

**The experience of being a mother with perinatally acquired
Human Immunodeficiency Virus (PHIV)**

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Abstract

Women with perinatally acquired HIV (PHIV) are surviving into adulthood, with many now becoming mothers. Little is known about the experience of having a child in the context of a diagnosis of PHIV. This Grounded Theory study aimed to explore and build a model of; the links between the experience of growing up with HIV; having a parent with HIV and becoming a parent; the relationship between the mothers' ability to bond with their children and their own HIV status; and the influence of the pregnancy and birth on the relationship between women with PHIV and their own mothers. Seven mothers with PHIV aged 21-29 with a total of 11 children were recruited and interviewed about their experiences.

Data analysis resulted in a theoretical model of motherhood within the context of a diagnosis of PHIV. The model comprised of three theoretical codes; conceiving, conception and pregnancy; birth, bonding and breastfeeding and establishing motherhood and future related thoughts. The experience of becoming a mother was characterized by powerful feelings of bonding with their children, warmth towards their own mothers and personal growth. Many women appeared to want to use their own experiences of growing up with HIV and being parented by an HIV-positive mother in a positive way to benefit their child. Feelings of anxiety and failure were also common, however, and affected the antenatal and perinatal periods in particular. Overall the experience of motherhood was both enhanced and diminished by the diagnosis of PHIV.

The findings highlight important areas for development in clinical practice and implications for local and global efforts to support the increasing numbers of mothers with PHIV, as well as those considering motherhood in the future are outlined. Suggestions for future research are offered.

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CHAPTER ONE: INTRODUCTION

Human Immunodeficiency Virus (HIV): a background

HIV is a blood borne virus which attacks the immune system, specifically CD4 T-lymphocyte cells, white blood cells that play a major role in protecting the body from infection. When these cells are attacked, individuals are more susceptible to infections and HIV can eventually lead to Acquired Immune Deficiency Syndrome (AIDS) (World Health Organization (WHO), 2011). An individual's CD4 count is an important indicator of how well their immune system is working; the higher the CD4 count, the better able an individual is to fight HIV and other infections.

Globally, there are over 35 million people infected with HIV (Joint United Nations Programme on HIV/AIDS, 2013). An estimated 107,800 people were living with diagnosed or undiagnosed HIV in the UK in 2013 (Public Health England, 2014). Whilst there is still no cure for HIV, the introduction of effective antiretroviral therapy (ART) in 1995 began to transform HIV from a fatal infection to a chronic, manageable life-long condition, particularly in resource rich countries such as the UK.

HIV can either be transmitted behaviourally, through sexual contact or sharing intravenous drug equipment, or mother-to-child transmission (MTCT) can occur, resulting in a child diagnosed with perinatal HIV (PHIV).

Perinatal HIV (PHIV): an introduction

An individual is considered to have PHIV if their mother had presumed or confirmed HIV and they were diagnosed under the age of 16 years in the absence of other risk factors, such as blood transfusions (Kenny, Williams, Prime, Tookey & Foster, 2012). Ninety per cent of all paediatric cases of HIV infection can be attributed to MTCT (The Centres for Disease Control and Prevention, CDC, 2005).

MTCT can occur at three different stages; during the antenatal period due to fetomaternal blood shunts within the placenta; during labour or a vaginal delivery (when an infant's oral mucosa is contaminated with infected vaginal secretions) or as a result of breastfeeding (Newell, Dunn, Peckham, Semprini & Pardi, 1996). Without any interventions the risk of MTCT is between 20% and 40% (Rosenvinge & Doerholt, 2013). Maternal viral load, the level of HIV in the blood, is the most salient risk factor; if this is undetectable (< 50 HIV copies in a sample of blood) at delivery then the risk of transmission is 0.1% (Rosenvinge & Doerholt, 2013).

PHIV: Prevention strategies

MTCT of HIV is now almost entirely preventable due to the introduction of several prevention strategies into maternal and child health services:

Antenatal diagnosis

Maternal HIV screening is recommended for all pregnant women in England as part of the UK National Screening Committee's NHS Infectious Disease in

Pregnancy Screening Programme, introduced in 2000. Uptake of antenatal screening remains high, in 2013, 16% (276/1,758) of the total number of women diagnosed with HIV in the UK were diagnosed as a result of antenatal screening during pregnancy (Public Health England, 2014).

Medication for pregnant and breastfeeding mothers

All pregnant and breastfeeding women living with HIV are eligible for and require ART medication to prevent MTCT. In 2013, WHO released new consolidated global guidelines on the use of ART for preventing MTCT of HIV, outlined in the table below.

Table 1: WHO recommended medication options for prevention of MTCT of HIV

Option A	Lifelong treatment <i>only</i> for pregnant and breastfeeding women eligible for ART (i.e. with CD4 counts <i>under</i> 500 or at clinical stage 3 or 4). For those who are ineligible for treatment (with CD4 counts <i>over</i> 500) ART should be initiated but stopped 7 days post-delivery.
Option B	Lifelong treatment <i>only</i> for pregnant and breastfeeding women eligible for ART, ART should be initiated and maintained after completion of breastfeeding. For those who are ineligible for treatment, ART should be initiated but stopped after delivery and completion of breastfeeding.
Option B+	Lifelong ART to all pregnant and breastfeeding women, regardless of CD4 count or WHO clinical stage. ART should be maintained after delivery and completion of breastfeeding for life .

WHO guidelines recommend that pregnant women follow Option B+, or Option B, if this is not possible (British HIV Association (BHIVA), 2012). In the UK, life-long triple ART is provided for all HIV-positive pregnant women, regardless of symptoms and CD4 count. Infants born to HIV-positive mothers also routinely receive post exposure prophylaxis (oral antiretrovirals) within one hour of birth, which is then given daily for 4 weeks following birth (BHIVA, 2012). These recommendations have been updated since advice in 2006 which recommended ART commenced only for pregnant women with CD4 counts below 350 cells/mm³.

Mode of delivery

For women in the UK taking ART, a decision regarding the recommended mode of delivery should be made after review of maternal viral load at 36 weeks gestation. Published data from the UK and other European countries have shown MTCT rates of < 0.5% in women with an undetectable viral load who are taking ART, irrespective of mode of delivery [Boer, England, Godfried & Thorne, 2010]. This supports the practice of recommending a planned vaginal delivery for these women. For women with a higher viral load a planned caesarean section is advised (Public Health Report, 2014). Among HIV-positive women taking ART in pregnancy and delivering between 2000 and 2006 in the UK and Ireland, there was no difference in MTCT rate whether they delivered by planned caesarean section (0.7%; 17/2,286) or planned vaginal delivery (0.7%; 4/559) (Public Health Report, 2014).

Infant feeding

Breastfeeding approximately doubles the risk of transmission of HIV; 36.7% compared to 20.5% for formula fed babies (Rosenvinge & Doerholt, 2013). UK standards of care state that all mothers known to be HIV-positive, regardless of whether they are on ART, should be advised to exclusively formula feed from birth (Public Health Report, 2014). This is in line with WHO guidance; that exclusive feeding with infant formula milk should be recommended for women with HIV where it is affordable, feasible and safe (WHO, 2013). The greatest population of women with HIV lies in Sub-Saharan Africa where the major causes of infant death are malnutrition and infectious diseases. In this context, formula feeding represents a considerable risk to infant survival due to limited hygienic options for the preparing and storing of formula milk (Morland et al., 2010). In these cases WHO guidelines recommend exclusive breastfeeding for 6 months, then continued breastfeeding until 12 months, as this may provide a greater chance of survival even when antiretrovirals are unavailable (WHO, 2011).

Infant screening process

WHO recommends that infants born to mothers living with HIV are tested within their first two months of life, using a virological test. Definitive exclusion of HIV infection in a non-breastfed infant is based on two or more negative virologic tests performed at various time points; the first 48 hours after birth and a second at 6-24 weeks of age. The final test should confirm the loss of maternal HIV antibodies at 18–24 months of age (BHIVA, 2014). Breastfed babies should be tested monthly (BHIVA, 2014). ART should be

started as soon as an infant is diagnosed with HIV, regardless of clinical and immune system status (WHO, 2014).

PHIV: Global figures

Globally, there were more than 1.4 million pregnant women with HIV in 2013 (WHO 2014). In 2011, a Global Plan was launched to reduce the number of new HIV infections via MTCT by 90% by 2015 (UNICEF, 2014). The number of pregnant women with HIV has remained relatively stable since 2009, although the proportion receiving recommended and effective ART regimens to prevent MTCT of HIV has increased steadily. The estimated overall rate of MTCT of HIV in 2013 declined to about 17% in low- and middle-income countries, an impressive drop from 26% in 2009 (WHO, 2014). The number of children newly infected with HIV by MTCT declined by 40% to an estimated 240,000 in 2013, down from the estimated 400,000 in 2009 (WHO, 2014). The table below shows the percentage across WHO regions of the 240,000 children newly infected by MTCT of HIV globally in 2013 (WHO, 2014).

Table 2: Percentage of children diagnosed with PHIV across WHO regions in 2013.

% of PHIV children	WHO Region
89	Africa Region
8	South-East Asia Region
1	Eastern Mediterranean Region
1	Americas Region
>1	European and Western Pacific Regions

PHIV: UK population

In the UK, data on pregnant HIV-positive women and their children are collected from all maternity units by the National Study of HIV in Pregnancy and Childhood (NSHPC). HIV-positive children are then followed up as the Collaborative HIV Paediatric Study (CHIPS) cohort. Within the UK, the vast majority of HIV-positive women are now expected to give birth to uninfected, healthy infants. The rate of MTCT of HIV from diagnosed women was 25.6% in 1993 at which time the interventions available now were virtually non-existent (Duong et al., 1999). Between 2000 and 2006, with high uptake of interventions, the overall transmission rate fell to 1.2%, and less than 1% among women who had received at least 14 days of ART. These low transmission rates persist, and were even lower in 2007–2011 at an estimated 0.57% (Townsend et al., 2014). Figure 1, below, illustrates the decrease in transmission rates.

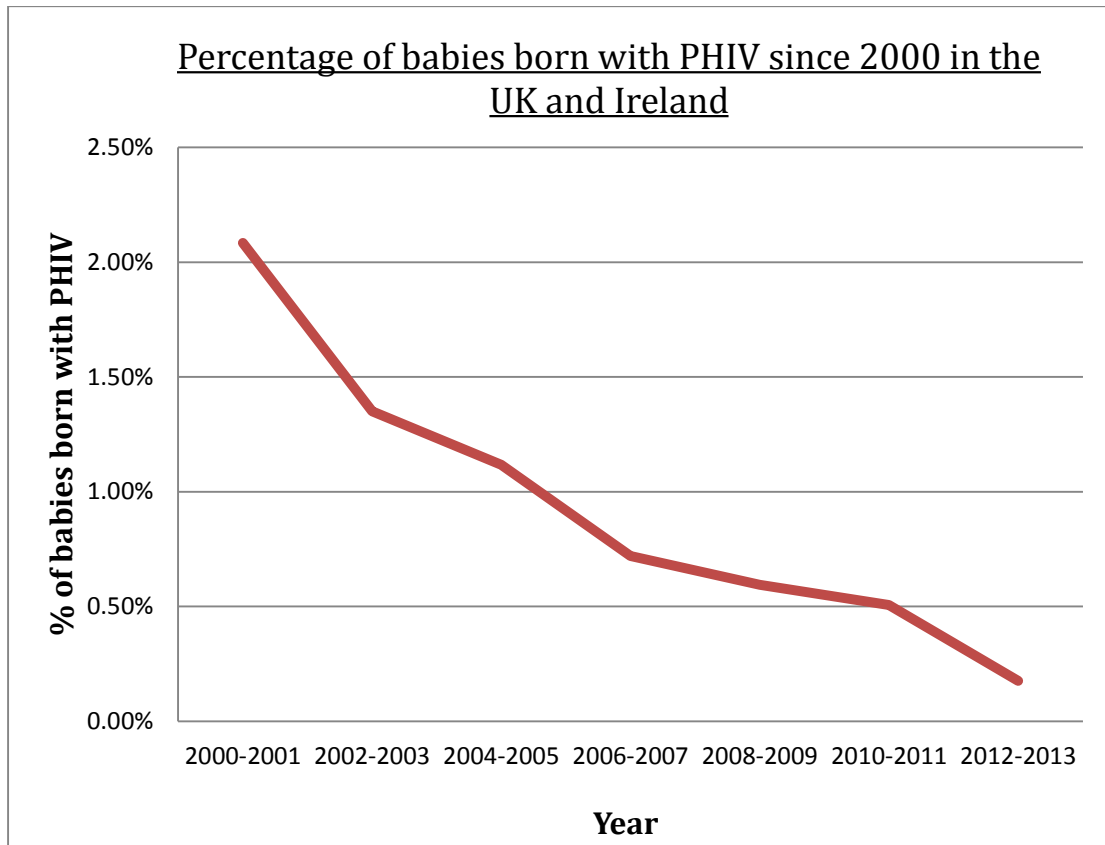


Figure 1. Percentage of babies born with PHIV since 2000 in the UK and Ireland. Data derived from Townsend et al., 2014.

There were 90 new PHIV diagnoses in the UK during 2013, the vast majority of whom acquired their HIV infection abroad (Public Health England, 2014). An audit of the circumstances surrounding the perinatal transmissions in England in 2002–2005 demonstrated that over two-thirds of these infants were born to women who had not been diagnosed prior to delivery (Children’s HIV Association (CHIVA) Standards of Care, 2007). About half of those undiagnosed women had declined antenatal testing. A smaller proportion had tested negative: these women presumably contracted HIV in pregnancy, or while they were still breastfeeding (BHIVA, 2014). 1,873 HIV-positive children in the UK had been reported to the CHIPS by the end of March 2014, 96% had a diagnosis of PHIV. 108 children were known to have

died whilst receiving paediatric care, including six deaths in 2008, six in 2009, two in 2010 and one in 2011 (CHIPS Annual Report 2013/2014).

PHIV: a changing population

PHIV was once regarded as an inevitably fatal illness in all parts of the world and prior to the advent of ART, 50% of children with PHIV progressed to AIDS or died by the age of ten (Rosenvinge & Doerholt, 2013). However, high uptake of antenatal testing and other prevention of MTCT interventions along with improved survival following ART has significantly improved the quality of life and prognosis of children with PHIV in resource-rich countries. In the UK and Ireland, the rate of AIDS and mortality combined declined from 13.3 cases per 100 person before 1997 to 2.5 per 100 person in 2003–2006 (Judd et al., 2007). In the UK, the proportion of the perinatally infected cohort aged over 15 has increased from under 1% in 1996 to 40% in 2012 (CHIVA, 2013). By 2012 almost 400 young people had transferred to adult care (BHIVA, 2014) and the majority of individuals living with PHIV are now of or approaching reproductive age (~75% aged 13-19, ~25% aged 20-24) (Jones, Chakatoura & Cook, 2013).

Regardless of the transmission route, young people with HIV face stressors such as uncertain long-term physical health and onward HIV disclosure concerns which will be more fully outlined in later sections. Other issues faced by those with PHIV relate specifically to having grown up with HIV, for example, the physical and psychological complications associated with lifelong ART. These can include lipodystrophy, a problem in the way your body produces, uses, and stores fat which can alter appearance. Another

potential long term side effect is a decrease in bone density, which can lead to an increase risk of injury and fractures (AIDS.GOV, 2009). Managing longstanding family secrecy about HIV is another specific issue relevant to those who have grown up with PHIV (Evangelini, Greenhalgh, Frize, Foster & Fidler, 2014). Many children with PHIV will have been raised by a mother with the illness, or suffered from maternal loss which may impact their well-being and HIV adjustment.

As will now be explored, the long-term survival of individuals with PHIV has raised new issues concerning relationships and parenthood, yet the psychological aspects of these experiences have been scarcely investigated.

Relationships & sexual behaviour

In their 2012 Grounded Theory (GT) study in the US, Fair and Albright explored the experiences of young people (mean age 20.7, age range 15-30 years) with PHIV, and their perceptions of challenges in relationships due to their HIV status. Although the participants experienced challenges to engaging in intimate relationships, relationships were desired and sought by *all* participants. Fear of rejection and concerns regarding trust were driving forces behind many relationship decisions. Most participants strongly encouraged others living with PHIV to seek relationships.

In their Interpretative Phenomenological Analysis (IPA) study, Greenhalgh et al., (under review) examined how HIV disclosure challenges are managed by young adults with PHIV in intimate relationships and found that a variety of strategies are used to minimise the pain of rejection by partners associated with HIV disclosure, including using condoms. The results indicate that

decisions about status disclosure are closely linked to relationships decisions and sexual behaviour within this population.

Research indicates that young people with PHIV are sexually active. Eight of the participants in Fair and Albright's (2012) study (25.7%) reported previous pregnancies but the study did not focus on their experiences of pregnancy and motherhood. Elkington and colleagues (2009) examined sexual behaviour among 57 young people with PHIV living in the USA and found that, despite the young age (mean 12.2 years) of their participants, 12% were sexually active. Renaud et al. (2013) examined the sexual behaviours of US youth with PHIV (N = 51) compared to youth with behaviourally acquired HIV (BHIV) (N = 92) and found the groups had similar sexual and HIV-related risk behaviours, but youth with PHIV reported using condoms at six times the rate of the BHIV group, suggesting a heightened awareness of the risk of HIV transmission within the PHIV population.

Motherhood and PHIV

Until the late 1990s public health concerns underpinned policies that discouraged people with a diagnosis of HIV from considering having children (CDC, 1985) due to the fact that survival from this then untreatable condition was unlikely. Therefore, a discourse of motherhood was mostly absent from the HIV literature (Yudin & Loutfy, 2011).

More recently, recommendations have shifted and HIV-positive individuals are now encouraged to reconsider their reproductive choices in favour of childbearing, should they wish (Cooper, Harries, Myer, Orner, & Bracken, 2007). There has been a steady increase in the numbers of HIV-positive

mothers in the UK (NSHPC, 2012), from 82 live births in 1990, to over 1,400 births a year since 2006 (Townsend, Cortina-Borja, Peckham & Tookey, 2012). Up until 2012 the recorded number of pregnancies to women with PHIV living in the UK was 42 pregnancies to 30 women (Kenny et al., 2012) with 6% having had one or more pregnancies (Byrne, Thorne, Foster & Tookey, 2015). Kenny et al. (2012) reported that 34/42 pregnancies to woman with PHIV living in the UK were unplanned and the median age of pregnancy was 18 years (range 14-22 years). At delivery, 33% of women had a detectable viral load and one infant contracted HIV.

Women with BHIV report uncertainty about how long they will be able to take care of their children and worry about who will care for their children should they die (Kennedy et al., 2010). Fears of MTCT of HIV and concerns that pregnancy may negatively affect their own health are also prominent (Evangeli et al., 2014). For some women, particularly those from African societies, social and cultural factors such as pressure to continue the family lineage also shape childbearing decisions (Nattabi, Li, Thompson, Orach & Earnest, 2009).

Studies suggest that HIV-positive women may be in a socio-cultural double bind, in which their desire for children violates beliefs about 'acceptable mothering' (Ingram & Hutchinson, 2000) in the context of their status. They therefore face the dilemma of risking MTCT of HIV or else setting aside long standing fertility desires (Beyeza-Kashesya et al., 2009). Yet, many HIV-positive women do have a personal desire to experience motherhood, believe

that it gives them a reason to keep living and that it is an important aspect of their lives (Ingram & Hutchinson, 2000; Kennedy et al., 2014).

Although challenges faced by mothers with a chronic illness have been widely studied in health-related research, few studies have specifically focused on motherhood within the PHIV population. Those that have are predominately medically focused, with few focusing on the psychological processes involved through conception, pregnancy and motherhood (Sheth et al., 2015; Munjal et al., 2013).

For young people with PHIV their illness is often an integral part of their identity and personal narrative (Dorrell, Earle, Katz & Reveley, 2008). They have experienced first-hand the potential risks posed to any unborn child, whilst simultaneously are likely to have had the experience of being mothered by a woman with HIV. Thus, the fertility desires of women with PHIV may be complex and shaped by different, sometimes conflicting sets of factors including; advances in HIV treatment (Cliffe, Townsend, Cortina-Borja & Newell, 2011); availability and effectiveness of MTCT prevention programmes (Ezeanolue, Wodi, Patel, Dieudonne & Oleske, 2006); whether they have disclosed their status (Finger et al., 2012) and their experience of the disease whilst growing up.

Evangelini et al. (2014) interviewed seven PHIV youth (aged 18-23 years) regarding their thoughts about childbearing. This sample wished to have children and were actively considering some of the issues associated with parenting in this context. However, only two participants involved in this

study were themselves parents and the study did not consider the influence of having had a mother with HIV on parenting desires.

Through their exploration of social workers' case vignettes of work with PHIV youth, Childs & Maxwell (2009) suggest that seeking sexual partnerships and pregnancy may reflect a yearning for intimacy that results from personal history of loss and illness within the PHIV population. Many spoke of a strong need to leave behind a legacy; for some, in the form of a healthy, HIV-negative child.

Research points to several other unique factors amongst this group which may influence their experience of motherhood which will be further investigated in the following section.

Motherhood, HIV and associated challenges

Cultural and religious factors and social complexity

HIV prevalence remains highest in the most deprived areas in England (Public Health England, 2014). Mothers living in these areas experience a significantly higher level of social need (Domek, 2006; Eastwood & Birnbaum, 2007). Many experience multiple psychosocial factors including; social isolation; illness in the family; employment instability and its related economic challenges; single parenthood and health related complications, culminating in a challenging familial environment (Bomba et al., 2010). These factors have been associated with increased parental stress and poorer maternal mental health and may interfere with the ability of these women to make effective and consistent healthcare choices for themselves and their children (Jones et al., 2013;

Lichtenstein, Laska & Clair, 2002), potentially impacting on their experience of pregnancy and motherhood.

The ethnic composition of PHIV youth in the UK mirrors that of the adult population, with the majority of new cases among ethnic minorities (De Santis, Garcia, Chaparro & Beltran, 2014). 85% of parents of PHIV children originate from countries outside of the UK, predominantly from Sub-Saharan Africa (Elkington, Bauermeister, Brackis-Cott, Dolezal & Mellins, 2009). Many Sub-Saharan African mothers living with HIV in the UK have a high level of social need (Ibrahim, Anderson, Bukutu, Elford, 2008), including social isolation (Doyal, 2009) and insecure immigration status (Cherfas, 2006) factors which may impact on their mental health, ability to access health care and may lead to increased parental stress and poorer maternal mental health (Lichtenstein, Laska, & Clair, 2002).

HIV-related stigma

A meta-synthesis revealed that stigma is virtually synonymous with the experience of being an HIV-positive woman (Sandelowski, Lambe & Barroso, 2004). Stigma, in relation to HIV, is traditionally defined by Goffman (1963) as an attribute which, in the eyes of society, serves to reduce the person who possesses it. Earnshaw and Chaudoir (2009) describe three stigma processes for HIV-positive people. 'Enacted stigma' refers to the actual experience of discrimination reported by people with HIV (Scambler & Hopkins, 1986); 'anticipated stigma' refers to the level of expectation that this discrimination will occur (Markowitz, 1998) and 'internalised stigma' is the degree to which

people with HIV endorse the negative beliefs associated with HIV about themselves (Link, 1987).

Literature highlights that exposure to enacted stigma has a profound effect on a child's experience of growing up with HIV. Anticipating such responses, young people with PHIV are often advised by family and professionals to keep their status secret and to 'pass' as uninfected. This contributes to difficulties as they later attempt disclosure to friends and begin sexual relationships (Bernays, Jarrett, Kranzer & Ferrand, 2014).

Having grown up with a stigmatized illness, women with PHIV may face new stigma challenges if they decide to become mothers. Mothers with BHIV have reported feeling anticipated stigma attached to their pregnancies and childbirth, fearing judgmental healthcare providers will have negative attitudes towards childbearing (Jones et al., 2013). This has the potential to impact on the development of the early mother-child relationships. Indeed, women with BHIV report feeling pressure from society to become a mother, but judgement for doing so as an HIV-positive woman (Ingram & Hutchinson, 2000). Additional complications may arise from providing explanations for having a caesarean section and abstaining from breastfeeding, which carry a risk of unplanned disclosure and can be very stressful for new mothers (Sanders, 2008). Mothers with HIV report feeling concerned about future enacted stigma their children may face (Sandelowski et al., 2004), with their desire to protect them from discrimination impacting directly on how widely mothers felt able to disclose their status to others (Wilson, 2007). Mothers with HIV have also been documented as showing a tendency towards

internalising stigma, experiencing feelings of guilt, shame and worthlessness as mothers because of their HIV status (Sandelowski et al., 2004; Lazarus, Struthers & Violari, 2009).

There may be more unique characteristics of stigma faced by women who have grown up with PHIV and who have decided to become mothers, however, no research has specifically explored this.

Guilt and shame

Motherhood in the context of an HIV status was once experienced as a 'deviant act that requires justification' (Sandelowski & Barroso, 2003). Women speak of the emotional pain they would feel if they were to miss their children's lives because of failing health or death (Sandelowski & Barroso, 2003). Many feel strongly that they would not risk having a child if they might not be able to participate fully in the child's life (Kennedy et al., 2014).

Parental guilt about transmission of HIV to 'innocent' children distinguishes this disease from other life-threatening non-transmittable paediatric illnesses. Qualitative studies interviewing BHIV-positive mothers postnatally report that levels of maternal anxiety are notably increased prior to confirmation of their infant's HIV status, suggesting that this process may impact on women's mental health and influence the maternal role during this period (Lazarus et al., 2009). Other studies also suggest that belief systems based on maternal fears and misconceptions around HIV transmission may negatively impact on the developing relationship between mother and infant (Ross, Stidham & Drew, 2012). Hejoaka (2009) found mothers with BHIV report anxiety

regarding transmission of HIV through sharing common objects such as toothbrushes and hairbrushes with their children. Some mothers were reluctant to kiss their children or use the same utensils and restricted bodily contact with their children.

Persistent and unresolved feelings of guilt over having infected their children made the administration of HIV medication difficult for 38% of mothers whose children had PHIV in a qualitative study by Wrubel, Moskowitz, Richards, Prakke, Acree & Folkman (2005). The women felt the medications served as a persistent reminder of the source of the illness.

There appears to be a lack of research investigating whether the same feelings of guilt are present within women who have PHIV and have become mothers themselves. There is also a significant lack of research into the relationship quality between young women with PHIV and their own mothers.

Attachment considerations

The early mother-child relationship and its subsequent impact on the child has received a high level of empirical attention in the general population, with the majority focusing on the concept of 'attachment'. This is defined as 'a close emotional relationship between child and parent, characterised by mutual affection and a desire to maintain proximity' (Ainsworth, 1991, p.17).

Bowlby's (1988) theory proposes that there are three types of attachment style: "secure", "anxious-avoidant" and "anxious-resistant". Infants who experience reliable and sensitive care in the first year of life are more likely to develop a secure attachment to their principal carer. When the child has not

had a 'secure base' from which to explore and learn about the world and others, perhaps due to disturbances in the early infant-parent relationship, insecure attachments develop. Insecure attachments have been linked to the child's socio-emotional adjustment, mental health, and behaviour problems (Boldt, Kochanska, Yoon & Nordling, 2014) due to the child having maladaptive strategies for interacting with the world (Riggs & Han, 2009). The effects of attachment, both good and bad, are far-reaching with consequences continuing into adulthood (Lowell, Renk & Adgate, 2014) as mental representations of this early relationship, via an internal working model (IWM), are argued to predict later psychosocial functioning (Bowlby, 1988). Authors have therefore made the argument for studying the development of this early relationship from the mother's perspective during the antenatal, perinatal and postnatal periods (Zee, Cates & Schaeffle, 2009).

