration, alongside negotiating the HIV label, to increase self-awareness. She attributes HIV for giving her the means of conducting the exploration. It is interesting to consider why it took an HIV diagnosis to be able to do this. But it appears that from something awful something good has happened.

Participant 4 similarly experiences a sense of appreciation towards her HIV:

Participant 4: “The HIV has made me stronger, it has made me look at stuff that I would not have necessarily looked at.” (424)

HIV is given credit for enriching her life in some way, again it has created an opportunity for this woman to explore and get to know herself better. It seems that some of the participants require a powerful force outside of themselves to enable them to act; before their HIV diagnosis they were not acting, not living, but now as a result of the HIV they have the ability to. Perhaps the “stuff” that HIV has enabled her to look at might be the difficult parts of her, the vulnerable and disliked parts of the self. Thus through sorting the “stuff” she has become stronger; she attributes this to the HIV and not to her reaction or successful negotiation of living with HIV – it’s all the HIV, not her!

Participant 4: “It took me a while to, you know, peel that and get to it. But that was a real turning point for me.” (62-3)

There is sense of the complexity of being a woman with HIV, a tough process requiring “peeling” to understand and accept. Contrastingly even though HIV has challenged, and in some cases stunted or suppressed, aspects of the women, there appears to be a new sense of closeness to and understanding of themselves for some of the participants. Again the HIV diagnosis has enabled access to who she is, to “peel” away and understand her desires, needs, self or hopes for life; perhaps to peel away or get to know and accept the bits of herself that she did not like.

Participant 5 shares participant 2 and 4’s gratitude towards HIV.

Participant 5: “I also feel more positive perhaps, like it happened because it should happen that way.” (503)

She is more “positive” in the sense that she is HIV-positive, yet ironically and against social discourses of the destructive nature of HIV, she is positive in a good not bad sense. She seems to be saying this through hope and faith, rather than the through positive self-change or the discovery experienced by participants 2 and 4; possibly as a way of trying to make sense of HIV being in her life. This could be a way of coping that helps to protect her from the painful and difficult emotions an HIV diagnosis evokes; to search and be hopeful of meaning. Yet it is also realistic to consider that we only grow in relation to something, and life experiences shape who we are, in this situation responding to an HIV diagnosis. Perhaps the HIV diagnosis was needed to be able to do this.

Both participants 2 and 4 further speak of the arduous and complex process of living with HIV.

Participant 2: “I’ve been working on myself for a long time now.” (203)

Participant 4: “Through the work that I have done on myself.” (296-7)

It appears that through being diagnosed with HIV both have had to exert a sufficient amount of psychological effort to learn to live with themselves as positive women. The women imply that they need to do work on themselves now, as perhaps HIV has reconstructed them in a way they don’t like and need to change. Perhaps this “work” on the self was always needed, prior to diagnosis, and yet again HIV gave them the motivation to do that work.

For participant 2 the “work” she has done on herself has required her to reflect on and learn about who she is.

Participant 2: “I learnt about myself...had to really go inside” (300)

She has experienced personal growth. A better understanding of herself may have enabled her to be more compassionate and forgiving of herself for acquiring HIV, in turn possibly helping to reduce feelings of shame and guilt, and their potential impact to her.

Participant 4 speaks of a similar experience of her journey with HIV.

Participant 4: “There’s been a lot of freedom in my journey....it was very liberating, incredibly liberating when I heard myself saying it.” (94-5)

It is interesting that a dominant experience has been of an HIV diagnosis being limiting and constraining, yet this woman implies the opposite; that for her HIV has been liberating in some way. She speaks as though she experiences herself as altered somehow, through the long process of negotiating living with HIV; she started in one place and is now in a different place, a better place. It also appears that she has reached a part of her journey that she is content with, whether or not the journey has ended, she has reached a point of self-acceptance, which in itself is freeing. Her HIV does not appear to have not consumed who she is, in fact it has possibly enabled her to find, to live and to be at peace with herself.

For both participants 2 and 4 there appears to be a sense of personal empowerment of being able to embrace the trauma of being diagnosed with HIV and then being able to take advantage of the resultant clarity. Participant 4 speaks of a new found confidence.

Participant 4: “I would not have been able to say, sort of then, years ago, or identify with that tenacity.” (427-8)

There is a feeling of pride in her negotiation of her journey with HIV. She is now able to identify herself as a strong woman, possibly through reflecting on her experiences since diagnosis. HIV appears to have enabled her to access a part of herself that was unknown before diagnosis; HIV was the outside force that put her in touch with a self that she appears happy and content with.

For participant 5 it seems like her journey to self-acceptance and peace is in its early stages.

Participant 5: “I would like to be more confident with that as well. I’m working through that path.” (178-9)

HIV has perhaps enabled her to start her journey of self-contentment. She acknowledges that it will be hard work but appears determined to succeed; perhaps HIV has allowed to access her hidden strength to do this, strength she was not aware of before. Has HIV in fact made her and some of the other women stronger not weaker?

6.0 Discussion

Siegal, Schrimshaw and Lekas (2006) have noted that women's ability to adjust psycho-sexually to HIV is not directly related to having better health due to medical advancements. The current study highlights that issues of trust, shame, guilt and emotional distress go beyond good physical health, and prevent positive women from engaging in sexual relationships and becoming a mother. The women in the current study struggle to negotiate the contradictory concepts of sexuality and motherhood in the presence of an HIV label, this is experienced and negotiated by the women to varying degrees of success and levels of impact to their psychological functioning and daily life. For all of the women, independent of their idiographic experiences and negotiations, the contradicting concepts of sexuality and motherhood in the presence of HIV affected the women's sense of who they are in some way. This chapter presents how the aforementioned subjectivity is experienced and negotiated by the positive women in the current study, paying particular attention to any clinical and research implications of the findings.

6.1 Renegotiating sexuality

Aligning with existing literature, HIV was experienced by some women in the current study as devastating to a woman's sexuality (Gurevich et al, 2007; Siegal & Scrimshaw, 2006; Squire, 1993). For the majority of participants their sexuality was ruined or 'broken' in some way by their HIV, and remained so. Consistent with Bova and Durante's (2003) suggestions, it appeared that it was not merely the presence of an HIV label itself that necessarily impacted on their sexuality, but the meanings that the women attributed to it. However and contrastingly, one participant had the ability to renegotiate her sexuality post diagnosis. She spoke of a happy and sexually fulfilled relationship; unfortunately this experience appears rare given its quiet, or perhaps underrepresented and non-validated voice in the existing literature.

Yet for the majority, HIV entailed severe limits on the way sex, love and intimacy can coexist; the women in the current study defined sexuality as a

combination of the three aforementioned elements, thus a women's sexuality can be consequently restricted by an HIV diagnosis. From the findings of the current study it appears that the unassailability of HIV in relation to a woman's sexuality, (and motherhood), remains a central dilemma for positive women.

6.1.1 Spoiled sexuality

HIV (or their perception of themselves with HIV) has caused the women to re-evaluate the way they relate to their sexuality. It appears that an HIV diagnosis facilitated them to look at themselves, including their sexual self, through a magnifying lens. The way in which the women viewed themselves through the lens affected how they related to their sexuality, how they behaved sexually and how they engaged, or not, with sexual relationships post diagnosis.

At some point, post diagnosis, all of the women viewed themselves as dirty and damaged women as a result of their HIV. Some struggled to view themselves other than through a lens dominated by the presence of an HIV label. For those women, HIV defined them and became their master status (Frale, 1993). However most wished not to be objectified by the disease and battled against the label. Some had, with effort, been able to shirk the labels that were attributed to them by themselves and others. Neimeyer (2004) suggests that when a person with a label comes to view themselves as nothing but the label, this can colonise their entire identity, affecting their relations with themselves and others. Thus, as seen in the current study, a change of self-perceptions and behaviours, including sexual behaviours post diagnosis with the adoption of the HIV label occurs for most of the women. The study did fail to explore in detail the women's sexual behaviours post diagnosis, other than through sexual intercourse with another. Future exploration of any nuances in how positive women may view sexual activity (and thus their sexuality), other than through sexual intercourse, may help expand the current literature and aid understanding when working therapeutically with positive women. However from the current study it appears that the women's sexual selves were impacted by their subjective perceptions of their status, and they questioned who they are as sexual beings and as women.

Existing research suggests that, when diagnosed with HIV, women suffer a sexual death, wherein their sexual identity as desirable, sexual beings is threatened or at worst destroyed (Ross and Ryan, 1995); the majority of the women in the current study echoed this. Sexual relationships and the women's relationships with their sexual selves were dependent on whether or not they viewed themselves as ruined by HIV. The women who viewed themselves as ruined by their HIV experienced a greater sense of shame, guilt and ultimately unhappiness.

The women in the current study appear to have to contend with the contradictory meaning of being a positive woman, on one hand a *good* woman is responsible, nurturing and non-sexual and yet on the other the *bad* HIV-positive person is dirty, sexually deviant and irresponsible, this is concurrent with previous findings (Valencia-Garcia, Starks, Strick & Simoni., 2008). The women in the current study have to negotiate such contradictions and in all cases, at some point post diagnosis, societal judgements appear to be internalised by the women, with the perception of themselves based on such judgements, shame and guilt experienced. Some of the women can't seem to break away from such labels and self-blame.

6.1.2. Suppressed sexuality

An HIV diagnosis for some of the women appeared to "nail the coffin" on their sex lives. The women spoke of sexual desires but four of them, (those not currently in relationships), simultaneously had decided that sex could no longer be a part of their lives. Some of the women in the current study spoke of a desire for sex, but a lack of drive to fulfil that desire with another. Existing research suggests that positive women block their sexual desires and needs (Saldanha de Almeida et al., 2010). One may question if the women are purposefully denying themselves of pleasure, intimacy, and love due to perceiving themselves as undeserving or undesirable. Additionally for the women it appears that sex is mixed with anxieties about their dirtiness, their contamination and potential destructiveness. Thus the women who are no longer interested in sex may be splitting off sex as *bad*, which manifests as a lack of desire for sex. Further

splitting appears to occur in other areas of their lives, which will subsequently be discussed in this chapter.

Suppression of sexual desires could be considered a coping strategy in the renegotiation of sexuality post diagnosis. For most of the women sex is deemed unobtainable, and in some way they have 'killed' their desires, if they do not want it, cant want it, it's not going to happen. Similarly Florence et al. (2004) suggested positive women experienced lower levels of sexual desire post diagnosis, and proposed that suppression of desires and needs may account for the reported reduction. One may question why positive women may suppress or reject their sexual desires and needs. The loss of interest in sex could be acting as a defence against the pain from the potential rejection by another. All of the women post diagnosis experienced fear around disclosure and the potential rejection by a sexual partner. By disengaging from sexual relationships they spare themselves the anxiety of disclosure and the possible pain of rejection. Those who experienced rejection were further reticent about becoming sexually involved; the rejection confirmed their perceptions of themselves as spoiled women. The women's fear of rejection could also represent further splitting; the women perceive the 'other' as potentially uncaring, rejecting and bad. The bad aspects of being HIV-positive and how the woman relates to herself with HIV is split off onto the 'other.' Thus even though the subjectivities between being HIV-positive, being a woman and sexuality may be socially constructed, it is experienced in the internal world of a positive woman.

An additional explanation for the suppression of sexual desires may be provided by the need to practice safer sex precautions when living with HIV; most commonly through the use of condoms. A condom may be a reminder for women of not having kept themselves safe enough; sexual desires may be suppressed as a way of protecting themselves from painful reminders of their perceived previous *irresponsible, bad* behaviour. In the Saldanha de Almeida et al., (2010). study, the new meaning attributed to the penis, as dangerous and untrustworthy, could contribute to the suppression or loss of sexual desire for positive women experienced in the current study. To cope with the anxiety of self-blame, seeing the penis (the man) as bad and untrustworthy may represent

the bad aspects of being HIV-positive split off and projected onto the man. The notion of oneself as deviant and bad is split off into others who come to represent the deviant. However in the current study it appears to be more complex than this, there are all sorts of bad objects, not just the penis, including; the bad mother, the deprived/abused child, the un-wanting partner, the bad sexuality.

6.1.3. Withdrawal from sex, intimacy and love

Most of the women in the current study experienced a spoiled identity, which as previously discussed was contributed to by the experienced subjectivity between being a woman, having HIV and thus being sexual; as a result withdrawal from sex or “accidental celibacy” was used to negotiate this subjectivity. Greene, Frey and Derlega (2002) report that positive women abstain from sex as punishment for their *deviant, promiscuous* past ways. As all of the women in this study reported that they contracted HIV through sexual intercourse, through denial of their sexual needs, by not engaging in sexual intercourse, they may be punishing themselves for their past irresponsible behaviour, or even making sure they do nothing else that is *bad*, like getting pregnant when being HIV-positive.

The majority of the women in the current study relate to and define sex and their sexuality through being with another; sex is only sex when with a partner and as the majority of women are not having sex with another, their sexuality was perceived as ruined or non-existent, rendering some of the women feeling lonely and unattractive. One may question if this is a gendered nuance, and if HIV positive men may define and view sex in the same way as some of the women in this study appear to. An exploration of how positive men view sex post diagnosis could help to develop both the HIV literature and the understanding of any gendered experience of HIV.

Additionally the women may not only be denying themselves the pleasure derived from sex but the potential to find love, be loved, show love, be desired and desire others. As discussed previously sex has become the ‘bad object.’ It appears that for some of the women the meaning attributed to HIV is so powerful that it can destroy love or the hope of finding love. One may consider if HIV is

being used on some level as an excuse for not finding love or having to find love, in these cases HIV is given a considerable amount of power and responsibility.

None of the women were in long-term relationships at the time of their HIV diagnosis. A partner's acceptance of their status at this time may have provided hope and acceptance, which helped to preserve their sexuality and prevented a withdrawal from sexual relationships. One participant spoke of having a sexual relationship just prior to her diagnosis, however she was shunned by her lover post diagnosis. This experience left her feeling dirty, ashamed, unaccepted, acting to further confirm her beliefs of being a ruined woman due to her HIV. Baumgartner and David (2009) suggest that fear of disclosure is the main reason individuals living with HIV become celibate. Therefore a woman's sexuality is not merely impacted alone by the presence of the HIV, but is constructed by one's experiences, and in this case by intimate relationships (Bova and Durante, 2003 argue this).

