

**Exploring the experience of mothers bonding with their infants
following a maternal diagnosis of Human Immunodeficiency Virus
(HIV) during pregnancy**

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Abstract

Women face a number of physical, emotional and psychological challenges following an HIV positive diagnosis during pregnancy. Psychological challenges, such as maternal anxiety and low mood, have been associated with disruptions to mother-infant bonding in the general population. Despite significant numbers of women receiving an antenatal HIV diagnosis in the UK each year, there remains a limited understanding about the experiences of this group in bonding with their babies.

This Grounded Theory study aimed to explore the experience of mothers in bonding with their baby following an HIV diagnosis during pregnancy. The study explored the perceived challenges to mother-infant bonding, and the factors mothers felt helped them to manage this process following diagnosis. Ten mothers diagnosed antenatally at a London sexual health service were interviewed about their experiences.

Data analysis led to a theoretical model of mother-infant bonding following a maternal HIV positive maternal diagnosis. The model comprised four theoretical codes: facing barriers to bonding; feeling disconnected from the baby; developing a special bond; and strengthening and moving on. These codes were comprised of challenges to mother-infant bonding, as well as factors relating to maternal strength and resilience. The model used a chronological structure, with processes plotted from the point of antenatal diagnosis through to following the infant HIV testing process after birth. Challenges with bonding were experienced primarily during the early stages after birth, with maternal resilience and positivity about the future developing towards the end of infant testing. Circular relationships, in which positive and negative processes fed into and influenced each other, were highlighted throughout.

The findings highlight important areas for development in clinical practice, including more targeted psychological support for women following an antenatal diagnosis, and the provision of timely information regarding mother-to-child transmission. Clinical implications from this study are discussed alongside suggestions for future research.

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Chapter 1: Introduction

Overview of the study

Despite an average of 400 women receiving an antenatal diagnosis of HIV each year in the United Kingdom (UK) over the past 10 years (Townsend, Cortina-Borja, Peckham & Tookey, 2012), there remains a limited understanding about the experiences of this group of mothers in bonding with their babies (Reichert & Foote, 2009). In recent years, the antenatal care provided to HIV positive women has been overwhelmingly focused on physical health and reducing the risk of transmitting HIV to the baby (vertical transmission) (Sanders, 2008). Much less is known about the emotional and psychological aspects of becoming a mother, and the experience of mother-infant bonding following an antenatal diagnosis of HIV.

This Grounded Theory study aimed to explore mothers' experiences of forming a relationship with their baby following a maternal diagnosis of HIV during pregnancy. Research has suggested that women can face a period of notable vulnerability following an antenatal HIV diagnosis, impacting upon feelings about pregnancy and motherhood (Alder, Fink, Bitzer, Hosli and Holzgreve, 2007), functioning as a mother (Psaros, Gelle, & Aaron, 2009) and the presence of suicidal thoughts (Kelly et al., 2012). However, no research has specifically explored how such challenges may impact on the development of mother-infant relationships, and the factors perceived to promote maternal resiliency in this context.

10 women diagnosed with HIV during pregnancy were interviewed about their experiences following diagnosis, the perceived challenges to mother-infant bonding and factors that helped them to manage this process. Data were analysed using a Grounded Theory framework (Charmaz, 2006), producing four over-arching theoretical themes comprised of a number of focused codes. A theoretical model of mother-infant bonding in this context was produced to inform healthcare professionals supporting this group of mothers during the antenatal and postnatal periods.

HIV in the UK: The current picture

Human Immunodeficiency Virus (HIV) is a virus that impairs or destroys immune system cells, weakening the immune system over time and making individuals more susceptible to infections (World Health Organization (WHO), 2011). In 2011, an estimated 91,500 people were living with diagnosed or undiagnosed HIV in the UK, with this figure expected to rise beyond 100,000 by the end of 2012 (Health Protection Agency (HPA), 2012). Whilst there is still no cure for HIV, the development of highly active antiretroviral treatments (HAART) over the past 16 years has revolutionised HIV treatment procedures and dramatically improved life expectancy (HPA, 2012). In the early years of its emergence in the UK, HIV was depicted as a disease predominantly affecting white homosexual men (Sandelowski & Barroso, 2003), with women often portrayed in the role of care-giver or carrier of the disease (Bova, 2000; Treichler & Warren, 1998). A steady rise in the prevalence of HIV amongst women in the UK (BHIVA, 2012) has been accompanied by a recognition that the unique circumstances of this group can no longer be ignored (Sandelowski & Barroso, 2003).

HIV and motherhood

There has been a steady increase in the numbers of HIV-infected women becoming mothers in the UK (National Study of HIV in Pregnancy and Childhood (NSHPC), 2012), from 82 live births to women with HIV in 1990, to over 1400 births a year since 2006 (Townsend, Cortina-Borja, Peckham & Tookey, 2012). These figures are predominantly made up from women diagnosed with HIV prior to becoming pregnant (80% of live births in 2010), but also include those diagnosed during pregnancy (20% in 2010, NSHPC, 2012). Interventions to prevent mother-to-child transmission of HIV have led to a marked reduction in perinatal transmission in the developed world (CDC, 2005). These interventions include a routine offer of antenatal HIV screening to all pregnant women in the UK; high rates of uptake for testing (HPA, 2011); use of antiretroviral therapy during pregnancy and after birth for the child (ART); planned mode of caesarean section delivery and advice to avoid breastfeeding. This has resulted in a decline in national MTCT rates in HIV positive mothers from 20% in 1990 (Duong, Ades, Gibb, Tookey and Masters, 1999) to under 1% by 2008 (Townsend et al., 2008).

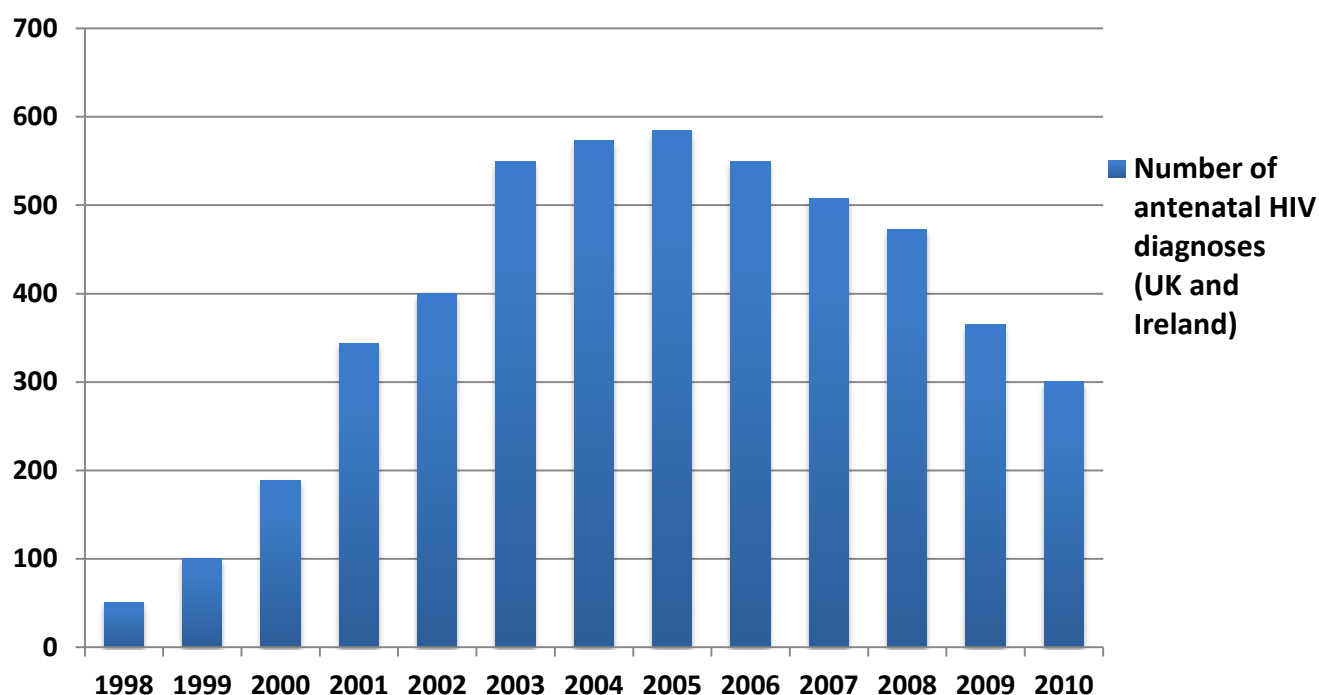
Current national guidance to HIV positive mothers is to avoid all breastfeeding and to engage in three infant HIV screening sessions for up to 18 months after birth. These tests currently take place during the first 48 hours after birth, at 6-24 weeks of age, and at age 18 months (British

HIV Association (BHIVA), 2012), although this can vary according to local practice. Until recently, the use of antiretroviral therapy for mothers during pregnancy has been dependent on the maternal CD4 cell count (a type of white blood cell that fights infection) at the time of diagnosis. Women with a CD4 count of under 350 cells/mm³ (indicating a weakened immune system) have typically commenced HAART immediately following diagnosis (HPA, 2010). However, guidance for preventing mother-to-child-transmission during pregnancy has recently been updated (WHO, 2012; BHIVA, 2012) stating that life-long triple antiretroviral drugs (ARVs) should be 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).