Mother-infant bonding

The ability of a mother to feel connected and close to, namely to 'bond with,' her child is not the same as forming an attachment with the child, although the mother's perceived ability to bond with her baby and attachment patterns in later life have been linked (Zee et al., 2009). Klaus & Kennell (1982) define bonding as an instinctual surge of maternal feelings following birth, a process which is highly vulnerable to disruption if certain risk factors are present (Morrissey, 2007). The two risk factors which have been most widely studied are social isolation (Hagen, 1999) and maternal post-natal depression (PND) (Moehler, Brunner, Wiebel, Reck & Resch, 2006). Disrupted bonding has also been found to be influenced by a lack of physical contact after birth; previous

maternal negative life events and restricted opportunities for breastfeeding (Boyd, Zayas & McKee, 2006).

A number of authors have suggested that maternal HIV may impact negatively on mother-infant attachment and bonding after birth (Oswalt & Biasini, 2010) due to the illness taking attention and energy away from mothering, whether in the form of illness or in worry about potential illness (Nelms, 2005). In their observational studies Murphy, Marelich, Armistead, Herbeck & Payne (2010) report finding that mothers who were anxious about their HIV status were assessed as being less confident in their parental role and more likely to exhibit poor parenting skills. However, it is important to note the limitations associated with many of the studies reaching these conclusions as argued by Bauman, Silver, Draimin, and Hudis (2007); most studies use cross-sectional data, large age-ranges, rely on parental retrospective reports and lack a control group.

Maternal post-natal depression (PND)

Women undergo considerable psychological adjustment postnatally (Gregory, Masand & Yohai, 2000) and although the majority adapt to parenthood with success (Lutz & May 2007), there are some who experience emotional distress. PND is defined as a major depressive episode that begins within one month of delivery (DSM-IV).

Emotional well-being is essential during pregnancy and after child-birth to facilitate attachment and develop the capacity to parent effectively (Paulson, Dauber & Leiferman, 2006). Kumar (1997) showed that women who were

suffering from PND had prolonged difficulties in developing maternal feelings towards their infants compared to women who were not depressed. Taylor et al. (2005) found a correlation between PND and bonding scores within the first 12 weeks postnatally. Hartley et al. (2010) examined a group of 83 mothers with BHIV and their HIV-negative infants and found a third of infants were socially withdrawn, with a large proportion of mothers in this group scoring in the clinical range for PND. PND has been linked to a variety of adverse developmental outcomes for children, including increased risk of childhood behavioural problems, poor cognitive outcomes and learning disorders (Buist, 2006). These studies illustrate the need to further research the experience of the early postnatal period and associated feelings within the specific context of PHIV, which may differ markedly from this early experience in some other populations.

Maternal sensitivity

A mother's sensitivity towards her infant's signals; including warmth, flexibility, and the promptness and appropriateness of her responses to the infant's needs, particularly those of distress, is important for the mother-infant relationship. Aspects of mothers' sensitivity predict children's academic readiness, self-regulation, and social competencies (Landry, Smith, Swank, Assel, & Vellet, 2001). Maternal sensitivity has also been found to predict later attachment security (Bigelow et al., 2010).

In contrast, maternal behaviours that emphasize control and negative displays of anger or rejection, have been linked to negative child psychopathology

(Brumariu & Kerns, 2010). Therefore, a mother's pattern of interacting with her child and level of sensitivity can play either a protective or detrimental role in the child's development.

As described, the psychological stresses faced by mothers with PHIV are likely to have a profound influence on the quality of their interactions with their children. Yet, few studies have explored this by collecting data on the perceived mother-child relationship after birth. French researchers Trocme, Courcoux, Tabone, Leverger & Dollfus (2012) carried out interviews with 60 HIV-positive mothers and found that 80% of mothers reported psychological stress, 72% 'suffered' from not being allowed to breastfeed their infant and 43.5% expressed a fear of transmitting the infection to the child. The authors state that the impact of these stressors were 'already noticeable within the early mother-child interrelations' indicating that psychological issues relating to maternal HIV status may negatively impact the mother-child relationship.

Maternal chronic ill health

Women with PHIV face motherhood with a chronic illness and may have experienced being mothered by a woman with chronic ill health. Chronically ill mothers can struggle to manage the combined physical and emotional demands of parenting with the effects of a chronic illness, which can have a significant impact on the mother-child relationship (White, Mendoza, White & Bond, 2009). Women with PHIV are at higher risk of HIV-related disease progression than women with BHIV (Phillips et al., 2011) which may lead to

increased concerns about their own health, concerns about the future of the child, and higher medication demands whilst pregnant.

Studies highlight the additional physical, psychological and emotional burden placed on mothers living with chronic illness through efforts to prioritise their role and identity as a mother above their illness. Findings suggest that mothers with cancer attempt to conceal any side effects of their illness (vomiting, fatigue) to protect their children from any suffering (Elmberger, Bolund, Magnusson, Lu'tze'n & Andershed, 2008). Compared to those without children, mothers report higher levels of fear of cancer recurrence and illness intrusiveness in intimate life domains (Arès, Lebel & Bielajew, 2014).

Like mothers with PHIV, mothers who experience severe and enduring mental health difficulties report encountering stigma and discrimination (Dolman, Jones & Howard, 2013), exacerbating women's problems by preventing them from discussing them openly (Diaz-Caneja & Johnson, 2004) and making them more reluctant to seek help (Ackerson, 2003). Studies have shown that some women with mental illness worry about the impact of their children witnessing their ill-health (Diaz-Caneja & Johnson 2004) and that many feel their illness had forced their children to take on too much responsibility in the home (Ackerson 2003). Like mothers with HIV, Davies and Allen (2007) found that mothers with mental health difficulties face 'particular challenges of identity management because of the inherent tension between the societal ideals around the 'good mother' and social norms associated with mental illness' (p. 369). Many were ashamed that they '*couldn't cope as a mother*' (Edwards & Timmons, 2005). These findings have led researchers to conclude

that stigmatising conditions such as mental illness and HIV are more threatening to a mother's self-concept than less stigmatising illnesses such as diabetes and cancer (Montgomery, Tompkins, Forchuk & French, 2006).

Overall, these findings reveal that women need to find a balance between the conflicting demands of a chronic illness and motherhood; they must be strong, yet allow themselves to be sick, and must find a balance between telling the truth and protecting their children (White et al., 2009).

Infant health related issues

The birth weight of babies born to women with PHIV (compared with BHIV mothers) is lower (Jao et al., 2012) and more advanced maternal HIV is strongly associated with prematurity (Kim et al., 2012) resulting in potentially weaker child immune systems and increased likelihood of other health conditions. Parenting an ill child can arouse a variety of feelings, such as guilt, anxiety, shock, denial, anger and confusion (Saadah, Hajar & Islam, 2014).

Farmer and Lee (2011) found that parenting stress directly affects maternal depression, parent-child interactions and subsequent bonding. Qualitative studies have found that HIV-positive pregnant and postpartum women worry about their infant's health, fearing that the infant has been infected (Ross, Stidham & Drew, 2012). Negative perceptions of the infant's health can compound the HIV mother's existing negative feelings of being incompetent, thus leading to depressive symptoms.

The literature shows that mothers of ill children develop care-giving coping strategies, defined as the active processes and behaviours that the family tries

to employ to help it to manage, adapt to, or deal with a stressful situation (Saadah et al., 2014). For example caregivers of PHIV youth limit the circle of those knowledgeable about the status of family members to avoid unwanted disclosure. This, however, limits the availability of others to provide social support. Family members not only remind youth to go to clinic, they bring them to clinic and are also available to help when they are sick. The continued and extensive involvement into the teen years may lead to “miscarried helping,” common to caregivers of children with a chronic disease (Anderson, Coyne, Johnson & Johnson, 1991). This extensive help may delay the development of the skills PHIV youth need to manage their illness on their own, something that will be pivotal once the young person is pregnant.

Breastfeeding restrictions

As discussed, UK HIV guidelines advise against breastfeeding even if antiretrovirals are available. The benefits of breastfeeding have been long documented in research studies. Breastfeeding can enhance and prolong positive social interactions between mothers and infants (Papp, 2014; Pearson, Lightman & Evans, 2011) and has been found to be associated with greater attachment security and less attachment disorganisation (Tharner et al., 2012). Many longitudinal studies illustrate that breastfeeding is strongly associated with better neurological and cognitive competence and a lower risk of psychopathology in later life (Alati, Van Dooren, Najman, Williams & Clavarino, 2009).

Whilst these findings seem compelling in their support for a link between breastfeeding and an enhanced mother-infant relationship, it is difficult to disentangle whether associations between breastfeeding and sensitive maternal responses are influenced by the act of breastfeeding or merely indicative of the existing differences in the women who choose to breastfeed. Many studies fail to account for potentially relevant factors such as maternal age and employment. Indeed, breastfeeding and intent to breastfeed are associated with higher maternal education and income (Jacobson & Jacobson, 2002) and these factors are also associated with sensitive parenting (Gutman, Brown & Akerman, 2009). This may suggest that women who are already more likely to be sensitive to their infant choose to breastfeed (Britton, Britton & Gronwaldt, 2006). However, a recent longitudinal study which took into account mothers' previous mental health and controlled for potential confounders such as socioeconomic factors, relationship status, prematurity and the intention of the mother to breast feed, also found that breastfeeding protected against PND (Borra, Iacovou & Sevilla, 2014).

Breastfeeding restrictions have been found to be culturally, emotionally and socially challenging for many mothers with HIV, especially for those originating from sub-Saharan Africa, where there is a strong cultural expectation to breastfeed. Studies show that breastfeeding restrictions provoke feelings of maternal inadequacy, guilt and a deep longing to provide nutrition for their baby (Lazarus, Struthers, & Violari, 2009). Women felt formula feeding signified their HIV status, and labelled them as bad and selfish mothers. Many had significant concerns about the physical and psychological

effects of formula feeding their child and struggled with the unexpected financial burdens due to formula feeding. Despite these fears, almost all HIV-positive women chose not to breast feed, driven by the desire to protect their child from contracting HIV (McCarthy, Rasanathan, Nunn & Dourado, 2013; Tariq, Tookey, Elford & Argenti-Pillen, 2012; Triesman, Jones & Shaw, 2014).

It is clear that the decision to avoid breastfeeding comes at considerable personal cost to many women living with BHIV. There are no known studies that examine this issue for women with PHIV.

Mental health considerations

Research indicates that PHIV youth experience emotional and behavioural problems, including psychiatric disorders, at higher than expected rates, often exceeding those of the general population and other high-risk groups (Frize et al., 2011). Along with familial circumstances, long-term exposure to ART and the effects of experiencing critical developmental periods prior to optimal HIV treatment may underlie these findings (Mellins et al., 2006). They may also be due to the difficulties faced negotiating late adolescence in the context of living with HIV (Frize et al., 2011). However, the specific role of HIV remains unclear, as uninfected youth with HIV exposure (born to mothers with HIV) or those living in HIV-affected households display similar prevalence rates of emotional and behavioral problems in some studies, higher rates in others and lower rates in others still (Mellins & Malee, 2013).

Medication and adherence factors

Young people with PHIV have required complex medical care since birth. Data on age appropriate drug dosing is scarce and dosing is further complicated by the changes in dosage as the child grows (Bernays et al., 2014). Little is known about the long-term effects of ART in children, particularly given that they are exposed to drugs when their physiological systems are immature (Bernays et al., 2014).

Viral suppression is dependent on adherence to medication which young people report as requiring a great deal of commitment and effort (De Santis et al., 2014). Research has shown that medication adherence is a dynamic phenomenon that is shaped by patients' cultural attitudes, beliefs, feelings about medication, and experiences taking medication (Wrubel et al., 2005). Factors related to the family are crucial to paediatric adherence because young children depend on a caregiver to administer medications (Steele & Grauer, 2003). Identifying this person is often problematic, especially when parents die or are impaired by complications of their own HIV infection (Hazra, Siberry & Mofenson, 2010). Effectiveness of ART is also dependent on the regularity of the treatment which can provoke anxiety in carers as many feel that even a short delay in the prescribed time may eliminate the effectiveness of the treatment (Hejoaka, 2009). Thus the child's day often has to be organised around timings of medication (CHIVA, 2011).

These strict requirements are further complicated within the context of the social complexity faced by families with HIV, factors which are often underappreciated with regards to facilitating treatment (Bernays et al., 2014).

For some mothers, stigma responses and disclosure related fears reduce adherence, despite knowledge that adherence to ART is the only way to control HIV infection (De Santis et al., 2014; Wrubel et al. 2005). Side effects of medication also influence adherence rates as some mothers feel emotional pain in having to 'force' their children to do something aversive.

Adherence to treatment of chronic illnesses is often seen to drop off during adolescence and, unfortunately, HIV is no exception (Nachega et al., 2009). At this stage, adherence is further complicated by normal social-cognitive developmental transitions that must be negotiated in the context of a stigmatized infectious disease. During the teenage years, the need for autonomy and potential rebellion against parental control, the peer focus and desire to be like other teenagers combined with an increased responsibility given to teenagers for taking the medication complicates adherence. This perhaps explains why adolescents (over the age of 13) with PHIV are less likely to achieve an undetectable viral load than children under the age of 13 with PHIV (Khan et al., 2009). Studies suggest that adherence may continue to decline as PHIV youth age into older adolescence and young adulthood (Koenig, Nesheim & Abramowitz, 2011). This may result in young women with PHIV beginning pregnancy having not been adherent with their medication for many years, if at all.

Issues around disclosure

Individuals with PHIV deal with disclosure issues on multiple levels.

Paediatric disclosure:

Disclosure of the child's HIV diagnosis (paediatric disclosure) is a challenge worldwide (Wiener, et al., 2007) and one of the most important yet most difficult issues for HIV-infected mothers (Nelms, 2005). 'Partial disclosure' is the term used for describing situations in which children are given some but not all information about their illness, for example being informed that they need medication but not disclosing the name of their illness. 'Full disclosure' occurs when children are told the name of the illness, disease specific information and how they acquired the disease (Wiener et al., 2007). 'Full disclosure' is frequently postponed due to concerns about immaturity, fears that the child may tell others (secondary disclosure) and feelings of guilt for having infected the child (Guerra & Seidl, 2009).

Paediatric disclosure can remind parents of their own experiences in receiving their diagnoses (Galano et al., 2012). Some mothers with HIV explain their orientation towards open disclosure as being established by their own childhood experiences with family secrets and their memory of feeling betrayed by parental silence regarding other important personal history (Lester et al., 2002).

Dorrell & Katz (2014) present the disclosure recollections of 28 young people with PHIV who report the disclosure event as being hugely important. Children should be old enough to understand that their medical information is private before they learn they have HIV by name (Hazra, et al., 2010).

Anticipated stigma is one of the major barriers to paediatric disclosure (Chaudoir, Fischer & Simoni, 2011). This can result in delayed and suboptimum paediatric disclosure. Indeed there is evidence that children can overhear adults referring to their HIV or are told abruptly by health care professionals (Haywood, 2014). This may result in psychological distress and changes in the child's adherence to medication regimes (Weiner et al., 2007).

Onward disclosure:

People with PHIV face a lifelong series of disclosure events, yet disclosure is one of the most complex psychosocial challenges. As close friendships develop, youth may want to reveal their status to alleviate any feelings of shame or leading a double life, however, their disclosure to friends or romantic partners often necessitates the “double-disclosure” (Abramowitz et al., 2009) of both the youth and parent's status and potential parental history of sexual behaviour and substance abuse (Fair & Albright, 2012).

Childs and Maxwell (2009) explore the impact of PHIV on the developmental challenges of adolescents through case vignettes taken from social workers' clinical practice in New York. The case reports suggest that partner disclosure is fraught with fear, often stemming from a history of rejection, harassment, unauthorized disclosure to others or social ostracism. Research also suggests that PHIV youth are less likely to disclose their status to friends than those living with BHIV (Abramowitz et al., 2009; Peele, D'Angelo Chandwani, Abramowitz, Koenig, 2012). Social relationships are often felt to be disrupted because of disclosure of an HIV status to partners (De Santis et al., 2014). Disclosure rates to sexual partners of PHIV youth range from 20% to 40%

(Michaud et al., 2009), lower than for adults with HIV in resource rich countries (68–86%) (Arnold, Rice, Flannery & Rotheram-Borus, 2008). The discovery of a pregnancy may result in a woman having to disclose her status to her partner for the first time. Disclosure of a pregnancy for women with PHIV to partners and professionals appears to be an understudied area.

Maternal HIV disclosure:

Women with PHIV will have to decide whether to disclose their own status to their children. Most women with HIV are reluctant to do this, believing that the potential costs (stigma, burden) outweigh any benefits (Nelms, 2005). The research suggests that ill parents disclose sooner than healthier parents, and older children are disclosed to more often than younger children, other than these two factors, there seems to be no difference between women who disclose and those who do not (Armistead et al., 2001). The majority of mothers who disclosed had no regrets about disclosure in one study (Murphy et al., 2003).

Ideally, prior to a disclosure, mothers should plan what they want to say, be educated in HIV and have age-appropriate materials available for the disclosure. Studies have shown that disclosure needs to be performed in a calm and natural manner to make the situation less stressful for children (Murphy et al., 2003). According to children who have been through the process of disclosure, parents need to be honest, hopeful, positive, and prepared to answer children's questions. Disclosing when children are 6 to 10 years old has been found to be optimum (Armistead et al., 2001). Children

need emotional support, reassurance and education, during and after disclosure, perhaps provided by a health care professional (Murphy et al., 2003).

HIV within the family: secrets and loss

PHIV is a household disease and unlike youth with other chronic illnesses, youth with PHIV are more likely to have experienced parental illness and the potential trauma of multiple family bereavements (Foster, Waelbrouck & Peltier, 2007). Maternal death has been found to be one of the most significant psychosocial issues faced by young people with PHIV (De Santis et al., 2014), bringing the child face-to-face with the implications of their own HIV status, something that many may not have previously fully understood (Wrubel et al., 2005). The death of a parent or carer can lead to family disruption and relationship breakdown (Weiner & Battles, 2006), resulting in young people being brought up by members of the extended family or placed in care and influencing their experience of being parented. This is particularly common in many parts of Africa (Foster & Williamson, 2000).

Corona et al. (2009) examined HIV related discussions between youth and their parent. Family members who reported feeling comfortable talking with each other about HIV described a close relationship and an open conversation style. Those who felt discomfort had concerns about a child's ability to understand and cope with the parent's illness and youth worried about upsetting their parents or reminding their parent about their HIV infection. Siblings generally did not talk to each other about HIV because

they worried about upsetting each other. Adult children reported 'learning lessons from their parent's experiences' for example, watching parents take medication, hospitalizations, and accompanying parents to medical visits. This subsequently reinforced HIV prevention messages for youth.

Having acquired the virus from their mothers, people living with PHIV feel they have to keep many family secrets (Weiner & Bettles, 2006). For example, when there is death from HIV it is difficult for a young person to be open about the cause of death, due to fear of discrimination and stigma, creating barriers in young people's social relationships (Dorrell et al., 2008). All participants in De Santis and colleagues (2014) GT study reported that HIV influenced family communication and dynamics. HIV's impact on the family was not only confined to concealing the diagnosis, but it also contributed to dysfunction in the family. This included blaming parents for HIV infection or becoming angry with parental denial of HIV infection, factors that are likely to have influenced the way a young person with PHIV will choose to parent.

Rationale for the current study

The literature above describes some of the challenges faced by young people with a diagnosis of PHIV. These include long-term health complications and adherence issues, a family environment characterised by secrecy, potential maternal bereavement and dealing with issues of disclosure through their teenage years.

However, there remains a significant lack of research into the impact of these challenges on the experience of motherhood with a diagnosis specifically of PHIV. Relatively little is known about the motivation and reproductive decisions of women with PHIV and the extent to which their illness affects their identity as a mother. There is little research into how the multitude of emotional, physical and psychological challenges faced by this group of women impacts on their relationship with their children and their relationships with their own mothers. Overall, there is a need for more knowledge about the perspectives of this group of women and the perceived impact of PHIV on the mothering experience to enhance the support that can be offered to PHIV mothers. The current study aims to explore these issues using a qualitative methodology with a small sample of individuals with PHIV to examine and build a model of the experiences relating to motherhood.

Research aims and questions

The purpose of this study is to explore the emotional and psychological aspects of becoming a mother and reflecting on being a mother within the context of having a PHIV diagnosis. The research questions are:

- 1) What are the perceived links between the mother's own experience of growing up with HIV, having a parent with HIV and becoming a parent with HIV.
- 2) Is the mother's ability to bond with her child perceived to have been influenced by her HIV status.
- 3) What is the influence of the pregnancy and birth on the perceived relationship between the participant and her own mother.

The data will be collected, analysed and reported following a Grounded Theory approach (Charmaz, 2006).

Practical and potential clinical implications

As the number of mothers with PHIV grows both nationally and internationally, understanding their adjustment to motherhood within the context of PHIV infection is an important public health issue and is crucial for the development and implementation of intervention programmes aimed at this group and their children. The findings from this study should enhance knowledge of a largely understudied but soon to be growing group of individuals. The theoretical model produced may inform professionals about how best to support this group of women in their journey through motherhood. It may help improve maternal health outcomes during this life-changing period, such as facilitating the development of a healthy mother-infant bond.

CHAPTER TWO: METHOD

Research design

This study used a cross sectional qualitative design. Grounded Theory (GT) (Charmaz, 2006) was used to guide the design, recruitment, analysis and subsequent reporting of the findings from semi-structured interviews with seven PHIV mothers.

Recruitment

Sampling

A systematic sampling approach was used; all eligible women were approached in order of their appointments. Women were eligible to participate in this study if they:

- had a diagnosis of PHIV;
- were fluent enough in speaking and comprehension of English to enable interviews to take place without the use of an interpreter;
- were over the age of 18 when they gave birth: to avoid complicating the findings with the additional challenges faced by motherhood in early teenage years (Lieberman, Le & Perry, 2014);
- had a child under the age of 5 years of age, to enable participants to reflect on the process of becoming a mother and bonding with their infant in their first few years.

Individuals were excluded if the clinical team considered that involvement would be likely to have an adverse impact on their emotional health.

Recruitment settings

Interviews for this study were carried out face-to-face at three different settings between July 2014 and January 2015. Two settings were HIV Services within inner-city hospitals that provide care for HIV-positive young people aged 16-24 years. The final setting is a voluntary sector site that supports children, teenagers and families living with, or affected by HIV. Figure two below illustrates the recruitment process.

Step 1: Engagement with staff:

Prior to ethical approval, the researcher organised meetings at each potential site. Key staff were invited to attend and the aims of the project were presented. Logistics, inclusion and exclusion criteria for participants were discussed.



Step 2. Participant identification and information giving:

Following ethical approval, eligible participants were approached by their known clinician or member of staff during a routine appointment or workshop and given an information sheet about the study (Appendix 1). If women were interested in the study they could consent to their contact details being passed to the researcher to organise an interview time, or they were able to sign up to a pre-existing interview slot.



Step 3. Informed Consent

Following the opportunity to ask any questions about the study, informed consent was taken from participants at the start of the interview (Appendix 2).



Step 4. Interview, debrief and further support

Upon completion of the interview each participant was given £20 in cash to cover expenses (including childcare). Participants were given a list of local supportive services they could access to speak to someone following the interview if required (Appendix 3).

Figure 2: The recruitment process

Participant recruitment and refusal rate

All eligible women were approached by clinicians at routine clinic appointments or at young parent workshops at the voluntary sector site. Seven of the ten women approached agreed to take part in the study. Three women declined to be involved in the study, citing the following reasons:

- Feeling that, as a new mother, they did not have time for the interview
- Inability to arrange appropriate childcare, despite the study funding
- No reason given for decline to be involved

This resulted in a final sample of seven women.

Participant characteristics

Tables 3 and 4 below outline relevant demographic characteristics of participants. This information was gathered from the women during

interviews using a simple form which they completed themselves (Appendix 4), to situate the sample and help provide context for the research.

Women were between the ages of 21 and 29 with a mean age of 25.6 years.

Two of the participants had mother's that were still alive, one participant had lost her mother after the birth of her second child and one participant lost her mother during her first pregnancy. All babies were bottle-fed. The

relationship status of each participant at the time of interview and during the pregnancy and birth of their first child is also shown to provide some context.

Two of the participants were in a relationship at the time of interview (one of these with a different partner to the father of her child), and all but one participant were in a relationship during the pregnancy.

One child contracted PHIV despite his mother's reported adherence to medication and avoidance of a natural birth and breastfeeding. This mother agreed to be interviewed on the basis that she would not be questioned about her son's status.

Table 3: Demographic information of participants

Participant No.	Age (yrs at interview)	Age of paediatric disclosure	Ethnicity	Country of origin	Relationship status at interview	Relationship status during pregnancy and birth	Age of child/ren at interview & gender	Planned/unplanned pregnancy
01	27	13	Black African	Uganda	Single	Co-habiting	4 years – boy	Unplanned
02	24	9	Black African	UK	Single	Co-habiting	18 months - girl 7 months – girl	Unplanned Unplanned
03	29	14	Black African	Zambia	Co-habiting	Co-habiting	8 weeks –girl	Planned
04	26	16	White British	UK	Co-habiting	Co-habiting	8 years – boy 8 weeks – girl	Unplanned Unplanned
05	27	12	Black African	Zimbabwe	Single	Co-habiting	7 years – girl 2 years – boy	Unplanned Unplanned
06	21	13	Black African	Tanzania	Married	Married	13 months - girl	Planned
07	25	18	Black African	Uganda	Single	Single	3 years - boy 23 months - boy	Unplanned Unplanned

Table 4: HIV-relevant demographic information

Participant No.	CD4 count (cells/uL) at interview	Viral load at interview	Father of child HIV status	Type of delivery (caesarean or vaginal delivery)	Child HIV status	Participant's birth mothers health status (age of participant at death)
01	174	200	Negative	Planned caesarean	Positive	Deceased (8 years)
02	Unknown	Unknown	Negative	Emergency caesarean Vaginal	Negative Negative	Deceased (22 years)
03	Unknown	Unknown	Positive	Planned caesarean	Negative	Deceased (12 years)
04	420	Undetectable	Negative	Planned caesarean Planned caesarean	Negative Negative	Deceased (21 years)
05	20	400	Negative	Planned caesarean Planned caesarean	Negative Negative	Alive
06	Unknown	Unknown	Positive	Emergency caesarean	Negative	Deceased (3 years old)
07	Unknown	Unknown	Negative	Vaginal Vaginal	Negative Negative	Alive

Qualitative analysis method of choice

This enquiry lends itself well to a GT method because this method facilitates a process of 'inductive theory generation' (Charmaz, 2008), and considers the psychological processes underlying complex phenomena (Charmaz, 2006). This is particularly pertinent given the paucity of literature on the psychological processes influencing the experience of motherhood with a diagnosis of PHIV. It was felt that this method would facilitate systematic deconstruction of the participant's complex experience, and generate a theory grounded in their experience and context.

GT is a method of abstracting theory from experience and was developed by Glaser and Strauss (1967) based on their belief that theories should be grounded in data. GT is concerned with actions, interactions, and social processes shared by participants. Glaser and Strauss (1967) were motivated by the notion that these sociological concepts should be an organic, integral part of social life rather than something artificially attached by remote experts. Therefore, unlike other research methods, the data collection and analysis process in GT is merged and the researcher moves back and forth between the two in an attempt to ground the analysis in data, resulting in a method which is integrated and cyclical in nature. It involves the development of a theory, rather than the testing of a theory (Willig, 2008).