For some of the women an HIV status transformed sex from an enjoyable act into a dangerous and anxiety provoking pursuit. As sex became a dangerous pursuit that can lead to disease and infected children the *best* way some of the women dealt with this was through "accidental celibacy." This is consistent with existing research where women view themselves as a vector of transmission, despite women being significantly more vulnerable to HIV transmission through sexual intercourse than men (Patton, 1994; UNAIDS, 2014).

6.1.4 No sex without disclosure

Four participants described themselves as single at the time of the current study and for these women issues of disclosure appeared in the forefront. They spoke of negotiating their sexual behaviour post diagnosis; at some point post diagnosis deciding *never* to have sex without disclosure. For some women this decision was made without having had any sexual experiences post diagnosis. For others the decision followed sexual experiences without disclosure, where they experienced that their pleasure and intimacy levels were compromised, perceived as a result of their undisclosed status.

For the majority of the women sex and disclosure appear fused together; a woman cannot have one without the other. Thus their definition of sex, and consequently sexuality, has been altered post diagnosis. One may question if this fusion is an additional gendered nuance. Exploration of men's definitions and perspectives of sex post diagnosis would be required to explore this theme more comprehensively. The need to disclose for the women may be considered to be a defence mechanism - a reason not to have to negotiate a sexual relationship with HIV that could possibly be difficult and painful. Disclosure may be experienced as a foreclosure of power and sexual agency; "sexual activity is not only my choice anymore" thus "no sex without disclosure" may be a strategy for preserving agency and power. Additionally HIV may provide the women with a reason to keep the other away.

Some women spoke of a compelling need to disclose, exacerbated in sexually intimate situations. Gurevich et al. (2007) found that responsibility and protecting the other delimits physicality, thus impacting physical enactments and restricting sexual identity. One may question if the women's need to disclose is solely as a result of protecting the other from infection. One participant spoke of "sex by permission," thus I wonder if through disclosure there is a need to feel accepted by another, which may help them to start to accept their positive status. However there is a risk alongside disclosure that the other is not accepting of their HIV and ultimately of them. Sex, which may have been associated with pleasure, intimacy and love, now has the potential to be more painful still.

6.2 HIV- an unfeminine illness

Most of the women spoke of HIV taking away a part of their sense of being a woman at some point post diagnosis, articulated in most instances as loss of femininity or womanliness. All of the women spoke of experiencing a difficulty in being a woman with HIV; the two appeared to be contradictory, a mismatch and difficult to negotiate in unison. This nuance is a novel finding of the study, the loss of femininity experienced as a result of living with HIV has not been previously been suggested or explored.

The loss of a sense of themselves as desirable, sexually attractive and feminine women was obvious for some in the current study. The women spoke of losses and strategies to preserve their sense of womanliness post diagnosis. One woman spoke of losing her hair due to her HIV medication, which had a huge impact of her sense of womanliness, as well as to her sexual being. Another woman spoke of preserving her femininity through her clothing, as she felt not longer able to express herself through physical intimacy and love-making, yet she appeared unsure about using her slim figure, which resulted from her medication, to enjoy her femininity. Thus, and a unique contribution of the study, is that the women appeared conflicted about the use of their femininity in the presence of HIV.

It appears that much of feminine identity, as well as sexuality, reside in the bodies of the women, their figures, their clothing, their hair and yet the virus lives within their bodies and as such a repulsion between the HIV, and femininity and sexuality exists. Interestingly it is also with the bodies of the women that sex cannot be had (and babies not be born); further repulsion between HIV and feminine assets. One woman spoke of having to reconnect with her femininity suggesting a need to close the divide that had been created by HIV. One may consider if the women defeminise themselves, through their own misconceptions about HIV and themselves with HIV, in a similar way that they withdraw from intimate relationships through their perceived impact that they have on the other. Consequently, and a further unique contribution of the current study, as sex is not being had by the majority of the women - and sex (and sexuality) is defined as being related to a man - their sense of womanliness was compromised through not being confirmed or accepted by a man. Thus most women in the study appear to define sexuality and femininity as being related to a man. What could be being spoken to here are discourses of being a “natural” woman/mother. Sexual intercourse is a natural and normative behaviour that people engage in, as most of the women in the current study are not having sex their “natural” or “real” woman statuses could be being compromised, and thus their sense of womanliness put into question.

6.3 Spoiled ‘mother’ identity

All participants spoke of motherhood as carrying one’s own child; thus having a biological connection. Similar to sexuality and femininity, the women relate motherhood with their bodies. Thus bodily connection between motherhood and HIV is experienced and appears difficult for most of the women to negotiate. From the women’s apparent definition of motherhood, as being a biological mother, discourses of being a “natural” mother may be adding to the fantasised construction of positive motherhood in these women’s minds. One may question if the bodily related or “natural” definition of motherhood was how they may have constructed their idea of what constitutes being a mother pre-diagnosis, and if the bodily connection has been emphasised as a result of HIV and its sexual connection to the body. The current study is unable to answer this, but further research could explore if women’s definitions of motherhood and being a mother change as a result of being positive.

Despite the very recent advancements in prophylactic medication (from 2010) enabling positive women to become mothers with a greatly reduced risk of transmission to their child, the positive women in the current study appear to have difficulty negotiating the idea of motherhood. A potential nuance for European women compared the more prolifically researched African populations of positive women, is an empowered choice whether or not to have children. A recent study explored the experiences of positive mothers in Kenya in relation to their choices of becoming a mother and choices relating to their pregnancy, such as opting for a home or facilitated birth (Dahlberg et al., 2015). The study revealed that the women felt the choices were not their own, in becoming a mother or the choices they made as a mother, they were culturally and socially determined. Thus potentially African positive women, as motherhood appears expected, pre-motherhood they may not *need* to negotiate the concepts of potentially being a bad or not “natural” mother in deciding whether or not to become a mother. However European women potentially do have to negotiate the two concepts, as most westernised women do have a choice around motherhood.

Most of the women spoke of guilt when thinking about an HIV-positive pregnancy, particularly in relation to the medication required for such a pregnancy, having to give the baby drugs post birth. Additionally the idea that they, as positive women, should not breastfeed was upsetting for the women, the thought that they could not provide the *best* form of nutrition to their baby. The women view themselves as potentially *bad* mothers due to their HIV, defined by two ways, too much of the drugs and not enough of breast milk. Feelings of badness and guilt are experienced when thinking about an HIV pregnancy, so much so that one of the women had decided not to have children. Blystad and Moland (2009) found that breast-feeding for positive women with children became to represent a dangerous act and challenged women's maternal identities. Yet the current study offers a further new contribution, and suggests that such challenges to women's maternal identities start before entering into motherhood.

Kirshenbaum et al. (2004) suggested that positive, pregnant women and mothers experience a conflict between society's interpretation of 'normal' motherhood and the negative perception of a positive woman choosing pregnancy. The women in the current study define a normal pregnancy and motherhood, as one without drugs and as having the ability to provide breast milk for the baby, therefore rendering an HIV pregnancy non-normal and undesirable. Despite many women bottle-feeding their babies, having caesareans or some form of medical intervention during childbirth, the women appeared to idealise a notion of a 'normal' pregnancy, which for them is unobtainable. A 'good' and 'normal' mother would not require interventions; thus the ability to be a 'good' mother is threatened by the presence HIV. Interestingly the women do not view the drugs or the bottle as acts of care, instead they represent inadequacy, selfishness and danger. This is reflective of findings of Ingram and Hutchinson (2000) and Stinson and Myer (2012) where positive mothers face a double bind, they are bad for giving baby infectious milk and bad for giving them the bottle.

It appears that the "good mother" themes and discourses may be influencing the participant's fantasised perceptions of themselves as positive mothers (Baker and Carson 1999; Bobel 2002; Garcia, Surrey & Weingarten, 1998; Hays 1996). The *natural* mother discourses, including the expectation of pregnancy, childbirth and

mothering all to be achieved naturally, threaten the ability of the women in the current study to be *good* mothers. Within the medicalised discourses breastfeeding is inseparable from the conception of being a *good* mother (Carter, 1995; Murphy, 1999). As positive women are advised not to breastfeed in order to reduce the risk of vertical transmission, their ability to become a *good* mother, which also has to be balanced with other *good* mother discourses, such as acting a responsibly. Thus in terms of being a *natural* and *responsible* therefore *good* mother, for the participants in the current study their fantasised perception of positive motherhood is that they can't be either. As the current study aims to explore the consideration of positive motherhood for European, childless women, the women in the study fantasise about how positive motherhood might look, this might be very different to the reality. In order to develop the literature, further studies exploring the concepts of sexuality and motherhood for positive, European mothers could offer insights into the reality of being a positive mother in a westernised society, to see how this fits, or not, with the fantasies of the women in the current study.

Long (2009) suggests that social representations still exist where positive women are seen as bad and threatening even when considered within the positive context of motherhood; the women in the current study appeared to experience themselves as potentially bad when thinking about HIV-positive motherhood. Additionally Valencia-Garcia et al's. (2008) study spoke of the difficulty participants had with perceiving themselves as both positive women and mothers. In the current study the women struggle to imagine themselves with the two identities simultaneously. They appear to split anything associated with HIV as bad, and alternatively anything not related to HIV as good. Thus the woman with HIV becomes the bad object (in the minds of the participants) transforming that that is deemed good to bad in the presence of HIV, such as motherhood and womanhood.

The role of the other has been discussed as a critical element in relation to the woman's sexuality, as well as their sense of womanliness; it also appears relevant in the context of HIV motherhood. Some of the women fear that having a positive mother would be too much of a burden for the child, so in some cases

they abstain from motherhood, as they did sex. There may be concerns that their own destructiveness and sense of wrong-doing could be transferred to, and has the ability to hurt the baby. Thus the women further experience the whore versus mother contradiction, where women are considered to be infectious to either their own children or to men (Sacks, 1996). One may also question if their perceived HIV-positive, mother identity has an impact on being a desirable woman; a man would not want a bad mother as a partner. Thus the women's idea of being a bad mother might influence their fantasises of how they would see themselves in the role or be seen by other, such as a partner.

Sandelowski (2003) and Giles et al. (2009) propose that it is difficult to escape ideas of positive motherhood, positive women and badness, and as a result positive women have to work harder than others at being 'good' mothers. The current study also suggests that positive women have to renegotiate identities to be able to portray themselves as good. In the current study as the women were childless this did not occur in the context of motherhood, however and a further unique contribution of the study, is a renegotiation of other identities to present themselves as good women. For example for some of the women who speak of "accidental celibacy" could be an attempting to be good women; what could be 'more good' than a non-sexual, pure woman? Possibly by presenting themselves as non-sexual helps them to alleviate the internal conflict of their identity of being good or bad with HIV. Most of the women in the current study have developed strategies to possibly present themselves as good, in order to deal with the incongruity between motherhood, sexuality and HIV, including through refraining from sex or relationships, denying or suppressing sexual desires and ultimately preventing themselves to be loved by another, a partner or a baby. Thus because of their conflict, they 'choose' one over the other, to be a good woman, they can't be a bad mother or partner. Again the current study may be touching on a gendered nuance here, that positive women potentially have to work hard to present themselves as good mothers, women and people. However as the current study has no comparison to male experience further research into such male identities, including positive fatherhood, could expand this area of the literature.

The women's negotiation of their thoughts and feelings around HIV-positive motherhood may have an impact on how they perceive themselves as women. As Allen and Hawkins (1999) suggest motherhood is an external validation of a woman's social identity. Some women experienced this as denied by their HIV status. Additionally as positive women are advised to bottle not breastfeed, the women may have experienced HIV as taking away a fundamental female capability; thus jeopardising their sense of femininity. This is consistent with the experience in Blystad and Moland's (2009) study where women viewed themselves as having failed bodies, especially in relation to breast-feeding. The attributed meaning of a failed body is particularly relevant to the women in the current study as they closely relate sexuality, motherhood and femininity with their bodies. Thus their compromised bodies, as a result of HIV, appear to diminish their ability to be feminine, sexual and to be mothers. For the majority of the women in the current study it appears that they struggle with the idea of being a sexual woman, a mother or both. From the findings of the current study it does not appear that the whore versus mother discourses and themes are the driving contributor to their construction of themselves as positive women, they appear more heavily influenced by ideas around their bodies and discourses being *natural* women and mothers. Their perceived failed bodied compromise their ability to be sexual women and to be *natural, good* mothers. The relationship between HIV and the women's bodies within which the virus resides appears to impede their ability to be sexual women and potential mothers.

6.4 HIV identity

Most of the women in the current study described experiencing HIV as a central, though not a unifying element, to how they perceive themselves. For some, HIV was considered to be a greater influence to their sense of who they are than others, such variation is consistent with existing research for other groups of positive individuals (Flowers & Davis, 2012). As Baumgartner and David (2009) suggest, an HIV diagnosis can disrupt an individual's identity, possibly further compounded by the fact that none of the women in the current study perceived themselves as vulnerable to getting HIV. Thus when the women were diagnosed with HIV, their existing self perceptions were challenged and internalised social

constructions of HIV began to play out; the *bad* woman, the *bad* partner, the *bad* mother, the *bad*, uncaring other.

None of the women desired to be defined by the HIV, yet some appeared to become consumed and defined by their status. Some worked hard to prevent it, in these cases there was a strong voice of resistance and strength. As such some women were able to identify an inner strength that they were not able to reach before diagnosis. One may question if an HIV diagnosis made the women stronger or whether or not it enabled them to harness an existing, unutilised strength within themselves.