Antenatal diagnosis

Maternal HIV testing has become a routine part of antenatal care in the UK over the past 10 years, with a greater number of antenatal diagnoses reported during this period than in previous years (National Institute for Health and Clinical Excellence, 2008; Townsend et al., 2008). Over 2000 women in the UK and Ireland have been diagnosed antenatally with HIV since 2009 (NSHPC, 2012), with annual numbers reducing since a peak of almost 600 antenatal diagnoses in 2005. The pattern of diagnoses in the UK and Ireland between 1998 and 2010 is shown in Figure 1 below.

Figure 1: Number of HIV antenatal diagnoses in UK and Ireland, 1998-2010 (NSHPC, 2012).



The Health Protection Agency (2012) has reported a higher prevalence of antenatal diagnoses in London than in other parts of the UK, with a reported 1 in 250 current births to an HIV positive mother in London compared to 1 in 449 births to HIV-infected mothers across England (HPA, 2012).

Psychological stressors and issues of religious and cultural identity

33% of all HIV diagnoses in the UK, and 66% of those amongst heterosexuals, are from people originating from sub-Saharan Africa¹ population (HPA, 2012). BHIVA guidelines (2012) state that 80% of pregnancies to HIV positive women in the UK are to women from Sub-Saharan Africa (HPA, 2012). In a report from the Office of National Statistics (2006) focussing on ethnicity and religion, 69% of black Africans living in the UK were reported to be of Christian faith, with 20% identifying themselves as Muslim. These data are relevant in studying the

¹ 'Sub-Saharan African' is defined as anyone who identifies themselves as originating from a country deemed by the United Nations Educational, Scientific and Cultural Organization (UNESCO) as sub-Saharan African (United Nations Educational Scientific and Cultural Organization, 2011). A list of countries making up Sub-Saharan Africa is provided in appendix 13.

experience of mothers living with HIV in the UK, as faith and religious belief are protective factors in helping to find meaning and hope for the future amongst these communities (Cotton et al., 2006; Maman, Cathcart, Burkhardt, Omba & Behets, 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 financial insecurity (Weatherburn, Ssanyu-Sseruma, Hickson, McLean & Reid, 2003), unemployment (ONS, 2001b) social isolation (Doyal, 2009) and insecure immigration status (Cherfas, 2006). These factors can impact on the experience of mental health difficulties and patients' access to healthcare (Kalichman, Graham, Luke, & Austin, 2002). Women within African communities in the UK are also found to be less likely to disclose their HIV status than British women, due to fears of HIV-related discrimination (Petрак, Doyle, Smith, Skinner, & Hedge, 2001). Further, single mothers are disproportionately highly represented amongst African mothers with HIV, and often face the additional challenges of poverty and insecure housing situations (Murphy, Harellich & Payne, 2010). These factors above have all been associated with increased parental stress and poorer maternal mental health (Lichtenstein, Laska, & Clair, 2002).

HIV-related stigma

Stigma has been defined as 'a powerful, discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons' (Alonzo & Reynolds, 1995; p. 304). The experience and impact of HIV-related stigma amongst mothers with HIV has been explored widely in the literature.

One framework for understanding HIV-related stigma defines three kinds of stigma experienced by HIV infected groups (Scambler & Hopkins, 1986; Earnshaw and Chaudoir (2009). *Enacted stigma* refers to the degree to which people with HIV report having actually experienced prejudice and discrimination (Scambler & Hopkins, 1986), whilst *anticipated stigma* refers to the level of expectation that this may happen in the future (Markowitz, 1998). *Internalised stigma* refers to the degree to which people with HIV endorse the negative beliefs and feelings associated with HIV about themselves (Link, 1987). These three distinct mechanisms have been defined as central processes through which members of infected groups experience stigma (Mak, Poon, Pun & Cheung, 2007).

Berger (2006) devised the concept of *intersectional stigma experiences* for HIV positive women, for whom HIV stigma intersects with other devalued or disempowered social statuses.

Ethnicity, class and gender suppression are outlined as combining with HIV stigma to further disadvantage those who occupy devalued statuses, such as black women of low socioeconomic status. This model has been supported by studies with HIV positive women from Sub-Saharan Africa, which detail the high levels of stigma and consequent mental health problems experienced by this group of women (Petra, Doyle, Smith, Skinner, & Hedge, 2001; Lichtenstein, Laska, & Clair, 2002).

Research has reported the high percentage of HIV positive mothers who feel the stigma attached to their pregnancies and childbirth very strongly, often impacting negatively on their experience of this period (Pierret, 2000). A meta-synthesis of findings from 93 qualitative studies exploring stigma in HIV positive women in different countries (Sandelowski, Lambe & Barroso, 2004) reported that both anticipated and enacted stigma were pervasive in the lives of HIV positive women. Mothers reported anticipating stigma very powerfully on behalf of their children, with their desire to protect them from discrimination impacting directly on how widely mothers felt able to disclose their status to others (Wilson, 2007).

There is also evidence that stigma can serve to impact negatively upon mothers' sense of hope about their own health in the future (Bird, Bogart & Delahanty, 2004; Roeloffs et al., 2003). One Grounded Theory study interviewing 20 mothers with HIV in the USA found that, despite the notable advances in life-expectancy for HIV positive mothers, a high proportion of mothers reported a very real fear that they would die before their children had grown up (Ingram and Hutchinson, 2000). Authors concluded that 'internalised stigma' made this fear loom larger for this group than for mothers with less stigmatising chronic illnesses (such as diabetes), and had the potential to impact on the development of the early mother-child relationships. Mothers in this study also described enacted stigma and discrimination from health professionals, who expressed disapproval of their decisions to become parents (Ingram & Hutchinson, 2000). Women reported experiencing a 'double bind', in which they felt pressure from society to become a mother, but judgement for doing so as an HIV positive woman (p.130).

These studies clearly outline the unique characteristics of stigma experienced by women with HIV who become mothers. No research has specifically explored the experience of stigma amongst women diagnosed in pregnancy, who may have fewer available choices around pregnancy termination due to the late timing of their diagnosis (BHIVA, 2012).

HIV in motherhood

Challenges faced by HIV positive mothers

Motherhood in the context of a chronic and stigmatising illness such as HIV has been found to bring with it many unique challenges (Nelms, 2005). Qualitative studies have reported mothers as struggling with incorporating illness into their identity; a fear of transmitting a serious disease to their unborn child; experiencing HIV-related discrimination; feelings of anxiety and shame; restrictions over breastfeeding and the dual challenges of caring simultaneously for themselves and their children (Ciambrone, 2003; Wilson, 2007; Murphy, 2009).

Catz, Gore-Felton and McClure (2002) reported levels of perceived stress and anxiety amongst a group of 100 mothers living with HIV in the USA as being significantly elevated compared to community norms. This anxiety was associated with a maternal perception of less social support, and evidence of fewer active coping strategies. Sanders (2008) conducted a similar qualitative study aiming to explore the lived experience of pregnancy and motherhood after a diagnosis with HIV. Interviews revealed significant emotional distress amongst women following an HIV positive diagnosis prior to pregnancy, anticipated stigma in relation to their subsequent pregnancy and resulting maternal ambivalence related to the pregnancy and impending motherhood (Sanders, 2008). These studies did not, however, explore the experiences of women diagnosed during pregnancy, for whom decision making around medication and potential termination of pregnancy is often more pressurised due to the timing of their diagnosis.

One group of findings reported that motherhood in the context of maternal HIV both intensifies and buffers the negative effects of HIV infection. Sandelowski and Barroso (2003) conducted a meta-synthesis of 56 reports of qualitative research involving HIV positive women. Whilst women across these studies felt motherhood enhanced their experience of being discriminated against, and their anticipated risk of HIV disclosure, it also had a salutary effect on their experience of HIV, boosting self-esteem, social support through parental networks and a reason to fight HIV infection (Sandelowski & Barroso, 2003).

Research has also highlighted a reciprocal relationship between support and protection amongst HIV positive mothers and their children. Mothers with HIV across a range of studies reported widespread reliance on their children for both practical and emotional support (Nelms, 2005). The same mothers also reported significant efforts to shield and protect their

children from any worry or anxiety, to preserve a positive mother-child relationship and model a healthy maternal identity. These studies highlight the often nuanced inter-relationship between motherhood and HIV for women diagnosed prior to pregnancy.