With GT it is expected that participants are selected purposefully because it is believed they can contribute to topic being investigated (Willig, 2008). GT methodology has three main features: iteration; constant comparison and theoretical sampling. Iteration is the practice of subjecting new data to analysis as

soon as they are collected to refine subsequent data collection. 'Constant comparison' occurs when statement is compared with statement, story with story, participant with participant, theme with theme. The researcher identifies emerging patterns in the data and systematically checks and elaborates these patterns against new data. This triggers the third feature of GT; theoretical sampling. Within this process the data collection procedures evolve to become increasingly focused on the key emerging themes to fully understand the themes and ensure no new information is being offered, a position which in GT is referred to as saturation (Lingard, 2014). Writing 'theoretical memos' at each stage of data analysis enables the development of codes and categories, allowing researchers to identify gaps in the data and further questions to address these (Charmaz, 2006). The themes, concepts and hypotheses that emerge from the data form the basis of a new theory (Charmaz, 2006). The emergent theory can then be compared to existing theories to consider how well previous literature explains phenomenon, and in which ways the new theory adds to this knowledge and understanding (Glaser & Strauss, 1967).

Considering other qualitative methods

Before selecting GT as the most appropriate method for this study a number of other qualitative methods were considered.

Discourse Analysis (DA) was considered as a potential approach for this study; a method concerned with language and its role in the constitution of social and psychological life (Willig, 2010). DA assumes there are multiple realities shaped by an individual's prior knowledge and experience. Although the current study

wishes to take a constructionist position in exploring the role of language and construction of events (Charmaz, 2006), the fact that DA focuses on broader societal narratives would hinder the exploration of individual experience and meanings set out in the research questions (Forrester, 2010).

Interpretative Phenomenological Analysis (IPA) was also considered. IPA is a method which aims to explore the research participants experience from their perspective whilst taking into account the fact that this research is influenced by the researcher's own view of the world, as well as the interaction between the researcher and the participant. Hence, the phenomenological analysis produced is an interpretation of the participant's experience (Willig, 2008). This method can prove insightful about individuals' experiences, however, the greater level of interpretation means IPA does not lend itself to the development of a theory grounded in actual experience. GT was thought to be more suitable in achieving the aim of developing a model of the experience of becoming a mother with a diagnosis of PHIV.

Divergent methods in GT

The original concept of GT was first introduced in 1967 by Glaser & Strauss and was developed from a philosophical viewpoint to produce theoretical analyses of social interactions, based on the interpretations of those involved (Charmaz, 2006). Since 1967, Glaser and Strauss have parted company, proposing differing directions for developing the theory with Glaser remaining loyal to the original methodology whilst Strauss co-authored works with Corbin and developed new technical procedures, including 'axial coding' in which categories and properties

of the data are related to each other (Corbin & Strauss, 2008). Numerous varying GT methods have emerged since this time with new authors developing divergent versions of the approach.

More recently, Charmaz (2006) has challenged the notion held by Glaser, Straus and Corbin that the researcher is able to maintain a neutral stance in the analysis. Charmaz is of the belief that the guidelines that describe the steps of GT research are not used in a neutral way by individual researchers. She believes it is not possible to ignore the assumptions and beliefs brought by and enacted upon by each individual researcher during the process. For example, a researcher's age, gender, cultural background and experiences will influence the interpretations made by the researcher and thus impact on data collection and analysis (Charmaz, 2006).

Rationale for using Charmaz's constructionist GT

Charmaz's (2006) constructionist version of the original GT acknowledges that 'we construct our grounded theories through our past and present involvements and interactions with people' (Charmaz, 2006, p.10). This approach to analysis was deemed appropriate for this study for a number of reasons. For example, Charmaz emphasises the flexible use of the methodological guidelines for GT, viewing them as a set of principles, not methodological rules and requirements. This is important as ethics committees often require an extensive review of the literature prior to data collection to ensure a study for a Clinical Psychology Doctorate is making a unique contribution to the research base, thus hindering the researcher's ability to start data collection without any prior knowledge or

assumptions. Flexibility was also required so that the model created could be used to inform and build upon existing knowledge and understanding of women with PHIV. Further, Charmaz's version of GT allows for the significance of the professional and personal positions of the researcher to be considered, and the role these might play in the construction of the resulting theory. This was particularly important in this study, as the researcher herself had become a mother during the course of the study (discussed further in the Personal Reflections section in the Discussion chapter).

Prior assumptions and reflexivity

Reflexivity is essential in any qualitative research. Charmaz states that it is important to recognise that researchers make assumptions about what is real, possess prior knowledge and experience and have a purpose that will influence their views during data collection. She states that researchers 'must be reflexive about what they bring to the scene, what they see and how they see it' (Charmaz, 2006, p.15).

Some of the assumptions, experiences, beliefs, and values which the researcher feels most likely influenced the research, include that the researcher is a white, middle-class, female trainee Clinical Psychologist who had a prior interest in mother-child interactions and relationships. The researcher had a number of prior assumptions about the ability of women to articulate their answers in a way that would fully capture their experiences. In particular she had concerns about how open and honest participants would be and whether their accounts would be

influenced by a fear of judgement or the fact that the researcher was not HIV-positive.

Importantly, the researcher was pregnant and gave birth during the course of the project. Sharing a 'direct experiential base' with the participant group provided new insights and understanding into the participant's experiences of pregnancy and labour, along with an understanding of the difficult adjustments and experiences all new mothers go through.

Alongside teaching on HIV as part of her clinical doctorate, the researcher also had clinical experience in working with women with HIV and had previously worked within a caring role for a female child with PHIV in a children's home. This allowed the researcher to gain valuable insight into the experiences and challenges faced by people with PHIV at various stages of their lives such as issues with deciding when and whom to disclose and potentially experiencing low mood. Prior to the study the researcher had been largely supervised from a psychodynamic and systemic perspective which may influence the interpretation of the findings.

The writing of a reflective diary throughout the study allowed the researcher to reflect on her position in relation to the research and to assess how and to what extent this position influenced the study. Any issues of sensitivity were discussed with the internal research supervisor. The reflective diary was started prior to any data collection to outline the researcher's prior assumptions about this group of women and the expected outcomes of the research, enabling the researcher to evaluate the influence of her position on the interpretation of the data. An extract from this diary is included in Appendix 5.

As previously described, the author was required to submit a literature review and research proposal for this project, which may have risked forcing previously known concepts or theories onto the data (Glaser & Strauss, 1967). However, authors have acknowledged that a researcher's professional background itself will make it impossible for them to approach a study with no prior understanding or knowledge (Heath & Cowley, 2004), with Corbin and Strauss (2008) even suggesting that previous knowledge and experience can actually enhance sensitivity to the data by enabling a researcher to better understand the significance of what participants are expressing in their language.

Interviewer Training

Prior to data collection, the researcher attended a day-long course on GT. A role-play interview was carried out with the internal supervisor to ensure that the depth and type of questions was suitable and adjustments made accordingly. The internal supervisor also provided feedback on the researcher's interviewing style during the first two transcribed interviews. The researcher also attended frequent peer supervision groups with fellow trainees undertaking GT studies, one of whom was also doing an HIV study with the same population. This provided important opportunities to discuss methodological and analytical queries.

Procedure

Gaining ethical approval

This study was granted ethical approval from the London Queens Square NHS Research Ethics Committee and from Royal Holloway University of London Ethics

Committee in April 2013 (Appendix 6 & 7). Research and Development (R&D) approval was subsequently gained from the two hospital sites in London (in May 2013) and at the charity site (in July 2013) (Appendices 8, 9 & 10).

Following ethical approval, a minor amendment to the ethics application was submitted to the REC in February 2014. Initially the researcher intended to access participant's medical notes to contextualise the results. It was later decided to not access medical notes but to verbally gain relevant medical information from participants. This alteration was made so as to gain R&D approval at both hospital sites. Approval for the amendment was approved on 2nd May 2014 via email (Appendix 11).

Due to the fact that this study involved recruiting women with PHIV and the handling of potentially sensitive data, particular consideration was given to possible ethical implications of the research for participants. Full details of how ethical considerations were addressed in this study are included within the Participant Information Sheet (Appendix 1). A sample of the ethical considerations addressed can be found here:

- **Voluntary basis of participation:** participation in this study was voluntary, with reassurance that decisions about involvement would have no impact on the participant's treatment or support from the service.
- **Confidentiality:** anonymity of participants' identities was maintained at all times, by anonymising all transcripts. Participants were informed about the limits of confidentiality if any significant risk was disclosed.

- **Informed consent:** information was provided to enable informed consent to be obtained, with opportunities to ask any questions provided at several points.
- **Safeguarding children:** procedures were put in place to ensure child safety and protection at all times, with preparation made for contact with the relevant authorities should this be necessary.
- **Emotional distress:** emotional support from a professional known to each participant was in place at the service during each interview in case of any concern over participants' welfare during or following an interview.

Data collection

To fully explore the mother's experiences, interviews with participants were selected as the method of data collection. The interviews were conducted with the use of a semi-structured interview guide to ensure that all participants were asked questions covering all important areas. All interviews were audio recorded, and observations, reflections and thoughts on the experience were recorded in a reflective diary at the end of each interview to enrich the data set.

Measures

To provide further context to the results, all participants completed the Hospital Anxiety and Depression (HADS) questionnaire, originally developed by Zigmond and Snaith (1983) (Appendix 12). The HADS is a fourteen item scale, seven of the items relate to anxiety and seven relate to depression. The questionnaire has been found to perform well in screening for the separate dimensions of anxiety and depression in patients from non-psychiatric hospital clinics (Bjelland, Dahl, Haug & Neckelmann, 2002). The anxiety and depression scores are categorised as

normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). The HADS has previously been used in HIV populations (Greenhaulgh et al., under review). Participants also completed the Parental Distress subscale from a shortened version of the Parenting Stress Index (PSI; Abidin, 1983) (Appendix 13). This subscale uses a 5-point scale to indicate the level of stress the parent is experiencing in her role as a parent; the higher the score the higher the perceived level of stress and distress. Psychometric properties of the PSI short form appear to be strong (Reitman, Currier & Stickle, 2002). This measure has also been previously used in the HIV population (Murphy et al., 2010). The outcomes from these measures will be reflected on further in the discussion section.

Table 5: Participants scores on collected measures

Participant number	HADS	Parental Distress subscale score
01	3/21 depression 2/21 anxiety	15/60
02	10/21 depression 10/21 anxiety	28/60
03	0/21 depression 3/21 anxiety	34/60
04	4/21 depression 15/21 anxiety	41/60
05	13/21 depression 10/21 anxiety	14/60
06	1/21 depression 1/21 anxiety	12/60
07	0/21 depression 1/21 anxiety	18/60

Interview guide

In collaboration with all supervisors, a draft interview schedule was developed at the outset of the research. In line with GT methodology, the interview schedule aimed to contain mainly open questions, to allow participants' own experiences to emerge and for them to discuss salient concerns, as well as providing space for the interviewer to go beneath the surface of what the respondent is disclosing (Charmaz, 2006). Questions relevant to the research area were drawn from the

existing literature on PHIV and HIV in motherhood (Ezeanolue et al., 2006; Kennedy et al., 2014) and mother-infant bonding (Bowlby, 1988). Sample items on the interview guide included: 'tell me about having a mother with HIV', 'before you got pregnant, what were your thoughts about having a child?' and 'how do you find being a mum?' The final interview questions asked if there was any additional advice women with PHIV would give to other women with their diagnosis who were considering having children.

Adapting the interview guide

The questions in the interview schedule needed to be worded appropriately and sensitively so that participants felt fully able to reflect on and share their experiences. A service user feedback process was therefore carried out to seek views on the interview guide before data collection began. Several mothers with BHIV were recruited from the charity site and were approached by a member of staff known to them. Guided by the researcher, the staff member asked the mother's opinions regarding the tone, clarity and sensitivity of the language used within the interview schedule. Feedback from these meetings was provided by email.

The majority of feedback with regard to the interview guide was positive; the women felt the questions were clear and appropriate. Only a few minor edits were recommended, mainly regarding the use of language and potentially confusing abbreviations such as PHIV. They also recommended sensitive questioning with regard to questions about the participant's relationship with their mother as many of them may have passed away (see Appendix 14 for the final interview schedule).

A second editing process for the interview schedule followed the completion of the first three interviews for this study. One of the defining features of GT is simultaneous data collection and analysis, with analysis conducted following the initial stages of data collection (Glaser & Strauss, 1967). In line with this approach, the first three interviews were transcribed and open coded before any further interviews were conducted. Emerging gaps, ambiguities and key areas of interest were identified from this initial analysis, and added to the interview guide to be explored further within subsequent interviews (see Appendix 15 for the updated interview schedule).

Interview process

After ensuring that participants met inclusion criteria, the researcher obtained written informed consent. All seven interviews were carried out by same researcher in private rooms within each setting. Interviews lasted between 40 and 82 minutes, with a mean interview length of 57 minutes. The interview schedule was used flexibly as a guide to ensure that the general topics were covered across all interviews, whilst allowing for specific questioning and further exploration to occur depending on the individual's responses and experiences, which is consistent with GT methodology. When required, prompt questions were used to encourage participants to expand on answers, especially around key topics. Reflective summaries of participants' answers were provided throughout the interview to ensure that the responses had been properly understood and interpreted (Forrester, 2010). Given the emotional nature of the material covered, sensitivity to the participant's needs was given priority. It was important

to acknowledge their feelings as several of the participants became tearful during the interviews. Charmaz (2004) has described temporarily abandoning the researcher role, when she has felt it important to validate participants. This was vital for maintaining rapport and to avoid any further distress. No participants were visibly distressed upon leaving the interview room and all participants were given contact information for further emotional support if needed. Two of the participants brought their babies to the interview as they were under two months old and too young to be left with anyone else. These babies slept through the majority of the interview. Following the interview, participants completed the demographic form and measures previously described.

Analysis process

Data analysis was a collaborative, constant comparative and systematic process that began with the first interview and continued throughout data collection.

Transcription

Interviews were transcribed verbatim as soon as possible after the interview and the data was anonymised and stored in a secure password protected computer. Guidelines were followed to ensure a systematic procedure was applied to all transcripts, for example in deciding what was to be transcribed (facial expressions, body language and background noise) (McLellan, MacQueen & Neidig, 2003). As recommended, all interviews were conducted by the researcher, thus ensuring a consistent method of data collection. The researcher also transcribed all seven interviews to enable them to feel immersed in the data and

to further their understanding of it (Charmaz, 2006). All elements of the participants' speech including pauses, emphasis and utterances (Davidson, 2009) were transcribed. This transcription approach helped to construct meanings in relation to a participant's language and specific experience.

Coding

To Charmaz (2006) coding is 'naming segments of data with a label that simultaneously categorizes, summarises and accounts for each piece of data' (p. 43) and she suggests that this process is the pivotal link between collecting the data and developing an emergent theory to explain the data. According to Charmaz (2006) GT analysis should consist of three distinct stages of coding: initial coding, focused coding and theoretical coding and diagramming. All three stages are linked and supported by on-going memo-writing. Details of how these different coding stages were carried out for this study are set out below.

First stage: initial coding

Initial coding, which is open-ended and done line by line, was conducted on each of the transcripts as soon as possible following the interview to enable the researcher to start to define and categorise the data. Often the participants own words (in vivo coding) or gerunds (words ending in *ing* that reflect process rather than topic) were used as codes. This was to convey a sense of action and imagery as well as to stay close to the data, and therefore the meanings the participants were conveying. This process is thought to prevent the researcher from coding the data in accordance with pre-conceived categories or theories in mind, and ensures

that the codes are grounded in the data; 'anchoring the analysis in the research participants' worlds' (Charmaz, 2006, p.57).

Second stage: focused coding

As line by line coding proceeds, recurring concepts will illustrate 'focused codes' (Charmaz, 2006). Focused codes represent what the researcher feels most accurately explain the recurring concepts that are beginning to emerge from the data. In GT data driven themes emerge through a process of 'constant comparison' (Glaser and Strauss, 1967). The coding of each interview is compared with those previously coded to confirm existing categories or produce new ones (Charmaz, 2006). The recorded interviews were listened to and transcripts read multiple times to elicit emergent codes. There is no such thing as an outlier in GT; no data is dismissed from investigation because of any non-central tendencies. Instead, the larger conceptual schemes are constantly improved by synthesizing new data or by new analysis of older data (Wasserman, Clair & Wilson, 2009). This constant comparative analysis directed the altering of interview questions over time.

Final stage: Theoretical coding and diagramming

The final stage of coding follows codes selected during focused coding and specifies possible relationships between these categories, describing how they relate to each other and how they can begin to be integrated into a theory (Charmaz, 2006). To facilitate this process, memo writing was carried out continuously throughout data collection. Memos established theoretical links and relationships between the codes, elaborating categories, advancing theory

development. Once this final stage of coding was complete, the emergent theory is compared to the existing literature which culminates in a theoretical model construction (Charmaz, 2006).

Memo writing

Throughout the coding process extensive memos of events, thoughts, concepts and ideas arising from the data were captured and explored. Glaser considered memos to be an essential part of the work of generating a theory as they provide a repository of ideas which can be revisited to chart out the emergent theory (Glaser, 1978). The process also helped to provide a space for the researcher to become actively engaged in the material, flesh out emerging concepts, identify gaps and inconsistencies in the data, thus fine-tuning further data collection (Charmaz, 2006). Further, the space provided an opportunity for reflection to guide the analysis process, enabling the researcher to retain an objective stance. Example memos are shown in Appendix 16.

Theoretical Saturation

The notion of saturation in GT is that data collection stops when saturation occurs. Charmaz (2006) states that saturation is when new data no longer trigger new theoretical insights, and new properties of core theoretical categories are no longer revealed (p113). According to Charmaz (2006), the notion of saturation of categories supersedes that of sample size, and sample sizes for some studies may be quite small, yet still achieve the requirements for a project (p114). A GT study needs to be representative, but researchers are advised that it is unnecessary and even defeating to collect huge amounts of data. The risk is that large files go

unanalysed, or the researcher becomes overwhelmed by the sheer volume of data and loses sight of the fundamental processes within the area of study (Stern 2007, p117). It was intended that later sampling would be guided by the evolving theory.

Research quality

A number of processes were followed to increase the validity of the findings based on Yardley's (2008) guidelines. As previously described, qualitative research can be highly subjective in nature and therefore researchers should reflect on their own position in relation to the research process. Through regular reflections in supervision and in keeping a reflective diary, the researcher was able to maintain a degree of reflexivity and sensitivity to the context within which the study took place.

The credibility of the study was enhanced using validation and triangulation methods. Transcripts of the first two interviews were read by the external and internal supervisors who independently identified major themes for coding. This was done to triangulate the perspectives of these codes and to ensure the analysis was not confined to one perspective. The investigators then met to discuss the themes and the coding system. Two other coded transcripts were read by a peer trainee clinical psychologist familiar with GT techniques.

Members of the research team with experience in providing clinical care to this population were asked to confirm the study's findings and to ensure that the data were congruent with clinical experiences (Elliott, Fischer & Rennie, 1999).

Research participants were also consulted on the emerging themes and to clarify

concepts, a process known as respondent validation (Silverman, 1993) to determine whether the emerging themes were representative of the participant's views. All participants stated at the time of the interview that they would be willing to participate in this process. The incorporation of these validation methods ensured that the researcher did not miss any important themes that may influence the emerging theory and meant that the data had been considered from multiple perspectives.

Included within this report are many examples of the themes generated during the analysis process. This should enable the reader to observe the analytic process and to gain some insight into the development of the theory and conclusions reached. Incorporated throughout the results section are quotations from the raw data, allowing the development of codes and memos to be understood and to provide evidence for the interpretations offered (Yardley, 2008). Readers are able to assess the 'fit' between the data and the researcher's interpretations (Elliot, Fischer & Rennie, 1999). To further aid the understanding of this process, sections of transcripts with initial coding are included in Appendix 17.

CHAPTER THREE: RESULTS

Participants are referred to using numbers 1-7 to maintain anonymity (see Table 3). The women provided rich descriptions of how their experiences were influenced by their diagnosis of PHIV and verbatim extracts from the transcripts are included to illustrate each theme and support the end model.¹ All identifying details have been removed from the extracts to maintain confidentiality.

Analysis of the data highlighted the emergence of three theoretical codes, comprising thirteen focused codes, each of these containing a number of specific properties developed during the initial stage of coding, outlined in table 6. A summary table presented in Appendix 18 documents the presence of themes across the women.

At the end of the chapter a theoretical model is presented in diagrammatic form, detailing the experience of becoming a mother with a diagnosis of PHIV.

¹ Words placed within square brackets (i.e. [*she thought that*]) have been added by the researcher so that the extract can be easily understood. A string of dots (...) denotes that a section of the extract has been removed to promote the clarity of the quote.

Table 6: Theoretical codes, sub-codes and properties.

THEORETICAL CODES	SUB-CODES (focused coding)	PROPERTIES OF THE CODES (initial coding)
1 CONCEIVING, CONCEPTION AND PREGNANCY	1.1 Wanting a baby	Worrying about infertility Experiencing abandonment upon status disclosure prior to pregnancy
	1.2 Discovering the pregnancy	Not actively trying to get pregnant Being in denial upon pregnancy discovery Feeling shocked at pregnancy discovery Decision-making process around keeping the baby Anxiety about announcing the pregnancy to own mothers
	1.3 Feeling a duty to protect the baby during pregnancy	Fear of HIV transmission to the baby Wanting a different childhood experience for own child Adhering to medication throughout pregnancy Pregnancy empowering mothers
	1.4 The role of professionals	Feeling supported by professionals Requiring support for pregnancy-related health issues

2 BIRTH, BONDING AND BREASTFEEDING	2.1	Missing out on a natural delivery & breastfeeding	<p>Sadness at being unable to have a natural delivery</p> <p>Feeling like a failure for not breastfeeding</p> <p>Having to explain reasons for bottle feeding</p>
	2.2	Developing a bond	<p>Positive experiences of bonding</p> <p>Negative experiences of bonding</p> <p>Fears for the child's health at birth</p> <p>Fearing the baby would be taken from them</p> <p>Anxiety around the infant screening process</p>
	2.3	Child as a protective factor	<p>Unconditional love for mother from the child</p> <p>Looking after yourself so you can look after the baby</p>
	2.4	Motherhood related stigma	<p>Experiencing stigma during pregnancy and birth</p> <p>Wanting to reassure other mothers about pregnancy and motherhood</p> <p>Desire to eradicate PHIV</p>

3 ESTABLISHING MOTHERHOOD AND FUTURE RELATED THOUGHTS	3.1	Growing in strength and confidence as a mother	<p>Motherhood resulting in growth and maturity</p> <p>Feeling empowered as a mother</p> <p>Challenges of motherhood changing over time</p> <p>Feeling resilient</p>
	3.2	An enhanced experience of motherhood	<p>Feeling grateful as many thought they would never be mothers</p> <p>Comparing oneself favourably to others</p> <p>Making the most of time as a mother</p> <p>Motherhood diminishing influence of PHIV for women</p>
	3.3	Thoughts on maternal disclosure to child	<p>Drawing from own experience of maternal disclosure</p> <p>Desire to be honest with child</p> <p>Ambivalence about age at which to disclose own status to child</p>
	3.4	Hopes and fears for the child's future	<p>Heightened awareness of risk</p> <p>Desire to protect child in the future</p> <p>Learning from own experience of having a mother with HIV</p> <p>Wish to educate child with regards to HIV and stigma</p> <p>Desire for health, strength and happiness</p>
	3.5	Motherhood influencing relationship with own mother	<p>Motherhood triggering memories of deceased mothers</p> <p>Motherhood altering perceptions of their own mothers</p> <p>Motherhood resulting in a healthier and closer relationship between participant and own mother</p> <p>Witnessing mother's relationship with her grandchildren</p> <p>Consideration of own parenting techniques in relation to mother's</p>

1. Conceiving, conception and pregnancy

1.1 Wanting a baby

Despite all wanting to have their own children, the majority of women reported having accepted that they would not be able to do so for different reasons. Four of the women recalled reproductive health concerns related to their PHIV infection. There seemed to be a belief that they were unable to have children as a result of infertility due to their long-standing illness and medication use.

With all the medications I have taken, since I was 5, I thought it would probably have messed up my womb a long time ago, so I didn't think it was physically possible for me to get pregnant. (P1)

The thing is, I always wanted kids, but I never thought I would have kids, because of my status.....I always thought I wasn't really fertile anyway. (P2)

Another three women felt that if even if they were able to have children, they would be unlikely to find a partner whom would both accept them with their diagnosis and would want to start a family with them.

I thought maybe I won't have children, because I would get to that stage and I would tell them {tell partners about status} and they would just all of a sudden disappear. (P3)

I just thought I would never have kids because of the whole status thing, I just thought that was too much to handle, I would have to tell the person I have this and I didn't think I would find someone that I could openly tell. (P5)

There was a sense of sadness about these early assumptions and beliefs as the women believed they faced a future alone. However, all of the women reported that the partners and lovers with whom they eventually had children were supportive following the disclosure of their HIV status. Some, though, were devastated by the news.

It {disclosing status to partner} went quite well....yeah he just said to me obviously it's not my fault, I couldn't have controlled what happened and stuff like that. (P1)

It's {disclosing status to partner} the first time I ever saw him cry – like a baby.....I just didn't expect him to cryI think he was just upset that he thought I was dying....I think he was scared as well. (P5)

1.2 Discovering the pregnancy

Perhaps linked to their beliefs that they were infertile, five of the women were not actively trying to get pregnant but yet were not using any form of contraception.

There was there no wanting and not wanting, it was just me being negligent with contraception.... but we weren't planning to get pregnant. (P4)

Children was something I definitely wanted, in my thirties.... it was like bottom of my list, like way at the bottom, but obviously I just did everything backwards. (P7)

Perhaps also linked to their beliefs of infertility all of the women, even those actively trying to get pregnant, described a sense of shock and disbelief upon

discovering that they were pregnant. For some mothers this disbelief lasted many months, until their first scan.

It was, I think, the biggest shock of my life.....I did it {the pregnancy test}, and I looked at the lines and I wasn't understanding it in my head....and then I did 5 more tests! Because I just didn't believe it.....but I went to the first scan, and I actually saw it....phwwwww. (P1)

Some women, especially those who had unplanned pregnancies and were single at the time, reported responses that were characteristic of denial about the pregnancy. These responses were perhaps fuelled by a sense of fear of the impact of pregnancy on their health, and their belief in their ability to be a mother.

On that night I found out {I was pregnant} I just nearly drank myself to like, a coma...so I could forget that I was pregnant, so I was just like 'shit' but then I think like a couple of days later, I was like 'oh my God I hope I didn't do anything wrong to the baby from doing that drinking cos I think I want it now!' (P7)

Even for the two women who were actively trying to get pregnant there was a similar theme of disbelief.

I didn't believe it until I came to the doctors, because I thought it's just a pregnancy test from a shop! I was really surprised! I was excited, surprised and scared all at the same time! So much emotion was going through me. (P3)

Three of the women went on to describe a decision making process they engaged in following a period of uncertainty over whether to continue with their

pregnancy. These women considered having a termination. For two of the women this was with regards to the perceived risk of HIV transmission to the baby, for the other this was due to feeling as though they would not cope as a single mother. For the women whose decision was influenced by the risk of transmission, reassurance from the specialist HIV midwife about the low risks of MTCT helped them make their decision to keep their child.