For some of the women there was a sense of ownership of HIV. It appeared to connect with them on a level that was greater than just the virus living within their bodies. For others, who appeared more distressed by their status, there was a clear rejection of the unwanted possession of HIV. Even so for most of the women their relationship with their HIV was confused and difficult to verbalise, suggesting that they were still negotiating an identity that included HIV. This finding is synonymous with existing research suggesting that following a trauma, such as an HIV diagnosis, alterations in certain aspects of the self, such as fragmented identity, negative self-perceptions and integration of the trauma into the self perceptions can occur (Brewin & Holmes, 2003).

Not all of the women have come through the ‘turmoil’ of being diagnosed as HIV-positive, some have been able to accept their new ‘possession’ each in her own way, others have not. Baumgartner (2007) argues, that for people diagnosed with HIV, their identities evolve, and suggests that in all cases people ultimately embrace their new identity. I did not find this to be the case as some of the women continually struggled to define and accept who they are with HIV, independent of time since being diagnosed. For these women there was a greater sense of what they had lost due to their HIV status, including good health, perceived control, perceived opportunities, loss of who they are as women. The focus on loss of identity for some of the women suggests that they were, and some still are, searching for a new identity post diagnosis. Burke (1991) suggests that people redefine themselves depending on their perceptions of the self and

societal perceptions of the self. As previously discussed the meaning that the women in the current study ascribed to their status and themselves is socially influenced. Stigma associated with HIV constructs discourses and meanings that restrict the identities of HIV-positive women as ‘fallen’ women, whether or not they adhere to the social codes of good and sexually responsible women, leaving women little room to negotiate identities that allow them to maintain their social positions (Valencia-Garcia et al., 2008).

6.5. Personal growth

Bury’s (1982) work helps us to understand the extent of the impact of an HIV diagnosis to a person, which is classified as a severely disruptive and potentially traumatic life event. From a Counselling Psychology, non-pathologising, perspective the current study gives an indication of what the potential trauma of an HIV diagnosis might look like for European, childless women; as a challenge to the perception of oneself as a woman, as a potential mother, as a partner, as a sexual being, and in some cases grieving for perceived losses (such as a past life, intimate relationships, perceived loss of opportunities).

However one woman in the study was able to recover from the stress of her diagnosis, and ultimately perceive her experience of HIV to be a positive influence on her life. This woman described positive psychological growth following her diagnosis; she attributes some defining positive qualities of herself to be as a result of the trauma of being diagnosed with, and living with, HIV. Post-traumatic growth (PTG) describes a process whereby individuals experience a positive transformation as a result of their struggle with adversity (Tedeschi & Calhoun, 2004). PTG has been reported across of a range of illnesses including HIV (Golub, Rendina & Gamarel, 2013). This particular participant described her HIV diagnosis as traumatic, yet somehow she was flexible enough to be able to accommodate what had happened to her. A couple of other women in the current study were also able to attribute something positive to their HIV; namely the identification of positive personal attributes that they were unable to identify, or harness, prior to diagnosis. However these women were less comfortable with their HIV status, and were unable to negotiate a happy and fulfilled life

following diagnosis. Others in the study were unable to view their HIV diagnosis as anything but negative; the diagnosis had resulted in a loss to themselves and their lives. Thus there appears to be a continuum of loss and growth when living with HIV. The women who had travelled along the spectrum towards growth had experienced loss and trauma but had been able to move along from this. The concept of trauma is subjective in itself, women may suffer varying degrees of trauma following diagnosis and some may not feel traumatised at all.

However, independent to the degree of trauma experienced, if experienced at all, interventions that reduce stress and promote growth, rather than solely focussing on symptom reduction may aid in the renegotiation process experienced by positive woman post diagnosis. This approach is even more important as Sherr, Clucas, Harding, Sibley and Catalan (2011) in a systematic review of HIV, post-traumatic stress disorder (PTSD) and PTG, found that positive women are more likely to be diagnosed with PTSD than positive men.

6.6 Implications and recommendations for clinical practice

6.6.1 Psychological therapy with positive women

6.6.1.1 Being a positive woman (*being a woman, being a partner, being a mother*)

The majority of positive women in the current study hold a rigid and limiting view of what constitutes being a woman, this in turn inhibits their sense of womanliness, which in turn impacts on their relationships with others, themselves and their overall psychological wellbeing. Their rigid view of *woman* is defined, at least in part, by most of the women as being a woman who is not positive, and thus consequently as positive women their sense of womanliness is compromised. The women additionally defined *woman* through being related to be a man, and in turn being positive, meant *man* was no longer obtainable and thus the women's sense of womanhood was restricted. Therapeutically the women could be helped to become less rigid and more flexible in terms of how they define themselves as women (not necessarily as positive women but more

importantly as women). Therapy could help to suspend and question the women's definitions of gender and explore their beliefs of how a woman is defined, exploring questions such as how can womanhood be defined other than through relating to a man? Therapy could also be a space where a detailed examination of the places, such as in bodies, clothes and personalities, where 'woman' or 'being feminine' lives, to help further expand their definitions, and aid acceptance to use their femininity when HIV-positive; this many of the women in the current study struggled to do.

Additionally the women in the current study similarly hold a rigid definition of sex, they relate to and define sex and their sexuality through being with another. Sex is only sex when with a partner, as the majority of women were not having sex with another, their sexuality was perceived as ruined or non-existent, thus they felt lonely and unattractive. Furthermore for the majority of the women sex and disclosure had become fused and defined together; one cannot exist one without the other. The women's definition and beliefs about sex in general (and sex when HIV-positive) could be explored in therapy, helping them to become more flexible in their views. Other opportunities of being in touch with one's sexual self other than relying on another could be explored, such as increasing intimacy with the self, perhaps through clothing or behaviour, or encouraging intimacy with others, other than through sex.

As with gender and sex, the women in the current study also hold rigid views of how motherhood should be, and HIV-positive motherhood does not fit into most of their definitions. Again therapy could help women to suspend these rigid ideas and develop more beneficial ideas around motherhood and what being a mother and mothering is.

The constrained view that most of the women in the current study have of themselves, post diagnosis, appears to contribute their difficulties as living happily as positive women. Some Counselling Psychologist's, dependent on theoretical standpoint, may refer to the view that the women have of themselves as their self-concept. As perspectives of the self-concept differ, the current study recommends that if the self-concept is applied in therapy when working with

positive women, it should be viewed as a multifaceted, dynamic concept that is socially influenced and capable of change, rather than conceptualising a self-concept that is unitary and stable (Markus & Wurf, 1987). A perspective of a self-concept that is stable for these women would be further limiting to the view they have of themselves. Alternatively a feminist approach may be useful in helping the Psychologist, and positive women, to conceptualise and understand the view they hold of themselves. Feminist philosophies speak of a self that is not necessarily coherent or homogenous, but is relational, dynamic and is wrapped up in the body, cultures and interpersonal settings (McAfee, 2003; Miller, 2014). Multifaceted and dynamic perspectives of the self may promote hope for change, without creating further limiting labelling of the self.

However unhelpful in nature the rigid and inflexible ideas about gender, sex and motherhood might give the women in the current study a sense of control and knowing, having felt a lack of a control over their lives from the shock of their diagnosis. The majority of the women appear dominated by their HIV compared with the degree that they are able to dominate it. The women could be helped in therapy to accept the degree to which their lives are within their control, or not within their control, and in turn enable them to gain a sense of personal power which may help them to challenge their view of themselves as positive women, partners and potential mothers.

For the women in the current study the view of themselves with HIV was limiting to themselves, to their relationships, to their lives, and ultimately to their happiness. All their issues with constructs including sexuality, gender and motherhood appear to be borne out of HIV. However one may consider if such issues existed prior to an HIV diagnosis, and are not solely as a result of HIV, yet post diagnosis they conveniently found a home within HIV. Perhaps it is more palpable for the women, for me, and for society to locate them here. Therapy could provide women with a space to explore these ideas, to understand what is as a result of HIV and what is not, or has potentially been confounded by HIV, so they can understand their way of being in the world, enabling agency and power to modulate issues if they elect to.

6.6.1.2 Personal growth

The current study acknowledges the potential of an HIV diagnosis to be a traumatic event for an individual, yet as such, also a potential opportunity for growth. This view aligns with Counselling Psychology philosophy of working with and harnessing strength and capacity for growth and promotion of wellbeing within the therapy room (Smith, 2006). Yet the current study suggests the possible need for other issues to be addressed before growth could be a potential focus of therapy, such as dealing with loss, working through to self-forgiveness, self-acceptance, having a less rigid view of oneself.

For the participant in the current study, who was able to achieve a position of self-acceptance and personal growth as a result of her diagnosis, she consistently reported challenging her perceptions of herself with HIV over a prolonged period of time, enabled through psychological therapy, that offered a space for self reflection and self acceptance to occur. However as this was a finding of the current study and not an initial aim, the study cannot offer a great deal of insight into specifically how she reached, and subsequently others could reach, a point of self-acceptance and even growth following an HIV diagnosis. Future research recommendations are made with regards to this in the following section. However this participant appeared to work through issues of how she viewed herself as a woman and a partner with HIV. Such issues may require addressing before growth can potentially occur.

All of the above recommendations could be applicable for use in both individual and group therapy settings.

This study brings hope for a paradigm shift in the way therapeutic work with individuals diagnosed with HIV can be approached. In line with Chwalisz's (2008) comments for the need for Counselling Psychologists to draw on positive psychology principles, this study has succeeded in identifying some growth responses that positive women can experience when renegotiating their lives with HIV. As Counselling Psychologists we can offer a different take on HIV, moving beyond the focus on medical and clinical difficulties, not bypassing or

ignoring the psychological pain and impact of an HIV diagnosis, but being inspired by those who are able to move beyond it and by using such examples in our clinical work and potentially publishing case studies to highlight such experiences.

6.6.1.3 Assessment

In order for therapists to ascertain if any of the above issues are relevant and potentially require addressing during the course of therapy for the client, a detailed assessment of the clients issues, should be implemented; being mindful of the issues highlighted in the current study. Assessment should also aim recognise strengths of the client that may be harnessed in therapy to aid a potential move towards a position of psychological growth.

In order to determine if any of the issues highlighted in the current study are relevant to the client, and are negatively impacting on their lives and psychological wellbeing, questions that explore such issues should be asked at the assessment stage. For example questions that consider the positive woman's view and definitions of gender, sex, motherhood, such as asking, how do you define being a woman? Or how would you define yourself as a woman other than relating to a man? Additionally any self-help materials that might be constructed for positive women could include such ideas and questions.

6.6.2 Education

Counselling Psychologists and other health professionals can act as expert representatives of HIV, we can play a crucial and influential role in educating the public about HIV. As such it is imperative that we reflect on and challenge any personal biases that could potentially hinder a clients adaptation. Apart from being relevant to our client work, it is also relevant to how HIV is presented by ourselves to the outside world; for example reflecting on what language we use when describing the condition, whether that be in clinic, in work we publish or how we generally refer to and talk about HIV in our general lives. Through our profession and other healthcare professions the fear laden messages and

derogatory labels, that influence positive women's definition and view of the themselves, could be challenged and indirectly help positive women in their lives through such systemic change.

Public health interventions could help to challenge existing discourses that impact on the successful negotiation of HIV for European women. A dominant discourse that emerged from the current study that impacts on the women's sense of femininity centres on HIV being a non-feminine illness (i.e. a male condition). Such discourses are disempowering and more empowering discourses need to be created advocating gender equality. Healthcare messages that challenge stigmatizing social norms should be promoted. It appears from the women's experiences in the current study that women experience a greater sense of responsibility for protecting themselves and others, which lead to blame and guilt as well as exacerbating self perception of irresponsible bad women. Healthcare messages should aim to create more of a sense of shared responsibility.

Additionally and in order to challenge the discourses around "otherness" attributed to HIV, "it happens to others, not me," which further encourages "bad" perceptions of people with HIV, discourses of "normality" should be promoted. The idea that someone is to blame has a significant history in HIV healthcare messages (Dodds, 2002). HIV is not an illness that only affects "others," anybody is at risk; this needs to be more widely disseminated. Furthermore "normality" discourses could be promoted by healthcare professional and healthcare messages including; the "normality" of sex when HIV-positive, the "normality" of being a mother when HIV-positive. The majority of women in this study withdrew from sex and the motherhood for reasons that included their perceptions of non-normal relationships/sex with HIV-positive, which are likely to have developed from internalised societal misconceptions about the *badness* of HIV.

6.7 Limitations of the current study

6.7.1 Methodology

As IPA is idiographic it does not aim to deliver definitive answers. Thus, it is not possible to apply generalist claims from the findings of the current study for the wider populations of counselling psychologists working therapeutically with positive women. Therefore it is necessary to acknowledge that the findings of the current study provide an in-depth insight into the salient themes of the participants' experiences. Thus the aim of the current study was theoretical transferability in contrast to empirical generalisability, therefore the study aims to enable readers to evaluate the transferability of the study's findings to people in similar contexts and make links between the findings and their own experiences, both personal and professional. The study does not aim to make claims for all Counselling Psychologists working with positive women but provide some understanding of the broader context, so that future studies might add to this and potentially make more general claims where applicable.

Although every attempt was made to be rigorous and transparent, as previously discussed, one limitation of IPA is that the researcher attempts to access participants' experiences through their own interpretations. Consequently other researchers may have highlighted different features or themes from the same data.

Furthermore the researcher is only able to interpret the experience of participants through the role of language and thus through what is spoken in the interview. Thus the ability of the participants to express themselves (as well as the researcher's interview skills), and thus communicate a rich texture of their experience that conveys details and nuances of their experience may vary. In the current study there appeared to be a variation in the ease and the detail by which the participants' were able to portray their experiences.

6.7.2 The sample

A further factor to consider is the selection bias amongst those that chose to participate. The experiences of those who did not participate may have been quite different from those who chose to participate. The majority of the women who participated in the current study were struggling with their sexuality post diagnosis, perhaps participation was perceived as a potential aid - to help them with their struggles in some way.

As the sample in the current study consisted of women, the study is unable to comment on experiences of positive men's sexuality and feelings about fatherhood. However as this is also an underdeveloped area of the literature, future research could explore samples of positive men for any gendered differences or similarities of experience that may occur.