The infant HIV screening process

Another factor impacting on all HIV women entering motherhood is the 18 month infant screening process following birth (NICE, 2008). Studies interviewing HIV positive mothers postnatally have reported that levels of maternal anxiety are notably increased prior to confirmation of whether their babies are HIV positive or negative, suggesting this could impact on women's mental health and maternal role during this time (Varga, Sherman, Maphosa & Jones, 2005).

Lazarus and colleagues (2009) interviewed 38 HIV positive mothers in the USA about their experiences of this postnatal infant-testing process, and reported a period of active mental preparation for mothers prior to each of these tests. This involved exploring a range of different possibilities, praying extensively for negative results and mentally preparing for how they might cope with a positive result. Women described using physical distractions, self-talk, refusing to dwell on worries and seeking reassurance from religious or philosophical beliefs during this period (Lazarus et al., 2009). Nearly all women interviewed described feeling their lives 'had been put on hold' during this 18 months after birth (p.331), feeling they were unable to look to the future until they received confirmation of a negative HIV status for their child. The infant medication administered following birth was also a cause for distress amongst mothers, who were responsible for administering this medication to their infants on a daily basis (Lazarus et al., 2009).

Guilt and shame

Mothers with HIV have been documented as showing a tendency towards internalising stigma, feeling guilty, worthless, dirty and deficient as mothers because of their HIV status (Sandelowski et al., 2004). Research has provided personal accounts of the specific burden that anticipated stigma can place on pregnant women and their personal relationships, with fears of disclosure outcomes leading women to 'deceive' and distance themselves from family and friends (Green and Smith, 2004). Mothers were also reported in one qualitative study as feeling a heightened sense of shame, which authors attributed to the comparison of innocence (represented by their baby) with their perceived sinful behaviour (represented by the HIV

infection) (Sandelowski, Lambe & Barroso, 2004). This phenomenon has been reported by other authors (Lazarus, Struthers & Violari, 2009).

Outcomes for children of HIV positive mothers

A steadily growing literature has demonstrated the high prevalence of poor long-term outcomes for children of HIV positive mothers, who are shown to be at risk of behavioural, developmental and emotional difficulties (Bauman, Silver, Draimin & Hudis, 2007). A mixed method study reported that children affected by maternal HIV displayed significantly more externalising problems (e.g. conduct disorders) and internalising problems (e.g. depression, anxiety) than children of HIV-negative mothers (Tompkins and Wyatt, 2008). The study involved only children who were HIV negative, and drew comparisons between 23 children of HIV positive mothers with 20 peers whose mothers were not infected. Groups were matched in terms of ethnicity, age and gender of child, maternal education and income. Another quantitative study involving 157 HIV positive mothers reported children between 8-12 years as showing a significantly higher number of cognitive and social difficulties than the general population (Bauman and colleagues, 2007).

Alongside others (e.g. Tomkins & Wyatt, 2008), these studies have largely failed to control for the potential impact of other related factors, such as single-parent status, financial difficulties and the presence of maternal mental health difficulties. Therefore, whilst clear associations between maternal HIV and poor child outcomes have been demonstrated, the mechanisms by which HIV may impact on child functioning remain relatively unexplored. There has also been little consideration of the role of the early mother-infant relationship, and how HIV-related factors may impact on this before and after birth.

Attachment and mother-infant bonding

Research has shown a significant impact of early mother-child relationships on subsequent child outcomes across different cultures and socio-economic levels (e.g. Bowlby, 1958; Bornstein & Cheah, 2006). Much research in this area has focused on the concept of 'attachment' between parents and their children, defined as 'a close emotional relationship between child and parent, characterised by mutual affection and a desire to maintain proximity' (Ainsworth, 1991, p.17). Extensive research has shown that 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, which endures through to adulthood (Waters, Merrick, Treboux, Crowell, Albersheim, 2000; Main, Hesse & Kaplan, 2005). Conversely, 'insecure attachment', which encompasses 'avoidant, ambivalent or disorganised' forms of attachment (Ainsworth, 1969), is associated with maternal intrusiveness, remoteness and insensitivity. This has been associated with poor developmental outcomes for children, including behavioural and mental health difficulties (Tomlinson, Cooper & Murray, 2005).

Mother-infant bonding

Mother-infant bonding, defined as 'the feelings of a mother towards her infant' (Myers, 1984) is considered to be closely related to, but distinct from, attachment. Whereas attachment is reciprocal and includes the relationship a child forms to their main care-giver, mother-infant bonding describes the development of the relationship from the mothers' perspective. A significant relationship has been found between early bonding and later attachment in the general population, with many studies showing the perceived quality of the early mother-child relationship in infancy as highly predictive of later attachment security and resulting child outcomes (Britton, Britton & Gronwaldt, 2006; Pawly, Hay, Sharp, Waters & Keane, 2009). On this basis, authors have made the argument for studying the development of this early relationship from the mother's perspective during the antenatal, perinatal and postnatal periods (Moehler, Brunner, Wiebel, Reck & Resch, 2006; Zee, Cates & Schaeffle, 2009).

Risk factors for mother-infant bonding

Bonding theorists have argued that mother-infant bonding stems from a natural and instinctual surge of maternal feelings after birth (Hannon, 1980; Klaus & Kennell, 1982). However, this process is thought to be vulnerable to disruption if certain environmental or situational risk factors are present (Morrissey, 2007).

Two of the most widely documented risk factors for disrupted bonding are social isolation (Hagen, 1999) and maternal post-natal depression (Moehler et al., 2006) with a high degree of interaction found between the two (Crouch, 2002). Studies have shown that the capacity of parents to provide care that promotes the development of a strong mother-infant relationship can be severely compromised in conditions in which social or financial deprivation and maternal depression are present (Cooper, McLanahan, Meadows & Brooks-Gunn, 2009). Additional factors associated with disrupted bonding include a lack of physical contact after birth; previous maternal negative life events; and appraisals of traumatic birth experiences and

restricted opportunities for infant breastfeeding (Pauli-Pott, Mertesacker & Beckmann, 2004; Boyd, Zayas & McKee, 2006).

Maternal post-natal depression

Research suggests that maternal emotional well-being is essential following childbirth to facilitate a secure bond to the infant and develop the capacity to parent effectively (Bowlby, 1951; McLearn, Minkovitz, Strobino, Marks & Hou, 2006). Maternal postnatal depression has been linked to multiple adverse developmental outcomes for children, including increased risk of childhood behavioural problems, poor cognitive outcomes, learning disorders and infanticide (Spinelli, 2004; Buist, 2006).

A broad literature around postnatal depression suggests that many new mothers with depression have prolonged problems in developing a loving attitude to their child (Murray, et al., 2011). Early observational studies provided evidence of less positive, less sensitive and less synchronous maternal behaviours than in the play of mothers with without depression (Field, 1992; Campbell, Cohn & Myers, 1995). More recent studies using video analysis methods have shown that depressed mothers typically show a restricted range of maternal responses² that may disrupt and limit interactions with their children (Brockington, 2004; Murphy, 2009). Conclusions from these studies suggest it may be the *absence* of desired maternal behaviours, as observed and reported by mothers themselves, that correlates with less positive mother-infant relationships.

Self-report studies with postnatally depressed mothers suggest that difficulties in forming a bond to their infant may start earlier than originally believed, prior to birth (Gaynes et al., 2005). First-time mothers may be particularly vulnerable to developing such depression, both antenatally and postnatally (Leahy-Warren, McCarthy & Corcoran, 2012). This is of relevance for women receiving a diagnosis of HIV during pregnancy, as the majority of antenatal HIV positive diagnoses are now received during first pregnancies (BHIVA, 2012; UCL, 2012). Perinatal depression in the context of HIV requires a focused examination of the interaction between depression and the experience of mothering with HIV (Murphy, Marelich, Stritto, Swendeman & Witkin, 2002). This will be addressed further below.

² 'Maternal responses' are typically defined as 'the prompt, contingent, and appropriate reactions parents display to their children in the context of everyday exchanges' (Bornstein, Tamis-LeMonda, Hahn & Haynes, 2008)

Maternal sensitivity

Research over several decades has established that maternal sensitivity (defined as promptness, consistency and appropriateness in responding to an infant's needs) is an important predictor of effective mother-infant bonding and later attachment security (Bakermans-Kranenburg, van Ijzendoorn & Juffer, 2003). Forcada-Guex and colleagues (2006) carried out an observational study evaluating the interactional behaviour of 73 mother-infant dyads over a 12 month period following birth. Results showed that the controlling and insensitive pattern of mothering was associated with poorer social development for children than for matched children with more sensitive mothers. These findings were taken as support for the suggestion that mother-infant dyadic patterns of interaction can either play a protective or a risk-precipitating role in contributing to developmental and behavioural child outcomes (Forcada-Guex, Pierrehumbert, Borghini, Moessinger & Muller-Nix, 2006).