I think every woman who doesn't plan to have kids when they are pregnant, I think in that first mind-set you contemplate both options, and I did contemplate both options.....whether to keep it or to have an abortion.....I had to see life in two different aspects, I had to see if I am still with my son's father, and see if I could cope if he's not around, would I be able to cope? So when I thought to myself 'I think that I would be able to cope with the supportive family that I have', that's why I continued with my pregnancy. (P1)

I really thought 'should have an abortion?' because like, obviously I don't know if the baby is going to get it, or if it was the right thing to do.....but then when I came here, they said that errrr they've got lots of medications that will not allow the baby to be infected, so I was like OK, so I really had a good thought about it and thought, 'no, I can't have an abortion' so I had him! (P7)

Women whose own mothers were alive for their first pregnancy recalled anxiety in disclosing the pregnancy to their mothers. Three women recall feeling saddened by their mother's responses, which seemed tainted with disappointment, blame and shame at their being pregnant and being HIV-positive.

When I told her... she told me that I should be more careful, um that my baby was going to come out deformed....and somehow I didn't think she believed me.
(P7)

1.3 Feeling a duty to protect the baby during pregnancy

A prominent fear described by all women was related to the health and wellbeing of their unborn children stemming from the perceived likely transmission of HIV to their baby during pregnancy.

I worried a lot, because I thought, because I got it from my mum, for me it meant I thought that it's everywhere in my body, cos I've been with it for how many years? That was my way of thinking.....because I thought ooooo if it's {the HIV} everywhere in my body it's going to be in my pregnancy as well, that was a big worry. (P3)

I think my only fear was him catching it, that was all, like, I thought to myself like 'I hope he doesn't catch it, I hope he doesn't catch it.' (P7)

For six of the women these concerns were the reason they adhered to their medication throughout their pregnancy, something many had not been doing regularly before becoming pregnant.

Before I got pregnant I wasn't really taking my treatment that well...in my pregnancy I was trying my hardest.....I had to remember every day to take it, and sometimes I'd be too tired, and just not want to take it, but I would force myself and just take it....I just thought 'let me try anything I can to make sure

that the child is fine and protected'....that was the reason {for} me taking my treatment during pregnancy. (P1)

Obviously I worried about giving it to her, and {having} the cycle again of me having to tell her 'oh, you have HIV'.....so I think me worrying about her contracting it was the thing that kept me on the medicine and kept me kind of going through it. (P2)

All of the women described a childhood characterised by secrecy and loss. Many felt they were not told sufficient information about their or their mother's status, being left to work things out for themselves. The women all described a strong desire to protect their child from experiencing the same childhood they had.

I didn't know what she {mother} passed from, the family wouldn't give me...wouldn't tell me..... when they gave me two answers, I just gave up....and didn't bother.....I put the pieces of the puzzle together myself. (P1)

The thing I was worried about was my baby being safe, cos, I don't want bring a child into this world and go through what I went through, no way!Every day I see her, and I can't believe I am in her life and I want to be there to continue taking care of her cos I didn't have my mum to take care of me and I don't want that for her, I just want to be there for her. (P6)

There was a sense that the experience of pregnancy empowered some of the women, giving them a sense of control over their lives and the lives of their unborn children, which had previously been lacking. This appeared to enable them to challenge their mothers and mother figures about aspects of the way they had been raised and protected as children.

I sat her {auntie} down.....and I told her to literally get over the fact that I am pregnant and there was nothing else, either be involved or don't be involved.

(P1)

It was like, she {auntie} wanted to know everything going on in my pregnancy and I was like 'it's nothing to do with you' and I was like, the way I was talked about to everybody – that's not how you're going to do it to my child, it's going to be different because um.....for me there was nobody to protect me {after my mother died}, but now I'm here to protect my child so I was just like, 'ok, I am going to leave your house', I just took everything. (P3)

1.4 The role of professionals

All the women described the support provided by professionals from the outset of their pregnancies and in their journey into motherhood. From initial education and the alleviation of any worries about transmission, to the provision of basics such as clothes and formula milk, the women all appreciated the advice and unwavering support offered from their specialist midwives and doctors. Many felt that these professionals were able to offer them a space where they felt contained, accepted and valued and there seemed to be a strong sense of the importance of professionals during this transition into motherhood.

My child doctor... I would always call him so he used to check up on me during my pregnancy and even sometimes come to appointments that I had, just to make sure that everything was fine....that was the best. (P1)

I developed a really good relationship with my midwife that I saw for both of my pregnancies...he really helped me.... I could call him about anything.... he would always leave his phone on. (P2)

They {professionals} were worried more than me....and they were quite helpful whenever I used to come, they had something to prepare me, sometimes they were giving me um new-born baby clothes and stuff like that, just getting me ready, yeah. So yeah I felt I free to ask anything I wanted to know. (P6)

This support was all the more important considering that six of the women described a very challenging pregnancy that impacted on their physical health and mood, made worse by the side effects of their HIV medication.

{Pregnancy} was a nightmare! It was probably the worst thing I've ever been through.....always sick, always just sick. Vomiting, constant vomiting with or without food, with or without the tablets, lost a lot of weight, and I was so sure that I would never, ever do it again! I spent a lot of time at hospital. (P5)

I was really ill, I was so ill with it {the pregnancy}. (P6)

The women unanimously believed that the physical side effects of the medication were worth it for the safe arrival of their babies.

I did struggle but I knew who I was doing it [taking the medication] for and why I was doing it, so it was quite easy....you actually get a good thing out of it, you get a child. (P6)

2. Birth, bonding and breastfeeding

2.1 Missing out on a natural delivery and breastfeeding

Four of the mothers described a sense of sadness at being unable to have a natural delivery due to following guidance from healthcare professionals. They felt the recommended caesarian would impact the number of children they could have in the future.

I was massively bothered that I had to have a caesaran, I was bothered that they were going to cut my body up..... and I didn't have the choice of that because of what I had. (P4)

I think I was.....upset about not being able to have a natural birth...cos it also limits how much kids you can have, and I always wanted five! (P5)

Other mothers expressed a sense of relief that their baby was 'out,' regardless of the method, as they feared the transmission of HIV was more likely whilst the baby was inside them.

I think I was happy to have her out! Cos really I wasn't worrying anymore, I was not worrying that 'oh I'm going to pass something to her', or 'oh she's inside, I don't know what's going on inside my body' I thought, it could be hiding somewhere- the HIV - so when she was out, at least I could breathe a sigh of relief, cos I thought at least she's out, I just have to give her the medication and then you just continue. (P3)

All women reported feeling intense feelings of concern about their baby's health at birth, anxieties and fears that stemmed from the perceived likelihood of

transmission of HIV and associated health concerns. Women reported not fully understanding the medical interventions faced by some of their new-borns and not knowing how to cope with this anxiety.

When they took her out of me... they started to do so many tests on her.... I didn't understand what was going on and why they were doing it....they done a brain scan on her cos something to do with HIV meant, it's something to do with how the brain forms, I think they wanted to see if there was a blood clot or something.... it was messed up because I didn't understand why. (P2)

I saw him and he was just this tiny 2lb 15 bundle of nothing, with wires left, right and centre, and I was just like, I didn't know how to cope with that.... I was just like 'he's going to die, he's going to die'. (P4)

Six of the women reported feeling that it was particularly challenging not to breastfeed. The majority saw the breastfeeding of their child as a central part of the maternal role, and their inability to do this led to feelings of sadness and maternal inadequacy. Women described facing a dilemma in knowing that they should abide by healthcare advice to avoid breastfeeding to protect their child from the transmission of HIV, yet simultaneously they reported experiencing a perceived instinctual maternal desire to breastfeed. For some women these urges were accompanied by a sense of guilt.

My mum had told me that {that was} how I contracted it, her breastfeeding me, so....that was a no-go, even though I really wanted to... my milk came in and it hurt! It really hurt! And my breasts desperately wanted to be suckled! (P2)

For many of the women the inability to breastfeed their babies resulted in a perceived hurdle in the bonding process between mother and child, and six of the women described a sense of longing for the attachment and closeness they believed breastfeeding would provide them with.

I do want to breast feed – I understand I can't and I would never put her at risk or anything, but it just.....it's like....just to know what that feeling is like, the attachment, would be amazing.....(P4)

I would like to have had that bond, you know when you breastfeed a child you feel, like, more of a connection but I just can't take that risk.....sometimes you have to make decisions that you don't like.....(P6)

For one woman, bottle-feeding her baby was something she would have chosen to do regardless.

I didn't mind, because I think, even if I was given a choice to breastfeed I still wouldn't breast feed...because I've had friends... and they've said that when they breast-fed their kid, like, it leaves their breasts kind of sore, some have actually bleed because of the kid.....yeah, from that I was just like, no. (P1)

Four of the women described a new series of challenges in explaining their 'choice' to bottle feed to those unaware of their status, especially where there was felt to be a cultural expectation to breastfeed. Feelings of failure to adhere to cultural norms and ideals around motherhood further exacerbated the distress experienced by these women.

I think my partner's family {did mind that I didn't breastfeed}, because in their culture a woman has to breastfeed so....at the beginning they were on my case about it, saying I should try and breastfeed him until he was about one and a half years old...so I just came up with a lie or an excuse to get them off my back, I just told them I tried it, it was painful.....and that I just want to stick to the bottle. (P1)

A lot of people were like 'why aren't you feeding her?' and I just said 'nothing is coming out' and they were like 'oh ok' so I was just like 'nothing's coming out, nothing's coming out.' (P6)

2.2 Developing a bond

Five of the women felt they experienced an enhanced bonding process with their baby as a direct result of having PHIV, perhaps due to the fact that they had previously felt that they would never experience motherhood. The majority of women described an instant rush of love for their babies and went on to develop a strong relationship with them, achieving this bond in spite of the notable barriers to bonding such as being unable to breastfeed and anxiety about their infant's health.

I cried, when I had her, I just burst into tears, when I had her in my arms because it was just such an amazing experience, that makes me want to cry more than anything. (P4)

I was just happy to my soul, I can't believe it, am I dreaming? Am I dreaming, I have done it. I was really happy, and I think the more I stayed with her, the more I loved her, the more love I got....I was like she's mine! I'm a mum I can't

believe it, I still can't believe it sometimes, she's like a little miracle to me, I love her so much. (P6)

Four of the women described a fear that their babies would be taken away from them following the birth, perhaps prompted by a belief that their child would be removed by medical professionals or social services due to their being unable to care for their babies appropriately.

I woke up and I was like 'where's my baby?' Because I realised there was no bump.....and I thought they had taken her away from me or something. (P2)

On the ward I would go to the toilet quickly and run back from the toilet! They said 'she's got a tag, you can go to the toilet'even when I went home I would worry that somebody might take her, I would even worry that my partner would take her in the car and go somewhere, that's how I was. (P3)

This sense of exaggerated maternal protectiveness resulted in women feeling the need to be in close proximity to their babies and not trusting others to look after them.

I wouldn't leave him in the little bed they gave me....I slept with him on me for the duration I was there....I just didn't want to leave him by himself. (P1)

People say I am a bit weird that I never want people to look after them {her children} cos I am like 'no, I want them near me, I don't want them nowhere else!' (P7)

Two of the women described a real difficulty in bonding with their infants, caused both by the infant's ill health and prematurity at birth and the impact of the birth

and early exhaustion on their own health. These factors resulted in them having less energy and time to focus on forming an attachment with their child.

I started to feel like I didn't really have that bond with my daughter because....I didn't really do much with her....it was all kind of a daze kind of thing....I knew I had a baby, but I wasn't really there.....I didn't really start getting that bond until after, when I started putting the hard graft in myself {night feeds etc.}.

(P2)

{Our relationship} had already been screwed up from the start. I just kept looking at this baby, and thinking what do I do? You know, I don't even want to hold you, I don't want to....I just constantly, never had no feelings for my sonthat's why I never wanted anymore kids. (P4)

All women described high levels of maternal stress and anxiety during their infants HIV screening process. For some women this anxiety continued despite their first tests at 48 hours and 24 weeks being negative and lasted throughout the first year of their child's life.

Since they {the initial tests} came back negative I am more relaxed, cos until they'd done it I was just waiting for it, waiting for it....I think the uncertainty was too much. (P3)

It was worrying, cos even though I knew she wasn't going to be positive, it was always, like, will she be actually? Am I sure? 'cos you don't know, as much as they are like 99.9% accurate, you just don't know....even now, she's been negative, but there's still 3 more tests to go, will one of them change? (P4)

For some women, the screening process forced them to contemplate a future within which their child had contracted HIV and the consequences of this. For some this included fears which were perhaps related to their own emotional responses to their mother's status and the perinatal route of infection. These thoughts contributed to their anxiety throughout the process.

*How am I going to explain this to him, how, how is he going to understand it?
He is going to like to probably hate me for like giving it to him or something, so
I thought to myself, 'do I want this? Do I want my child to hate me for
something that I didn't mean to do?' (P7)*

For the six women whose children were found to be negative there was a tangible sense of elation and pride at having successfully protected their children, allowing them to begin to hope for a healthy future for their children and a different life from their own.

*I felt elated, you know, I felt like you know what? I've done my job, so my
daughter doesn't have to...be like me, she doesn't have to worry about her life.
(P2)*

*I couldn't believe it, I couldn't believe it.... yes, that was the best thing ever, best,
best thing ever she can live free, she can lead a normal life! (P6)*

2.3 Child as a protective factor

In the majority of cases, women felt that their babies brought happiness back into their lives. This captured the seeming reparative function of motherhood for the participants, enabling a sense of closeness, belonging, and feeling loved, needed

and accepted. They described finding comfort in the unconditional love provided by their children, something many felt they had never experienced from others.

I always felt like I was alone, so I thought if I have children at least I will have somebody who willwho will love me for me, and would not be judgemental or 'she's got this' or 'look at her, she's like that but she's got this.' (P3)

She looks up to you, which is something really special, no one else does, you know, she needs you, which is a good feeling, unconditional, no matter what, it's amazing. (P6)

All of the women felt that becoming a mother gave them new focus and motivation to remain on their medication. This was particularly powerful for four of the women who had felt they were unable to conceive. There was a well-defined connection for six of the women between the start of their pregnancy and the start of a healthier lifestyle for themselves.

It's made me make sure my health is always good, because, if it's just me, then I can afford to play about with my life...but now I have to make sure I am there for him.....I want to be there to see him grow up.... so I think that pushes me more to take my treatment. (P1)

To be honest, if it wasn't for my girls I don't think I would be here right now.....I'm taking my medication to keep my health OK....that's why I keep moving, they {my children} give me the strength and determination to keep on moving. (P2)

2.4 Motherhood related stigma

The majority of women felt that they experienced HIV-related stigma at various stages in their journey into motherhood; during pregnancy, birth and as a new mother. For some women this was most poignantly felt from non-specialist professionals and their perceived negative attitude towards the ability of the women to protect and care for their children, something the women found very painful.

I was just under so much pressure as well....from the doctors, social services - they are not really educated... so they automatically assumed that I didn't want to take medication, because I was struggling and especially with the vomiting and stuff so.....um.....they put me under a child protection plan before my child was even born, they obviously got the police involved, they wouldn't let me take my newborn home....stayed a whole month with my child, a whole 28 days, the first 28 days in hospital. (P5)

Whenever people come to my house, like professionals, they are like 'oh my God, does she have it?' and I am like 'no, she doesn't' and they see me in a different way.... just because I have it.... I do take care of my child....it doesn't affect me as a mother. (P6)

The anticipated stigma from HIV-negative mothers impacted on their experience of being a new mother, resulting in some of the women limiting their social activities with their new-born babies and contributing to the difficulties in bonding previously described.

I always worried that people were judging me....and {because of } that I never went to no baby groups, once I think I went and I never went again. (P4)

Whilst there was a strong desire from all the women to eradicate HIV, they all wanted to reassure women who had the same diagnosis that their pregnancies were 'normal' and that they shouldn't let the HIV dominate their experience of becoming and being a mother.

I just hope that they....that they put a stop to this..... this curse that I've got. (P5)

Your pregnancy is normal, you're going through the same as everyone else, the only difference is that you have HIV, and don't let the HIV control your pregnancy, because.... it is normal, the only difference is that you are controlling the virus that is within your body to not transfer to your baby.....and obviously to be strong. (P2)

3. Establishing motherhood and future related thoughts

3.1 Growing in strength and confidence as a mother

Many of the women felt that the experience of motherhood had resulted in them growing and maturing, strengthening their belief in their ability to be a parent and manage the associated challenges.

Raising a child is, it's not been easy, but it's made me grow up a lot.....like I actually preferred to stay at home, then go out at the weekends. (P1)

I was actually ready to move back home, because I knew how to do everything, learning from my mum and stuff like that, and my sister I was actually confident about it. (P7)

In a similar way that the pregnancy had empowered some of the women, motherhood seemed to have the same effect, especially for the single mothers within the group.

I feel strong, I feel like I am independent, I can do it all, and even if he {partner} was here, you know men, I don't think there is that much they can do, but I feel like I can do it on my own and I obviously have the support of my auntie, but most of the time I do most of it {parenting} on my own and that makes me stronger. (P6) (N.B Participant 6's husband lived abroad).

The women felt that their HIV status presented unique challenges as their children got older, such as explaining the reasons for their medication and keeping this out of reach.

It's definitely different, so much different, like they are more aware of things like when they see me taking my medication they are like 'mummy sweet' and I am like 'no you can't have this, it's not for you, it's not a sweet' so they know now not to touch it.....they are starting to grasp and understand what is good and what is bad. (P7)

My little one is everywhere now and she needs to be safe... we have to be protective the more she grows up. (P6)

The women showed resilience throughout their lives, but particularly as they faced this new chapter. This capacity for self-reliance was something that some of the women were able to reflect on and be proud of.

I was going through it all really, but to be fair as much as it would damage a lot of people I think I came out on the strong side of it....I've got emotions, I've got a lot of emotions, but I am quite a strong person and I don't.... let things get to me as much as a lot of people would, you know because I think my life has never been straight forward.....everything is a battle. (P4)

I've always thought to myself, it's just HIV – if they find a cure, they find a cure, if they don't and I live with this for the rest of my life, then I live with this for the rest of my life, there's nothing I can do, that's how I see it as now, so I just think to myself it's like....having any other sort of disease, it's just the same thing, apart from taking a pill for the rest of my life. (P7)

3.2 An enhanced experience of motherhood

A recurring theme was that of women feeling fortunate and grateful to have become a mother despite their diagnosis.

She's like a little miracle to me, I love her so much...I've lost so many people in my life, but having her feels like I have gained a lot.... it just makes you feel normal, like I can have a child, which I can love, who can love me (P6)

Several women compared themselves favourably to other women who had not had the same medical opportunities to maintain their health and protect their children. Others felt grateful that they had been accepted and supported by their friends and family.

I worked for HIV charity, volunteering....I did do buddying with somebody as well, it was really hard cos her family didn't accept it, yeah she was born with it

as well, she's being highly affected by it, she's paralysed down one side, she's blind in one eye, yeah but she's lovely but she's got nothing about her now, it's kind of ruled her life and I look at her and I think 'I am so lucky, I am so lucky'.

(P4)

You have to be thankful, and I do try to be positive....some people are dying out there that don't have medication and I have got it and just got to take it. (P6)

One woman reported feeling grateful that she had not been diagnosed with HIV during pregnancy as she felt this would have been too much to take on at once.

Growing up knowing my status helps me take precautions, makes me know like the seriousness of the illness cos.... if I was diagnosed when I found out I was pregnant I would have just been clueless and I would have had to learn first how to be a mum and then being a mum with HIV. (P5)

The same participant also felt a sense of guilt that her child had been born negative despite her struggling with her medication at various points in her pregnancy, whereas a friend of hers had strived to reliably take her medication and had passed the illness on to her child.

I actually felt guilty because obviously I wasn't good with the medication with my pregnancies, and she was a star! So...it just felt like maybe she's thinking 'why me?' you know you get that thought? (P5)

Four of the mothers felt that their status motivated them to make the most of the time that they had with their children, enabling them to savour the small things and appreciate the moment more so than mothers in good health.

I think I just spoil them a bit more... growing up and being through what I have been through has made me think that life is too short.... so I tried to be as close with my children as possible, if anything was to happen that they do actually remember me. (P5)

I love it {motherhood} like I think that's like... my pride and joy those two boys – I don't know I just like being around them, like they sleep in my bed I don't know, we sit, we watch movies together and we play together, it's just, it's amazing. (P7)

Five of the mothers discussed how the birth of their baby was associated with an identity shift, from one associated with disease, medication and ill health to a strong identity as a mother. With this new role came a diminishing of the hold of the PHIV over their lives as they were able to look to a happier future; their HIV now represented just one part of their identity and motherhood was a far more important part of themselves.

Now I try to make sure my health doesn't get too much in the way, of stuff like that.....of being a mum. (P1)

After I gave birth I just didn't really think about it, like after that I never once thought oh 'I've got HIV' like I never actually thought like that.....I think being a mum is more important than anything that would ever affect me in life. (P7)

Others felt that their status had always little influence over their identity both prior to and since becoming a mother.

It's {being a mum} no different to being someone normal, well, what we would class as normal. (P4)

I'm no different to anyone else, like I am the same, it's just that I have got this one problem with me and it's under control. (P6)

3.3 Thoughts on maternal disclosure to child

HIV communication in the women's past was thought about in relation to how they planned to disclose their own status to their children. All the women described their own experiences of being disclosed to about their and their mother's status; experiences that they found traumatic, life changing and uncontained.

I was just really angry that I was lied to....my whole world came crashing down, it was just like, what else would you be lying to me about? (P2)

I was extremely angry and upset and obviously infuriated and the first thing I wanted to do was kill my mum. (P4)

Many of the women described being unsure of who knew of their status and who did not as they were growing up. They described feeling as though family members disclosed their status to others at random, leaving them with the sense that the disclosure of their status was not something they had a choice about or any control over.

Auntie phoned some people and told them as well, I don't know the extent of the number of people she told.....it didn't feel good because she told them before

I knew and I don't who she told! So I'd be like chatting to someone and they would already know my situation. It wasn't good. (P3)

During this time the majority of women were advised to keep their and their mother's diagnosis a secret and not to discuss it with any person, within or outside the family unit. The need to conceal their diagnosis from family and friends contributed to the atmosphere of secrecy previously described. It appears to be fuelled by the taboo that surrounded HIV within the women's families; many reported feeling unable to talk about their illness and associated fears.

I didn't really know what HIV was... but I just knew it was something you didn't talk about at all...{that was} something I think I learned from my mum....you just don't talk about it. (P5)

The secrecy and taboo surrounding HIV resulted in many of the women having pervasive negative feelings about themselves and their HIV status from when they became aware of their status. One of the key emotions described was a sense of shame about their illness, which came out in their interactions with peers.

I said 'there's something....something really bad about me and I don't know how to tell you'. I then realised how detrimental it could be, because if it went around the school and everyone found out.....it would be really yeah, messed up. (P2)

This shame was frequently reinforced by the behaviours of those who were aware of their status, contributing to a sense of loneliness and injustice within the women's childhood.

There's so much that was said about me, when people heard about this... um....my auntie's friends, yeah they didn't want me to go to their houses, they wouldn't even share the same toilet with me, it was really, really, really heart breaking, you felt 'what have I done to deserve this?' and there were a lot of tears, a lot of tears. (P6)

With hindsight and having become mothers themselves the women were more able to understand why some of their parents and families has disclosed to them at a late age and had encouraged them to keep their HIV status hidden at all costs.

It's kind of made me think, maybe that's what my mum was going through when she found out about me {having PHIV}, so it's just I guess just added some understanding, being a mother as well now. (P2)

However, there was a desire within all the women to be more honest with their own children, despite the associated fears of rejection and anxiety that this may cause.

I am going to have to tell her at one point about me, how am I going to tell her about my status, how it happened and is she going to feel resentful to her grandmother, even though she's not alive?I can imagine her being like 'oh, mummy's going to die' and I don't know when to do it, how to do it.... I don't want her to be worrying about me when she is young, I want her to have a lovely childhood and go through things, and you know, go through the motions. (P2)

I'm worried about when I have to tell her, I think she will be a bit, um, like now she's grown a bond with like, really close, like she is a mummy's girl, she doesn't

like to be away from me too long, she worries when I am ill, she is worried, I think I would have to educate her on it first before I told her. (P5)

Sometimes I do think, when she's older, am I supposed to tell her? How am I going to tell her and how is she going to react to it?like what if she hears it from other people, will she believe it....and it's just not me it's the both of us, me and her dad.....so.....that does worry me sometimes.... I do think about it and I think about how will it affect her, how will she see me, will she see me the same, that's the thing. (P6)

The women spoke at length when asked about their thoughts on maternal disclosure. There was a theme of ambivalence around when and how to tell their children, with thoughts influenced by their own experiences of discovering their mother's status. All mothers wanted a different experience for their own children, with a strong desire to tell them about their illness themselves, rather than have a professional involved. Yet many of the mothers, especially those with younger children, were considering waiting to disclose their status until their children were older than when they themselves had found out about their mothers status.

I think it's one of them things that I feel like when the time is right, I will sit him down.... I would rather tell him myself, just me and him.... because sometimes, I think when, when other professionals are there they might not want to say everything that they want to say, so I think I would rather tell him about myself just me and him, so if he has any questions, I can answer the questions myself. (P1)

I will tell them, but I think I will tell them when they are like... I think maybe when they are 16, or something, old enough to understand....yeah about 16, maybe 18 I don't know! I definitely want to be the one to tell them yeah because obviously it's better for them to hear it from their mum then from someone else cos they will think, 'hang on wait a minute how comes she didn't tell me'. (P7)

3.4 Hopes and fears for the child's future

The women felt that their own status and experiences meant that they had a heightened awareness of the risks faced by teenagers as they begun sexual relationships. They hoped that having a close relationship with their children would help educate and protect them in the future, but also felt it was important to educate their children about the importance of treating everyone equally, regardless of their health.

As she becomes a teenager I will start worrying.....cos I'm aware of so many things that are out there that she wouldn't be aware of... like diseases, so that's why I want to have a close relationship so that she can ask me anything. (P3)

Since I do have it, it makes me know that I can educate them and like when they get older I can say to them 'you've got to be a lot careful these days cos you don't know, but never ever, like if someone does have it, don't ever just think of them differently....you just accept them for who they are and not what they have. (P7)

Women described the loss of their own mothers and the experience of witnessing her health deteriorating. They all wanted to protect their own children from having this experience and the associated emotional pain.

I was predominately worried {as a child} about her {mother} and her well-being....because I didn't want her to die, I didn't want to be by myself...I started having nightmares, and night terrors and insomnia...because my main fear was that she was going to go and I wouldn't have anyone. (P2)

I knew there was no help for her, she couldn't afford the medication and things like that and already we were not living in a good condition, and errr when, when they took her to the village um that's when it got worse and I started staying at my auntie's house. (P3)

Mothers also wanted to protect their children emotionally against any potential HIV-related stigma. Having themselves grown up with a mother with HIV, the women could anticipate their child's future and felt there was significant potential for the child to encounter discrimination and difficulties in life. All seven women were the only children from their family unit to contract the disease from their mothers, with their siblings remaining uninfected. Many spoke of the sense of injustice and loneliness this experience left them with.

I have got a brother, there is just two of us, he's fine, and then it was like 'why me? Why me?' and I just felt like I will never know, because she's gone. (P6)

'Cos there is five of us, five of us kids and I'm the only one that got it, so it's just like 'oh my God'. (P7)

The women did not want their own children to feel alone in the world, and they felt as though they needed to protect them by providing a sibling.