The women in the current study identified themselves as heterosexual, thus the focus of the findings of the study were directed towards heterosexual relations and how they might be experienced post diagnosis. Alternative sexual orientations may impact the experience of female sexuality and considerations of motherhood post diagnosis differently. Given the impact of an HIV diagnosis to the to sexuality of the women in the current study and the connection between this and a man, alternative intimate relationships, such as lesbian relationships, and subsequently female sexuality, maybe experienced or impacted in a different way.

In distinguishing European, women from the rest of the HIV population the study marks gender and ethnicity as differentiating criteria. Gender is considered to be a defining variable according to the women in this study. However it must be remembered that each woman's view and experience of womanhood is varied. In terms of ethnicity many current studies have focussed their attention to black, African women living in Africa; the current study hoped to explore the experiences of European women. The inclusion criteria being expanded from British to European was considered not to affect the homogeneity of the sample greatly as the participants possessed commonalities that were relevant to the

research question; also remembering that the majority of studies include African women, so European women's including British women's experiences could be explored through this study. Though one participant commented that being a black positive woman in a predominantly white area of the UK impacted on her experience and feelings of isolation; thus within the sub-group of women eligible under the inclusion criteria variation most likely occurred. As the category of woman was so central in the analysis and findings of this study, perhaps future research could explore this further in relation to different types of women; for instance exploring the experiences of European women of varying ethnicities to understand if the support needs of sub-groups differ.

A point of difference of the current study was sampling childless positive women, to explore how they considered motherhood when living with HIV. As such the women appeared less able to talk to great extents about their feelings around positive motherhood, in contrast to how most spoke more freely about their sexuality. As the women were not mothers this was to be expected, and also as most of the women were not engaging in intimate relationships the probability of the being a mother diminished, thus may have been given less thought. As such the women not being mothers must be kept in mind when considering the findings in the current study around motherhood.

All the women in the current study assumed that they were able to become biological mothers (they believed had the physical ability to conceive and carry a child and had not been informed otherwise). Given one of the study's objectives to consider motherhood, women who are aware of a lack of ability to become a biological mother may experience thoughts and feelings about motherhood differently.

Additionally, and as previously discussed, the participants' defined motherhood as having a biological child, thus were speaking from their experiences relating to this definition. Perhaps positive women whose definition included being a mother through other means (adoption/fostering etc.) would experience similar or different subjectivities to the women in the current study; particularly given

the connections between the body, sexuality and motherhood revealed by this study.

One participant in the current study was diagnosed pre-HAART (highly active anti-retroviral therapy) and not all the women were on HAART. Participants' experiences did not appear to differ greatly due to such variation (and as did not surface in the interviews), thus has not been discussed further. However experiences may differ if future studies created more homogenous samples in relation to time since diagnosis and medication. The women did not speak of differences in their feelings about their sexuality or feeling about motherhood in relation to being 'undetectable'; however the interview questions did not specifically address if HAART has an effect on sexuality or feelings around motherhood, which may account for its omission in the women's narratives. Further research could explore the impact of HAART on positive women's sexuality and feelings around motherhood, as well as their overall sense of wellbeing. Such findings may be an important factor when considering HAART, for not only physical advantages, but also potentially psychological benefits.

None of the women were in a relationship at the time of their diagnosis and only one woman (the participant who attributed growth to her HIV status) was in a relationship at the time of the current study. Future studies could explore the role of existing and subsequent intimate relationships in the role of potentially assisting (or not) in the successful negotiation of an HIV diagnosis. Further IPA studies could sample single positive women and those in a relationship, both at the time of diagnosis and following, to explore the role of intimate relationships in negotiating HIV, and consider if issues raised in the current study around defining oneself, sex, and motherhood differ amongst varying relationships statuses.

6.7.3 Validity

A continued debate in the literature focuses on the usefulness of participants' validation as a means of ascertaining credibility of the findings, it is suggested as a method for checking the researcher's understanding and to ensure the

participant's views are not distorted (Angen, 2000, Yardley, 2008). However some argue the it can lead to confusion as the participants may not understand some of the interpretations made, they made have changed their minds about what they said or may feel unable to comment upon the researchers interpretations (Angen, 2000, Yardley, 2008). Moreover, this method relies upon the assumption that there is a fixed truth or reality against which accounts can be measured, so continuing the positivistic assumption of an independently existing external reality (Angen, 2000). It was therefore decided that the use of participant validation would not be appropriate for the current study, as the interpretative element of analysis could have made it difficult for participants to relate to the analysis. However given the decision not to include this method of validation in the current study, the study could be considered less collaborative thus placing a limitation on the present study in terms of validity.

6.7.4 Researcher's limitations

The current study was my first qualitative study and thus I consider myself to be a novice qualitative researcher. In some areas of my study I believe that some decisions I made reflected this novice status, and following the culmination of the study I have gained essential learning that I will practice in future research projects.

The interviews themselves posed a challenge to me as a practitioner as, although I was used to dealing with people in a professional context, I needed to create and inhabit a researcher persona that bracketed common interactional habits, such as sharing my experiences and knowledge, exercising my clinical judgement or steering participants towards new and more positive appraisals of their experiences (Smith, Flowers & Larkin, 2009). One of the ways in which I attempted to address these issues was to prepare for each interview as thoroughly as possible by focusing on the task, being mindful of my role as researcher as oppose to practitioner, and having an awareness of the power dynamic inevitably present in the role of interviewer, interviewee. My reflexive journal helped me

manage this process and enabled me to see how difficult this task was. Declaring these challenges helps to ensure that the views I am representing is separate from that of my participants whilst acknowledging the inevitable impact on the research process itself. However during the interview process I believe, particularly in the early interview that I focussed too intently on this persona in trying too hard to conduct my research “by the book.” Even though the data from the interviews was rich, through listening more, and concentrating less on my researcher role and interview schedule, I could have attended to and perhaps probed more to reveal further nuances of the participants experiences. An area where I think I could have probed further was when speaking about sexuality and current sexual behaviours, for instance exploring if the women are able to ascertain sexual pleasure in other ways than being (and in most cases not being) intimate with a man. Through the current study I have learnt how to conduct myself in an IPA interview and in future I intend to listen more intently for participant nuances.

Power-sharing was considered to be important and promoted within the study; by enabling women to choose their interview venue, viewing them as the expert, loosely structured interviews to enable them to speak freely about their experiences. However on reflection there was part of my early process that hindered the promotion of power sharing; administering GAD7 and PHQ9 in order to provide me with some indication of the women’s state of mental health to see if I deemed them non-suicidal and thus safe for them to participate in the study. I could have simply asked the participants not to participate if they were suicidal; thus enabling them to make their own decision rather than me setting up a power differential as I may have with dispensing the questionnaires. I hope that my actions to further promote power sharing post this served to reduce any power differential that may have occurred. I think my actions here reflected my anxieties as a novice researcher and my need to be an ethical researcher. In future research I aim to consider how my actions may affect the balance of power in research, just as I consider regularly in my clinical practice. Yet it also shows me how easily I, a European, feminist, trainee Psychologist, was pulled into action so instrumentally on the *other* group, and thus how easy it is to get into splitting

processes, as such awareness of this is required when working therapeutically with positive women.

6.8 Recommendations for future research

A dominant experience in the current study was that HIV resulted in the women feeling defeminised; they all attributed this to their HIV status. Future research could explore how these women used their femininity prior to diagnosis, as this was not explored in the current study, and how this differs (if at all) post diagnosis. An IPA study using a similar sample of positive women could consider if HIV is being used a vehicle for depositing issues relating to femininity, and other possible issues around sex, self, motherhood, that existed prior to diagnosis. Recommendations for therapy could possibly be made as a result of such research.

Further investigation would be required to explore if the positive women are able to satisfy their sexual desires themselves, through masturbation, as it was not covered in the current study. Such research could explore the relational aspects of positive women's sexuality; to investigate the role of the other and the impact of the other on sexuality. Further insight into women's relationship with their sexual self could aid therapeutic understanding when working with positive women; understanding the need to address the difficulties of forming and maintaining sexual relationships with others, but possibly also with the self.

Additionally all the women in this study reported that they contracted HIV through sexual intercourse. Given the findings of the study, particularly in relation to a restricted sexual self post diagnosis, this study's findings may not be applicable to women who have HIV as a result of other means. Further research would be required to explore the experiences of women living with HIV in relation to their sexuality and feelings about motherhood who have not contracted it through sex.

Further research could explore how healthy adjustment to HIV, and even personal growth, can occur. The research could explore why some women

experience positive negotiation, why others do not, and ways to assist successful negotiation and growth in psychological therapy. In this case of the findings of this study; how did the discussed participant manage growth following an HIV diagnosis? Further studies could explore factors that may promote or inhibit growth. Grounded theory studies, through sampling positive women that attribute growth to their HIV, could be carried out in order to present potential theories of how growth or successful adjustment occurs for different cohorts living with HIV, such as European, childless women. Maybe such research could explore if there are different adjustment stages post diagnosis for a positive woman, and when interventions aimed at encouraging potential growth would be best suited. Such research findings may help to increase the frequency of the occurrence of positive negotiation and personal growth for positive women.

6.9 Final reflections

My perception entering this project was that HIV is potentially devastating, in a psychological sense, with the stigma and prejudice still associated with the illness difficult to negotiate. On a personal level I did hope to find some stories of optimism and confidence to help ease my discomfort with the plethora of negative and depressing stories of women with HIV. At times during the research process this was difficult as much of the literature consists of hopeless stories; I remember writing in my reflexive diary about the lack of encouraging and optimistic accounts of living with HIV.

In meeting the women who participated in my study I could see that they found it difficult to experience their own selves amongst the negativity of an HIV label. Yet I was inspired by the women's determination and fight not to allow HIV to engulf their lives. Some had not yet found a way to do this, others had just started and one had found a way to live beyond the negativity. The women inspired and enabled me to do the same in my research. Whilst acknowledging the pain and loss experienced from an HIV diagnosis the women showed me, someone who has not directly experienced HIV, that HIV does not have to be devastating to one's life and can have the potential to be life affirming.

Throughout the analysis I made sure that I stayed close to the women's words so I could portray both the good and bad experiences accurately.

At many points during this project I felt close to the women who participated. I consider the closeness that I felt to be as a result of experiencing some of the same issues around gender, sexuality and motherhood, despite my sero-negative status. As such, perhaps it would be a mistake to position the issues discussed in the current study solely as a result of HIV, as some of these ideas found a home in me; I found some issues around sexuality, gender and motherhood relevant to me.

In some sense I also felt a great deal of responsibility for the participants and their experiences that they had generously and bravely shared with me. Throughout the period of the study I had many discussions with my partner, family and friends about HIV, with particular reference to women. I felt at times the feminist in me emerging strongly in these discussions, particularly as I felt it my responsibility to defend the blame away from women with HIV and many times saying "it's not their fault!" This led me to contemplate where this strong sense of needing to defend my participants and positive women from blame was coming from; I think that was identifying with the women and fearful others' misconceptions about positive women and me. Again issues of sexuality, gender and motherhood were finding a home in me. I also noticed that I was assuming what the 'other' might be thinking about women with HIV and that my reaction was through defensive responses; throughout the analysis it became apparent that the positive women were doing the same.

Despite being a feminist psychologist in training, reflecting back at the process of this study, I noticed that ideas of vertical transmission with regards to sexuality were at the forefront of my mind. When the women were talking about their diminished sex lives and lack of intimacy with another, I did not explore their sexual selves apart from relating to another. Similarly with motherhood, I was drawn into the biological sense of mothering, I did not explore with the women other perceptions or ways of being a mother. I now question why these ideas were so far from my mind (as well as the minds of the positive women) at interview; I remain without an answer. However this demonstrates how easily

one can be pulled into these fixed ideas of what constitutes being a sexual woman and potential mother and how other perceptions and ideas of these definitions appear so far away. Thus it is essential that when working therapeutically with positive women to be aware of this phenomenon, in order to prevent oneself from being pulled into a unilateral way of perceiving sexuality, motherhood and womanhood, as I was, that could ultimately hinder the successful negotiation of HIV for positive female clients.

Conducting this research has given me a small snapshot of the pressures an HIV diagnosis can bring and the difficulty of negotiating these. As an HIV-negative woman working with positive women I was able to see the immense potential for negativity that positive women face, I found this difficult to contend with, thus my admiration for the strength and tenacity that I witnessed in my participants knows no bounds.

7.0 References

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8.0 Appendices

Appendix A

Literature search strategy

The papers consulted and presented throughout the current study were accessed through online databases such as PsychINFO, PsychArticles, and EBSCOhost. I used a large and varying combination of search terms, which included; ‘HIV’, ‘AIDS’, ‘HIV/AIDS’, ‘HIV positive’, ‘sexuality’, ‘female sexuality’, ‘sex’, ‘motherhood’, ‘mother’, ‘chronic illness’, and ‘identity’. Utilising the snowballing technique, the papers retrieved from initial searched were used, through their reference sections, to search for further relevant papers and authors.

Specific journal searches were also conducted in journals that were considered to potentially include some relevant content to the current study, including; ‘HIV and AIDS Review’, ‘Journal of AIDS and HIV Research’, ‘AIDS Patient Care and STDs’, ‘International Journal of Sexual Health’, ‘International Journal of Sexuality and Gender Studies’, ‘Psychology and Sexuality’, ‘Counselling Psychology Quarterly,’ and ‘The Counseling Psychologist’. I read approximately 160 articles, and further book chapters and article abstracts.