There are limitations to recent research on mother-infant bonding in the context of maternal depression and insensitivity. The methodologies used to assess mother-infant bonding have been heterogeneous: with the use of video-observations (Anisfeld & Lipper, 1983), clinical reports and short questionnaires (Taylor et al, 2005) making it hard to draw comparisons between studies. There is also a dearth of qualitative research exploring mothers' perspectives on the potential impact of depression or anxiety on their developing relationships with their infants under these conditions. It is important to note the high potential for social desirability in this research, with maternal reports found to be strongly influenced by cultural and societal expectations of motherhood (Paulson et al., 2006).

Breastfeeding

Researchers have long recognised that breastfeeding can elicit positive and intimate social interactions between mothers and their infants (Fouts, Hewlett & Lamb, 2012). Several longitudinal studies involving large samples have shown that breastfeeding is strongly associated with better neurological and cognitive competence in offspring, and a lower risk of psychopathology in later life (Alati, Van Dooren, Najman, Williams, & Clavarino, 2009). However, the literature around the impact of breastfeeding on the mother-infant relationship is mixed.

Some studies have suggested that breastfeeding is associated with the development of sensitive maternal behaviours during the early postpartum period. In a group of observational

studies involving mother-infant dyads at 1-3 months following birth, breastfeeding mothers exhibited more interactive behaviours towards their infants during feeding (including touching, gazing and affectionate responses) than bottle-feeding mothers (Kuzela, Stifter, & Worobey, 1990; Lavelli & Poli, 1998). More recently, Britton, Britton & Gronwaldt, (2005) carried out a quantitative study involving 152 mothers to look for a relationship between breastfeeding and enhanced mother-infant attachment. This study found no direct relationship between attachment and breastfeeding, but reported a significant relationship between breastfeeding and maternal sensitivity in responding to the cues of their infants in early infancy.

Further studies have shown that breastfeeding may protect mothers against low mood and mental health difficulties after birth, with further neurological research showing breastfeeding mothers to have increased parasympathetic nervous system modulation, lower perceived stress levels and fewer depressive symptoms (Groer, 2005; Mezzacappa, Kelsey, & Katkin, 2005). Kim et al. (2011) have argued that such close physical contact from breastfeeding, coupled with protection from negative mood and stress, may contribute to maternal attunement to the infant's physical and mental needs.

Whilst these findings seem compelling in their support for a link between breastfeeding and mother-infant bonding, they do not account for the possibility that mothers who are more likely to be sensitive parents, may be more likely to choose or persevere with breast-feeding options. They also fail to account for potentially relevant factors such as maternal age, employment, feeding difficulties and infant temperament. Differences in findings may also be attributed to methodological differences, with samples varying in age, size and socioeconomic characteristics. The influence of cultural expectations around breastfeeding, and research around breastfeeding with HIV positive mothers, is outlined further below.

Infant threatened ill health

Infant chronic illness (e.g. diabetes, cancer, heart problems) or threatened infant illness (e.g. through premature delivery) can be associated with disruptions to effective and timely mother-infant bonding (Waters, Merrick, Treboux, Crowell & Albersheim, 2000; Hoke, 2001). In a quantitative longitudinal study involving infants with Congenital Heart Disease (CHD), levels of maternal intrusiveness and anxiety about their child's health were stronger predictors of behavioural outcomes for 4-year-old surviving children than disease or surgical factors (McCusker et al., 2007). Rempel and Harrison (2007) further explored the parenting of children

with a potentially life-threatening heart condition through a Grounded Theory study, in which parents were reported to engage in 'extraordinary parenting' to cope with uncertainty over their child's health (p.827). This included actively working on developing a close relationship with their baby, normalising their situation and using distraction and denial techniques to manage worry and anxiety.

Mother-infant bonding has been a major focus of study in preterm babies, due to the mediating role this can play between infant health risks and the later developmental outcomes of the infant (Singer et al., 2003). Several studies have found preterm birth to be a risk factor for the early developing mother-infant relationship (Minde, Faucon & Falkner, 1994), with observed maternal behaviour described as more controlling and less emotionally sensitive than mothers of full-term infants (Muller-Nix et al., 2004; Forcada-Guex et al., 2006). One group of studies reported mothers to be particularly controlling, overly-protective and lacking in sensitivity when they had experienced high stress during the perinatal period (Affleck, Tennen, & Rowe, 1991; Muller-Nix et al., 2004). Another study reported such parents as exhibiting acute stress reactions, which negatively impacted on early interactions between the baby and their mother (Forcada-Guex et al., 2011). These findings are of relevance to research with mothers receiving an antenatal diagnosis of HIV, since the shock of diagnosis coupled with maternal anxiety about infant HIV status can lead to significant levels of maternal stress throughout this period (Sandelowski & Barroso, 2003).

Maternal chronic ill health

A recent meta-analysis reviewing over 40 qualitative and quantitative studies concluded that early mother-baby relationships may be at risk in families where a parent has a chronic health condition such as cancer, diabetes or HIV (Anderson, Riesch, Pridham, Lutz & Becker, 2010). Authors have claimed that a woman's identity as a mother may be threatened by chronic illness through a perceived interference with her ability to care for her children (Wilson, 2007; Vallido, Wilkes, Carter & Jackson, 2010).

The concept of *Disrupted Mothering* was introduced by Jackson (2000), who suggested that women experience guilt and distress when their idea of ideal mothering is disrupted due to their illness, with potential long-term repercussions for the mother-child relationship. Vallido and colleagues (2010) carried out a review of the perceived impact of such disruption in the context of maternal chronic illness such as cancer, diabetes and inflammatory arthritis. This

study reported maternal distress to be prevalent amongst mothers when fatigue, physical symptoms or hospitalisation prevented them from caring for their children as they would like to (Elmberger, Bolund & Lutze, 2005). 'Disrupted mothering' has also been cited in the context of anxiety over future maternal disability, anticipation of possible separation from children and impending maternal death (Backman, Smith Del Fabro, Smith, Montie & Suto, 2007).

A small number of studies have explored the mother-infant relationship within families affected by maternal cancer (Raveis and Pretter, 2005; Hoke, 2001). A qualitative study by Elmberger and colleagues (2008) reported that mothers often attempted to protect their children from any suffering linked to their condition, by concealing the effects of treatment such as nausea, vomiting and fatigue. Mothers with breast cancer in another study expressed guilt because of the genetic nature of their illness, their physical frailty due to the side effects of treatment and their feeling that they could no longer fulfil the role of a good mother (Elmberger et al., 2005). These studies highlight the additional physical, psychological and emotional burden placed on mothers living with cancer through efforts to prioritise their role and identity as a mother above their illness.

Women in a qualitative study of mothering in the presence of chronic arthritis described their ability to perform mothering tasks as '*sometimes I can, sometimes I can't*', illustrating the impact of their fluctuating physical state (Backman et al., 2007, p. 383). Women in this study reported having renegotiated their ideas of themselves as mothers to accommodate their physical restrictions, lowering their expectations of what they could accomplish for their children. While some expressed sadness, feeling that their illness restricted their children's activities and development, others were more pragmatic, accepting their limitations (Backman et al., 2007).

Research with mothers with severe and enduring mental health problems has reported the widespread experience of stigma and discrimination (Mowbray, Oyserman, Bybee, MacFarlane & Rueda, 2001), which is comparable to that experienced by mothers with HIV. Davies and Allen (2007) interviewed 11 mothers with chronic mental health problems, who experienced guilt and failure due to the perceived incompatibility of being mentally ill with their own ideas of being a good mother. Participants often avoided disclosing their mental illness if they felt it would impact upon how others perceived their mothering capacity. Women with mental health problems in a study by Montgomery and colleagues (2006) reported the constant struggle to

provide a façade of good mothering skills to friends and family, which depleted their emotional reserves and exacerbated their condition. This group of women also resisted seeking help for worsening symptoms due to the stigma surrounding their condition. These findings led researchers to conclude that stigmatising conditions such as mental illness or HIV are more threatening to a mother's self-concept than less stigmatising illnesses such as diabetes and cancer (Montgomery, Tompkins, Forchuk & French 2006).

Taken together, these studies provide insight into the range of psychological, emotional and physical challenges these groups may battle against whilst trying to balance their maternal role with managing a chronic illness. Whilst clearly informative, the focus of these studies is weighted towards mothers with older children (including adolescents), with little insight into the experiences of new mothers forming relationships with their infants in the first year of life. There is also scant research involving women diagnosed with chronic conditions during pregnancy, which may throw up additional challenges including maternal adjustment and decision-making about pregnancy, birth and medication during the antenatal period.