I wouldn't want her to be alone, I'd want her to have a brother or a sister to play with or be friends with, and um somebody would have her back.....cos um I'm not always going to be there..... not the way I always had to look out for myself. (P3)

Overall, all mothers wished for their children to be healthy, strong and happy, qualities many felt their own childhood lacked.

I just hope for her to grow up and having a normal life, that's all.....and to have good health as well! Yeah....and appreciate life, it's precious. (P3)

I just hope they make it in life, and that they are very careful and don't have to go through this. (P5)

3.5 Motherhood influencing relationship with own mother

Becoming a mother triggered memories for those whose own mothers had died, bringing with them a powerful sense of sadness and loss.

I always think about her {birth mother}, even before I was pregnant, but now I just see it as, I know she's up there watching down on me, and she's probably proud, so that's how I just see it. (P1)

I used to cry all night, it's like I wish she {mother} was there, because I felt what being a mother is like, I had a difficult time.... I was so unhappy I used to cry at night and then I know there was nothing I could do, she could never

come back.... especially at nights, I wouldn't sleep, I would be like 'why!?' Why?'
(P6)

When I was pregnant every time I would think of her {mother}, and now I've got a little one it's like I've got her back in a little way. (P3)

For women raised by their birth mothers, motherhood often challenged their existing perception of their own mothers, leading to new feelings of appreciation and awe at their ability to manage their illness and parenthood.

{Becoming a mother} has, in a way, um, made me think about her {mother} differently - how she would do things even if she was not well.... even if she was ill, she didn't show it that much until towards the end so she would do stuff for us, me and my brothers. (P3)

Being a mum now, and being so ill and in so much pain and having to do so much to maintain the house and stuff like that, I see what my mum went through so I can see her differently, I see how strong she is, she is stronger than I can be. (P5)

Perhaps as a result of this change in perception, the majority of women felt that becoming a mother had enabled them to a healthier and closer relationship with their own mothers, both those alive and deceased.

I could bond with my mum, I think 'cos I finally, I was able to talk to her rather than shout at her.....I'd never had that bond with my mum {before}. (P3)

{Our relationship} is a lot better, I can talk to her about anything, I talk to her about medication now.....we are just bit closer, yeah..... she's helped me with things. (P5)

Those women whose mothers were still alive struggled with the bond that formed between their mothers and their children. For some this was fuelled by a jealousy at their close relationship and others felt anger and envy at the different experience their children were having of their own parent.

I spent a lot of time in and out of hospital so she {daughter} spent time away from me....so I think for a while she probably thought my mum was her mum, which was horrible.... she bonded with my mum the most... she would actually cry for my mum sometimes....it was just horrible! I just had to tell myself it was ok, it's not that she loved anyone better, or she chose to love anyone better it was just my mum did actually do everything. (P5)

They {her children} love my mum....I said to my mum the other day I said to her 'oh, how come you couldn't treat us the way you are treating my kids' and she was like 'oh' cos I am not ill' and I was like 'no, don't use your illness as an excuse'....(P7)

Many of the women gave consideration to their own parenting techniques in relation to how they felt parented by their mothers. They described the parts of their mothers parenting techniques and attitudes that they intended to recreate or abandon.

We grew up quite disciplined in a way in our house, so that discipline.....I implement with my son....and we grew up with a routine, so he has a routine as

well, and stuff like that..... I do think some of how I was brought up is the same way. (P1)

*My mum was easy-going about certain things, she didn't necessarily spoil me, but.....I'll just say loved, she gave me all the love, even when I pushed her away and that's how I will be with my children, so I will love them no matter what.
(P2)*

Model of the experience of motherhood in the context of PHIV

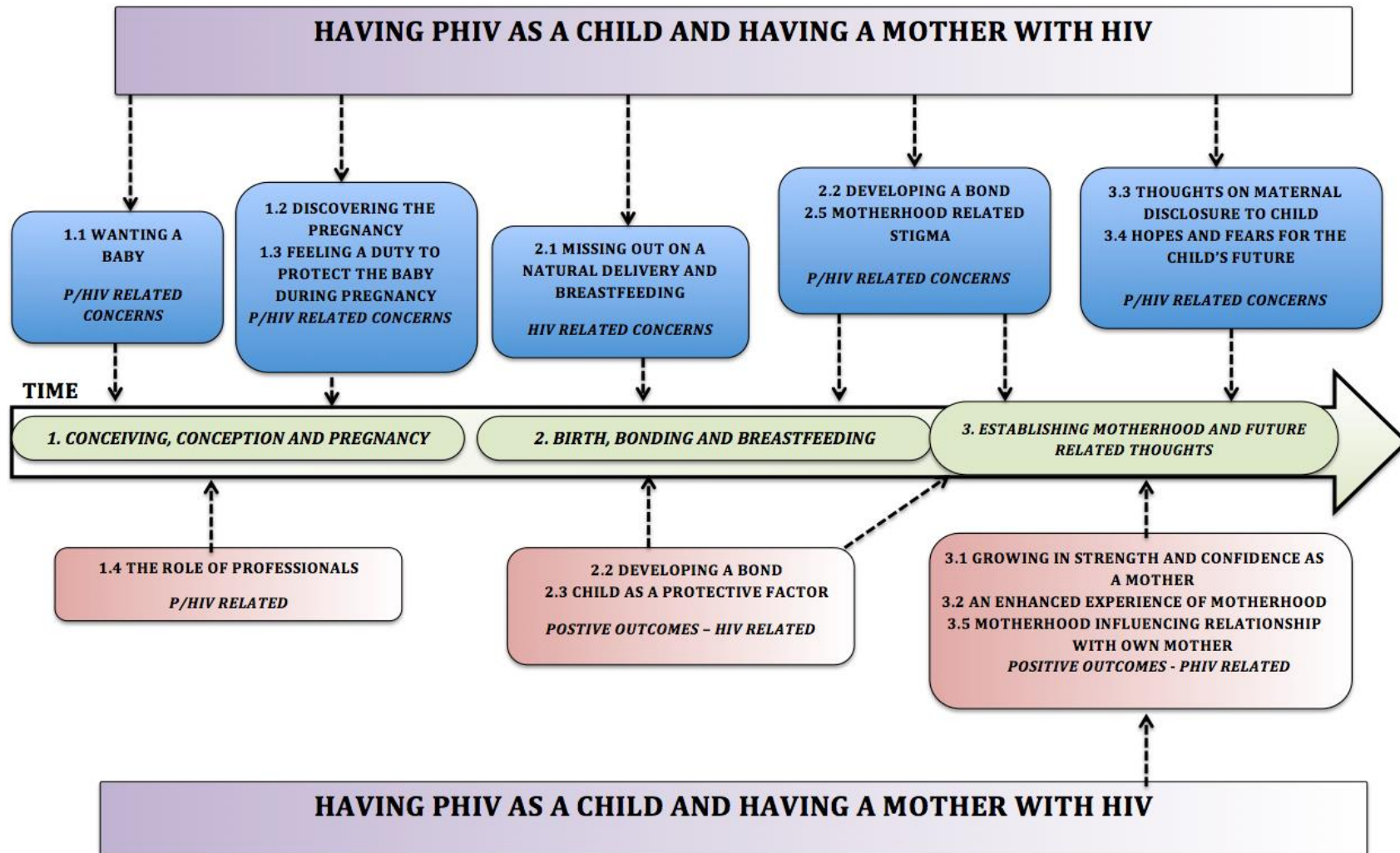
The final aim of this study was to develop a model of the experience of becoming a mother within the context of having a diagnosis of PHIV, which is outlined in Figure 3 below.

This model uses a chronological structure (the middle large arrow), with codes plotted across a timeline from pre-conception to becoming an experienced mother. The concerns and challenges faced by women with PHIV are displayed above the time line and the positive influences of PHIV are displayed below. Some of these are linked to their HIV status in general, others are more specifically due to the perinatal route of their infection. All of these factors are set within the larger context of having grown up with HIV and having had a mother with HIV, experiences that influenced the process and experience of motherhood at all times. The arrows show how each of these factors are linked to and may influence each step of the experience. For example having grown up with PHIV and having a mother with HIV influenced the women's reaction to their pregnancy as many did not feel they were able to have children. These experiences also contributed to feelings of wanting to protect their baby during pregnancy, thus influencing their experience of conceiving, conception and pregnancy.

P/HIV related concerns are present throughout the process, predominately within the themes at the pre-conception stage and at birth related to; sickness during pregnancy, fears of transmission, being unable to breastfeed and worrying about future disclosure of their status. At other stages there are perceived positive influences of their PHIV status; the pregnancy has a positive effect on the mother's

well-being and outlook and later enhances their experience of motherhood as this was something many thought they would not be able to experience, allowing them to savour their time with their children.

Figure 3: Model of the experience of being a mother with PHIV



CHAPTER FOUR: DISCUSSION

This study explored the experience of being a mother with a diagnosis of PHIV. Seven mothers with PHIV were interviewed and data were collected and analysed according to the principles of GT (Charmaz, 2006). The following areas were explored:

- a) The perceived links between the mother's own experience of growing up with HIV, having a parent with HIV and becoming a parent with HIV
- b) Whether the mother's perceived ability to bond with her child had been influenced by her HIV status
- c) The influence of the pregnancy and birth on the perceived relationship between the participant and her own mother.

Three main themes were derived from the interview data. These were mapped onto a chronological model outlining PHIV related concerns and positive outcomes from pre-conception to established motherhood. The themes related to:

- 1) Conceiving, conception and pregnancy
- 2) Birth, bonding and breastfeeding
- 3) Establishing motherhood and future related thoughts.

Overview of findings

The experience of motherhood was both diminished and enhanced by their PHIV status. Some of the factors influencing their experience were specifically related to the perinatal nature of their illness, others were as a result of having HIV and may also be present for mothers with BHIV. For some mothers their status negatively impacted their experience of motherhood from the outset and contributed to difficulties in bonding due to infant health concerns and HIV related exhaustion.

These difficulties were compounded for some participants due to being unable to have a natural delivery and to breastfeed. In addition, there were on-going concerns about when to disclose their status to their children, fears of them encountering discrimination from others and a heightened awareness of the risk of sexually transmitted diseases faced by their children as they grew into teenagers and started relationships of their own. These findings are related to their HIV status in general and have also been found in the BHIV population (Gardiner et al., under review).

Simultaneously, feelings of joy and elation were described as many women had felt that motherhood was something that would not be possible for them, specifically due to their PHIV status. This also resulted in powerful feelings of love and bonding with their infants. They appreciated their children and enjoyed being with them and compared themselves favourably to those who were unable to conceive. Some women felt empowered by the experience of pregnancy and motherhood, feeling that it gave them a new reason to live, to be strong, look after themselves, adhere to their medication and focus on the future. Several mothers reported that without their children they did not think they would still be alive. Others reported that their new-found identity as mothers resulted in the diminishment of the hold of their status over their identity, a finding that may be specific to the nature of their status.

The findings from this study overlap with a previous metasummary investigating motherhood in the context of BHIV, highlighting the similarities between the two populations. This study found that motherhood both intensified and mitigated the negative and social effects of HIV infection. It suggests that the lives of mothers

who have HIV can be challenging but can also be a reason to live, remain adherent to their medication and contribute to a sense of determination for the future (Sandelowski & Barroso, 2003).

1) The perceived links between the mother's own experience of growing up with HIV, having a parent with HIV and becoming a parent with HIV

The mothers predominantly described wanting to learn from their experiences of being raised in a family affected by HIV to benefit their child. Many wanted to provide a different experience for their own children, whether they had been raised by their birth mother or a family member following her death. These findings are unique to the PHIV population as mothers with BHIV would not have had these experiences.

As identified in other studies with PHIV youth (Evangeli et al., 2014), the women reported concerns about MTCT of HIV during pregnancy and birth. The fear that this would mean that their children would have a similar childhood experience to themselves motivated the majority of the women to report adhering strictly to their medication throughout pregnancy and postnatally. Some of the women had been unreliable in their adherence prior to becoming pregnant, as found in other studies of youth with PHIV (Koenig, Nesheim & Abramowitz, 2011). Improved ART adherence among pregnant compared to non-pregnant women with BHIV has also been found (Bardeguet et al., 2008). Although pregnancy has not been found to exacerbate HIV disease (Munjal et al., 2013), ART adherence has important implications throughout pregnancy; non-adherence may lead to increased risk of

MTCT, need for caesarean section, and long-term maternal morbidity. Munjal et al. (2013) also identified deteriorating immunologic health post-delivery for women with PHIV compared to those with BHIV living in the US, suggesting that the post-partum period appears to be the most vulnerable time for these women.

The Theory of Planned Behaviour (TPB) can be used to explain adherence during pregnancy for women with PHIV. TPB posits that a person's behaviour is best predicted by her intentions to perform a particular action and that this intention is predicted by three cognitive determinants; (A) attitude - the expected consequences of performing a specific behaviour (whether her child contracted HIV or not and thus experienced a childhood similar to their own). (B) Subjective norms - social pressures an individual feels to perform or not to perform a behaviour (perceived pressure from medical professionals and social services), and (C) perceived behavioural control - the individual's perception of the extent to which the behaviour is easy or difficult to perform (confidence in their being able to take their medication even when they feel unwell) (Ajzen, 1991). Applied to adherence, TPB predicts that an individual's behavioural intention is a function of the individual's attitude toward adherence, influence of important others regarding adherence, and personal control over adherence.

Women reported that the consequences of ART adherence during pregnancy were difficult to endure with some suffering from extreme exhaustion and vomiting, side-effects that typically occur during the first three months after ART initiation, or after a regimen change (Bartlett & Finkbeiner, 2006). This could suggest that during pregnancy, and beyond, adherence was commonly a result of behavioural

beliefs regarding protecting their child from HIV transmission which were stronger than beliefs about anticipated side effects.

Postnatally a mother with HIV has the new demands of motherhood, she is likely to be recovering from a caesarean section and studies have shown that she is at risk from suffering with PND (Hartley et al., 2010). Case reports show that these factors can contribute to young women with PHIV reverting to pre-pregnancy adherence behaviours (Childs & Maxwell, 2009). In contrast to reports of post-natal non-adherence, six of the women in this study described continued adherence to their medication. Reportedly this adherence was for the sake of their health and well-being so as to be as healthy as possible for their children, something many felt their own mothers were not able to be. The reason for the differences in adherence is unclear, although the age range of mothers in Childs and Maxwell's study was younger than in the current study (18-21 years), which may have contributed to the behavioural differences.

Women who had lost their birth mother described powerful feelings of grief upon her passing, with many not having been told the reason for her death at the time. Others described a sense of loss of childhood and loss of innocence in having grown up with HIV, findings that may be specific to the PHIV population. Grief is a common human response to a perceived loss. The emotional, physical or psychological symptoms that characterize grief are distressing and may interrupt personal or social functioning (Corless, Cartier, & Guarino, 2011). Women experiencing HIV-related grief may be at risk for complicated grief, where the survivor has a prolonged period of distressing symptoms (Mallinson, 2013). Like

women in other studies, mothers described facing a variety of personal or social factors that may inhibit the grieving process including stigma, guilt, social ostracism, and secrecy (De Santis et al., 2014). The women described symptoms associated with complicated grief such as a prolonged period of distressing symptoms, withdrawal from others, sleep disturbances and yearning for the deceased (Horowitz et al., 2003). These factors may have influenced the experience of bonding with their child and their experience of motherhood, factors that will be discussed below.

Studies have shown that families affected by PHIV have low family cohesion, report more isolation, have more communication difficulties and more intra-family conflicts compared to families where all members are healthy (Alderfer, Navsaria, & Kazak, 2009; Pai et al., 2007; Weiner & Bettles, 2006; De Santis et al., 2014). These factors were mirrored in the childhoods of many of the mothers in the current study and all of the participants wanted to break the cycle of PHIV to protect their children from being '*like me*' and encountering the same challenges. Similarly to the findings in a study on the developmental experiences of youth with PHIV (De Santis et al., 2014), many women described their own childhoods as being characterized by secrecy, loss and stigma. The majority of women wanted to create an open and honest family environment, within which their children could ask questions about their health, something many had felt unable to do with their own mothers. This is a finding that may be specifically linked to their PHIV status.

Participants expressed the desire to be honest with their children about their own

health. In some cases this contrasted with the women's intentions to withhold information about their status until their children were young adults. Many women made links with their own experiences of being disclosed to and desired a different experience for their own children. Some women were clearly preoccupied by this process and had started to think about this whilst their child was in the womb, whilst all had considered it as mothers. The potential for secondary disclosure by their children and the associated risk of social stigma played a role in their decision to reveal their status or not. The main concerns were related to protecting their children from the knowledge that they had a life-threatening disease. These concerns were linked to the mother's own experiences of having grown up with a mother who was unwell, having witnessed her health deteriorate and, for some, her death – concerns that seem specific to the PHIV population. Many did not want their children to have the same experiences.

Research from the US shows that mothers with BHIV often perceive the potential costs of disclosure to their children as outweighing the potential benefits (Armistead et al., 2001). As found in other studies, the women in this study believed that their children should be old enough to understand and cope with the knowledge that their mother has HIV (Armistead et al., 2001, Visser et al., 2012). In this study none of the mothers had fully disclosed her status to her children, although the two with older children (7 and 8 years) had partially disclosed and begun to speak about being unwell.

Participants felt some ambivalence about the age at which to disclose, alternating between wanting to wait until their children were young adults, and wanting to

disclose as soon as possible. Murphy et al. (2013) found that open communication in families affected by HIV can increase the closeness of mother–child relationships. Mother’s disclosure of their HIV status has been found to be associated with beneficial outcomes for children (lower depression, more positive self-concept, and more positive orientation to school) (Murphy et al., 2002, Murphy, Austin & Greenwood, 2006). However, as many of the mothers themselves found, disclosure can also create a secret that a child has to keep and this can become burdensome (Murphy et al., 2002; Vallerand et al., 2005).

Children growing up in a household affected by HIV may continue to have psychological difficulties in adulthood and experience deficits in their own parenting, factors that may be specific to the PHIV population (Visser et al., 2012). Many of the women in this study described wanting to be different mothers from their own, which appeared empowering, but also resulted in them recognizing what they did not have. Yet many mothers described raising their children in a similar way to how they were raised and planned to disclose at a similar age to which they had been disclosed to. Drawing on systemic theory, the concept of ‘replicative family scripts’ suggests that a parents’ conscious desire to correct their past, and parent differently from their own, may be insufficient to override powerful unconscious pressures to re-enact past parental roles and behaviours with their own children (Byng-Hall, 1995). These pressures are particularly salient in the context of parental illness (Byng-Hall, 2008). Psychoanalytic theory suggests that breaking the repetitive cycle occurs when the parent is able to emotionally process childhood emotive states and integrate past experiences (Lieberman et al., 2005) and would recommend psychotherapy for women with

PHIV who acknowledge dysfunctional and problematic patterns of behavior within their families.

Importantly, two of the participants did not seem to have fully accepted or adjusted to their PHIV status as reflected in their quotes about their illness and high HADS scores. Successful adjustment or not to their HIV status may have influenced the experience of motherhood but was not the focus of this study.

2) Whether the mother's perceived ability to bond with her child has been influenced by her HIV status

The presence of maternal HIV, regardless of the route of infection, may directly and indirectly compromise a mother's ability to respond appropriately to and bond with her baby (Johnson & Lobo, 2001). Direct effects include maternal ill health and increased likelihood of infections. The social stresses of enacted or anticipated stigma and profound uncertainty about MTCT of HIV are indirect effects of HIV which can influence the quality of interaction between mother and child (Black, Nair & Harrington, 1994). Experiences of bonding varied within participants in the current study. Two of the women struggled to bond with their newborns, possibly due to difficulties relating to their child's health at birth and their own delayed recovery following the birth. These findings are similar to those found by Nelms (2005) and the literature showing that threatened infant ill health (e.g. through premature delivery or risk of HIV transmission) may be associated with mother-infant relationship difficulties and successful mother-infant bonding (Amankwaa, Pickler & Boonmee 2007).

The potential for mothers to form a secure attachment and successfully bond with

their infants within this study was further threatened by the fact that the women reported having limited options with regards to childbirth and feeding. As has been found in studies involving women with BHIV (Murphy, 2009; Gardiner, Evangeli, Anderson & Scourse, under review), restricted opportunities for breastfeeding were associated with feelings of maternal inadequacy and sadness. Despite being aware of the risk of MTCT, the women worried that they were unable to experience the same attachment and bonding process with their baby than if they had been able to breastfeed. Others reported that it felt unnatural to bottle-feed and raised suspicion from others who did not know their status. Whilst there is no compelling evidence that caesarean births and bottle-feeding lead to significant long-term implications for mother-infant attachment in the general population (Britton, Britton & Gronwaldt, 2005) the maternal perception of disruption to this developing relationship is of relevance in this study. The majority of mothers experienced guilt and low mood as a result of not breastfeeding.

Literature suggests that not breastfeeding is a particular challenge for African mothers (Kebaabetswe, 2007). Six of the women in this study were from Sub-Saharan African communities and many felt a cultural pressure to breastfeed. The internalisation of cultural expectations may have contributed to the feelings of maternal inadequacy.

Another hurdle to bonding experienced by the women was the newborn HIV screening process. This is unlike most other newborn tests as it requires multiple tests over a period of months and carries with it anticipated uncertainty about

infection, potential feelings of guilt for the mother and associated issues of stigma (Lazarus et al., 2009). Maternal anxiety around the health of their unborn child following an antenatal HIV diagnosis has been well documented (Oswalt & Baisini, 2010; Gardiner, Evangeli, Anderson, & Scourse, under review; Treisman, Jones & Shaw, 2014). The fear of infant ill-health was pronounced in the current study; many women reported high states of anxiety, uncertainty and stress during pregnancy, immediately following birth and during the infant screening process. These anxieties can be understood using Mishel's (1988) 'uncertainty in illness' theory which states that uncertainty is the inability to determine meaning in illness-related events. It occurs when the significance of such events cannot be determined or when the outcomes of such events are not predictable. Parental uncertainty, that is, parents' uncertainty about illness situations in their children is an adverse experience for adults, one that has consistently been associated with emotional distress, poor psycho-social adjustment, and disruption of family relationships (Mishel, 1997). Support from pediatric health care providers has been found to be an effective means of reducing parental uncertainty during the testing phase for women with BHIV (Santacroce, 2000; Shannon, 2015) and was apparent within this study with women reporting the calming influence of reassurance and support from professionals during this time.

Previous studies have found that mothers with BHIV who were diagnosed during pregnancy felt some hesitancy in completely attaching to their infants emotionally and physically during the screening process (Gardiner et al., under review; Shannon, 2015) which was only resolved upon learning of their negative test results. The women in the current study did not report feelings that reflected this

reluctance to attach to their children. This may be due to the fact that only one mother in both of the samples of previous studies had PHIV. Perhaps mothers with PHIV feel more able to bond with their children as they have had many years since learning of their PHIV diagnosis to adjust and process the risk of HIV transmission and have themselves survived into adulthood with the illness. Some mothers reported a greater attachment and a heightened desire to protect their child perhaps linked to a sense of identifying with their baby in a way that mothers with BHIV would be unable to do (having also been born with the illness). Importantly, the screening process was not spoken about by the participant whose baby did contract PHIV. Her experiences may have been different and it is unfortunate not to have captured this, an issue that will be further reflected upon below.

The majority of women in the current study described powerful feelings of closeness to their infants and felt they bonded immediately following birth. This could be because being able to be pregnant and give birth to a healthy, uninfected infant was a life goal many felt had not thought possible when they first were diagnosed with PHIV. The powerful bonding experience could also be explained in relation to self-determination theory (SDT; Deci & Ryan, 1985, 2000). SDT is a theory of human motivation which posits three needs; relatedness, competence, and autonomy, as experiential nutrients essential for well-being (Deci & Ryan, 2000). SDT suggests that relatedness (i.e., to feel close and accepted with important others) is a basic psychological need. The theory considers whether or not social environments have met people's needs, ultimately supporting (or not) their motivation, growth, and well-being (Deci & Ryan, 2000). The women's childhood experiences of loss and secrecy may have resulted in them feeling as

though they have unmet needs in relation to feeling close and accepted by others, thus resulting in the bond with their child being especially desired and appreciated. This finding may be specific to the PHIV population.

Mothers expressed feelings of gratitude for their child. Gratitude has been shown to have important implications for psychological well-being, in particular, increased trait gratitude can predict lower depression scores (Wood, Maltby, Gillett, Linley, & Joseph, 2008). The broaden-and-build theory of positive emotions can be used to examine the role of state gratitude. This theory asserts that negative emotions, such as the fear experienced by some mothers during pregnancy and the screening process, narrows an individual's momentary thought-action repertoire to promote quick and decisive action such as "fight or flight". In contrast, positive emotions, such as the elation the women described at the birth of their child, broaden momentary thought-action repertoires, which widen the array of thoughts that come to mind. For instance, joy appears to broaden the thought-action repertoire by creating the urge to play, be creative, push the limits, and so on (Fredrickson, 2001). Fredrickson argued that such broadening emotions build enduring personal resources such as social bonds, potentially explaining the powerful feelings of bonding described. Support for the broadening and building role of gratitude has been discussed extensively in the literature (Wood & Tarrrier, 2010; Lambert, Fincham & Stillman, 2011).

In contrast to earlier studies with women with BHIV (Nelms, 2005; Gardiner et al., under review; Sandelowski & Barroso, 2003) the women interviewed did not focus on concerns about dying and leaving their children without a mother,

perhaps reflecting advances in HIV treatments which have resulting in a prolonged life for HIV-infected mothers. Many spoke of feeling very close to their children, of wanting to make the most of the time with their children, enjoying the moment and allowing them to form happy memories. This may also be also linked to the fact that women with PHIV specifically have had to manage an uncertain future since they discovered their illness and hence do not dwell on this as much as those diagnosed during pregnancy.

Two of the participants in this study scored within the clinical range for depression using the HADS, indicating that they may have met criteria for PND. The prevalence of PND is estimated to be between 10% - 15% in resource rich countries (O'Hara & Swain, 1996), and similar rates have been reported for low- and middle-income countries, including countries in sub-Saharan Africa (Parsons et al., 2012). As described, pregnant women living with HIV face additional stressors which may increase the risk for PND symptoms among HIV-positive women. Furthermore, women who discover their HIV-positive status during pregnancy may be more likely to develop depressive symptoms than those who were already aware of their HIV-positive status before pregnancy (Kwalombota, 2002). Studies have found PND to be associated with impaired patterns of early communication between mother and infant (Murray & Cooper, 1996). For example, Tomlinson et al. (2005) both found a strong association between PND and insecure infant attachment in South African mothers with HIV. PND may contribute to a large number of adverse child social development outcomes such as infant social withdrawal, poor mother-child interactions, and failure to thrive (Rahman, Harrington, & Bunn, 2002; Tomlinson, Cooper, Stein, Swartz, & Molteno,

2006). Although not reported by the participants, these factors may contribute to these mothers' perceived ability to bond with their child.

3) The influence of the pregnancy and birth on the perceived relationship between the participant and her own mother

Several of the mothers reported feelings of shame and guilt which stemmed from a fear of disclosing their pregnancies to their own mothers. The anticipated response was that their mothers would be ashamed of their pregnancies due to their being HIV-positive, out of wedlock and young. These fears resulted in a reluctance to disclose their pregnancies. Shame is the emotional consequence of internalised stigma (Earnshaw & Chaudoir, 2009), which can lead to women endorsing the negative beliefs and feelings associated with HIV about themselves (Link, 1987). Some of their mothers did react in a blaming and unsupportive way whilst others were supportive from the outset.