Appendix B

List of organisations contacted for recruitment purposes

Positively UK (PozFem UK)
BASELINE
National AIDS Trust
UK Community Advisory Board – HIV Treatment Advocates Network
Waverley Care
Positive Nation
George House Trust
+me (www.plusme.org)
The BHA (The Arise Project Manchester)
Body & Soul
Positive Action
The Crescent
Cara Life
Positive Help
Sussex Beacon
SHE
We Care (Women in Europe and Central Asia)
Positive Pulse
Women for Positive Action
AB plus Birmingham
Terrence Higgins Trust
BHA Leeds Skyline
Freshwinds
Faith in People
Positive Support
The Food Chain
LASS (Leicestershire AIDS Support Services)
Beyond Positive
Hertfordshire SAID
Sophia Forum
The Eddystone Trust
River House
Grounds Well Trust
St Peters House
Thames Valley Positive Support
Positive Action
Embrace Life Luton
Summit House Support
UK-CAB

Appendix C

Email template sent to organisations for recruitment support

Subject bar: Doctoral Research Study into Sexuality and Motherhood after an HIV Diagnosis

Main body text:

Dear X,

I am Melissa Biggs, a Trainee Counselling Psychologist studying for a Doctorate in Counselling Psychology at London Metropolitan. As part of the Doctorate I am required to conduct a research project for my final thesis.

I have designed a research project that involves me meeting with women who have been diagnosed with HIV, and talking to them about their experiences post diagnosis. My research project has a particular focus on how women experience their sexuality and feelings of motherhood post diagnosis. There is an evident lack of literature in how women, in particular European women, experience living with HIV. This research project aims to add to the HIV literature focusing on women and additionally aims to gain an insight into how women are best supported for the challenges they face, with an emphasis on women's sexuality and motherhood.

I am aiming to recruit European, childless women living with HIV, who if willing would be required to take part in face to face interview lasting approximately an hour (the research will be anonymised). At this stage in my research process I am contacting organisations like yourselves in order to enquire if you are able to in some way to help in my recruitment process. Any help that you are able to give in me accessing my desired population would be greatly appreciated.

Yours thankfully,

Melissa Biggs

Email: mlb0032@my.londonmet.ac.uk

Tel: 07712171429

Appendix D

Recruitment poster

School of Psychology
London Metropolitan
University



Volunteers required for a research study exploring the experiences of HIV-positive women

I am conducting a research study exploring the experiences of an HIV diagnosis on European, childless women's sexuality and feelings around motherhood. Women in HIV research are underrepresented and little is known to how positive women gain support for the challenges they may face post diagnosis. Your involvement in my research study would help to better understand how women experience the challenges of being diagnosed with HIV in order to help support women. Your involvement would require a one hour face to face interview to be conducted at a time and place that is convenient to you, your anonymity and confidentiality will be maintained throughout the study.

Are you a European, HIV-positive, woman without children over the age of 18 years and would like further information? Then please contact:

Melissa Biggs
Email: mlb0032@my.londonmet.ac.uk
Tel: 07712171429

This research study has been approved by the London Metropolitan University Research Ethics Review Panel.

Appendix E

Information pack

Title: Sexuality and motherhood after an HIV diagnosis

- An IPA exploration of the experiences of European, childless women.

Researcher: Melissa Biggs

You are being invited to take part in a research project. Before you decide if you would like to take part, it is important that you understand the purpose of the project and what it will involve. Please take time to read the following information and please do not hesitate to contact me if you have any questions.

What is the purpose of the research project?

The project aims to explore the experiences of women living with HIV, with a particular focus on sexuality and feelings around motherhood. Additionally the project aims to add to the lacking HIV literature around women's experiences of HIV and also aims to understand the challenges faced by women in order to be able to provide support.

Why have I been chosen?

I would like to interview women living with HIV, exploring their experiences with a focus on sexuality and feelings around motherhood post diagnosis. Participants will be required to be over 18 years old and currently not have any children (or not to be pregnant).

What will I have to do?

If you are interested in taking part, my contact details are below so please email or call me. We will then have a conversation where I can explain the project in more detail, if you are still interested in taking part, you will be invited to an interview that will last approximately one hour, at a time and location that is convenient to you.

The interview will focus on your experiences of living with HIV particularly your experiences of your sexuality and feelings around motherhood. The interview will be audio recorded and I will send you a copy of the transcription of your interview for you to check its accuracy.

Do I have to take part?

There is no obligation to take part in the study. If you do decide to take part, you can withdraw from the interview and study without having to give a reason up to six weeks post interview. Any further time after this analysis of the data will have begun and it would be difficult to separate your data from other participants.

What are the possible disadvantages and risks of participating?

There are no known risks associated with taking part in this study. However talking about your experiences living with HIV is a sensitive and emotive subject, thus needs to be considered carefully before agreeing to take part in the study. Any concerns regarding this matter, please discuss this with myself before taking part, or at any point after agreeing to take part in the study. Additionally during the interview if you feel uncomfortable please me know, and if I think that the interview is causing you distress I will stop the interview. I will also provide contact details for support after the interview if the interview has caused any difficult feelings that are hard to cope with.

What are the possible advantages of participating?

The study will hopefully give a better understanding of the experiences of women living with HIV and aid in the development of support required for challenges that women may face.

Will the information I give be confidential?

Yes, the information you give will be confidential and anonymous.

What will happen to the results of the study?

The results of the study will be used for a thesis for a doctorate in Counselling Psychology. The findings may be published in an academic journal and/or may presented at a professional conference. However you will remain anonymous in all instances.

What do I do now?

If you have any questions regarding the above information or would like to register your interest in taking part in the project please contact me on the details below.

Many thanks for your time,

Melissa Biggs
Trainee Counselling Psychologist
Email: mlb0032@my.londonmet.ac.uk
Tel: 07712171429

Appendix F

List of organisations that displayed the recruitment poster

Terrence Higgins Trust (in research section on their website)

Positively UK (on their premises)

George House Trust (on their premises)

Sussex Beacon (on their premises)

AB Plus (on their premises)

Faith in People (on their premises)

The Food Chain (on their premises)

NAT (on their website)

River House (on their premises)

Thames Valley Positive Support (on their premises)

Embrace Life Luton (on their premises)

UKCAB (on their website)

Appendix G

List of organisations that dispersed the information pack to their service users

Terrence Higgins Trust (A London branch and East Susses branch)

Positively UK

George House Trust

Sussex Beacon

AB Plus Birmingham

The Food Chain

Thames Valley Positive Support

Appendix H

Demographic questionnaire

Please can you indicate as best you can the answers to the below questions:

Are you a woman who has been diagnosed with HIV?

How old are you?

What is the length of time since your HIV diagnosis?

Are you currently childless or to your knowledge not pregnant?

What is your relationship status (for example single, in a relationship etc.)?

Do you know the possible origin of HIV infection? If so, please can you specify?

What is your country of residency?

How you identify yourself (for example as British, English, European etc.)?

How would you best describe your ethnicity?

Are you currently taking antiretroviral medication?

Appendix I

GAD7 and PHQ9

Table 3: Table displaying the Generalized Anxiety Disorder 7 Questionnaire (GAD7)

Over the last 2 weeks, how often have you been bothered by the following problems? <i>(Use bold [B] to indicate your answer)</i>	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Table 4: Table displaying the Patient Health Questionnaire 9 (PHQ9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? <i>(Use bold [B] to indicate your answer)</i>	Not at all	Several days	More than half the days	Nearly everyday
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself, or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving .around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.	0	1	2	3

Appendix J

Ethical consent certificate



London Metropolitan University,
School of Psychology,
Research Ethics Review Panel

I can confirm that the following project has received ethical approval to proceed:

Title: *Sexuality and motherhood after an HIV diagnosis - An IPA exploration of the experiences of white, British, childless women.*

Student: **Melissa Biggs**
Supervisor: Dr Angela Loulopoulou

Ethical approval to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed:

A handwritten signature in blue ink, appearing to read "of Chandler".

Date: 19/11/13

Dr Chris Chandler
(Chair - School of Psychology Research Ethics Review Panel)
chandler@staff.londonmet.ac.uk

Appendix K

Information sheet

My name is Melissa Biggs. I am a postgraduate student studying for a Doctorate in Counselling Psychology at London Metropolitan University. As part of my doctorate I am conducting research on women experiences of HIV, sexuality and motherhood. The focus of my research is exploring the how childless women experience and adapt to a positive HIV diagnosis, with particular attention to women's sexuality and feelings about motherhood. I am currently looking for individuals who might be willing to take part in this research.

Women interested in taking part in this study should be over 18 years of age, European, have no children and have been diagnosed with HIV.

Interviews will last up to one hour and will be organised at a time and location that is convenient to you. Your confidentiality and anonymity will be protected at all times during the research process. The interviews will be recorded and only accessed by myself, they will be storage in a secure place. You will not be identifiable through the research, in the research report you will be given a different name to ensure your anonymity. The research is voluntary and if you wish to take part you will be asked to sign your consent. You have the right to withdraw taking part in the research, without giving a reason, at any point up until six weeks after your interview if you choose to.

Due to the sensitive and emotive topic of the research potential participants need to be aware of the intense feelings that may be generated as a result of the involvement within the study. Please consider this when deciding if you wish to take part and any concerns regarding this matter can be discussed with myself before taking part.

If you do wish to take part in this study I would be very thankful and you will be providing a valuable insight into how European, women manage the chronic condition of HIV, where there is a current lack of knowledge.

Many thanks for your time.

Best wishes,

Melissa Biggs
Trainee Counselling Psychologist
Tel: 07712171429
Email: mlb0032@my.londonmet.ac.uk

Project supervisor – Dr Russel Ayling
Email: R.Ayling@londonmet.ac.uk / Tel no: 0207133265

Appendix L

Participant consent form

Dear participant,

Thank you for taking the time to be a part of this study. Please read the following statements and if you agree, sign your consent at the bottom of the page. Additionally please write your initials after each statement in order to indicate your agreement. By signing this form you agree with the below statements and are consenting to take part in this study.

- I understand that I will take part in a face-to-face interview that will last approximately one hour. I understand that I am not obliged to answer the interview questions and that I can terminate the interview at anytime. I understand the interview will be audio recorded and later transcribed by the researcher.
- I understand that my personal details will remain confidential and an alternative name will be used in the transcription and throughout the study.
- I understand that audio recordings and other data form (e.g. consent forms) will be stored securely and that the data will be destroyed after this study has been examined.
- I understand that the data collected for this study will be used only for the purposes of this research project with the possibility of being published in psychological journals or presented at psychological conferences, at a later date.
- I understand that participation is voluntary and I can withdraw, without giving reason, up to six weeks after the interview date, upon which any of my data will be deleted.

- I understand that the study will be conducted in accordance with the British Psychological Society Ethics and Code of Conduct.

Name of participant:

Signature of participant:

Date:

CONTACT DETAILS

Melissa Biggs (researcher)

Email: mlb0032@my.londonmet.ac.uk / Tel no: 07712171429

Dr Russel Ayling (supervisor)

Email: R.Ayling@londonmet.ac.uk / Tel no: 0207133265

Appendix M

Distress protocol

This distress protocol has been formulated taking into account the possibility that participants may become distressed during the process of being involved in the current study, due to the nature of the sensitive and personal information being discussed. Having a distress protocol in place enables the researcher to identify, and minimise any potential distress or anxiety experienced by a participant as a result of the research process. It is not expected that participants will experience extreme distress and that action will be required, however the distress protocol is in place in the unlikely event of an emergency.

The protocol proposed is devised from the recommendations of Draucker, Martsof and Poole (2009) on the development of distress protocols for research concerning sensitive subjects.

The researcher is required to be able to identify indicators of participant distress and then to take the appropriate course of action dependent on the level of participant distress. See Table 5 for the current study's distress protocol.

Table 5

Table displaying the study's distress protocol

Indicators to look out for	Steps for researcher to take
<p><u>Mild distress</u></p> <p>Participant indicates they are experiencing some stress or emotional distress <i>OR</i> they display behaviours such as crying, difficulty speaking etc.</p>	<ol style="list-style-type: none">1. Ask participant if they feel OK to continue2. Offer them time to pause the interview and time to compose themselves3. Remind them they can stop at any time they wish
<p><u>Severe distress</u></p> <p>Participant indicates that they are experiencing a lot stress or emotional distress <i>OR</i> they display behaviours that the interview is very stressful, including uncontrollable crying, inability to speak coherently and symptoms of panic, such as shaking etc.</p>	<ol style="list-style-type: none">1. Stop the interview2. Debrief immediately3. Express concern, empathy and reassurance that their reactions are normal4. Help the participant to compose herself, for example through talking or engaging in relaxation techniques5. Encourage the participant to contact their healthcare provider and provide support organisation details

Appendix N

Debriefing sheet

Dear participant,

Thank you for taking part in this study, your contribution is extremely valuable and will help to gain more understanding of the experiences of women living with HIV. If you have any questions or queries that have arisen from the interview today, about the research project in general or if you wish to withdraw your consent please don't hesitate to contact me via phone on 07712171429 or via email at *mlb0032@my.londonmet.ac.uk*.

Alternatively if you prefer you can contact my supervisor at the following details:

Dr Russel Ayling
London Metropolitan University
School of Psychology
Faculty of Life Sciences and Computing
London Metropolitan University
166-220 Holloway Road
London N7 8DB
Email: R.Ayling@londonmet.ac.uk
Tel: 02071332650

If you would like a copy of your interview transcript and/or would like a copy of the study's findings I can send these to you, so please let me know if this is something you are interested in.

If you feel that as a result of participating in this study you are experiencing any difficult emotions that you would like attend to, I have provided a list of contact details of places that offer support.

PozFem: A network of women living with HIV in the
UK who provide support, care and advice to positive women.
Tel: 0845 790 90 90 / Website: www.poz-fem-uk.org

Terrence Higgins Trust: UK's largest HIV charity that provides support for people living with HIV.

Tel: 0808 802 1221 / Website: www.tht.org.uk

BPS: The British Psychological Society provides a directory of chartered psychologists. On the BPS website, click on the 'Psychology & the public' tab and follow the link to 'find a therapist'.

Tel: 0116 254 9568 / Website: www.bps.org.uk

Appendix O

Interview schedule

[Prior to questioning]

Introduction to the study and to myself, go through the information sheet with the participants and signing of the consent form. Give the participant an opportunity to ask any questions or voice any concerns that they may have.