Maternal HIV and mother-infant bonding

In an attempt to explain the poor outcomes seen amongst some children of HIV positive mothers, a number of authors have suggested that maternal HIV may impact negatively on mother-infant bonding after birth (Matthey, Guedeney, Starakis, & Barnett, 2005; Oswald & Biasini, 2010). Johnson and Lobo (2001) argue that the combination of the social and psychological stresses of stigma, uncertainty about one's own health and anxiety over the HIV status of the infant, is likely to have a profound influence on the quality of interaction between mother and child. However, few studies have explored this further by collecting data on the perceived development of this mother-child relationship after birth.

Self-perception and self esteem

In a qualitative study interviewing 17 HIV positive mothers in the United States, HIV was perceived by mothers to have impaired their maternal performance and sense of adequacy as a mother (Reichert & Foote, 2009). Mothers reported struggling to find coping strategies that would help them manage the unique constraints of being HIV-positive, whilst living up to the cultural expectations of themselves as 'good mothers'. In a set of observational studies,

mothers who were more anxious about their own HIV status were assessed as being less confident in their parental role, and more likely to exhibit poor parenting skills (Murphy, Marelich, Armistead, Herbeck & Payne, 2010). Mothers were observed to display poorer parent-child relationships over the first year and had less consistent discipline as children started to walk (Dutra et al., 2000; Bauman, Camacho, Silver, Hudhumis & Draimin, 2002).

From these studies, it seems reasonable to suggest that maternal HIV could serve to disrupt the mother-child relationship. However, Bauman and colleagues (2007) argue that this literature is limited, in that most studies use cross-sectional data, large age-ranges and rely on parental retrospective reports from several years later. They also argue these studies largely ignore the powerful role of stigma and post-natal depression in HIV, and sidestep other factors which are likely to play an important role in the mother-child relationship.

The role of maternal postnatal depression in HIV

There is much evidence supporting the high prevalence of postnatal depression (PND) amongst HIV-positive mothers (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007), with one study estimating the overall prevalence amongst HIV positive mothers as 30% (Kapetanovic et al., 2009). This compares to an estimated prevalence of 10-20% within the general population (Gjerdingen & Yawn, 2007). Cho, Holditch-Davies & Miles, (2008) documented from an observational study that maternal HIV, paired with elevated postnatal depressive symptoms, was associated with less infant attention from the mother and poorer mother-infant interaction. A study involving a sample of 83 HIV-infected mothers and their HIV-negative infants found a third of infants in this study to be socially withdrawn, with a large proportion of mothers in this group scoring in the clinical range for post-natal depression (Hartley et al., 2010).

The interaction between maternal HIV and postnatal depression has been further explored through qualitative research. One study showed that mothers with HIV who experienced depression, and became aware of its impact on their children, became even more depressed due to guilt about their inability to fulfil the expected parenting role (Murphy et al., 2002). Other research suggests that a withdrawn mothering style, which can undermine infant social behaviour in postnatal depression, is likely to be further compromised and exaggerated by maternal HIV infection and ill-health (Cho et al., 2008; Guedeney, Foucault, Bougen, Larroque & Mentre, 2008). These studies make the case for further research to examine the experience of

postnatal depression within the specific context of maternal HIV, which may differ markedly from the experience of depression in other populations.

Misconceptions and fears around transmission

A small group of studies suggest that maternal fears and misconceptions around HIV transmission may impact on the developing relationship between mother and infant. Schuster, Beckett, Corona & Zhou (2005) found that maternal HIV infection prompted some mothers to limit behaviours such as kissing and sharing utensils with their infants because of fears about transmission. Qualitative studies support these findings, showing that transmission-related fears were identified in a majority of families affected by maternal HIV, with many of these fears based on misconceptions about how HIV is transmitted (Meursing & Sibindi, 2000). Lazarus et al. (2009) also reported from their qualitative research with HIV positive mothers that, whilst the majority of women had a basic understanding of HIV, many held incorrect beliefs about transmission, with misconceptions related to lower levels of confidence as mothers and increased levels of stress during the first year after birth. Whilst studies exploring the impact of such misconceptions are scarce, it seems likely that such belief systems may impact negatively upon the mother-infant relationship through limited physical affection and contact.

Cultural variations around breastfeeding

As outlined above, all HIV positive mothers are advised to abstain from breastfeeding their babies, to minimise the likelihood of vertical HIV transmission (BHIVA, 2012). A central theme emerging from the research has focused on the emotional difficulties experienced by many HIV positive mothers who are unable to breastfeed their babies (Hebling & Hardy, 2007). Qualitative studies have reported feelings of maternal inadequacy, guilt, failure as a mother and a deep longing to provide nutrition for their baby (Lazarus et al., 2009).

It is important to consider the significant cultural variations that exist in expectations around breastfeeding, with women from some regions (e.g. Jamaica and sub-Saharan Africa) experiencing additional societal pressure to breastfeed, and the risk of disclosing their HIV status if they abstain (Santacroce, 2000). This can create an unusually stressful set of circumstances in which mothers are expected to bond with - and provide nourishment for - their baby (Murphy et al., 2002). Ethnographers have acknowledged that breastfeeding encompasses more than nutrition, forming part of a socially rich context that varies cross-

culturally and developmentally (Bird-David, 2008). In sub-Saharan Africa, there are strong cultural expectations that mothers will breastfeed their offspring, with intergenerational advice on breastfeeding providing a conduit through which older women communicate with younger women about motherhood (Iwelunmor, Zungu, Airhihenbuwa, 2010).

Yovsi and Keller (2003) focused on the culturally specific nature of traditions around breastfeeding amongst Nso farmers and nomadic Fulani pastoralists in rural West Africa, citing distinct differences in breastfeeding styles observed between the two communities. The authors proposed that practices and attitudes toward breastfeeding are deeply embedded in parental ideologies about mother-infant bonding, which vary depending on cultural and ecological settings (Yvosi & Keller, 2003).

Enhanced mother-infant relationships

Whilst the majority of previous research focuses on the challenges faced by mothers diagnosed antenatally with HIV, it is important not to ignore the few studies suggesting that mother-infant relationships could in fact be *enhanced* by the presence of maternal HIV. Qualitative studies have suggested that maternal HIV status could serve to strengthen the mother-infant bond within the wider context of negative factors (Sandelowski & Barroso, 2003). Reasons for this include maternal efforts to compensate for the absence of breastfeeding through increased attention and physical closeness; a strengthened exclusive mother-infant bond due to the lack of familial and social support (Hebling & Hardy, 2007); and mutual dependency strengthened by a 'bond of secrecy' between mother and child (Andrews, Williams & Neil, 1993, p. 193). Reichert and Foote (2009) further reported HIV positive mothers claiming their experience of HIV had expanded their maternal motivation to protect their children from future harm, prompting frank and open conversations about safe sex and drug use as children grew up.

The significance of an antenatal diagnosis

Experience of HIV diagnosis

Receiving an HIV positive diagnosis can be traumatic at any time, bringing with it the potential for poor psychological adjustment (Hult, Maurer, & Moskowitz, 2009), denial (De Santis & Barosso, 2011), fear of disclosure (Stevens & Hildebrandt 2006), isolation and feelings of

depression (Anderson et al. 2010). Stevens and Hildebrandt (2006) interviewed 55 women diagnosed with HIV in the USA to understand more about their reactions to diagnosis in both the short- and longer-term. Women's immediate reactions were largely characterised by devastation and indignation towards those who might have infected them, whilst longer-term reactions included depression, suicidality, shame and escalating drug and alcohol use. A later qualitative study interviewing 25 HIV positive Afro-Caribbean people in London (Anderson et al., 2010) reported that respondents were faced with a multifaceted sense of loss through diagnosis: loss of their known self; their present life; their envisioned future and, in many cases, their partner. These findings were taken to promote the importance of healthcare practitioners engaging closely with newly diagnosed patients to understand their specific psychological needs at this time (Anderson et al., 2010).

In more positive findings, many mothers diagnosed with HIV described diagnosis as the critical event that led them to improve their health, lifestyle and relationship with their partners and children (Barroso & Sandelowski, 2005). After the initial shock, HIV has been described as a turning point that can prompt a new and more positive way of life. Mothers have also been found to demonstrate stricter adherence to HIV medication than women without children, with lower than average rates of drop-out from HIV support services and better monitoring of overall health status (Carter, 2009).

Experience of an antenatal HIV diagnosis

A small number of qualitative studies have explored the experiences of women receiving a diagnosis of HIV during pregnancy. These studies have suggested that pregnancy and motherhood following an antenatal diagnosis can bring a period of notable vulnerability and disruption in the lives of prospective mothers (Kelly, Alderdice, Lohan & Spence, 2012). Whilst pregnancy itself can be a stressful and demanding time for many women (Geller et al., 2004), the news of HIV-infection during this period can be devastating, affecting a woman's ability to cope (Kelly et al., 2012), her feelings about pregnancy and motherhood (Alder, Fink, Bitzer, Hosli and Holzgreve, 2007) and functioning as a mother (Psaros, Gelle, & Aaron, 2009). A metasynthesis of studies by Sandelowski & Barroso (2003) outlined the often paradoxical experience of an HIV positive diagnosis during pregnancy, with the diagnosis - representing a threat to life - often coinciding with the diagnosis of pregnancy - an affirmation of life. However, none of these studies has specifically explored maternal reflections on bonding with their baby following an antenatal diagnosis.