Women in this study found that entering motherhood altered their perception and/or memories of their own mothers. Chodorow (1978) holds that women are more likely than men to maintain certain parts of their primary relationship with their mother. Chodorow (1978) contended that mothers and daughters engage throughout their lives in personal identification (identifying with someone else's personality, values and attitudes) as opposed to positional identification, (identifying with specific aspects of another's role). A young girl's identification with her mother is suggested to continue throughout life, thereby maintaining the mother-daughter relationship while establishing her identity, whereas a young boy's identification with his mother is broken and switched to his father (or

another male figure). Because of their prolonged identification with their mothers, daughters often perceive themselves as more "like" their mothers than sons are "like" their fathers (Chodorow, 1978). Women in this study reported identifying with their mother, especially once they had become mothers themselves and described aspects of their parenting behaviours that they wanted to re-create.

Overall, many of the women found that motherhood resulted in a warmer and healthier relationship between themselves and their mother. Fischer (1981) found that during transitions such as a first pregnancy, a reordering of the mother-daughter relationship is triggered, moving it toward greater dyadic interaction. The conflicts reported in adolescence (Fox, 1979) and young adulthood (Boyd, 1987) give way to reports of increased closeness (Baruch and Barnett, 1983; Fischer, 1981) and greater empathy (Berti, 1981) and mutuality (Bromberg, 1983; Fischer, 1986), all of which were reported in the current study. Motherhood seems to increase a daughter's desire for closeness and continuity with her mother (Fischer, 1981).

Some mothers reported feeling envious of their own mother's relationship with their children. Hammer (1976) suggests that a mother, through her daughter, re-lives both her own childhood and her own mother's identity. The women may witness their children having needs met by their mother which they felt their mother's had been unable to meet during their own childhood, which may explain these envious feelings and may be findings specifically relevant to the PHIV population.

Perhaps as a result of feelings of anxiety and guilt experienced during the screening process, women seemed more able to appreciate what their mothers had been through with themselves as infants. Rasmussen, Dunning, Cox & O'Connell (2008) investigated diabetes in women and found that there was a 'guilt dynamic' between mother and daughter, with mothers feeling guilty that something they had done may have given their daughter diabetes. The daughters felt guilty of the effect their diabetes had on their mothers, creating a two-way dependency between mothers and their daughters. It was found that even though there were feelings of guilt, the transition into motherhood strengthened the relationship between mothers and daughters, as was found in the current study, even for those whose mothers had passed away.

The relationship between women and their own mothers tends to be recreated in relationship between women and their infants. Mothers who remember being accepted by their mothers as children, and who currently have healthy relationships with their mothers, have been found to be more sensitive and less intrusive with their infants (Kretchmar & Jacobvitz, 2002). Women in this study who reported a particularly positive relationship with their own mothers reported greater attachment to their infants. Social learning theorists would describe this using principles of modelling, suggesting that girls learn to mother, and to be like their mothers, by consistently and positively being reinforced when they imitate their mother's behaviours (Weitzman, 1984). Psycho-analytic theorists would emphasize daughters' unconscious internalization of maternal values and behaviours, as well as the meaning of these values and behaviours.

Strengths

A key strength of this study was the successful recruitment of a new and understudied population whose experiences of motherhood have not yet been fully explored. Seven out of ten women who were deemed eligible and approached by professionals participated in the study. Six out of the seven participants in this study were of African descent and the average age of participants was 25.6 years. Thus, the sample appears to be broadly representative in terms of the age and ethnicity when compared to the total population of mothers with PHIV living in the UK (CHIPS Annual Report 2013/2014). A number of factors increase the external validity of the study; the sample showed variation in psychopathology despite the small size as evidenced by the participants scores on the HADS. Four of the mothers had more than one child, suggesting that the emergent model could also be relevant to both first time mothers and mothers with more than one child. There was also a mixture of planned and unplanned pregnancies, although two of the five women with unplanned pregnancies reported using contraception at the time they conceived. Five of the mothers had disclosed their status to their partners prior to their pregnancies, two disclosed their status shortly after the birth of their babies.

A number of procedures were used to maintain quality and allow for validation of the categories and the emerging theory (Madill, Jordan & Shirley, 2000). Involving service-users in the development of the study by consulting on the interview schedule provided valuable feedback regarding the use of language and terminology and may have increased the potential acceptability of the study to the mothers, increasing participation rates. Internal and external supervision

alongside a peer-support group involving other Royal Holloway trainees who were conducting GT research helped to provide validation, ensure clarity of the coding and that important themes were not missed.

Following the initial analysis of data, a small number of participants who had consented to being contacted during their interview were contacted to help increase the quality, reliability and clarity of the emerging codes and to validate the model (Elliot et al., 1999). The participants felt the model was a good representation of their experience. Additional consultations of the model's clarity and relevance were carried out with specialist HIV professionals at recruitment sites.

Another strength of this study is the level of demographic information that was collected and the use of standardized measures, which provided extra context for the sample.

A reflective diary and memos (Appendix 5 and 6) were kept throughout the research process. These processes helped in capturing early concerns about researcher influences on the study findings, such as the potential undue influence of knowledge gained from the literature search.

Limitations

For course and ethics committee requirements, prior to the collection and analysis of data, a literature review was carried out which may have compromised the study in forcing previously known concepts or theories onto the data (Glaser & Strauss, 1967). In an attempt to limit the effect of this prior knowledge on any data collection, the researcher acknowledged prior assumptions and tried to avoid any

leading questions during interviews. The researcher also focused on what was emerging from the data, by incorporating the actual words of participants during analysis, and making continual comparisons within and between data to ensure the emergent theory was grounded in the data (Charmaz, 2006).

The small number of participants in the study may be considered a limitation of the work, however, the number of participants in this study is in keeping with other doctoral GT studies and the ultimate quality and credibility of the work lies with the richness, depth, suitability and sufficiency of the data (Charmaz 2006, p18).

The participants for this study were recruited from two inner-city hospital sites and a HIV charity site in the same city, potentially limiting the external validity and generalisability of the findings to other populations of PHIV women due to geographic setting.

All of the women in this study received HIV-specific specialist care at centres where extensive experience and support systems were available to them. Women with PHIV without access to specialist perinatal and paediatric HIV clinical services might have had a different experience of pregnancy and motherhood due to the limited educational, medical, and social resources available to them.

Therefore the findings may not be applicable to young adults with PHIV who are not engaged in care.

The researcher did not have access to medical information and formal measures of the health status of participants were not collected, nor were the perspectives from medical or social service providers obtained. Health may be an important variable to consider when assessing the experience of motherhood as HIV-infected

women who are more symptomatic of HIV disease might have different foci of concern, focusing more perhaps on maternal health issues and concerns for the future. Overall, the health of participants was poor and health related concerns were frequently mentioned during the interviews. Adherence rates prior to, during and post pregnancy were unfortunately not collected directly from the participants.

The subjectivity of the researcher adds a layer of complexity to the research process as the research is filtered through a personal lens. The notion of researcher bias is acknowledged in this study, not dismissed, and is addressed through reflexivity.

While the qualitative approach facilitated rich narratives of experience, this retrospective design ultimately relied on the mothers' memories of pre-conception, pregnancy and birth rather than capturing it 'in the moment.' The data may have been subject to recall biases (Kazdin, 1998) and other biases linked to face-to-face interviews such as social desirability, which may have compromised the reliability of the results (Nass, Moon, & Carney, 1999). The researcher attempted to limit the potential for such bias, by narrowing the inclusion criteria to include only those with a child under four years of age (six out of the seven participants had children under the age of two) and by emphasising confidentiality and ensuring anonymity.

It is unlikely that all categories in this study reached saturation, due to the small sample size. However, the researcher felt confident that there were few novel codes developed on the basis of the final two participants.

Suggestions for future research

The study highlights several areas of potential further research. Although the emotional difficulties associated with pregnancy and early days of motherhood were captured, it may be beneficial to carry out a longitudinal study from pregnancy to the end of the first year of motherhood. This may illustrate how the evolving fears, concerns and experiences encountered by these women change and interact with time and may provide a more reliable reflection of the experience of becoming a mother with a diagnosis of PHIV. Findings from such a study may inform the design of targeted interventions that address developmentally relevant issues, with appropriately timed interventions.

Mothers alluded to their fears for the future which included experiencing potential rejection by their children as a result of their status and a fear that they would replicate their own experiences of being parented. A future study exploring the experiences of mothers with PHIV of adolescents may inform professionals and new mothers of the challenges that may arise as their children reach different developmental stages.

Another valuable area of research would be to carry out a dyad study involving women and their mothers. This study could explore their shared experience of living with the disease and the differences and similarities in their concerns about becoming and being a mother.

Alternatively, a dyad study could be carried out with the partners of mothers with PHIV, allowing us to learn more about the partner's experience, what enables

fathers to adjust and support their partner through this process and their joint experience of becoming parents.

Personal reflections

Prior to and throughout the research process I reflected on my own cultural background as a white, middle-class, female professional, whilst interviewing a group of HIV-positive women predominantly from Sub-Saharan Africa. I kept a reflective diary throughout the process and drew on the ideas of Agyeman (2008), who stresses the need for an anti-discriminatory research model when working as a white female researcher with a black female participant group.

It is important to reflect on the fact that I was pregnant and became a mother myself whilst carrying out this research project. I carried out my literature research, initial meetings with sites and ethical application whilst pregnant and started my interviews as a mother. I shared a 'direct experiential base' with my participant group something that Dwyer and Buckle (2009) suggests has advantages and disadvantages. For example, these experiences may have increased my ability to access, engage, and connect with the participants. I felt able to empathise with the struggles of new motherhood they described and feel I had a level of insight from my own experiences into aspects of the participants' pregnancies and labours. I feel my own experiences helped me to explore certain areas of motherhood that, had I not experienced it for myself, I would perhaps not even have been aware of such as the difficulties of the early days post-partum and anxieties about the health of your new baby. Having breastfed my child I felt more able to empathise with those mothers who so longed for the connection and bond

that this can bring. However, these experiences may also have influenced the analysis and interpretation the data by compromising objectivity (Armstrong, 2001). To counteract any potential compromises, throughout the study I have tried to maintain awareness of how my own experience of motherhood might affect my interpretation of findings, and separate my own feelings from those of the participants (Fitzpatrick & Olsen, 2015).

I reflected on issues of similarity and difference regarding age and my relationship status. I also reflected on the fact that I myself am not HIV-positive, and whether women in this study may have made assumptions about my own HIV status during the research process. At times during the interviews I felt a strong sense of sadness for these women and the battles many of them had faced from day one. I was able to reflect on these feelings, and others, through my reflective diary, allowing me to appreciate any impact of both my own views and background and emotional response to the data on all aspects of the research. I feel this reflection enabled me to have a deeper insight into the participants' experiences, thus I valued rather than marginalised my emotional response to the research, a technique recommended by Fitzpatrick and Olsen (2015).

I collected a large amount of data from the participants and felt that I would not be able to adequately represent all the experiences of each participant due to the brevity of my dissertation. Research supervision helped me to focus my analysis and to accept the limited scope I had to represent all potential themes. Perhaps it would have been useful if I limited how much data I collected, focusing more on the experience of motherhood and less on the impact of growing up with PHIV, to reduce a sense of being overwhelmed.

I feel the majority of women I interviewed were open and honest about their experiences. However, previous qualitative research has shown the high potential for social desirability in qualitative research (Paulson et al., 2006), with maternal answers in studies about motherhood found to be particularly influenced by societal expectations. For safeguarding purposes I had to inform women that I had a duty of care to report any concerns of safety for their child. These factors may have influenced their answers to questions asked regarding their relationships with their infants and their ability to bond with them, through a fear of how these answers may be perceived or acted on by me.

One of the women had a child who had contracted PHIV and she had made it clear from the outset that she did not want to discuss her child's status or answer any questions about her experiences of managing this during the interview. Whilst respecting her wishes I felt frustrated that I could not explore and appreciate her experiences more fully, capturing this experience to contribute to the final model.

I was consistently impressed and inspired by the resilience shown by the women I interviewed. Many had been through so much (maternal loss, immigration, hospitalisations) at such a young age yet the majority of women seemed to be coping well with motherhood and the associated challenges and, despite life's adversities they all presented as positive, optimistic and empathic individuals.

Clinical implications of the findings

The findings have implications for clinical interventions with HIV-affected families in general. Importantly, they highlight factors that may be relevant to

professionals working with women specifically with a diagnosis of PHIV through all stages of motherhood.

1) Psycho-education and professional support pre-conception and antenatally

Mental health interventions are most effective when they are tailored to specific populations and cultures (Mellins & Malee, 2013). Existing BHIVA guidelines (2014) for working with pregnant HIV-positive women do not offer advice for women specifically with PHIV who may have unique concerns such as grief-related complications and additional health concerns relative to women with BHIV and hence require additional and modified support during pregnancy. The current guidelines focus on the medical management of HIV prevention of MTCT and there is limited focus on the psychological needs of women during this period. This study suggests that some women with PHIV consider a termination due, in part, to the perceived risk of MTCT. Yet existing BHIVA guidelines (2014) for working with HIV positive women antenatally do not offer guidance with regard to the decision as to whether to have a child in the context of having a diagnosis of HIV and provide limited information about the risk of MTCT. It is clear from this study that fears of infertility and concerns about MTCT influenced the experience of motherhood from the outset and suggest women with both BHIV and PHIV may benefit from psycho-education in this area. Clearer information and reassurance about transmission rates are required for all women with HIV. Research shows that written information produced in accessible formats can help in normalising the experiences of mothers with HIV and encourage support-seeking during this vulnerable time (Murphy et al., 2002).

As the findings show, pregnancy in the context of HIV can trigger anxieties and concerns and can lead to a sense of vulnerability, regardless of the route of infection. The support provided by HIV specialist midwives to the women in this study was invaluable. The study found that specifically trained health-care providers (HCP's) who are non-judgmental, available and supportive were sought after, and women revealed that their greatest sources of support were professionals who had been involved in their care over a number of years. Along with alleviating MTCT concerns women reported that information giving, adherence support and general preparation for motherhood were areas covered by their midwives. Similar to findings by Kelly et al. (2013) in their work with mothers with BHIV, many mothers in this study also mentioned being grateful for the willingness of clinicians to take time to listen to them, respond quickly to their enquiries and be patient when they needed reassuring about their infant's health. The importance of this support was particularly poignant in the responses of women who had lost their own mothers prior to pregnancy, perhaps reflecting the need for a mother-figure during this life changing period.

Many of the women felt motherhood re-awakened feelings of grief about the loss of their own mothers. Bereavement interventions for those mothers who felt that they were suffering from complicated grief may be beneficial to this population. Sikkema and colleagues (2006) randomized HIV-infected bereaved adults to a 12-week CBT group intervention or individual therapy upon request. The group intervention addressed six areas over the course of treatment, including (a) development of social support and group cohesion, (b) identification and expression of emotion, (c) identification of coping difficulties specific to AIDS loss,

(d) identification of current coping strategies, (e) goal setting, and (f) implementation of adaptive coping strategies to reduce psychological distress (e.g., depression, anxiety, traumatic stress). Intervention techniques included group discussion, exercises, role-plays, and assignment of tasks to practice between sessions. This bereavement coping intervention was specifically tailored to address the unique issues surrounding HIV and the complexity of both coping with HIV-related loss and living with HIV. Participants in both conditions reported decreases in grief symptom severity; however, the participants in the CBT groups reported significantly lower grief severity scores than participants in individual therapy post-intervention and at long-term (12 months) follow-up. The authors concluded that interventions for complicated grief must be tailored to the needs of individuals to be most effective (Hansen et al., 2006).

To address complicated grief reactions in the context of high morbidity and mortality from HIV in South Africa, Drenth and colleagues (2010) developed a Complicated Grief Intervention Model which suggests a client-centered, CBT approach that focuses on prioritizing activities, goals, and timelines with the griever. It promotes incremental change and adaptation to the loss and uses narrative therapy (i.e., storytelling) for both assessment and evaluation purposes. The goal is to strengthen the griever's personal skills and capabilities in an effort to restore social functioning. Aspects of both these interventions (role-play and help with problem solving and goal setting) could also be implemented at a lower-intensity (for example delivered by non-psychologist).

For women with PHIV, perceived stigma impairs social functioning, and increases physical symptoms, health-related anxiety, and alcohol use (Murphy, Austin &

Greenwell, 2006.) HIV-positive individuals are also more likely to be diagnosed with major depressive disorder than HIV-negative individuals (Sherr et al., 2011a). Support groups and interventions for HIV-infected women need to focus on normalizing HIV as a chronic disease, and on cognitive-behavioral strategies to deal with perceived stigma, stigma-related thoughts, and guilt surrounding any potential enacted stigma faced by their children. Psychological interventions for depression and anxiety that incorporate a cognitive-behavioural component have been found to be particularly effective in HIV-positive populations (Clucas et al., 2011; Sherr et al., 2011).

2) Post-natal support

Although the majority of women in this study bonded well with their children, the findings suggest there may be a need for psychological interventions that focus specifically on women with PHIV's emotional and psychological transition to motherhood and on the developing relationship with their baby.

Some women articulated difficulties with bonding with their baby associated with factors that would be present for a mother with BHIV; breastfeeding restrictions, infant health concerns and exhaustion due to their own HIV-related health issues. Support in managing and coping with the emotions and difficulties in relating to and bonding with their infants as a result of these factors would be helpful for other new mothers with both PHIV and BHIV. There are currently extensive waiting lists for such specialist services available within the NHS (Perinatal and Infant Mental Health Services based within CAMHS) (Barlow et al., 2010). Therefore mental health professionals working with mothers with PHIV who

report difficulties in bonding with their babies should provide targeted and timely support. Monitoring mothers' interactions with their infants and providing a non-judgmental space for any attachment concerns may identify those who need more support with bonding. In addition, mothers can be advised that this feeling has been reported by other mothers during the early days of motherhood and can resolve over time. Behavioural interventions for enhancing mother-infant bonding for at-risk families could be adapted for mothers with PHIV. These could include the modification of interactions between mother and child through reviewing videotaped interactions and discussions of emotional needs (Zeanah, Strafford & Zeanah, 2005). Interventions that offer support and relief, such as respite care for their children, for mothers during periods when their health is more compromised would also be a positive outcome.

Although not described in this study, previous studies have found that women with PHIV may revert to pre-pregnancy behaviours with regards to ART adherence (Childs & Maxwell, 2009). Andersen's Behavioural Model (ABM) of Health Service Use (Anderson, 1995) provides a theoretical framework for understanding how patient and environmental factors impact health behaviours and outcomes. These factors can be grouped into seven domains: patient factors (predisposing, enabling, perceived need), health care environment factors (system, clinic, provider), and external environment factors. ABM has been used to examine health care and adherence among HIV-positive individuals (Saint-Jean et al., 2011) and there has been recent empirical support for the use of ABM as a framework for classifying factors influencing HIV-specific health behaviours (Holtzman et al., 2015). Interventions to assist new mothers to continue to be

adherent to their medication post-birth could be based on this model, focusing on problem solving to break down perceived barriers to adherence.

Considerations should be made regarding the planning of services for the management of PND within this population given that data suggest that young people with PHIV are at high risk for mental health problems, although the HIV infection may not be the primary mechanism for these issues (Mellins & Malee, 2013). There are few evaluations of evidence based mental health treatment programmes for women with PHIV and whilst recognising the importance of psychological support in the post-natal period the BHIVA (2014) and BPS (2011) guidelines do not offer advice as to which psychological interventions may be most beneficial to women with PHIV. The women in this study reported facing multiple sources of shame throughout their lives and into motherhood. Therefore it would be useful to consider providing therapies where required that would reduce the shame associated with their internalised stigma and pregnancy and introduce a calming sense of well-being. This could be done at varying levels of intensity from a self-help mindfulness programme (Cavanagh, Strauss, Forder & Jones, 2014) to higher intensity therapies such as Acceptance and Commitment Therapy (Hayes, Kirk & Kelly, 2011) and Compassion Focused Therapy (Gilbert, 2009).

3) Systemic considerations

As PHIV infection has an impact on the entire family, from children to grandparents, interventions should include a systemic programme of support ideally at varying levels of intensity. A level of social isolation was described by

the women in this study, due to a reluctance to disclose to HIV-negative peers, a lack of sibling support and many of the women having lost their own mothers. BHIVA (2013) guidelines suggest that midwives, health visitors and social workers can play a role in supporting mothers with HIV to forge links with key organisations and facilitate the development of supportive peer relationships. A specific support group for expectant and new mothers with PHIV may be useful for women to manage their anxieties and reduce isolation during this difficult time, a format that has been shown to support new mothers in the general population (Dennis et al., 2011). These groups could focus on supporting women with issues and events that were raised as being particularly challenging by participants; the first few weeks of motherhood, dealing with issues of not breastfeeding, the infant screening process and the impact on their relationship with their own mothers. At a lower intensity, peer mentoring could be implemented. This has also been shown to be beneficial in Africa (Teasdale & Besser, 2008) where mothers living with HIV are trained to work alongside doctors and nurses in understaffed health centres as members of the healthcare team. They provide essential health education and psychosocial support to other HIV-positive mothers on how they can protect their babies from HIV infection, and keep themselves and their families healthy in both individual and group settings.

For those women whose mothers were still alive, considerable changes and challenges were faced in their relationship following the birth of their babies. Where required, these challenges could be discussed with the specialist midwife and joint interventions, such as family therapy, could be carried out with both

mother and grandmother to help facilitate a positive pregnancy and birth experience.

Support by HCP's is also vital for women with PHIV who are becoming mothers as they consider the risks and benefits of disclosure or non- disclosure of their own status to their children. Developmentally appropriate interventions are required to assist women who choose to disclose and support is required for those who choose not to. A family based model of disclosure has been piloted in South Africa and provides examples for healthcare practitioners in supporting mothers with HIV disclose to their PHIV infected children (Rochat, Mkwanazi & Bland, 2013). WHO (2011) has developed guidance for healthcare workers on how to support children 12 years of age and younger, and their caregivers, on disclosure of HIV status. The guidance is intended as part of a comprehensive approach to the physical, emotional, cognitive and social well-being of a developing child following the child's own diagnosis of HIV or that of a parent or close caregiver.

Caring for an HIV positive parent or losing a mother to AIDS/HIV can have long lasting social and psychological effects on young children (Richter, Manegold & Pather, 2004). Consideration should therefore be given to the children of women with PHIV. Studies have shown that children have different perceptions of health and illness depending on their age and stage of development. Children's perceptions of illness change as their cognitive abilities mature (Bibace & Walsh, 1980). Findings show that providing age-appropriate information at the time of disclosure is key to ameliorating the impact of later parental loss, and has a positive impact on a child's well-being. Reassurance should also be given to

mothers that research has shown that maternal HIV disclosure has not been found to be predictive of child functioning (Armistead et al., 2001).

Evidence about interventions to address the psychosocial challenges for children affected by HIV/AIDS is severely lacking, especially in low and middle-income countries (UNICEF, 2008). King, De Silva, Stein & Patel (2009) found only 11 interventions for improving the psychosocial well-being of children which actually administered an intervention to children, with many of these ignoring the interactions between mother and child.

Visser et al. (2012) developed and piloted a mother-child intervention to improve the well-being of mother and child, enhance the interaction between them and to promote the resilience of young children affected by HIV living in South Africa.

Follow-up interviews indicated that a focus on the personal well-being and parenting style of mothers had positive implications for their relationships with their children and the psychosocial functioning of the child, an intervention that may be beneficial to women with PHIV who are struggling with the experience of becoming a mother.

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Appendix 1: Participant Information Sheet

Project title: The experience of being a mother with perinatally acquired HIV

We are carrying out a study exploring women's experiences of being a mother whilst having a diagnosis of perinatally acquired HIV.

We would like to invite you to be interviewed by Faye Millner, trainee Clinical Psychologist, at Royal Holloway, University of London about your experiences of being a mother. The interview will last no longer than 1 ½ hours, and will include questions about your diagnosis, what it was like to grow up with this, how you felt before and during your pregnancy, after your child was born and your thoughts about the future.

Before you decide if you want to take part, it is important that you understand why we are doing this study and what will happen if you take part. **Please read this sheet carefully.** If you want to discuss taking part in the study with your partner or family before you decide whether or not to take part, please feel free to do so and to ask any questions you may have.

Why are we doing this research?

We would like to find out more about what it is like to become a mother with perinatally acquired HIV. We are particularly interested in women's different experiences before becoming pregnant, during pregnancy and in bonding, or feeling connected, with their child.

Why are you asking me to take part?

We are asking you to take part in this study because you are a mother who has perinatally acquired HIV and attend (clinic/hospital).

What will happen in the interview?

The interview will include a number of questions, some asked at the beginning will be about your general circumstances and how many children you have, who you live with and the important people in your life. You will be welcome to ask any questions you have about the project before we begin.

Where will the interview take place?

The interview will take place in a quiet and private room at (clinic/hospital). To allow you to be able to speak freely, we would ask that you arrange for any children you have to be looked after elsewhere during the interview.

Do I have to take part?

No, you do not have to take part. If you decide not to take part in the study, your care will not be affected at all. If you decide to take part now you'll still be free to stop taking part at any time, without giving a reason at all. If you decide to withdraw from the study at any point your care will not be affected.

Will the interview be confidential?

We will treat the information from interviews as highly confidential and keep it in a locked and secure location. Only you and Faye Millner will know that you have given the answers you have. Her supervisor, Dr. Michael Evangeli, Clinical Psychologist, will have access to the answers you give but not to any other information that might identify you with them.

The only exception is if you tell Faye something during the interview that suggests that you or someone else might be at risk of serious harm (for example, if you say that you are planning on harming yourself or someone else), Faye may need to speak to your clinical team so that they are able to provide you with support. Faye will let you know during the interview if this is going to be necessary.

What will happen with the information we collect?

The consent form, which we will ask you to sign if you decide to take part in the study, will be the only document that will have your name written on it. The consent form will be kept separately from the responses you provide, in locked filing cabinets at the site where the interview took place.

Your answers will have a code written on them, the same code will also be written on the consent form, linking the two together. This is so that if you decide to withdraw your consent after the interview has taken place, we will be able to locate your answers and withdraw them from the study.

The interviews themselves will be recorded on a Dictaphone before being transcribed and stored as word documents in password protected computer folders. These will be deleted once they have been anonymously transcribed. The consent forms you sign will be kept for at two years and then destroyed. These will be kept apart from the corresponding transcribed interviews.

Who will be writing up the research?

Faye Millner will use the information to write a thesis as part of a professional qualification to become a Clinical Psychologist. You will have an opportunity to look at the main themes from the study and give feedback on these if you wish to. This will happen 3-6 months after the initial interview, and can take place over the telephone. If you do not wish to have any further involvement at this stage, there is no need to do so.

We hope that these findings will also be used to inform health services for the future. The data collected may be used to write academic papers or presented at conferences. All identifying information will be removed.

Are there any disadvantages or risks of taking part?

Some people can find talking about HIV difficult and upsetting. The questions will be asked in a sensitive way. There are no right or wrong answers, we are interested in hearing about *your* experience. You do not have to answer any question that you do not want to. If you want to talk to anyone from your clinical team about things that you've discussed in the interview we will arrange this.

Are there benefits of taking part?

You may find talking about your experiences and decisions helpful. The information you provide will help to increase knowledge about the experiences of mothers with perinatally acquired HIV and for those considering having children. This knowledge could help to develop better services for people in your situation in the future.