General

Can you tell me a little bit about yourself and who you are?

What made you want to be a part of this research?

What do you expect of the interview today?

Motherhood

What thoughts come to mind when thinking about motherhood?

What does motherhood mean to you? / Are you able to define it?

Is the thought of motherhood an important aspect of your life?

Has this changed at all since your diagnosis? If so, how and in what way? Why do you think this change has occurred? / Do you think that HIV has had any effect on how you think about motherhood? If so, how?

Do you think that you express that way you feel and think about motherhood in anyway? If so, how? Has this changed since diagnosis? If so, how?

Sexuality

What thoughts come to mind when thinking about sexuality?

What does sexuality mean to you? Are you able to define it?

Is sexuality an important part of your life?

Has this changed in any way since your diagnosis? If so, can you tell me a little bit more about that? (How/What has changed? Why do you think this change has occurred?) / Do you think that HIV has an effect on sexuality? If so, how?

How do you think your sexuality is expressed, if at all? Has this changed since diagnosis? If so, how?

Sexuality and Motherhood

What thoughts come to mind when thinking about sexuality and motherhood together?

For you, can they be thought of together in this way? If so, how? If not, why?

Do you think that your sexuality can have an impact on how you think about motherhood (or visa versa)? If so, how? Do you think this has changed since diagnosis? If so, how?

Do you think that your thoughts and feelings around how you describe yourself sexually are affected by your thoughts and feelings around motherhood? If so, how?

Do you think this has changed since your diagnosis? If so, in what way? Why do you think this change has occurred?

What does HIV mean to you in terms of your sexuality and feelings around motherhood?

Ending

Do you have any other thoughts or comments about what we have discussed today that you would like to talk about?

How do you feel about what we have discussed today?

Is there anything you would like to ask me?

Appendix P

Extracts from reflexive diary

16/01/2014

People I speak to, mainly my friends and family don't understand HIV. I am surprised at how little they seem to know. Most of them still think that it's a gay man's illness and/or that it occurs mainly in Africa, not really the UK. There appears to be a lack of understanding of what it is, what it does to the body and what the psychological consequences can potentially be. I was particularly surprised when speaking to single friends that HIV does not appear to be a primary consideration when engaging in sexual relationships, other STDs and worries around getting pregnant seem to be of greater concern. I wonder why HIV is so far from their minds?

24/04/2014

All the literature I read is doom and gloom for positive women, there are few stories of hope, love, and relationships post diagnosis. It's a fairly depressing picture. If women living with HIV are trying to find uplifting and hopeful accounts and stories, I don't know where they would find them - this saddens me greatly.

26/02/2015

Throughout this study I have felt I have had to defend women who are living with HIV, defend them for their sexual history that lead them to getting HIV. I question as to why I feel such a strong need to do this. I think on some level I am defending women, defending myself, for our own sexuality, and that somewhere within me there is a sense of guilt and shame about being a sexual woman. By defending positive women, am I trying to convince myself that it's OK to be a sexual woman, for me to be a sexual woman!

Appendix Q

Transcript Example

Figure 1. Example of the annotated transcript from participant 4, displaying the development of emergent themes.¹

	<p><u>Exploratory Comments</u></p> <p style="text-align: center;">P4</p> <p style="text-align: right;"><u>Emergent Themes</u></p>		
<ul style="list-style-type: none"> • Sex as gender • research/development • I wonder why you kept gender = gender? • Sexuality as fluid • I wonder how sexuality + gender relate (if)? • Sexuality + relationship with oneself - observational - observational - external. • Sexuality = Freedom of expression • I wonder if that has implications for ongoing expression/observational gender? • Sexuality + Spirituality - (S + nonsexual) - all tied up - intertwined in sexuality. 	<p>29 then we'll pull them together - so, sexuality and motherhood. So, the term,</p> <p>30 sexuality, what comes to mind, when just thinking about sexuality, for you?</p> <p>31 Participant 4: Um, oh, well. I mean I guess the most, the, the first part would be</p> <p>32 around gender. Um, and also orientation - sexual orientation. And that's been</p> <p>33 very fluid for me in my life. Um, I am currently in a relationship with a man. I</p> <p>34 have, I mean, I identify as bisexual, I spent the previous er... ten years, with</p> <p>35 women. Um, it's also about, for me, how I feel about myself, in terms of, um, my...</p> <p>36 attractiveness. Um, there's something very much about sort of tied up in it all,</p> <p>37 freedom of expression. The freedom to be able to express myself... I think there's</p> <p>38 something very, for me, very spiritual around sexuality. Um... and um..... the</p> <p>39 motherhood side of things is very much all, tied up in that as well. So yeah.</p> <p>40 Researcher: Ok. That's really interesting, you mention for you as well that</p> <p>41 sexuality is something that's spiritual about it. Can you tell me a little bit more</p> <p>42 about what you mean about that?</p>	<ul style="list-style-type: none"> • research = neuro/human • Sexuality expressed through feminine characteristics. • Sexuality as an expression of self ID. • Sexuality as transsexual/fluid • feminine sexuality different to masculine sexuality. • Sexuality = freedom/choice + be who you are. • Sexuality + the body - linked. • Sexuality as self expression. • Sexuality - out of control → nondescriptible - spiritual. • Sexuality as observational. • Connection between body + sexuality. 	

3

¹ Exploratory comments were first noted on the left hand side of the page, following by emergent themes noted on the right hand side.

² A list of emergent themes was created for each of the five participants. The line numbers correspond to the line/s of the transcript from which the theme was derived.

³ Initially the list of emergent themes (Appendix R) for the participant was cut out onto individual

Exploring Gender

PA

- Time to reach a place of acceptance - what place? how? how long?
- 43 Participant 4: So, it's taken, or it took me, quite a while, um, if we were to look at the sexual orientation side of things, to reach a place of acceptance around that
- 44 And acceptance, for me, is like a spiritual principle. And... I think, I think also because I spent a number of years abusing my body, um, there's been a significant journey and process in the last eleven years to really start having a relationship with my body. Rediscovering my femininity. Because I, in my using, in my active drug addiction, um, I became very hardened, through experiences. I was exposed to a lot of violence and... I guess in rediscovering myself and my desires, which I'd kind of really put to one side, um... there had to be a really, kind of, gentle path for that. And, I had to invite in a lot of forgiveness. Um, and compassion and also like once, I'd received my diagnosis, there was an impact of that, sort of, internalised stigma. Um, which I know played out.
- 56 Researcher: How did it play?
- 57 how? how did it play out? can't have been fun!
- 58 Shame, duty - blame / guilt.

Emergent Issues

- sexuality as a journey
- journey of self acceptance
- own one's sexuality.
- sexuality can be lost / suppressed / rejected.
- returning + re body - close link.
- sexuality + femininity linked + (body + femininity)
- Abuse oneself - loss of femininity (kxv dats through HIV/abuse? oneself?) - abuse?
- Wrongdoing / deviant women!
- Only self to blame.
- Aethy HIV requires self forgiveness.
- Internalised stigma = blame (Shame).
- Being (incl. to self vs. Being (self forgiveness)). Being (incl. to self) (blame)

Exploratory Conversations

(14)

- 57 Dirty with HIV - Shameful I blame self.
- 58 Still engaging in rel - were these different post-D? How?
- 59 functioning fear a place of shame. (just functioning)
- 60 → not living? what died? → no love life? why?
- 61 Researcher: Why do you think that was? Where do you think that place of shame was coming from? It's source?
- 62 Participant 4: I'd internalised the like, societal stigma. It took me a while to un-
- 63 you know, peel that and get to that. But that actually was the real turning point for me. Because I, I realised that I was carrying, the shame I was carrying wasn't mine to carry. So I kind of just handed it back.
- 64 Researcher: It must have been a difficult, difficult process?
- 65 Participant 4: Yeah. Yeah, it was, I mean God it was. I did it with a lady who you mentioned earlier, um, so yeah, it really was. And, and also, unfortunately, I was in quite an abusive relationship. And they became quite shaming. So, I mean I left it eventually, or got out of it... That was in my early years of living with HIV,
- 66
- 67
- 68
- 69
- 70
- 71

Subjective

- HIV stops living - only allows one to function.
- Inner shame.
- Dirty the positive woman carry on - but internal struggle.
- The peel with HIV
- Bad outside good inside
- Creating a new self with HIV.
- Higher built woman required I'm not bad with HIV.
- self acceptance
- Shift of blame.
- raising control.
- self acceptance vs acceptance of our

Exploring careers

P4

Emergent careers

- Keated different by 72 so I would still become very affected by people's responses to me. And now, I don't because of HIV - why? how so? who? 73 have, I still have my struggles, but I have a very grounded acceptance of myself.
- constant struggle, but 74 And so I'm not - although it might hurt if somebody is, you know, discriminatory now must accept myself. What struggles? 75 towards me, I can hand it back to them because its there fear or ignorance or what else does look like? 76 whatever, it's not mine. It's not mine to carry.
- why have them? how 77 Researcher: So it sounds like it's been a real journey for you. With or without the cage? 78 HIV it's was a journey for you anyway in terms of what we're talking about
- It's not mine to carry - 79 sexuality and then HIV. In early two thousand was there something else in the knowing weight of HIV - 80 mixing pot.
- cause him about - 81 Participant 4: Was there? headed you headed back? Passes you team there? 82 Researcher: I mean, you said that it was something else. It added another layer
- rejection of HIV? 83 of difficult a barrier. But it sounds like now, you're in a place like you say, of if back to about that? 84 acceptance.
- hard for me to hold? 85 Participant 4: Yeah, yeah, totally. Totally. But it's taken, it's taken a while. A few
- Time looked with HIV - 85 living with HIV = not-easy 86 journeys to get there.
- A few journeys together to a place of self acceptance. 87
- get out one place -> to another 88
- old self -> new 'new' self? 89
- HIV rejection by others 90
- others fear/discriminate 91 someone with HIV
- HIV as the person. 92
- fear of living with HIV. 93
- rejected by others but rejected 94
- increased self awareness 95
- spitting -> HIV too difficult 96
- hard to understand (pain to 97
- HIV to accept self 98
- Need to accept self. 99
- living with HIV constant 100
- struggle to accept self 101
- Need to accept self. 102
- Rejection of self by 103
- self. 104
- Process past Δ of 105
- rejection + acceptance 106
- of self. (cautious) 107
- HIV as a journey 108
- of self acceptance. 109
- New Old self -> New self. 110

Exploring careers

(14)

Engel's views

- 87 Researcher: But that's good, it sounds like you're in a good place with that. And
 - 88 would you say that your sexuality is now an important part of your life? Of who
 - 89 you are?
 - 90 Participant 4: Definitely. Definitely. Yeah, um... yeah. And I, I, and I think.....
 - 91 yeah, it's, it's, it's hard to, it's hard to articulate it sometimes but there's been
 - 92 a lot of, as I said, there's been a lot of freedom in my journey. Um and when I,
 - 93 kind of, honoured myself around, you know, my orientation, you know, there
 - 94 were questions to, you know, was I engaging in women, because I experienced so
 - 95 much violence in my using? Um, er, and but it was very liberating, incredibly
 - 96 liberating when I, kind of, heard myself saying it and, um, yeah, yeah.
 - 97 Researcher: Would you say that sexuality can be liberating, it can be a liberating
 - 98 experience, kind of, that journey of discovery?
 - 99 Participant 4: Definitely, definitely. And I, and I think because women, um,
 - 100 because of the stigma with HIV, women... um, it can be very..., er oppressive.
 - 101 Researcher: Right
- HIV as opportunity.
 • HIV as a journey.
 • HIV creates a journey
 of self discovery? (e.g.
 sexual orientation
 acceptance)
 • Learning more about
 self with HIV.
 • Understanding/accepting
 HIV as self = linked
 to sexuality.
 • Good enough person vs
 not good enough person
 (struggle).
 • Different for women (stigmatizing)
 • Gendered experience
 • More oppressive /
 risky / stigmatized
 for women (HIV).
 • HIV related sexuality /
 norms / understand.

Appendix R

Emergent themes for participant 4

Table 6. Table displaying emergent themes for Participant 4²

Line number	Emergent theme
8	HIV as part of self
32	sexuality expressed through feminine characteristics
37	sexuality as an expression of self identity
33	sexuality as fluid/transient
35	sexuality and self acceptance
37	observable sexuality
38	emotional/mental relationship with sexual self
39	closeness between mother self and sexual self
44	sexuality as a journey towards self acceptance
48	loss of sexual self
48	rediscovering sexual self
48	disconnect with body
49	Disconnect with sense of self
52	self compassion
52	wrong doing/deviant HIV positive woman
52	Internal change of attitudes/feelings towards self
54	internal vs. external stigma vs. impact to self
54	dirty HIV positive woman
54	Impact of stigma on sense of self
59	Bad self
59	old self vs. new self
59	change of behaviour/decisions in line with 'bad' self
62	external stigma vs. internal stigma
62	Perception as dirty, deviant woman with HIV
63	Deep and complex internalised stigma
64	Taking control
64	others stigma vs. own stigma
64	own self acceptance vs. others acceptance of self
69	Loss of confidence/self worth
71	self acceptance vs. others acceptance of the self
72	taking control
73	Rejection/pain
74	strength
74	control
73	dirty, deviant HIV positive woman

² A list of emergent themes was created for each of the five participants. The line numbers correspond to the line/s of the transcript from which the theme was derived.