One recent study focused on the case studies of four women diagnosed antenatally with HIV, exploring the experience of testing positive for HIV during this period (Kelly, Alderdice, Lohan and Spence, 2012). Drawing on Becker's (1997) 'Theory of disruption', the authors concluded that an antenatal diagnosis at this point led to notable disruptions in the women's health, relationships and social identity. Anxiety about the threat of HIV was experienced most notably in relation to women's unborn child, rather than in relation to their own health and future wellbeing. Whilst this study provides a useful insight into the unique experiences of this group of women, the authors acknowledged the small sample size as significantly limiting the extent to which findings could be generalised to a wider population. There was also no exploration of the perceived impact of this diagnosis upon the developing relationship between the mother and the child.

Unique characteristics of an antenatal diagnosis

A small group of studies suggest a number of ways in which women diagnosed during pregnancy may have differing experiences to those diagnosed prior to pregnancy or after birth (Kirshenbaum et al., 2004; Simpson & Forsyth, 2007). Whilst no studies have directly explored maternal perspectives on mother-infant bonding amongst those diagnosed in pregnancy, research points to several factors amongst this group which may have the potential to disrupt the development of this crucial mother-infant bond:

Disrupted adjustment to the diagnosis: Pregnancy is a vulnerable and emotionally-demanding time for many women (Schetter and Glynn, 2010), and a diagnosis at this point brings with it a unique set of circumstances in which women are forced to adjust to the reality of living with a life-threatening and stigmatising condition. Women diagnosed antenatally have little time for adjustment to HIV before the birth of their child (Kelly, Alderdice, Lohan & Spence, 2012), and there is high potential for maternal anxiety around the health of their unborn child to impact upon this process (Ciambrone, 2003; Wilson, 2007).

Heightened shock around diagnosis: With the majority of diagnoses during pregnancy resulting from routine antenatal screening, antenatal diagnosis has been found to be unexpected and shocking (Donovan & Palumbo, 2010). Recent statistics from the Institute of Child Health (2012) report that only a third of women (35%) diagnosed antenatally since 2009 had a CD4 count of under 350 cells/mm³ at diagnosis, suggesting that few will have been experiencing HIV-related symptoms or have expected they might be HIV positive prior to diagnosis (BHIVA, 2012).

Additionally, studies have reported a heightened level of shock associated with diagnoses from routine screening across HIV populations (Blaney et al., 2004), which can impact negatively on adjustment and acceptance of the news.

Heightened experience of stigma for self and baby: HIV-related stigma has been closely associated with psychological distress and can interfere with coping, adjustment and management of the disease (Sandelowski, Lambe & Barroso, 2004). Research suggests that women diagnosed antenatally may be particularly vulnerable to the stigma associated with continuing a pregnancy following a positive diagnosis, experiencing stigma on behalf of their children as well as themselves (Kelly et al., 2012). As women diagnosed in pregnancy are likely to experience HIV related stigma and discrimination for the first time during their antenatal period, it seems possible this could impact on their pregnancy and birth experience.

Decision-making around medication: Sanders (2008) has suggested that adjustment to HIV diagnosis during pregnancy can impact on a woman's adherence to medication, which can in turn impact negatively on her physical health. For women diagnosed antenatally, the decision-making process to begin medication may occur simultaneously with the need to process initial shock and adjustment to the HIV diagnosis. The urgency with which some pregnant women are guided to commence medication to avoid transmission to the infant during pregnancy can create the need to make decisions under extreme pressure. Qualitative research with this group reports that a 'psychological crisis' can arise at this time, as women grapple with understanding the meaning of the diagnosis, questioning how HIV was contracted and coping with fears about their life-expectancy (Sanders, 2008). There is also the potential for child protection procedures to be enacted if there are concerns about antenatal adherence to medication (BHIVA, 2012).

Decision-making around disclosure: Many mothers with HIV report avoiding disclosure of their HIV status to friends and family members due to anticipated stigma (Earnshaw and Chaudoir, 2009). This decision-making process may be impacted by the need for support from close friends and family during pregnancy and following birth. Studies have shown that new mothers with HIV feel they receive less support from family and friends than if they had a less stigmatising chronic illness (Murphy et al., 2002). Additional complications may arise from providing explanations for having a Caesarean section delivery and abstaining from breastfeeding, which carry a risk of disclosure and can be very stressful for new mothers (Sanders, 2008).

Mental health difficulties: Kwalombota, (2002) conducted a large-scale quantitative study in Zambia comparing the psychological states of HIV positive women who had either been diagnosed antenatally, or at some point prior to becoming pregnant. Results from self-report rating scales showed that women diagnosed antenatally were more severely depressed, showed more anxiety and a greater number of somatic complaints than women diagnosed prior to pregnancy. The author concluded it was possible the mother-child relationship may be affected by the mothers' changing attitudes towards motherhood in the context of their new diagnosis, although this was not specifically explored within this study. No further research appears to have been carried to explore the mother-child relationship within this context.

Rationale for the current study

The literature above highlights several important sets of findings, which have led to the development of the proposed study. Firstly, mothers with HIV face a multitude of emotional, physical and psychological challenges, some of which may impact on their relationship with their infants. Secondly, the studies suggest that an HIV positive diagnosis during pregnancy brings with it a unique period of maternal vulnerability, coinciding with an anxiety-provoking perinatal and postnatal period. Thirdly, many of the known characteristics of mothers with HIV (e.g. high prevalence of postnatal depression, lack of social support, restrictions on breastfeeding) map directly on to the documented risk factors outlined for disrupted mother-infant bonding (Moehler et al., 2006). Taken together, these studies introduce the possibility that stressors relating to a maternal antenatal diagnosis may influence the development of the mother-infant bond. Gaps in the literature create a need for more knowledge about the perspectives of this group, and the perceived impact of an antenatal diagnosis on the mother-infant bonding experience.

Research aims and questions

This project aims to collect data from interviews with women diagnosed with HIV during pregnancy to develop a theoretical model of mother-infant bonding, coping and resilience following an antenatal HIV positive diagnosis. This model will be discussed and analysed in relation to findings from previous literature and research.

Previous research with HIV positive mothers has been largely quantitative, with few studies examining mothers' lived experiences through interviews (Murphy, 2009), and none to date outlining a model of mother-infant bonding following an antenatal maternal diagnosis of HIV. An explorative approach to research is often thought to be more appropriate in areas in which little research has been carried out previously (Forrester, 2010).

Elliot (1995) states that qualitative research lends itself best to understanding participants' perspectives and allowing interviewees to elaborate on areas that feel most important to them. Whereas quantitative methodology is used to explore the 'reality' of the world, qualitative methodologies can also allow for the generation of theory based on individuals' constructed meanings (Forrester, 2010). As experiences related to pregnancy and early motherhood are constructed from the meanings women ascribe to those experiences, a qualitative approach allows for a deeper exploration of the complex psychological issues involved.

The main research questions for this study are as follows:

- a) *What is the experience of mothers diagnosed antenatally with HIV in bonding with their baby?*
- b) *What are the main challenges, and what helps women to manage during pregnancy and the first 18 months after birth?*

A Grounded Theory approach (Glaser & Strauss, 1967) will be used to guide the data collection, analysis and reporting for this study. The rationale for using Grounded Theory is set out in the Methods section below.

Practical and clinical implications

The findings from this study have the potential for both practical and clinical implications. Firstly, these findings will fill a gap in existing knowledge about the experiences of women diagnosed antenatally in bonding with their baby alongside HIV. The theoretical model produced will enhance understanding about how best to support this group of mothers and their infants during pregnancy and after birth, and help facilitate the development of a secure mother-infant bond during this period of adjustment. This model will also be useful for clinicians such as psychologists and healthcare professionals supporting HIV positive mothers and their infants during the infant-screening process.

Chapter 2: Method

Research design

A cross sectional qualitative design was used for this study. Grounded Theory (Charmaz, 2006) guided the design, recruitment, analysis and subsequent reporting of the findings from 10 semi-structured interviews with mothers diagnosed with HIV during pregnancy.

Sampling, inclusion and exclusion criteria

A systematic approach to sampling was used. Women were deemed eligible to participate in this study if they:

- A) were fluent in speaking and comprehension of English:** to enable interviews to take place without the use of an interpreter;
- B) were over the age of 18 when they gave birth:** to avoid confounding the findings with the additional challenges faced by motherhood in early teenage years (Helne, 2008);
- C) had received a diagnosis of HIV during pregnancy:** with the post-diagnosis child born between May 2008 and October 2010;

The sample was limited based on the age of the first post-diagnosis child so that mothers could reflect on bonding during the 18-month infant-testing process after birth. Four years of age was selected as the cut-off for inclusion to reach a balance between recruiting enough participants and maintaining validity (Li, Scanlon & Serdula, 2005).