Will I get anything personally for taking part?

We will reimburse your time for taking part in the interview to the value of £20 in cash.

Who is organising and funding the research?

The study is being organised and funded by Royal Holloway, University of London. The researcher Faye Millner is not in receipt of payment for conducting this study, it is being completed as part of a professional qualification to become a Clinical Psychologist.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London Queen Square Research Ethics Committee. This means that these Committees are satisfied that your rights will be respected, that any risks have been reduced to a minimum and that you have been given enough information to decide whether to take part or not.

What if I feel unhappy with the interview or the way I am treated?

If you are unhappy with anything to do with the research, please contact Faye on the email address or number provided below. If you are still unhappy, or you do not wish to talk to Faye about it, please contact The Patient Advice and Liaison Service (PALS) at (clinic/hospital) who will be happy to listen to you and will help you make a formal complaint. Their number is XXXXXXXX.

Liability for the protocol of this research study and the activities of the staff and students of Royal Holloway, University of London is covered by the university's professional indemnity insurance and public liability insurance.

Thank you for taking the time to read this information sheet.

Faye Millner, Trainee Clinical Psychologist
Department of Clinical Psychology
Bowyer Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Email: Faye.Millner.2011@live.rhul.ac.uk Tel: 01784 414012

Appendix 2: Participant consent form

Study title: The experience of being a mother with perinatally acquired HIV

Name of Researcher: Faye Millner

Participant identification number for study: _____

Ethics Committee Reference number: 13/LO/0622

Please initial box:

1. I confirm that I have read and understand the information sheet for the above study dated and have had the opportunity to consider the information and to ask questions which have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time. I do not have to give any reason for withdrawing and my medical care and legal rights will not be affected.
3. I agree to have my interviews with Faye Millner audiotaped.
4. I agree to having my anonymous quotations used in the reports produced for this study.
5. I understand information will be stored confidentially according to the NHS code of ethics.
6. I agree to take part in the above research study.
7. I would like to be contacted for feedback on the results as the study progresses. To facilitate this I give permission for my address to be held until late 2015 by the above named researcher. **Yes/no**

Name of participant:

Date:

Signature:

Name of researcher:

Date:

Signature:

Appendix 3: Participant support contact details

Dear Participant,

Thank you for taking part in the study. In the event that you feel distress as a result of taking part in the study, either now or in the future, we would like to provide you with a list of organisations you can contact should you feel that this would be helpful. In the first instance, please contact your care team at the sexual health service at the Mortimer Market. They may be able to provide support directly or help to refer you on for additional support. You may also wish to speak to your GP.

If you feel at any serious risk of harming yourself or someone else, please contact **NHS Direct on: 0845 46 47** or go to your nearest **Accident and Emergency department**. The following organisations may be able to provide more general support for distress, concerns or questions related to your diagnosis:



Positively UK: **Website:** www.positivelyuk.org **Phone:** 020 7713 0222

“Positively UK believes in human rights, equality and justice and actively seeks to serve the community it represents. Our peer-led services support people living in the UK every year, challenge prejudice and promote fair access to health and care for everyone.”

Terrance Higgins Trust: **Website:** www.tht.org.uk **Phone:** 0808 802 1221



“Whatever your sexuality, HIV status, gender, cultural background or ethnic origin, THT has services set up with your needs in mind. If you’re affected by HIV, then we’ll try to help.”



Women for Positive Action: **Website:** www.womenforpositiveaction.org
Email: WFPA@litmus-mme.com

“Women for Positive Action is a global initiative established in response to the need to address specific concerns of women living and working with HIV.”

Appendix 4: Demographic Sheet

Basic initial questions

Age	
Where were you born?	
When did you arrive in the UK? (If not born in the UK)	
Number of children	
Age of children	
CD4 count	
Viral load	
Child HIV status	

How would you describe your ethnic background? (circle)

White: British

White: Other (Please specify.....)

Mixed: (Please specify.....)

Asian or Asian British

Black British

Black African

Chinese

Other (Please specify.....)

Appendix 5: Excerpts from Reflective Diary

November 26th 2013

I took a 'keeping in touch' day from maternity leave today and made my way up to Cambridge University for a workshop on Grounded Theory. This was really helpful and it was interesting to meet people from all different professions who all intend to use this method. I've realised that I won't be doing 'pure' GT for my thesis as I can't follow the rules exactly - I have already completed a literature review before I have begun to think about data collection. This could mean that my knowledge of the current literature has influenced the questions I have chosen to ask and the way I will code the data. I will have to bear this in mind and refer back to my prior assumptions when I come to analysing the data.

July 17th 2014

I carried out my first interview today. I was anxious beforehand and had been doing a lot of role-play practice, both with Michael and my husband! Overall it went well. It was difficult as the participant had told me she didn't want to talk about her son's HIV status (sadly he was positive) or discuss their relationship. This meant I had to avoid a lot of questions that I had intended to ask. Despite this, the interview flowed well and she was a lovely, warm, open and inspirational woman. I was impressed at her resilience and her ability to articulate her emotions and life experiences. The charity was clearly very important to her.

I came home and transcribed and had my first go at coding the interview within 24 hours. It took a long time but it was helpful to do it whilst it was all so fresh in my mind. I am amazed at how many interesting themes seem to be coming up already. I've also learned a lot about my questioning style listening back to the tape, I need to reflect more and ask more about feelings. I also used too many closed questions - I need to remember to keep it more open to get as much information as possible. I have to send the transcript to Michael and then meet with him to see how else I can improve.

January 22nd 2015

I've just completed my 7th interview. Although I hope I can get a couple more I have a feeling this will be the final one as the outlook for reaching any more is not looking great. The fact that this could have been my last one leaves me with a mix of emotions – relief that I've reached the end of 'data collection' and a sense of excitement at really being able to start analysing the results. However, I also feel a sense of sadness. I've really enjoyed meeting these women and hearing their stories. It's been such a privilege and I've loved immersing myself in their lives as I transcribe – it's been my favourite part of the research process by far and I can't believe it's over.

March 31st 2015

Just finished another meeting with the Grounded Theory trainee support group. So helpful to reduce rising anxiety levels and also in helping with motivation for this final push. We talked through our theoretical models and ensured each other's made sense and could be understood out of context. Everyone seems to be going through the same level of panic and dread as the hand in date looms so it was good to realise how far we had all come and how we are all basically on track. I've decided to write a mini 'to do' list that I can work on when I have the odd hour (eg. when commuting) to maximize the time on my research days to write the discussion and make changes to my introduction.

We've decided to do some viva prep together and also meet to go through our thesis presentations for the course along with our general thesis support group meetings. The support is invaluable as I had been feeling alone with the stress as we aren't currently having regular teaching/contact with the cohort.

Appendix 6: NHS Research Ethics Committee approval letter



Health Research Authority

NRES Committee London - Queen Square

HRA Head Office
Skipton House
80 London Road
London, SE1 6LH

Telephone: 020 7972 2556

22 July 2013

Mrs F Millner
Trainee Clinical Psychologist
Camden & Islington Foundation Trust
Royal Holloway, University of London
Egham Hill Egham, Surrey
TW20 0EX

Dear Mrs Millner

Study title: The Experience of Being a Mother with Perinatally Acquired HIV
REC reference: 13/LO/0622
IRAS project ID: 122529

Thank you for your letter of 10 July 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mr Thomas McQuillan, NRESCommittee.London-QueenSquare@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

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

Non-NHS sites

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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

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

Sponsors are not required to notify the Committee of approvals from host organisations

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of insurance or indemnity		01 August 2012
Investigator CV	Mrs. F. Millner	
Other: support info sheets x 3	1	18 March 2013
Other: RHUL Research Sub-Committee - Approval		22 January 2013
Other: Main Research Project Proposal Response	1	
Other: RHUL Research subcommittee - Provisional Opinion		11 December 2012
Participant Consent Form	2	10 July 2013
Participant Information Sheet: showing logos x 3	1	18 March 2013
Protocol	1.3	18 March 2013
Questionnaire: HADS		
Questionnaire: Parental Distress Subscale		
REC application	1	12 April 2013
Response to Request for Further Information		10 July 2013

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/0622

Please quote this number on all correspondence

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

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

Yours sincerely



pp

Dr Gella Richards
Vice-Chair

Email: NRESCommittee.London-QueenSquare@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to:



Appendix 7: Email approval from the Departmental Ethics Committee

From: Blackman, Carol [Carol.Blackman@rhul.ac.uk]
Sent: 30 January 2013 14:00
To: Millner, Faye (2012)
Cc: Evangeli, Michael; Lock, Annette
Subject: Ethics Proposal 2013/014

Dear Faye,

Ethics Proposal 2013/014: The experience of being a mother with perinatally acquired HIV

Your above ethics proposal has been reviewed by the DEC, and has received ethical approval for 13 months.

Good luck with your study.

Best Regards,

Carol

Miss Carol Blackman

Faculty Administrator

Psychology Department

Royal Holloway University of London

Egham

Surrey TW20 0EX

Tel: +44 (0) 1784 443528; Fax: +44 (0) 1784 434347

Email: carol.blackman@rhul.ac.uk

Appendix 8: Research & Development 1

[Redacted] [Redacted]

NHS Trust

[Redacted]

Research Governance Manager

12/05/2014

[Redacted]

NHS Trust

[Handwritten signature]

Dear [Redacted]

RE: JRCO Study Approval

Project Title: The Experience of being a Mother with Perinatally Acquired HIV

Joint Research Compliance Office Reference number: 14SM1934

Ethics reference number: 13/LO/0622

Principal Investigator [Redacted]

I confirm that this project has now been approved by the Joint Research Compliance Office. The project may now start at [Redacted]. Please note that the start date of the project is the date of this letter and the duration is the same as that provided in your application form.

The list of documents reviewed and approved by the Joint Research Compliance Office under requirements of the Research Governance Framework are as follows:

Document	Version	Date
Patient information sheet	2	14 March 2014
Divisional approval		25 April 2014
SSI form		27 March 2013
Evidence of Insurance		01 August 2013
Support Information Sheets	1	18 March 2013
RHUL Research Sub-committee Approval		22 January 2013
Protocol	1.3	18 March 2013
REC Application		12 April 2013
Consent form	2	10 July 2013

Before you commence your research, please note that you must be aware of your obligations to comply with the minimum requirements for compliance with the Research Governance indicators 17 (Data Protection); 25 (Health and Safety) and 22 (Financial Probity). Details of the requirements to be met can be found in the Research Governance Framework available on www.dh.gov.uk.

Under the Research Governance regulations, Serious Adverse Event Reports, Adverse Reactions and amendments to the protocol or other supporting documents must be forwarded to the Joint Research Compliance Office and Ethics Committee.

[Redacted]

[Redacted]

[Redacted]
[Redacted]
[Redacted]

In accordance with the Research Governance Framework, research projects carried out in the Trust will be randomly chosen by the Joint Research Compliance Office for auditing. Please see the attached checklist for documentation that will be required during the audit.

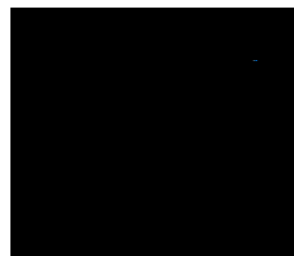
I wish you well in your research.

Yours sincerely



[Redacted]
Research Governance Manager

Appendix 9: Research & Development 2



02 May 2014

Mrs Faye Millner
Royal Holloway University of London
Egham Hill
Egham, Surrey
TW20 0EX

Dear Mrs Millner

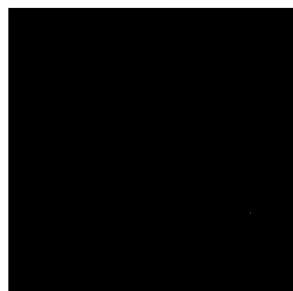
I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below**:

Study Title:	The Experience of Being a Mother with Perinatally Acquired HIV	
R&D reference:	122529	
REC reference:	13/LO/0622	
This NHS Permission is based on the REC favourable opinion given on 02 May 2014 and the most recent amendment submitted to REC on 23 March 2014		
Name of the trust	Name of current PI/LC	Date of permission issue(d)
[REDACTED]	[REDACTED]	02 May 2014
If any information on this document is altered after the date of issue, this document will be deemed INVALID		

Yours sincerely,

[REDACTED]

Cc: [REDACTED]
Dr Michael Evangeli, Sponsor Contact
Andrew MacLeod, Sponsor Contact and Representative



May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Serious Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Research Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Research Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Research Ethics Committee and R&D Office as soon as possible.
- **Monthly / Annually Progress report:** you are required to provide us and the Research Ethics Committee with a progress report and end of project report as part of the research governance guidance.
- **Recruitment data:** if your study is a portfolio study, you are required to upload the recruitment data on a monthly basis in the website:
http://www.cmcc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment/
- **Amendments:** if your study requires an amendment, you will need to contact the Research Ethics Committee. Once they have responded, and confirmed what kind of amendment it will be defined as, please contact the R&D office and we will arrange R&D approval for the amendment.
- **Audits:** each year, no-clor select 10% of the studies from each service we have approved to be audited. You will be contacted by the R&D office if your study is selected for audit. A member of the governance team will request you complete an audit monitoring form before arranging a meeting to discuss your study.

Appendix 10: Research & Development 3



Health Research Authority

NRES Committee London - Queen Square

HRA Head Office
Skipton House
80 London Road
London, SE1 6LH

Telephone: 020 7972 2556

12 August 2013

Mrs F Millner
Trainee Clinical Psychologist
Camden & Islington Foundation Trust
Royal Holloway, University of London
Egham Hill Egham, Surrey
TW20 0EX

Dear Mrs Millner

Study title: The Experience of Being a Mother with Perinatally Acquired HIV
REC reference: 13/LO/0622
SSA reference: 13/LO/1136
IRAS project ID: 122529

The REC gave a favourable ethical opinion to this study on 22nd July 2013.

Notification(s) have been received from local assessor(s), following site-specific assessment. On behalf of the Committee, I am pleased to confirm the extension of the favourable opinion to the new site(s) and investigator(s) listed below:

Research Site	Principal Investigator / Local Collaborator

The favourable opinion is subject to management permission or approval being obtained from the host organisation prior to the start of the study at the site concerned.

Statement of compliance

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

13/LO/0622	Please quote this number on all correspondence
-------------------	---

Yours sincerely

Mr Thomas McQuillan
Assistant Committee Co-ordinator

Email: NRESCommittee.London-QueenSquare@nhs.net

Appendix 11: REC Approval of Ethics Amendment



Health Research Authority
National Research Ethics Service

NRES Committee London - Queen Square

HRA Head Office
Skipton House
80 London Road
London
SE1 6LH

Tel: 0161 625 7819/7827
Fax: 0161 237 9427

01 May 2014

Mrs F Millner
Trainee Clinical Psychologist
Camden & Islington Foundation Trust
Royal Holloway, University of London
Egham Hill Egham, Surrey
TW20 0EX

Dear Mrs Millner

Study title: The Experience of Being a Mother with Perinatally Acquired HIV
REC reference: 13/LO/0622
Amendment number: Substantial Amendment 1- Updated PIS
Amendment date: 23 March 2014
IRAS project ID: 122529

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The amendment requested approval to revise the Participant Information Sheet to reflect the fact that it was no longer intended to access patient medical records.

The Sub-Committee identified no ethical issues with the proposed amendment.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter: REC Amendment to PIS letter- From Faye Millner- V1		20 March 2014
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1- Updated PIS	23 March 2014

A Research Ethics Committee established by the Health Research Authority

Participant Information Sheet: Participant Info Sheet [REDACTED] R&D	V2	14 March 2014
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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

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

13/LO/0622:	Please quote this number on all correspondence
-------------	--

Yours sincerely



On behalf of:-
Dr Yogi Amin
Chair

E-mail: NRESCommittee.London-QueenSqaure@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: [REDACTED]

NRES Committee London - Queen Square

Attendance at Sub-Committee in Correspondence

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Yogi Amin	Consultant in Neuroanaesthesia & Neurocritical Care	Expert
Mrs Claire Reynolds	Radiotherapy Radiographer	Expert

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Noel Graham	Regional Manager – Manchester

Appendix 12: Hospital Anxiety and Depression Questionnaire

Hospital Anxiety and Depression Score (HADS)

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important

A	I feel tense or 'wound up': Most of the time A lot of the time From time to time (occ.) Not at all	3 2 1 0
D	I still enjoy the things I used to enjoy: Definitely as much Not quite as much Only a little Hardly at all	0 1 2 3
A	I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all	3 2 1 0
D	I can laugh and see the funny side of things: As much as I always could Not quite so much now Definitely not so much now Not at all	0 1 2 3
A	Worrying thoughts go through my mind: A great deal of the time A lot of the time From time to time, but not often Only occasionally	3 2 1 0
D	I feel cheerful: Not at all Not often Sometimes Most of the time	3 2 1 0
A	I can sit at ease and feel relaxed: Definitely Usually Not often Not at all	0 1 2 3

D	I feel as if I am slowed down: Nearly all the time Very often Sometimes Not at all	3 2 1 0
A	I get a sort of frightened feeling like "butterflies" in the stomach: Not at all Occasionally Quite often Very often	0 1 2 3
D	I have lost interest in my appearance: Definitely I don't take as much care as I should I may not take quite as much care I take just as much care	3 2 1 0
A	I feel restless as I have to be on the move: Very much indeed Quite a lot Not very much Not at all	3 2 1 0
D	I look forward with enjoyment to things: As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all	0 1 2 3
A	I get sudden feelings of panic: Very often indeed Quite often Not very often Not at all	3 2 1 0
D	I can enjoy a good book or radio/TV program: Often Sometimes Not often Very seldom	0 1 2 3

Appendix 13: Parenting Distress Subscale

Parental Distress Subscale

Please circle the statement you most agree with for each question:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. My child rarely does things for me	1	2	3	4	5
2. Child does not like me or want to be close	1	2	3	4	5
3. Child smiles at me less than expected	1	2	3	4	5
4. My efforts for child aren't appreciated	1	2	3	4	5
5. Child doesn't giggle or laugh much when playing	1	2	3	4	5
6. Child doesn't learn as quickly as other children	1	2	3	4	5
7. Child doesn't smile as much as other children	1	2	3	4	5
8. Child isn't able to do as much as expected	1	2	3	4	5
9. Takes a long time for child to get used to new things	1	2	3	4	5
10. Expected to have closer feelings for my child	1	2	3	4	5
11. Child does things that bother me to be mean	1	2	3	4	5
12. Child cries or fusses more often than other children	1	2	3	4	5

Appendix 14: Interview schedule

Introduction

The purpose of this research study is to find out more about the experiences of women deciding to become a mother, and being a mother with a diagnosis of Perinatal HIV. The aim of the study is to gather information to help professionals to better support these women, their babies and their families as well as other young people with PHIV who are considering becoming parents.

This interview will include some questions about your own experiences of having grown up PHIV, having had a mother with HIV and your thoughts about what it is like to be a mother with PHIV.

Confidentiality and consent

- Explain standard confidentiality procedures
- Remind participant that they have the right to withdraw from the study at any point, without need for explanation and state that withdrawing will have no impact on the healthcare they receive from the relevant health setting.
- Gain consent and signatures (x3)

Any Questions?

Start with basic demographic questions

Warm up questions:

- How did you get here today?
- Who are you currently living with?
- Who helps you look after your child/ren?
- Who are the important people in you and your child's/children's lives?

Initial questions (to be explored using further prompting):

I'd like to start by going back to the time you first heard about your HIV diagnosis and what it was like to grow up with this diagnosis.

- **Tell me about how and when you were you told about your HIV status**
 - Who told and what told
 - Response to the news at the time/after
 - What was helpful at this time

- **Tell me what it was like growing up with HIV?**
 - Telling others
 - How was general health
 - Attending medical appointments/taking medication
 - Feeling different to others
 - Thoughts about the future
 - What was difficult – friendships/relationships
 - How talked about in the family/who talk to about it

- **Tell me about having a mother with HIV**
 - Her health whilst growing up
 - What was difficult/any fears?

Pregnancy: (could be more than one pregnancy to discuss)

- **Before you became pregnant, what were your thoughts about having a child?**
 - Always want to have children? How many?
 - How was the possibility of becoming a parent communicated to you?
 - What was your partner's thoughts/attitude? (If appropriate)

- **Tell me about your pregnancy**
 - Was it planned? How long did you try for?
 - What were your hopes, fears, expectations? (in relation to HIV)
 - Did you feel supported within your health care team with regard to your decision to have a baby?

- **Tell me about telling others that you were pregnant (focus on mother)**
 - Telling partner/mother/professionals
 - How feel about telling – any fears?
 - What were their reactions and how was the support?

- **How did the pregnancy impact on your own health?**
 - adherence to medication
 - support from professionals

Children:

- **How do you find being a mum?**
 - How was the birth?

- How was it at the start
 - Best and most difficult parts of being a mum
 - How changing as child gets older
- **How would you describe your relationship with your baby/child/children?**
 - Was there anything about your relationship with your baby that worried you?
 - Did you breast or bottle feed your baby? How feel about that?
 - How did you/are you coping with the uncertainty regarding your child's diagnosis?
 - Did you/do you feel supported during this time?
 - Do you think that having HIV influenced your experience of this time at all?
- **What do you think makes you approach parenting the way you do?**
 - Do you feel you parent in a similar or different way to how you were parented?
 - Doing anything deliberately differently or the same?
- **Has your relationship with your own mother changed since you have become a mum? (If mother still alive)**
 - How?
 - What is hard about it? What's helpful?
- **What are your thoughts about your child's future?**
 - Your relationship
 - Their health
 - Future disclosure of your status

Final questions

- Do you think growing up with PHIV has affected how you are as a mother?
- What advice would you give someone with PHIV who was considering having a child?
- If you were going to describe your experience to someone of being a mother with PHIV what would you say?
- Is there anything else which you think might be important for me to know about your experience of being a mother with PHIV?

Thanks for participation and close

Appendix 15: Updated interview schedule

Introduction

The purpose of this research study is to find out more about the experiences of women deciding to become a mother, and being a mother with a diagnosis of Perinatal HIV. The aim of the study is to gather information to help professionals to better support these women, their babies and their families as well as other young people with PHIV who are considering becoming parents.

This interview will include some questions about your own experiences of having grown up PHIV, having had a mother with HIV and your thoughts about what it is like to be a mother with PHIV.

Confidentiality and consent

- Explain standard confidentiality procedures
- Remind participant that they have the right to withdraw from the study at any point, without need for explanation and state that withdrawing will have no impact on the healthcare they receive from the relevant health setting.
- Gain consent and signatures (x3)

Any Questions?

Start with basic demographic questions

Warm up questions:

- How did you get here today?
- Who are you currently living with?
- Who helps you look after your child/ren?
- Who are the important people in you and your child's/children's lives?
-

Initial questions (to be explored using further prompting):

I'd like to start by going back to the time you first heard about your HIV diagnosis and what it was like to grow up with this diagnosis.

- **Tell me about how and when you were you told about your HIV status**

- Who told and what told
 - Response to the news at the time/after
 - What was helpful at this time
- **Tell me what it was like growing up with HIV?**
 - Telling others
 - How was general health
 - Attending medical appointments/taking medication
 - Feeling different to others
 - Thoughts about the future
 - What was difficult – friendships/relationships
 - How talked about in the family/who talk to about it
 - **Tell me about having a mother with HIV**
 - Her health whilst growing up
 - What was difficult/any fears?

Pregnancy: (could be more than one pregnancy to discuss)

- **Before you became pregnant, what were your thoughts about having a child?**
 - Always want to have children? How many?
 - How was the possibility of becoming a parent communicated to you?
 - What was your partner's thoughts/attitude? (If appropriate)
- **Tell me about your pregnancy**
 - Was it planned? How long did you try for?
 - Did you enjoy being pregnant?
 - What were your hopes, greatest fears, expectations? (in relation to HIV)
 - Did you feel supported within your health care team with regard to your decision to have a baby?
 - Did you feel close to your unborn child?
- **Tell me about telling others that you were pregnant (focus on mother)**
 - Telling partner/mother/professionals
 - How feel about telling – any fears?
 - What were their reactions and how was the support?
- **How did the pregnancy impact on your own health?**
 - adherence to medication

- support from professionals

Children:

- **How do you find being a mum?**
 - How was the birth?
 - How was it at the start
 - Best and most difficult parts of being a mum
 - How changing as child gets older
- **How would you describe your relationship with your baby/child/children?**
 - Was there anything about your relationship with your baby that worried you?
 - Did you breast or bottle feed your baby? How feel about that?
 - How did you/are you coping with the uncertainty regarding your child's diagnosis?
 - Did you/do you feel supported during this time?
 - Do you think that having HIV influenced your experience of this time at all?
- **What do you think makes you approach parenting the way you do?**
 - Do you feel you parent in a similar or different way to how you were parented?
 - Doing anything deliberately differently or the same?
- **Has your relationship with your own mother changed since you have become a mum? (If mother still alive)**
 - How?
 - What is hard about it? What's helpful?
- **What are your thoughts about your child's future?**
 - Your relationship
 - Their health
 - Future disclosure of your status
 - Do you want any more children?

Final questions

- Do you think growing up with PHIV has affected how you are as a mother?
- What advice would you give someone with PHIV who was considering having a child?
- If you were going to describe your experience to someone of being a mother with PHIV what would you say?
- Is there anything else which you think might be important for me to know about your experience of being a mother with PHIV?

Thanks for participation and close

Appendix 16: Example memos

Memo on experiences growing up with HIV (5th August 2014)

The interviewees so far have made many references to growing up within a web of deceit and lies; initially experiencing being lied to themselves prior to discovering their and/or their mother's status, and then feeling they have to continue to lie to those close to them after they have discovered their status. There seems to be a theme of living a 'double-life', presenting as normal teenage girls but having to keep their 'true' identity hidden; lying to their friends, teachers, partners etc. about their status – something that the women wanted to avoid their own children from having to go through.

'.....I didn't know what she passed from, the family wouldn't give me...wouldn't tell me..... when they gave me two answers, I just gave up....and didn't bother.....I had to put the pieces of the puzzle together myself' (P1)

'no one knew at school, not even teachers, nobody....I think my family thought just them needed to know, unless something dramatic happened, which it never did' (P1)

'{when asked about attending medical appointments} I pretended, I used to just give the excuse that I had a chest infection that needs to be checked...every 2 months' (P1)

'{HIV} wasn't really talked about in the family, because my mum, she didn't want to talk about it...so when I would ask a question, it's like she didn't feel comfortable talking about it, so half the time I just left it' (P2)

'cos we didn't really talk about HIV a lot, it wasn't a thing that which I wanted to bring up, there was occasions where I asked certain things, and wanted to find out but um, I didn't really' (P2)

'at home anyway there were nobody who would talk to me about it, it was just brushed under the carpet.....it was just something that was there but I had never talked about it' (P3)

'... I was just angry that I was lied to and upset and it kind of made my life kind of change on that day so.....' (P2)

With hindsight and now being mother's themselves they seem to appreciate why their parents and families lied and encouraged them to keep the HIV part of themselves hidden at all costs. This understanding seemed to create some ambivalence around telling their own children about their status; be it their own or the child's. Many could not decide when to do it whilst others seemed to want to disclose at a similar age to that at which they had found out about their own mothers.