75 Increased self awareness
 84 deep and complex internalised stigma
 84 strength/determination
 85 fluid sense of who she is
 85 Place of self acceptance
 84 hard work to find a place of self acceptance
 91 Opportunity to grow/increase self awareness
 94 Gaining a closeness to self
 95 sexuality as confining sense of self/ID vs. liberating sense of self/ID
 99 HIV as stunting/confining sexual self/sense of self
 99 dirty, deviant HIV positive woman
 99 self punishment/harsh treatment of self
 101 treated by other as different
 102 sexual deviant/wrong doer/irresponsible
 104 Bad HIV positive mother
 105 Loss of human rights/basic needs
 105/6 Loss of respect as a human being
 105/6 Internal stigma vs. external stigma
 104-6 HIV as part of self
 106-7 self non/acceptance vs. other non/acceptance
 107 strength/confidence
 107 self acceptance
 108 self acceptance vs. non acceptance of others
 108 single minded/confident
 112 Need to be in control vs. having been out of control
 112 loss of control vs. taking control
 144 sexual self integral to overall identity/sense of self
 145 vulnerable sexual/sense of self
 150 loss of femininity
 150 Loss of identity
 153 Loss of sexual self
 165 mother self part of sexual self
 165 motherhood as a observable expression of sexual self
 165 sexual self to be embraced
 170 ignited mother self
 177 relationship with ones body changes over time
 186 motherhood as the point of joining/completing element of the self
 186 motherhood as self actualising
 187 dormant mother self vs. activated mother self
 187 Innate mother self
 190-1 attuned with mother self
 199 time pressure to fulfil mother role and complete sense of self
 199 attuned with mother/sexual self
 199 connected self
 210 activation/closeness with mother self
 212 dormant vs. active mother self

222 motherhood as integral to complete sense of self
 234 motherhood as completing sense of self
 234 sense of self/identity as multifaceted/complex
 234 Elements of ID fit together to form sense of self
 241 activated mother self
 241 mother self integral to overall sense of self
 246 can be a mother living with HIV
 251 barrier to fulfilling mother self
 251 increased sense of responsibility
 258 importance of mother role/fulfilling mother self
 296 fixing wrong self
 296 confused/new/unknown/changed self
 296 struggling self
 297 strength
 301 loss of sense of who she is if don't fulfil mother role
 322 expression of mother and sexual self is the epitome of womanliness
 325 connection/relationship with one's body
 326 Motherhood and sexuality and part of ID
 327 identity as fluid/evolving
 329 Hierarchy of identities with the self
 330 HIV not a barrier to having children
 347 taking control
 349 strong sense of who she is
 349 determination
 349-350 internal vs. external battle with stigma
 350 deserving vs. non-deserving woman with HIV
 356 determination
 356 conscious effort to accept self with HIV
 359 internalised vs. external stigma
 360 life long battle of self acceptance
 362 increased responsibility
 363 persistent psychological burden of HIV
 361 psychological costs of HIV
 363 accepting living with HIV vs. non-acceptance/inability to accept HIV
 363 Normal life vs. non-normal life
 366 HIV positive woman as undeserving
 366 HIV positive woman less than human
 368 HIV challenges sexuality
 368 Taking control
 369 successful negotiation of sexual self (vs. non-successful negotiation)
 378 global perception of bad/wrong HIV positive woman
 380 western experience of shame less than African experience
 386 second class citizen
 386 less of a woman
 386 reduced rights/less respect (infrahumanisation?)
 387 variation in stigma across the world

392 acceptance of the burden of HIV vs. challenging the burden
 392 taking control vs. loss of control
 412 absence of HIV as part of ID
 414 changed/evolved ID post diagnosis
 414 strength
 414 HIV as a battle
 414 win vs. loose battle with HIV
 416 increased self awareness/acceptance
 423 acceptable self vs. unacceptable self
 423 wrong doing, irresponsible woman with HIV
 424 increased ability to be able to acknowledge one's strengths
 426 strong self vs. vulnerable self
 427 opportunity for introspection
 429 physical vs. psychological vulnerability
 429 attacked HIV positive woman
 429 others hostility towards HIV
 429 psy vulnerable to self perception vs. vulnerability to others perception
 430 need to keep self safe from others vs. from self
 430 sense of who she is open to attack (from who? – HIV/self/others)
 432 private self vs. public self
 440 increased non-acceptance of others
 441 focussed on own needs
 441 knows what wants
 441 rejection/discrimination
 442 HIV as part of who she is
 445 wrong/deviant HIV positive woman
 447 Pain of loss of relationships
 447 taking control
 447 strength
 450 increase self worth
 452 moral woman with HIV vs. immoral woman pre diagnosis
 8 woman with HIV
 37 freedom of expression (HIV)
 45 reaching a place of acceptance
 45 liking/learning to live with self
 52 inviting forgiveness in
 54 the internalised stigma
 54 shame/guilt/blame
 56 Impure HIV positive woman
 59 functioning from a place of shame
 63 The peel – getting rid of ‘dirty’ self
 63 HIV became part of core self/got to the core of self
 64 Carrying the shame
 64 the given shame
 64 my shame or others shame/fear?
 75 Not mine to carry – splitting/rejecting HIV

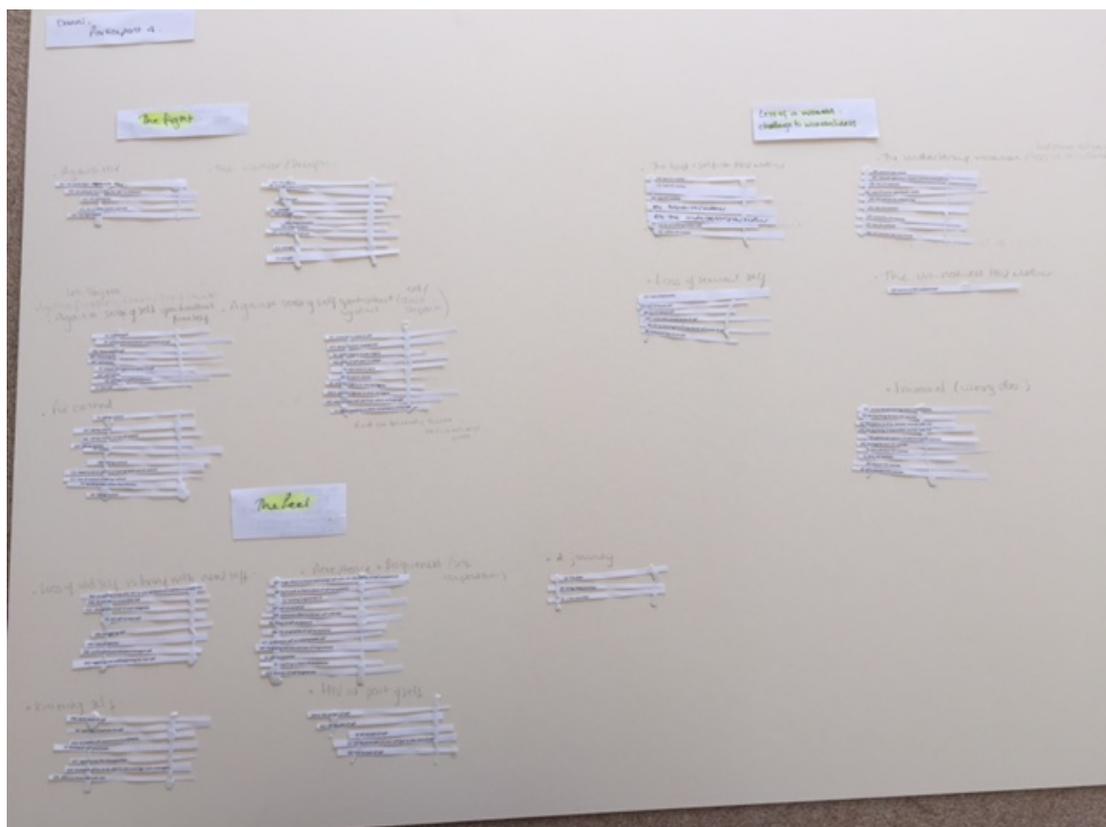
75 handing back others fear/shame...
75 rejection of others perceptions
85 HIV as a journey to self acceptance / enabling journey
85 tiring, long journeys
91 HIV as a barrier vs. journey
99 self blame/self punishment
104 selfish HIV positive woman
104 bad HIV positive mother
105 unworthy HIV positive woman
105 less of a woman
170 mother self as a deep, burning desire to have children
152 gain HIV vs. loss of parts of who she is (woman, sexual person?)
212 innate mother self
242 Can I have children?
251 less of a woman
251 bad HIV positive mother
453 regaining lost self/searching for lost self
251 unnatural HIV positive motherhood
251 selfish HIV positive mother
296 effort to know self with HIV
296 work done of self
322 motherhood as celebration of womanliness
251 uncelebrated HIV woman/womanliness
326 sexuality and motherhood intertwine
huge effort to know and accept self with HIV (the journey of self
347 acceptance)
347 shame/guilt
347 self blame
347 self dislike
347 forgiving self (the journey of forgiveness)
349 not allowed HIV to stop the right to pleasure
349 The fight/battle
349 strength
361 the anxiety (responsibility and transmission)
392 potential to destroy self
392 The battle/fight
414 The warrior
423 Journey of self forgiveness (HIV enabling the journey)
428 journey vs. barrier
453 Finding my voice
453 finding voice vs. being silenced

Appendix S

Example of the process of creating the super-ordinate theme table for participant 4.

Figure 2

Photograph of theme table for participant 4.³



³ Initially the list of emergent themes (Appendix R) for the participant was cut out onto individual pieces of paper, so each theme was on a separate piece of paper. They were spread out onto the mount-board, and the clustering process as described in the methodology was adhered to. This resulted in the creation of theme tables, on separate mount-boards, for each participant. The large-scale nature of this process enabled all themes to be viewed at once for the purpose of clustering, as well as enabling flexibility, as theme clusters could be altered easily (individual theme labels were ‘blu-tacked’ to the mount-boards enabling easy rearrangement).

Figure 3

Close up photo of a super-ordinate theme and subordinate-themes from the above table for participant 4.

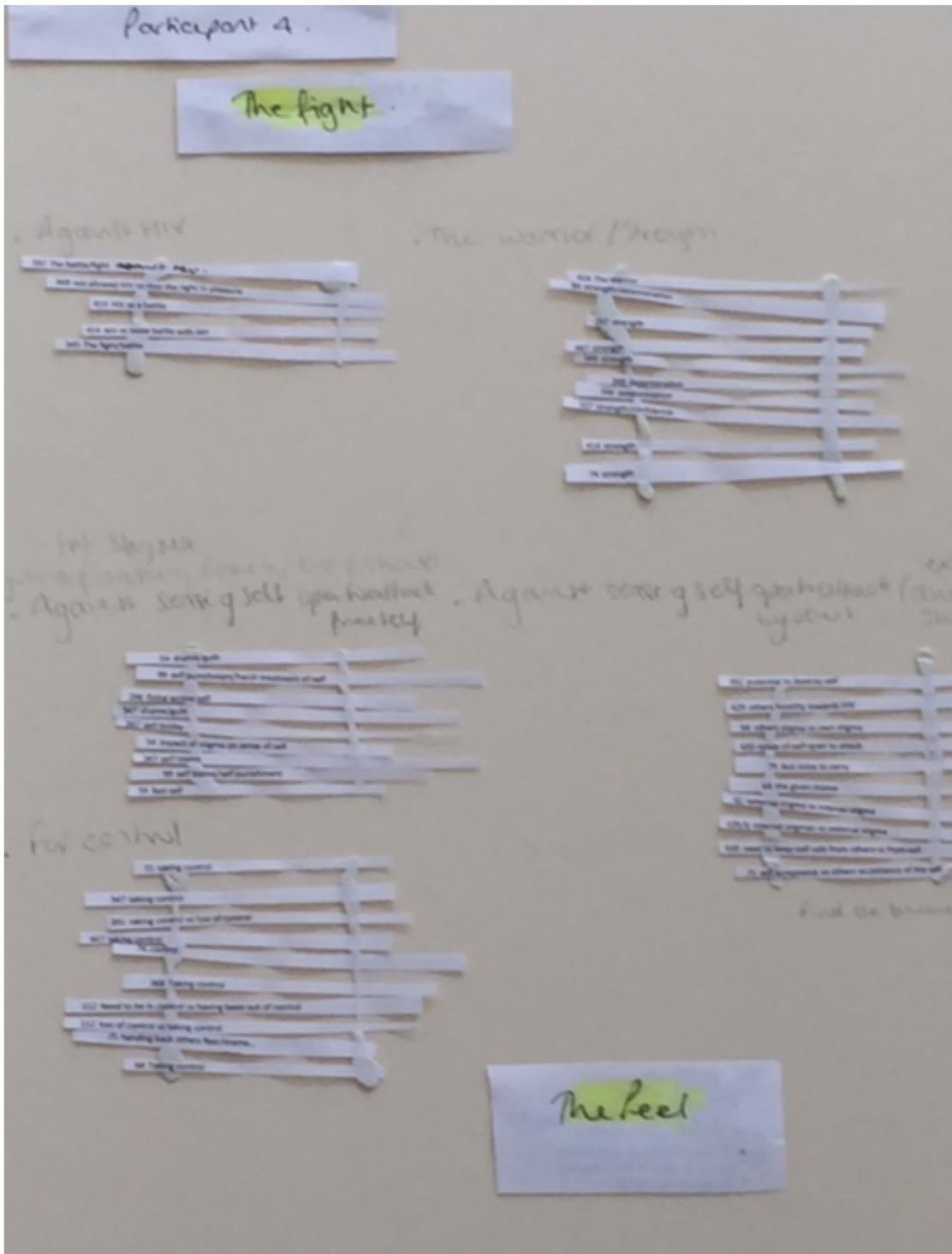


Table 7Table displaying super-ordinate and subordinate-themes for participant 4⁴

Themes	Transcript line number/s
The Fight	
Against HIV	392, 349, 414
The warrior (strength)	84, 297, 447, 349, 356, 107, 74
Against the self (self preservation)	54, 99, 296, 347, 59
Against others	392, 429, 64, 430, 75, 105, 430
Gaining control	72, 347, 112, 64
The Peel	
Loss of old me vs. living with new me	363, 426, 414, 59, 296, 150, 296
Self acceptance and forgiveness	347, 84, 52, 360, 423, 45
HIV as part of who I am	104, 442, 8, 63, 307
The journey	63, 85
HIV as a magnifying lens	296, 94, 416, 75, 427
Less of a woman	
The undeserving woman	386, 105, 251, 366
Loss of femininity (including sexiness)	150, 48, 145, 99
The bad, selfish and un-natural mother	104, 251
Dirty and impure woman	102, 52, 62, 423, 445, 73, 56