Mothers who were documented as suffering from Post Traumatic Stress Disorder (PTSD) following a traumatic childbirth experience were excluded from this study, due to the likely effect on mothers' recollection of experience following birth (Ehlers & Clark, 2000). In line with the service research policy, patients were also excluded if they had been treated under the Community Mental Health Team (CMHT) during this period for severe and enduring mental health problems.

Recruitment

Service setting

Interviews for this study were carried out face-to-face at a Sexual Health Service within an inner-London teaching hospital between May and September, 2012. The Borough in which the service was located has higher levels of deprivation and higher prevalence of HIV than national averages. This service currently has 400 adult patients (both male and female) with HIV, and offers a comprehensive and confidential sexual health service including screening for HIV infections, sexual health information, treatment, monitoring, counselling and psychology. There have been four to five antenatal diagnoses of HIV at this service per year since 2005.

Engagement

The initial stages of the recruitment process, outlined in Figure 2 below, involved engagement with key staff and clinicians internally within the hospital to ensure they were on board with the project and informed about the aims of the study. This staff engagement process was particularly important for this study, with recruitment in HIV populations reliant on clinicians introducing the study to patients to maintain confidentiality.

Figure 2: Five step recruitment process


Step 1: Engagement with staff: The researcher attended research meetings, clinical team meetings and a staff training morning at the hospital to present the aims of the project and inclusion and exclusion criteria for participants. Written materials about the project were provided to research and admin staff supporting the recruitment process (Appendix 1).




Step 2: Participant identification: Eligible participants were entered into an anonymised database, which was shared with the researcher. Forthcoming patient appointments were highlighted, and the relevant clinicians were informed about their patients' eligibility for the study through patient notes and a reminder phone call on the morning of the appointment.



Step 3: Information giving: Clinicians introduced the study to patients during routine appointment and at blood tests. If patients were interested in the study they were referred to the researcher or research assistant in a private consultation room. The patient was given the information sheet to read, and the opportunity to ask any questions about the project.



Step 4: Informed consent: If patients were willing to take part in the study, they were given the option to book a time for their interview, or carry out the interview on the day. Informed consent was taken in writing at the start of the interview (Appendix 2). A copy of this signed consent form was also added to the patient file for each interviewee.

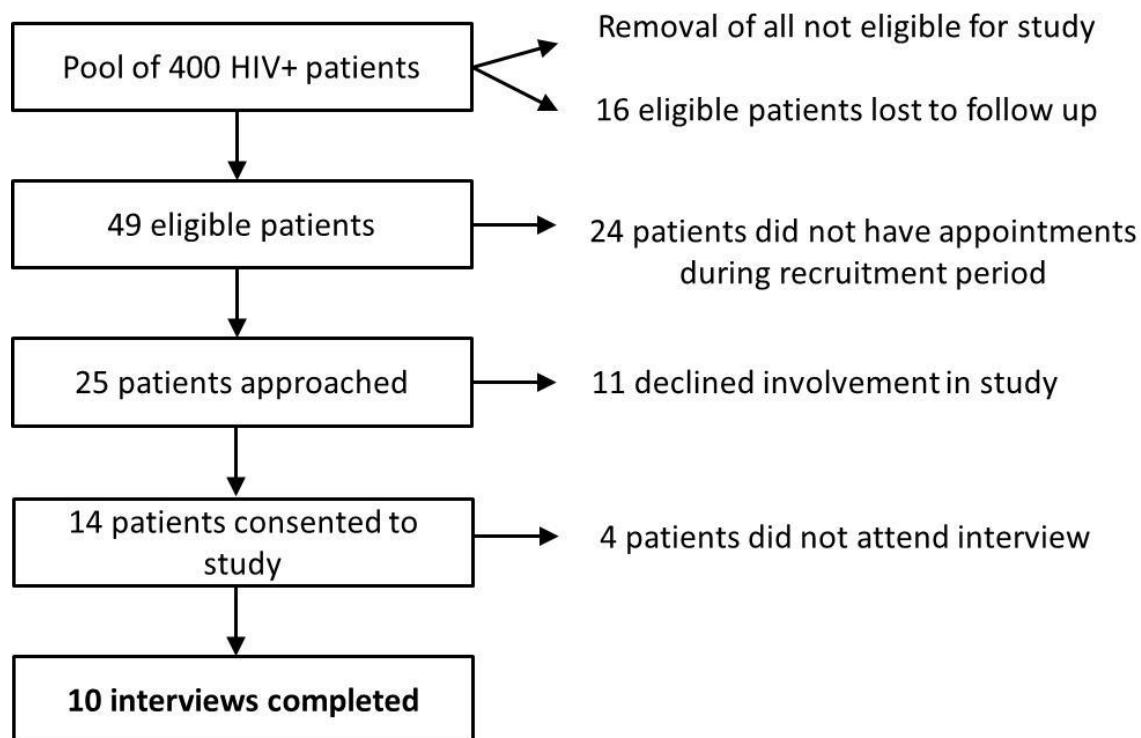


Step 5: Debrief and further support: £20 in cash was given to each participant on completing the interview to cover expenses (including childcare). Participants were given a list of support they could access to speak to someone following the interview (Appendix 3).

Participant recruitment

A database of over 400 patients (consisting of all adult service-users with HIV at the service, both men and women) was filtered down to exclude those who did not meet the inclusion and exclusion criteria for the study. This process was carried out by a research assistant at the service, who manually checked the notes of eligible patients to screen for CMHT history or PTSD symptoms following birth. 2 patients were excluded due to recent CMHT involvement and 16 were 'lost to follow up', indicating that they had disengaged from the sexual health service at some point following diagnosis. This process resulted in a sample of 49 patients who were deemed eligible to take part in the study. A recruitment flow diagram can be seen below in Figure 3.

Figure 3: Recruitment flow diagram



25 eligible patients were approached by clinicians at routine clinic appointments between 15th May 2012 and 6th September 2012. 11 patients declined to be involved in the study, citing the following reasons:

- Inability to arrange appropriate childcare, despite the study funding (2 women);
- Feeling the subject matter was too painful for them to speak about (3 women);
- Not being permitted to take part by their partner (2 women);
- No reason given for decline to be involved (4 women).

14 women agreed to take part in the study and be interviewed, but 4 of these women did not attend their scheduled interview slot and were subsequently uncontactable. This resulted in a final cohort of 10 women who completed interviews as part of this study. It was not possible to compare the characteristics of those who did and did not take part in the study due to lack of ethical approval for this. This will be discussed further in the Discussion chapter.

Participant characteristics

Tables 1 and 2 below outline relevant demographic characteristics of participants, to situate the sample and help provide a context for the research. The demographic information for this

table was gathered from both data held by the sexual health service, and from women themselves during interviews.

Table 1: Participant demographic information

Ppt no.	Age (yrs at interview)	Age (yrs at diagnosis)	Ethnicity	Country of origin	Relationship status at diagnosis	Relationship status year after birth	Number of children	Number of children prior to diagnosis	Age of first – post-diagnosis child (yrs)	Planned/ unplanned pregnancy
01	35	32	African	Nigeria	Co-habiting	Single	1	0	3	Unplanned
02	38	34	African	Zambia	Co-habiting	Single	1	0	3	Unplanned
03	27	25	African	Angola	Co-habiting	Co-habiting	2	0	2	Planned
04	25	22	Caribbean	Jamaica	In relationship	Single	1	0	3	Planned
05	38	34	British	England	Married	Married	4	2	3	Planned
06	41	37	African	Nigeria	In relationship	Single	2	0	3	Unplanned
07	31	28	African	Nigeria	Married	Married	2	0	2	Planned
08	26	24	African	Ghana	In relationship	Single	1	0	1	Unplanned
09	33	30	African	Uganda	Co-habiting	Co-habiting	1	0	2	Unplanned
10	32	29	African	Zambia	In relationship	Single	4	3	2	Unplanned

Table 1 also shows the relationship status of participants, both at diagnosis and at the point of interview. This shows that whilst all 10 interviewees were either in relationships, co-habiting or married at the point of diagnosis, 6 out of 10 of the women were subsequently single during the first year after the birth of their post-diagnosis baby. The four participants who were still married or cohabiting one year after birth all remained with the same partner. The other 6 women all reported their relationships breaking down shortly after disclosing their HIV status to their partners. This will be reflected on further in the results section.