'it's kind of made me think, maybe that's what my mum was going through when she found out about me, so it's just I guess just added some understanding, being a mother as well now...' (P2)

'I probably won't wait until 13 like they did with me, because I realise in this time in age, kids are getting younger when they know a lot about stuff like that, so.....probably around the age of 9 or 10...I've not really thought about it....I don't have any thoughts about it, I just think, I think it's one of them things that I feel like when the time is right, I will sit him down.... I would rather tell him myself, just me and him.... because sometimes, I think when, when other professionals are there they might not want to say everything that they want to say, so I think I would rather tell him about myself just me and him, so if he has any questions, I can answer the questions myself' (P1)

'I am going to have to tell her at one point about me, how am I going to tell her about my status, how it happened and is she going to feel resentful to her grandmother, even though she's not alive?' (P2)

'I have a vision, but I don't know because I can imagine her being like 'oh, mummy's going to die' and I don't know when to do it, how to do it.... yeah I

just don't know how to go about it, and she's still young and I don't know whether to start implementing about sex at an early age, and talking like 'oh mummy's not well but she will be ok' so when she hears it, it will be something to used to..... but then I don't want her to be worrying about me when she is young, I want her to have a lovely childhood and go through things, and you know, go through the motions, I don't know.....' (P2)

Memo on breastfeeding (12th September 2013)

The perceived fear of transmission of HIV was the reason many mothers did not breastfeed their babies; something that many of them struggled with.

'my mum had told me that {that was} how I contracted it, her breastfeeding me, so....that was a no-go, even though I really wanted to... my milk came in and it hurt! It really hurt! And my breasts desperately wanted to be suckled!!' (P2)

Maternal distress around limited options for feeding may have been exacerbated by a feeling of failure to adhere to cultural norms around motherhood. A sense that everybody else was feeding naturally seemed to contribute to a general sense of mothers having failed their child, and failed to live up to cultural ideals.

'I think my partner's family {did mind that I didn't breastfeed}, because in their culture, which is similar to ours...a woman has to breastfeed so....at the beginning they were on my case about it, saying I should try and breastfeed him until he was about one and a half years old...so I just came up with a lie or an excuse to get them off my back, I just told them I tried it, it was painful.....and that I just want to stick to the bottle' (P1)

'because in our culture, they say that breast milk is the right milk, and they think that if you give your kid bottled milk, they aren't going to develop in the same way.... which I don't believe in.....so that was my reason when people were like 'why are you not breastfeeding?' I said that it has not been proven that people who are breast fed and people who are bottle fed that one is smarter than the other, or one will develop more than the other.....' (P1)

'she started crying so I put her on my chest, and I thought is she hungry? Because obviously I couldn't breast feed her so I gave her bottle....even though there was one nurse that said to me that I could breastfeed, but I didn't really act upon it....because the nurse was like 'oh, you are undetectable, you're really good, you're really doing well with your medication and stuff like that' literally I was really, really good and then nurse was like 'oh you can breast feed if you're actually undetectable' and I was like 'oh really?' but I didn't want to take that risk, and obviously I spoke to someone and they said 'whoever told you that, that's rubbish, don't take that' and I knew there were studies that say you can breastfeed and some people in undeveloped countries still do breast feed their babies who are undetectable, so it can happen, but it felt like I couldn't do that' (P2)

For other mothers, bottle feeding their babies was something they had come to terms with and stated they actually preferred to do prior to the baby being born

'I didn't mind, because I think even if I was given a choice to breastfeed I still wouldn't breast feed.....because I've had friends that have had kids and they've said that when they breast fed their kid, like it leaves their breasts kind of sore, some have actually bleed because of the kid.....yeah, from that I was just like no' (P1)

Memo on an enhanced and diminished experience of motherhood

(5th January 2015)

PHIV seems to both enhances and diminishes the experience of motherhood, enhancing it as mothers felt they were never going to get this opportunity, wanting the best for the children and savouring the time and putting energy into their relationship, keeping them healthy by giving them a reason to take medication, often improving their relationships with their own mothers, giving them hope.

Yet it also seems to diminish the experience, from the moment the women find out they are pregnant; their health is compromised - sickness, exhaustion, protecting themselves and the baby feels like hard work, anxiety about HIV transmission cloud the whole experience of pregnancy - plus stigma from those who know of status . Then once the baby is born (many are unable to have a natural delivery) the mothers have to manage their own health, are unable to breast feed and instantly think of the future either in worrying about disclosing own status or in the fear of future stigma for their children.

Appendix 17: Example sections of transcripts

Participant 2

Line		Open Coding
634	Int: could we go back a little bit, to when you found out you	
635	were pregnant what was it like telling professionals and did	
636	you feel supported with your pregnancy?	
637	P2: um....the thing is that I felt supported because um I was	Location of
638	here when I kind of when I found out I was pregnant and they	discovery of
639	were like 'whoa, this is the kind of the next steps that we are	pregnancy -
640	going to take, we are going to forward you for this scan, and	being at
641	we've got this place up there'xxxx in the maternity unit,	hospital
642	and it was kind of really nice, they all supported me and stuff,	Professional
643	they were all really helpful with me so I got really um good	support with
644	support with that actually	pregnancy
645	Int: did you have any fears about your pregnancy?	
646	P2: I did, I was worried about giving birth, I was worried that	Fears about
647	my child would contract HIV, I was worried about losing my	pregnancy and
648	baby, I was worried about still born, I was worried about it	birth - fear of
649	being another ectopic	MTCT/death
650	Int: lots of fears	Lots of fears
651	P2: lots of fears	regarding birth
652	Int: did you have somewhere to go and talk to someone about	
653	all those fears?	
654	P2: I did, I could either speak to someone here, obviously a	Having
655	member of the team, or I could speak - cos I developed, with	somewhere to
656	my first midwife I spoke to them but then they left and I	take fears
657	developed a really good relationship with my um midwife that	Importance of
658	I saw for both of my pregnancies	professional
659	Int: that's good, was she on call?	support -
660	P2: it was a guy! Yeah it was a guy! He really helped me, he	consistent
661	was like worried for me and stuff like that actually I should go	support
662	see him after this, but um yeah, like I could call him about	Professionals
663	anything and with him I could call him anytime, he would	on call

664	always leave his phone open and um	Professionals
665	Int: that was important	offering extra
666	P2: yeah that was good, but then he tried to go for a	support
667	permanent position but they didn't give it to him, so they	
668	changed it to a lady, she was really nice but it was a little bit	Change in
669	different with her because she didn't have her open line all	midwife
670	hours and stuff, so that was a little bit weird and when they	Not being on
671	changed I was always running to him, but I couldn't really go	call
672	to him, because he was dealing with all his other patients and	Returning to
673	stuff like that, because he was dealing with the multiples,	previous
674	those mothers and ob....ob...stetrics..... I can't say it! (laughing)	midwife for
675	and he was like 'oh, you can't really come to me now' so then I	support
676	ended up developing a relationship with her and she was	Developing a
677	alright and she supported me and I was like still kind of closed	relationship
678	off about certain things, but anything that popped into my	with new
679	head that I was worried about that I felt needed to be checked	midwife
680	up, or I needed to be reassured about I could go to her.	Seeking
681	Int: Ok, and you've mentioned that you couldn't breastfeed,	reassurance
682	that you had been advised to bottle feed	
683	P2: yeah even though there was one nurse that said to me that	Being told
684	I could when xxxx was born, that I could breastfeed, but I	could
685	didn't really act upon it, because my mum had told me that the	breastfeed
686	reason how I contracted it was her breastfeeding me, so I kind	Mother
687	of was like 'that's a no-go', even though I really wanted to!	warning not to
688	Because the nurse was like 'oh, you are undetectable, you're	breastfeed
689	really good, you're really doing well with your medication and	Being 'well'
690	stuff like that' literally I was really, really good and then nurse	enough to
691	was like 'oh you can breast feed if you're actually	breastfeed
692	undetectable' and I was like 'oh really??' but I didn't want to	Avoiding risk
693	take that risk, and obviously I spoke to someone and they said	Incorrect
694	'whoever told you that, that's rubbish, don't take that' and I	medical advice
695	knew there were studies that say you can breastfeed but some	Researching
696	people in undeveloped countries that still do breast feed their	breastfeeding
697	babies who are undetectable, so it can happen, but it felt like I	for self
698	couldn't do that, and I know that because I told my partner	Partners

699	that that's how I contracted it, it would be a no-go for him	opinion on
700	either way....but I felt like I was kind of missing out on that	feeding taken
701	kind of contact, and I wanted to because my milk came in! and	into account
702	it hurt! My breasts hurt! And my breasts desperately wanted	Feeling like
703	to be suckled!! But it didn't happen.....so I had to do endure	'missing out' on
704	the pain of the milk until they gave me a pill to stop it after a	bond with baby
705	whole week! So I had lumpy, hard breasts	when nursing
706	Int: So a big part of you wanted to breastfeed, and it felt like a	Physical impact
707	natural thing that your body wanted to do to, but there was an	of not being
708	overriding fear and your partner and your professionals	able to feed
709	saying it's a no-go and you decided not to take that risk....and	Feeling torn
710	it may have impacted on that early bonding that you said was	with regards to
711	already a bit fuzzy because of everything else you were going	breastfeeding
712	through...	
713	P2: yeah, exactly	
714	Int: and can you tell me about the process that you went	
715	through with finding out your daughter's diagnosis	Recalling the
716	P2: well the thing is that, we went to xxxxx for her check-ups	HIV testing
717	and her to be weighed so she had um when she was um born	procedure for
718	they done the first test, she was negative, and I remember the	daughter
719	doctors telling me um that if the first two tests are negative,	Discovering
720	your child's most likely to be negative, so the first test was	daughter's
721	negative was born and the other one that they done in the	negative status
722	hospital was negative too...	
723	Int: and what was it like?	
724	P2: I felt elated, you know I felt like you know what I've done	Elation
725	my job, so my daughter doesn't have to kind of like be like me,	Protecting child
726	she doesn't have to worry about her life kind of thing,	Not be like her
727	obviously there are going to be other things in her life that	Different
728	may come up, but she doesn't have to worry about that.....	worries
729	but then it switched and it was like, I am going to have to tell	Fears about
730	her at one point about me, how am I going to tell her about my	disclosing
731	status, how it happened and is she going to feel resentful to	status to child
732	her grandmother, even though she's not alive	Fear of child
733	Int: have you thought about how you are going to tell her?	resenting

<p>734 735 736 737 738 739 740 741 742 743 744 745 746 747 748 749 750 751 752 753 754</p>	<p>P2: I haven't.....because.....I don't know..... I haven't thought about it yet.....I have a vision, but I don't know because I can imagine her being like 'oh mummy's going to die' and I don't know when to do it, how to do it, but then it's kind of made me think, maybe that's what my mum was going through when she found out about me, so it's just I guess just added some understanding, being a mother as well now...yeah I just don't know how to go about it, and she's still young and I don't know whether to start implementing about sex at an early age, and talking like 'oh mummy's not well but she will be ok' so when she hears it, it will be something to used to Int: she'll be aware of it P2: Yeah, but then I don't want her to be worrying about me when she is young, I want her to have a lovely childhood and go through things, and you know, go through the motions, I don't know..... Int: so it's something that is certainly in your mind, P2: yeah it's in my mind but I don't know yet... Int: is the way you found out – obviously you don't want that to happen to her? P2: I don't want that to happen to her,</p>	<p>grandmother No thoughts about how to disclose to child, wanting to protect child Realising what mother went through Unsure when and how to start disclosure Wanting to protect child for as long as possible, wanting child to have care-free childhood Not wanting child to discover status for self</p>
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Participant 7

Line		Open Coding
263	Int: and you said about finding out you were pregnant, tell me	
264	more about that, were you trying for a baby?	
265	P7: no, that's the thing cos I was working, studying at the same	Not trying for a
266	time, so babies weren't on my mind, like I wanted to get my	baby
267	carer going before I thought babies and like, yeah, cos I	Wanting the
268	wanted a stable life for a baby, so when I found out I was just	best for a child
269	like 'oh my God' like I was shocked, I was like kind of going, I	Wanting to get
270	was like, 'can I still go to university and do what I need to do?'	education
271	but.....what I think, what I chose, I wanted to have, I really	Debating
272	thought 'should have an abortion?' because like, obviously I	having an
273	don't know if the baby is going to get it, or if it was the right	abortion due to
274	thing to do, like I know my mum weren't agree if I decide to	MTCT
275	have an abortion but then when I came here, they said that	Professional
276	errrr they've got lots of medications that will not allow the	advice sought
277	baby to be infected, so I was like OK , so I really had a good	Lengthy
278	thought about it and thought, 'no, I can't have an abortion' so I	decision
279	had him!	making process
280	Int: so tell me a little bit more about that moment when you	
281	found out	
282	P7: about being pregnant?	
283	Int: yeah, did you know, did you have any inkling?	
284	P7: no, I had no idea, because my periods are irregular all the	Being unaware
285	time, so to me I thought 'oh I haven't been on for 2 months' so	of pregnancy
286	I just thought 'oh I will come on next month or something' and	due to irregular
287	then I didn't get no morning sickness, nothing, so I just was	periods
288	like this is a bit weird and then the third month comes and I	No other
289	was like - no this is not right, I should have come on at least,	symptoms
290	so I must have taken the test, it was near enough Christmas, I	
291	think, I found out and I took the test and I was like 'shit' I can't	First thoughts
292	tell my mum (laughs) she will tell me off! So I was just like, it	upon
293	was just a complete shock, so much shock I was like 'oh my	discovering
293	God, no way!'	status

294	Int: were you pleased?	about mother's
295	P7: not at the time, no because...this sounds so bad....on that	reactions
296	night I found out I just nearly drank myself to like, a coma...to	Shock and
297	oblivious so I could forget that I was pregnant, so I was just	disbelief
298	like 'shit' but then I think like a couple of days later, I was like	Drinking to
299	'oh my God I hope I didn't do anything wrong to the baby from	block out
300	doing that drinking cos I think I want it now!' but yeah....	reality of
301	Int: so huge amounts of shock and a bit of denial and trying to	pregnancy
302	sort of blank it out, and then a really tough decision that you	
303	had to make it, whether or not to go ahead with the pregnancy	
304	and that was influenced by your worries about whether the	
305	baby would get it?	Fear for safety
306	P7: yeah	of child
307	Int: can you tell me a bit more about those worries before you	
308	had the chat here?	
309	P7: um, because I thought, I don't know, if he grown up, cos	Wanting to tell
310	obviously where I didn't know that I had it, obviously he	child if he were
311	would know because I would obviously tell him from an age	to contract HIV
312	he could understand so I just thought to myself 'how am I	Thoughts on
313	going to explain this to him, how, how is he going to	the future and
314	understand it, he going to like to probably hate me for like	how to disclose
315	giving it to him' or something so I thought to myself, 'do I want	Fears he will
316	this? Do I want my child to hate me for something that I didn't	hate her for
317	mean to do?' But.... I just thought, 'oh do you know what, if it	giving it to him
318	happens it happens, they will soon realise that it wasn't my	Acceptance that
319	fault'	he may contract
320	Int: has it made you think any differently about your own	HIV
321	mum?	
322	P7: um..no, no....(laughs) I never hated her, I just....I don't	Never hated
323	know, it wasn't her fault that she gave it to me and she never	mother, mother
324	knew until she came to London, so obviously she didn't know I	unaware of own
325	had it, or she had it so....it was just yeah.....but, yeah...	status until
326	Int: so before you found out you were pregnant, what were	moved to UK
327	your thoughts about having children, you said you wanted to	
328	have a stable life for them, so children was something that you	

329	definitely wanted?	
330	P7: yeah, yeah, yeah children was something I definitely	Desire for
331	wanted, in my thirties (laughs) but it, it was, it was like bottom	children later
332	of my list, like way at the bottom, but obviously I just did	in life, low
333	everything backwards...(laughs)	down on list of
334	Int: and did you feel that you were able to have children,	priorities
335	despite your status?	
336	P7: um.....yeah.....umm I think so, I don't know, (laughs)	Unable to recall
337	Int: so it wasn't something you perhaps had thought about	thoughts on
338	whether or not it would be a possibility?	fertility
339	P7: yeah, no, I didn't think it was a possibility, cos like	Naïve to truths
340	obviously I didn't know much this what HIV was, I thought	of transmission
341	like, cos when we were younger, like all these rumours like	of HIV
342	getting like when you sit on a toilet seat, I thought all those	Believing she
343	types of scenarios or you can't get pregnant were true, so	was unable to
344	when I come here and they told me everything, like it basically	have children
345	put my mind ease knowing that I could have a child, and you	Having mind
346	can't catch it though the toilet seat and that, so it was quite	put at ease by
347	yeah...	professionals
348	Int: ok so it was really reassuring coming up here and having	
349	that initially chat...	
350	P7: yeah	
351	Int: do you remember telling your partner that you were	
352	pregnant? Was he with you at that point?	Text news of
353	P7: no, I...what did I do?...I think I text him (laughs)	pregnancy to
354	Int: he's finding out a lot by text!	partner
355	P7: yeah (laughs), no I don't like talking to people so I just like	Not like to talk
356	text all the time, but like, yeah I think I text him, yeah	to people
357	Int: and was he supportive?	Being alone,
358	P7: ummmm he couldn't be like, cos he used to work from I	partner
359	think it was 8 in the morning til 8 in the evening so by the time	working long
360	he got home it was about 9/10 so I barely saw him and like the	hours
361	only time I would get to see him was on the weekends and I	Attending
362	weren't going for no appointments at the weekends, so....I was	appointments
363	just like OK, I knew I could do it no matter what, but I was like	alone

364	'when this baby comes we need to decide what we are doing'...	Wanting
365	Int: so you were kind of alone with the pregnancy?	support
366	P7: yeah	organised
367	Int: what was it like taking the medication through your	
368	pregnancy?	
369	P7: um....	
370	Int: did you take your medication through your pregnancy?	
371	P7: yeah, yeah I took the medication through the pregnancy	Taking
372	which was - I think it was only the one pill, so yeah, no I was	medication
373	on the one, so it made it easier that I was only taking one a	through
374	day....so..... but I think I forgot a lot of the time, to take it,	pregnancy
375	because of like, I don't know, my brain just started shivering	Initially
376	(laughs), I just thought to myself, ok um, I better put an alarm	forgetting,
377	on my phone, to remind me to take it because this is getting	having to set an
378	ridiculous for me to keep forgetting,	alarm
379	Int: and were you worried about your own health or the	
380	babies at that point?	
381	P7: more the babies health cos I thought if I don't take it um...	Awareness of
382	what was it, was it my viral load, something, but I just thought	imp of viral
383	if it goes down, then it's the likelihood that the baby will catch	load, wanting to
384	it, so it would just be like, yeah, so I just thought yeah I need to	protect the
385	take it every day, and so that's what I did	baby
386	Int: and what was it like telling your mum that you were	
387	pregnant?	
388	P7: she....oh God.....my mum always believes that education	Mother's
389	comes first, and then after, once you've got your carer then go	disappointment
390	and have your family, but to her, when I told her, she was just	at pregnancy
391	like oh what did she say? Oh she told me that I should be more	and negative
392	careful, um that my baby was going to come out deformed, I	response
393	was like oh my God you are so evil and I don't, and somehow I	Not feeling
394	didn't think she believed me, so I was just like, do you know	supported or
395	what, do what you want, I am having this baby whether you	believed by
396	like it or not, I am like 22, yeah so, I don't know why you are	mother
397	jumping on my case about it, I am old enough to understand	Being
398	what's going on here, so she was like 'OK' but now she is	independent

399	supportive, so, it's good....(laughs)	and strong
400	Int: so her initially reaction was not great, to say the least, but	
401	now she's there for you?	
402	P7: yeah	
403	Int: and did you have any fears during your pregnancy? Can	
404	you remember what your worst fears were? Or any worries?	Fear of baby
405	P7: I think my only fear was him catching it, that was all, like, I	MTCT - helped
406	thought to myself like 'I hope he doesn't catch it, I hope he	by professional
407	doesn't catch it' like but the support I had in the hospital was	support
408	just brilliant, so I just thought to myself, well if they are just,	reducing stress
409	they were reassuring to me to make that sure that I wasn't too	levels
410	stressed over it, the situation, so it put my mind at ease,	
411	Int: so the professional support in that respect was really	
412	important	
413	P7: yeah	
414	Int: and tell me a bit about the birth? Did you go full term? Did	
415	you have a natural birth? C section?	
416	P7: um, I went, I went full term, I think I was like, was it 2 days	Able to have a
417	early, yeah I went into labour two days early, yeah it was a	natural birth
418	natural birth	
419	Int: that's good	
420	P7: a painful natural birth! (laughs) so yeah, so that was like,	Memories of
421	yeah like 18 hours was just too much! (laughs)	pain and a long
422	Int: but he came out healthy?	labour
423	P7: yeah, he came out, yeah he definitely come out healthy,	
424	healthy and yeah, strong	
425	Int: and what was it like seeing him for the first time?	Healthy baby
426	P7: I cried, I don't know whether it was the pain killers or	Emotional
427	something but I couldn't stop crying, and I was just like 'oh	response to
428	god' and I think I spent about 2 minutes with him before they	seeing baby,
429	took him, so I was just like ok, he needs to get his medication	being
430	and all of that and I need to sort myself out, then go up, and	separated
431	then when I saw him I was just like, I think I didn't sleep for	Staring at baby
432	the like whole night I just couldn't stop staring at him I was	whole night
433	like 'oh my god you are so cute' (laughs)	Feeling

<p>434 435 436 437 438 439 440 441 442 443 444 445 446 447 448 449 450</p>	<p>Int: so it felt pretty amazing? P7: yeah! I was just like wow Int: and how did it feel hearing that he was negative, because they have the first test don't they within 48 hours P7: yeah I think when I first heard it was last year, was it last year? Yeah last year was when I found out I think – I was just so relieved I just got to make sure he doesn't do anything to like catch him himself, so obviously to me it makes me feel that, since I do have it, it makes me know that I can educate them and like when they get older I can say to them 'you've got to be a lot careful these days cos you don't know, but never ever, like if someone does have it, don't ever just think of them differently, they are always going to be the same person who they are they just got one little problem with them and that's it so you just accept them for who they are and not what they have. So that's what I am going to make them know.</p>	<p>amazing</p> <p>Relief at discovering child's negative status</p> <p>Wanting to educate child about HIV and about safe sex</p> <p>Wanting to reduce stigma</p>
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Appendix 18: Reference table of themes occurring across participants

THEORETICAL CODES		SUB-CODES		1	2	3	4	5	6	7	
1	CONCEIVING, CONCEPTION AND PREGNANCY	1.1	Wanting a baby	6:204	9:558	3:159	2:60	4:180	1:50	2:55	
				9:563	3:161	2:61	4:197	4:185	2:93		
				10:587	4:164	5:219	4:201		4: 171		
					4:172	5:221	8:402		5:233		
					5:268			5:243			
		1.2	Discovering pregnancy	7:225	9:555	4:212	5:262	4:182	5:253	4:184	
				7:230	10:588	4:216	8:395	4:196	5:256	4:190	
				7:248	10:599	5:221	9:451	4:214		4:205	
				8:251		5:226		5:219		4:209	
				8:267		5:252				5:233	
				8:285		5:254				6:289	
				9:289		7:339					
				9:315							
		9:322									
		1.3	Feeling a duty to protect the baby during pregnancy	9:305	6:336	4:193	8:432	8:430	5:257	5:259	
				9:308	7:341	5:233	8:436	8:432	6:293	5:267	
9:310	7:444			5:237	9:475		7:341	6:279			
11:366	8:467			5:241				6:283			
11:373	9:567			5:244				6:291			
	11:644			5:267				6:299			
		6:327									
1.4	The role of professionals	10:342	11:637	4:197	7:348	5:224	5:268	6:301			
		10:348	11:641	6:299		5:226	6:302				
			11:650	6:303			6:305				
			11:656	6:314							
				7:330							

THEORETICAL CODES		SUB-CODES		1	2	3	4	5	6	7
2	BIRTH, BONDING AND BREASTFEEDING	2.1	Missing out on a natural delivery & breastfeeding	11:385	8:471	4:199	9:460	5:245	6:282	7:356
				13:441	8:502	7:347	13:693	5:268	6:323	7:364
				13:444	11:673	8:416	13:694	5:270	6:326	
				13:448	11:675	8:419	13:697	5:272	7:333	
				13:456	12:684	8:430		5:280		
				12:685						
		2.2	Developing a bond	12:417	7:419	7:363	8:385	5:257	4:199	6:319
				13:432	7:424	7:368	8:422	6:323	6:296	6:321
					8:495	7:377	10:504	7:337	6:299	6:323
					8:498	7:383	10:509	8:419	6:314	7:331
					8:504	8:384	10:517	8:426	6:317	7:344
					9:512	8:389	10:519	9:464	8:389	9:470
					9:529	8:392	10:520			9:474
					9:540	8:405	10:533			
					12:698	8:409	11:556			
					12:703	9:485	11:570			
				9:487	12:642					
		11:564	13:671							
		11:567	14:718							
			14:740							
2.3	Child as a protective factor	15:520	13:766	4:184	8:401		7:364	8:412		
		15:523	13:769	8:402	8:436		9:450			
		15:527			9:443					
		15:536								
		16:544								
18:634										
2.4	Motherhood related stigma	10:326	13:780	6:275	6:306	5:232	8:429			
		10:328	13:791	6:324	6:326	5:236	8:434			
		17:597	13:796	7:348	7:335	6:295	9:439			
		17:602	14:800	7:356	11:563	6:320				
				9:455	11:594	10:535				
		10:525	14:767	11:553						

THEORETICAL CODES		SUB-CODES		1	2	3	4	5	6	7
						11:551	15:781 16:866			
3	ESTABLISHING MOTHERHOOD AND FUTURE RELATED THOUGHTS	3.1	Growing in strength and confidence as a mother	14:468 14:475 15:514 18:623	9:534	9:488	3:127 5:249 5:254 8:407 11:598 12:626 16:869	9:482 9:490	8:410 8:413 8:422 9:456	8:404
		3.2	An enhanced experience of motherhood	15:524 18:616	14:766 14:813	7:383	15:793 15:796 16:873	9:444 9:457 10:544 10:547	3:111 3:133 9:445 9:447	8:392 8:396 8:415 9:396 10:545
		3.3	Thoughts on maternal disclosure to child	2:38 2:55 3:80 3:88 4:130 17:575 17:584	1:50 2:67 2:91 4:200 9:565 12:707 12:712 12:720	1:9 1:34 2:72 9:444 9::449	3:156 16:829	1:16 2:83 9:463 9:472	7:342 7:348	1:52 5:223 9:488 9:492 10:495
		3.4	Hopes and fears for the child's future	5:151 16:549 16:562 16:572	3:142 3:154 4:211 5:233 5:248 5:256 5:264 5:278 6:316 8:402	2:88 2:101 3:117 3:133 6:281 5:269 9:443 9:455 9:473 9:479	1:37 3:130 16:847	1:48 3:109 8:427 10:533	2:65 3:161 4:197 7:365 8:397	3:129 7:333 9:480 10:533 3:154 8:423 8:429 9:445 9:479 10:534

THEORETICAL CODES		SUB-CODES		1	2	3	4	5	6	7
						10:500 10:502 10:512				
		3.5	Motherhood influencing relationship with own mother	5:167 5:177 6:187 11:378 14:483 14:485 14:493 16:572	6:293 10:610 11:627 14:805 14:811	3:143 9:465 9:470	2:56 4:181 8:384 8:388 8:391 8:412 12:630 14:749 15:817	7:351 7:349 7:355 7:368 9:455 10:497 10:507 10:522	7:372 7:377	3:154 5:228 8:422 8:429 8:437 9:445 9:448 9:455 9:461