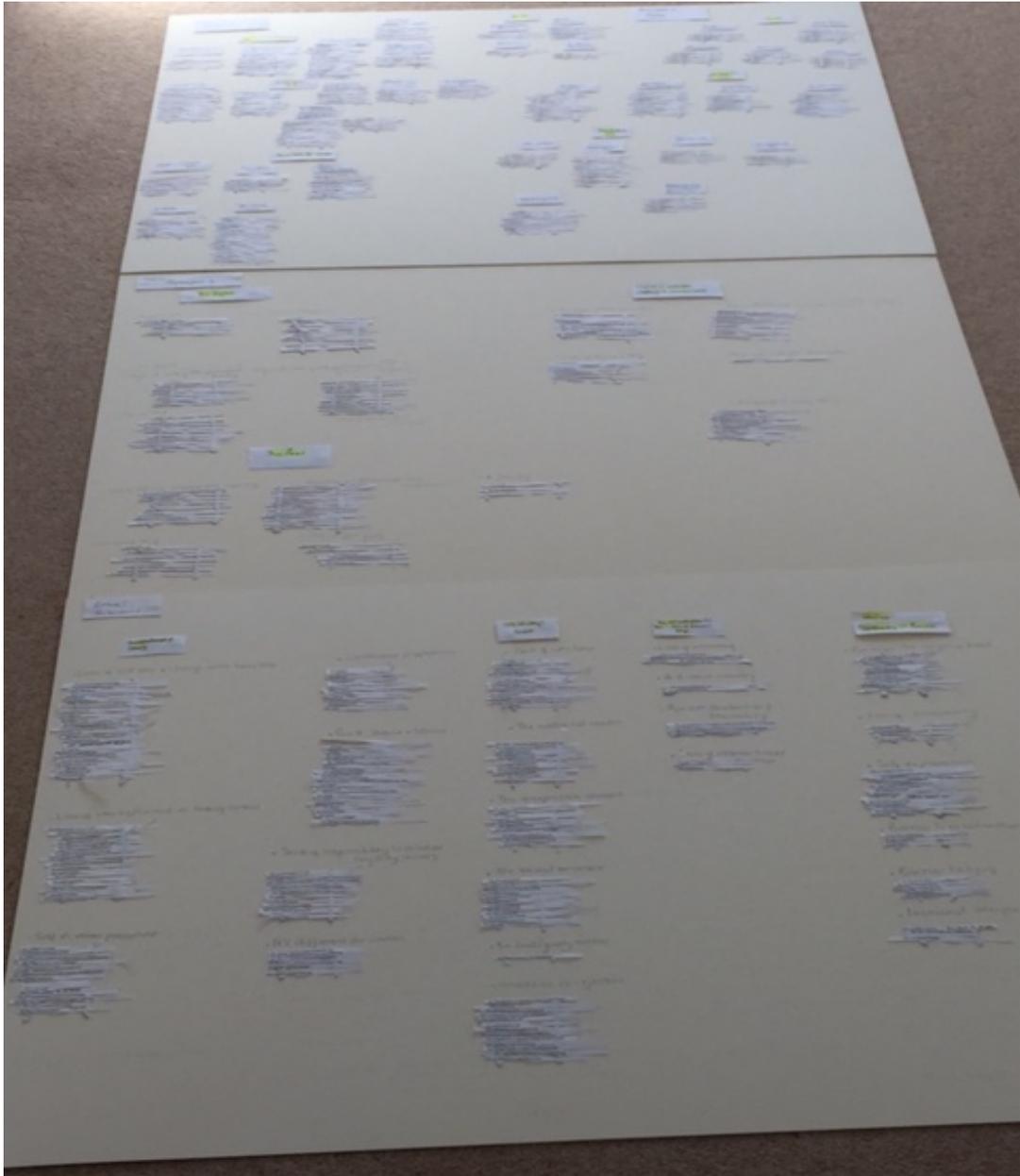
⁴ Tabular form of the photographed table (Figure. 2) from the mount-board for the purpose of being able to view the content clearly.

Appendix T

Hand-constructed participant tables.

Figure 4

Photograph showing each of theme tables for all five participants⁵



⁵ In order to create the master table of themes (Appendix U), the mount-boards displaying the each of the five participant tables were spread out on a large surface so they could be viewed simultaneously. Adhering to the process outlined in the methodology the master table of themes for the group was created.

Appendix U

Master table of themes for the group

Table 9

Table displaying the super-ordinate and sub-ordinate themes for the group

THE EVEN WORSE THAN UNDATEABLE WOMAN		
The promiscuous woman	Transcript	line
<u>Participant 1:</u>	1	
“That’s the last thing he’s going to necessarily expect me to say, you know, I’m HIV-positive. Whereas you know with two gay guys, <i>I’ve got something I need to tell you</i> , it would be the first thing that the guy would think he’s going to be told.”		440-442
“I’m, you know, not an ex sex worker. I didn’t use to do intravenous drugs.”		120
“And then a week later his <i>serious ex-girlfriend</i> came back on the scene and umm he <i>was not able to see me anymore</i> .”		492-3
“Even if I do physically fancy them the likelihood of that guy wanting an HIV girlfriend is pretty low....”		428-9
<u>Participant 2:</u>	2	
“...when you tell somebody, ah their faces you, it’s not like oh you know I have a heart problem, <i>oh poor you or oh how well you are doing</i> . But when you say <i>I am positive or I have...HIV</i> . Oh you know the impact that you have on others.”		571-4
“...I still feel that shame and guilt...”		195
“it’s a dirty one, because it means you’ve done something wrong or you have poor judgement, or you have something		604-607

hiding in your history, or you are up to something naughty or you've been naughty..."		
"...feeling shitty and guilty and shame and you know undeserving and unworthy..."		303-304
"that there's something wrong with you, or your choices, or quality of life or something, you know. So they think there's something wrong about you as a person."		592-594
<u>Participant 3:</u>	3	
"You know I watched the undateables....my god even they are managing to get dates, even they're managing to have a partner ...why can't I have something simple that other people have?"		146-156
"..so I told him. He was gone like a shot."		221-22
"I've got this disease and no one will want me"		194
<u>Participant 4:</u>	4	
"...we're given all kinds of labels, of being promiscuous, or um you know junkies or um whatever and it's shaming and um not liberating"		101-103
"I had to invite in a lot of forgiveness"		52
"I had to learn about compassion for myself and forgiveness towards myself."		423
"I think because women, um, because of the stigma with HIV and women, it can be very oppressive."		98-99
<hr/> <i>The bad, HIV-positive mother</i> <hr/>		
<u>Participant 1:</u>	1	
"...now I have HIV, It won't really be a natural method"		295-297
"comments from Anne like, <i>you know, you'd be a good Mum</i> and like that.....And me going, <i>would I, would I?</i> "		
<u>Participant 2:</u>	1	
"So I felt it was too much of a burden to pass it onto somebody."		198-9

<u>Participant 4:</u>	4	
“Now I remember feeling quite strongly that I wouldn’t want to put that onto my unborn child.”		251-2.
<u>Participant 5:</u>	5	
“On the other hand you have to take drugs and give drugs to your child and you cannot breastfeed....I would not feel I would want to bring up a child if I had to give drugs to a little baby... and I think breast feeding is so important for babies.”		310-315.
<hr/> <i>You have to tell</i> <hr/>		
<u>Participant 2:</u>	2	
“I feel like as a woman, you have to tell. You cannot just say nothing because it’s very difficult. Very difficult.”		107-110
<u>Participant 3:</u>	3	
“So if the person has not consented to having sex with me, who has HIV, for me in my head it doesn’t work, I would be thinking about it, I couldn’t relax.”		249-251
“I’m thinking <i>my god you know I could never do that to somebody else.</i> And I think it need to be by permission almost.”		209-211
“ <i>I’ve got to tell him. I’ve got to tell him. I’ve got to tell him.</i> That was all that was in my mind.”		219-221
“I would never want anyone to feel like I did that day I was diagnosed. Never. I would never do that to anybody else.”		262-3
<u>Participant 5:</u>	5	
“We are women so there’s a double stigma....I think that we women have to disclose more, disclose more.”		41-45,
“I really think that we are women, we care more about it. Like I’m, <i>oh my god I’m going to transmit this to some other person.</i> I think that, I don’t know if I’m being too sexist here but I think that men don’t have that big concern.”		453-455

“I said to myself that I would not have sex again, with a person, with a person without disclosing my HIV status.”	121-122
“I am scared of telling them because perhaps they will treat me differently.”	422-3
“also disclosing, because you think that the other person will be scared of you, they will treat you different. I think that’s why I don’t disclose more often”	175

NOTHING CAN SPARK MY SEXUALITY

Loss of femininity

<u>Participant 1:</u>	1
“Sometimes I probably would have done. I might have had a little more confidence about it.” (talking about flirting)	511-2
“There’s not many men that would take me on anymore now.”	528-9
<u>Participant 2:</u>	2
“I said, <i>I am a woman</i> . And try to be more, do the best with what you have.”	309
“One of the nice things about being so thin is that you can get away with lots of lovely dresses. And I think <i>why not?</i> It’s the only thing I have left you know, so why not.”	281-2.
<u>Participant 4:</u>	4
“rediscovering my body, rediscovering my femininity.”	48
“I had an experience a couple of years ago with an interaction with medication and I lost loads and loads of hair. My hair is a massive part of my identity and femininity....so when that’s taken away you could really see the impact on my self-esteem and confidence.”	149-153

Not bothered by sex

<u>Participant 1:</u>	1	
“You must remember to look at men tonight, you must remember to look around.....I just forget to look!”		371-380
“nothing can spark my sexuality to come to the surface.”		468
“I am as horny as hell, but not really bothered about sex.”		617
“There’s that little period of time where you are still a bit, Oh I’m missing sex, that goes away quite quickly for me, and then i’m kind of, you know, I don’t really think about that anymore.”		346
<u>Participant 2:</u>	2	
“I have not had a partner for a long time.”		248
“well it’s been such a long time that not had this (sex) and somehow I’m not bothered by it.”		267-268
<u>Participant 3:</u>	3	
“But for me I can’t imagine having sex with anybody.”		215
“And then you have HIV, it’s just another, well for me, it’s just like a coffin nailed.” (talking about her sexuality)		231
“They say, <i>are you sexually active?</i> And I say, <i>what the fuck!...god how can you even ask that question!</i> ”		192-3
“I can’t even think about that (sexuality) because all I can think is, I’ve got this disease and no one will want me... please don’t ask me if I am involved with somebody, because it’s like saying <i>have you won the lottery?</i> It’s not going to happen.”		193-200
<u>Participant 5:</u>	5	
“We all think about that. But I am not doing it.” (talking		143-4

about sex)		
“before I was more free.”		153
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<i>You stupid cow</i>		
<hr/>		
<u>Participant 1:</u>	1	
“ <i>What a stupid cow you’ve been.</i> ”		88
“I should have used condoms more.”		101
“I thought I least my parents are dead. I don’t need to tell them.”		694-702
“My initial thing was just so, I just felt so stupid.”		84-5
 <u>Participant 2:</u>	 2	
“It was my fault, you know, it was my poor decision....and I feel responsible for what happens to me.”		196-8
“I protected myself to not get pregnant but not for everything else that happened.”		457-8
“So there’s all that guilt and shame underneath.”		193
“But it’s me who has to live with myself and with my body.”		646
 <u>Participant 5:</u>	 5	
“hurting your mother, hurting your grandmother, what will they say, my god!”		187
“I wish I was more respectful with that before.”		234-5
<hr/>		
YOU HAVE TO ADAPT...I OWE IT SOMETHING		
<hr/>		
<i>Why can’t you just go away?</i>		
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<u>Participant 2:</u>	2	
“If you put it to the back of your mind, it’s always there.”		528-9
“Even though I keep using I am positive, which means, implies, that’s who you are. You know and it’s not true, is		522-23
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it?"		
“You sometimes think, <i>oh shit, why can't you just go away.</i>		353-4
But obviously it's not going to.”		
<u>Participant 3:</u>	3	
“Because HIV is a part of me, it's not the whole of me.”		422-3
<u>Participant 4:</u>	4	
“I do know that that is very specific to my experiences of people around my HIV.”		442-3
“I am a woman with HIV.”		8
“because I'm HIV?”		303
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<i>The fight</i>		
<u>Participant 2:</u>	2	
“I don't even feel like I've lived at all.”		86
“You have to adapt.”		258-9
<u>Participant 3:</u>	3	
“I should have made the most of it.”		462
“I know you should not regret things, but I would probably have lived differently.”		38
“I have never allowed HIV to stop me.”		349
“but again, it's like <i>do I over come that? Yes.</i> ”		392
“there's a real warrior.”		414
<u>Participant 5:</u>	5	
“We really have to fight against that.”		433
“We have to fight to make it something common.”		413
“I try to deal with that. Cope with the challenge....I'm a fighter.”		449-486

I owe it something

<u>Participant 2:</u>	2	
“It gave me to tools to explore myself, who I was.”		307-8
“Being positive means so much negative stuff to my life, I owe something to it as well.”		297-8
“I’ve been working on myself for a long time now.”		203
“I learnt about myself...had to really go inside.”		300-5.
<u>Participant 4:</u>	4	
“It took me a while to un, you know, peel that and get to it. But that was a real turning point for me.”		62-3
“Through the work that I have done on myself.”		296-7
“There’s been a lot of freedom in my journey.....it was very liberating, incredibly liberating when I heard myself saying it.”		94-5
“I would not have been able to say, sort of then years ago, or identify with that tenacity.”		427-8
“The HIV has made me stronger, it has made me look at stuff that I would not have necessarily looked at.”		424
<u>Participant 5:</u>	5	
“I also feel more positive perhaps, like it happened because it should happen that way.”		503
“I would like to be more confident with that as well. I’m working through that path.”		178-9