Table 2 below shows information relating to the HIV status of participants, their partners and children. This shows that 3 out of 10 participants had a CD4 count of under 350 cells/uL at the point of diagnosis (indicating a significantly weakened immune system), with one participant as low as 40 cells/uL (viral load 158857). Participants' viral load indicates the levels of HIV in the blood, with high viral loads likely to correspond with lower CD4 counts. The table indicates that the majority of participants are likely not to have been feeling unwell at the point of diagnosis, which was supported by participants in interviews.

Table 2: HIV-relevant demographic information

Participant no.	Years since diagnosis (years)	Week of pregnancy at diagnosis	CD4 count (cells/uL) at diagnosis	Viral load at diagnosis	Partner HIV status	Method of feeding (breast or bottle)	Type of delivery (caesarean or vaginal delivery)	Child HIV status
01	3	20	613	26645	Unknown	Bottle-fed	Caesarean	Negative
02	3.5	12	810	633	Unknown	Bottle-fed	Caesarean	Negative
03	2	12	341	16137	Positive	Bottle-fed	Caesarean	Negative
04	3	12	290	32769	Unknown	Bottle-fed	Caesarean	Negative
05	4	24	231	22852	Positive	Bottle-fed	Caesarean	Negative
06	4	12	40	158857	Negative	Bottle-fed	Caesarean	Negative
07	3	20	424	5914	Negative	Bottle-fed	Caesarean	Negative
08	1.5	12	443	246503	Unknown	Bottle-fed	Caesarean	Negative
09	3	12	490	399	Negative	Bottle-fed	Vaginal	Negative
10	3	13	451	727	Unknown	Bottle-fed	Caesarean	Negative

Choice of methodology

Qualitative analysis: Grounded Theory

Grounded Theory (Glaser & Strauss, 1967) is a method of qualitative analysis developed to explore processes, meanings and perceptions based on individual experiences (Payne, 2007). The method leads to the development of a theoretical model to explain phenomenon emerging from the data, with the resulting theory guided by what participants identify as important to them (Henwood & Pidgeon, 1992).

The Grounded Theory approach allows for a more theoretical understanding of the interview data than other qualitative methods, with the dynamic relationship between data collection and analysis enabling researchers to be more faithful to the data, rather than forcing it to fit a specific theory (Charmaz, 2006). Writing '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 (Bryant & Charmaz, 2010). The findings from each stage of data analysis guides further data collection. The process of constant comparison of data within and between individuals allows for theoretical saturation to be determined and for data collection to be terminated at the point at which no further theoretical insights emerge (Charmaz, 2006).

Grounded Theory is unique in qualitative analysis in allowing concepts and hypotheses to emerge to form the basis of a new theory (Charmaz, 2006; Forrester, 2010). 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). This approach was well suited to the research aims of this study, to develop a model of mother-infant bonding and maternal resilience in the context of an antenatal diagnosis of HIV.

Exploring other qualitative methods

A number of qualitative methods were considered before Grounded Theory was selected as the most appropriate approach to meet the research aims of this study.

Interpretative Phenomenological Analysis (IPA) was considered, which involves interpretation of the data to hypothesise the meaning participants ascribe to their experiences (Forrester, 2010). Whilst this method can prove insightful about individuals'

experiences, the greater level of interpretation means IPA does not lend itself to the development of a theory grounded in actual experience, or to comparison with existing theories (Smith & Eatough, 2007). As a primary aim of this study was to develop a model of mother-infant bonding in this context, Grounded Theory was thought to be more suitable in achieving this.

Discourse Analysis (DA) was also considered as a potential approach for this study. DA focuses on the way language is used to create the reality of participants' worlds (Forrester, 2010), and assumes there are multiple realities shaped by prior knowledge and assumptions. Although the current study wishes to take a constructionist position in exploring the role of language and construction of events (Charmaz, 2006), the outward focus of DA on broader societal narratives was not thought to allow for the exploration of individual experience and meanings set out in the research questions (Forrester, 2010).

Divergent methods in Grounded Theory

The methodological and epistemological approach of Grounded Theory has been debated since it was first set out (Glaser & Strauss, 1967), with authors developing divergent versions of the approach in recent years (Heath & Cowley, 2004). The theory originally arose from a philosophical viewpoint of symbolic interactionism, in which meanings are derived from actions and social interactions, based on the interpretations of those involved (Forrester, 2010). Since 1967, Glaser and Strauss have developed the theory in differing directions. Whilst Glaser has remained close to the original methodology, Strauss and Corbin developed a modified version focusing on a specific process of relating categories and properties to each other, known as 'axial coding' (Strauss & Corbin, 1998; Corbin & Strauss, 2008).

Despite these diverging methods, Glaser, Strauss and Corbin have all maintained the underlying assumption that the researcher remains a neutral stance in their analysis, to ensure the emergent theory is true to the data. More recent authors have suggested that researchers cannot remain entirely neutral in the research process (e.g. Bryant, 2002; Clarke, 2005; Charmaz, 2006). Charmaz (2006) in particular has argued that it is not possible to ignore the pre-existing experiences, assumptions and beliefs a researcher brings to the research. The interpretations a researcher makes will be influenced by factors such as the researcher's age, gender and cultural background through the impact these have on data collection and analysis. These factors can both influence the way a participant shapes the

narrative of their responses, and the way a researcher interprets and makes sense of the data they gather (Charmaz, 2006).

Rationale for using Charmaz's constructionist Grounded Theory

A constructionist version of the original Grounded Theory, as set out by Charmaz (2006), explicitly acknowledges that 'we construct our grounded theories through our past and present involvements and interactions with people' (Charmaz, 2006, p.10).

This approach was deemed appropriate for this study for several reasons. Firstly, in contrast to previous authors, Charmaz (2006) highlighted the importance of researchers using Grounded Theory strategies flexibly. Charmaz acknowledges that ethics committees often require an extensive review of the literature prior to data collection to ensure a study is making a unique and novel contribution to the research base (Payne, 2007). This was important, given the confines of the Clinical Psychology Doctorate in which this study was being carried out. This flexible approach to Grounded Theory also allowed for the generation of a clinically relevant model of mother-infant bonding, which could then be used to inform existing knowledge and understanding of the experiences of this group of women. Additionally, Charmaz's version of Grounded Theory 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 seemed particularly relevant in this study, in which the researcher herself became pregnant during the course of the research (discussed further in the Personal Reflections section in the Discussion chapter).

Sensitivity to the data

It was important to address the author's sensitivity to the data in the present study (Charmaz, 2006) through acknowledging any prior experience or knowledge which could influence the analysis process. As mentioned, 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, Heath & Cowley (2004) acknowledge that a researcher's professional or personal background means they are likely to have some degree of knowledge in the field they are exploring, making it difficult to entirely disregard any prior understanding. Corbin and Strauss (2008) go further in suggesting that previous knowledge and experience can actually enhance sensitivity to

the data, and enable a researcher to better understand the meaning and significance of what participants are expressing in their language.

The researcher for this study was a female trainee psychologist with an interest in working with people with HIV and sexual health difficulties. This interest had developed following clinical experience working therapeutically with women with HIV (including mothers with young children), and learning about some of the challenges of living with a stigmatising and chronic health condition such as HIV. The researcher therefore had some previous knowledge of the issues that may be facing this group, such as decision-making around disclosure, experience of stigma and discrimination, low mood and anxiety about the future. The researcher was encouraged through supervision to reflect on her position in relation to the research by keeping a reflective diary throughout all stages of the study. This allowed for reflection upon any 'internal processes' and issues of sensitivity (Stiles, 1993), and for these to be discussed with the research supervisor as they emerged.

Prior to starting data collection, a key entry to this reflective diary outlined the researcher's 'prior assumptions' of this group of women, and the potential or expected outcomes of the research. This was particularly important to reflect on during the analysis process to ensure the interpretation of the data was not unduly influenced by prior assumptions or 'common sense theorising' (Schutz, 1967). An extract from this diary is included in Appendix 4. Peer supervision with fellow trainees undertaking Grounded Theory studies was also useful in providing invaluable opportunities to discuss methodological and analytical queries.

Procedure

Ethical approval

This study was granted ethical approval from the London Bloomsbury NHS Research Ethics Committee and from Royal Holloway University of London Ethics Committee in April 2012 (Appendices 5 and 6). Research and Development (R&D) approval was subsequently gained from two hospital sites in London in May and August 2012, to enable interviews to take place at both sites. The second site was never used as recruitment had been completed at the first site by the point of approval point.

Following ethical approval, it became clear that an amendment to the ethics application may be beneficial. This was largely to aid the practicality of the recruitment process and

ensure that a broader range of mothers could be included within the sample. One amendment with three changes was submitted to the REC in June 2012 (Table 3 below), and approved on 15th June 2012 via email (Appendix 7). Approval for the amendment was granted, and the R&D department at the hospital site was informed of this change.

Table 3: Changes submitted within Ethics Amendment (June 2012)

Change 1	A request to have the option to carry out interviews on the day of recruitment, to avoid additional travel costs and raise the likelihood of interview completion.
Change 2	A request to include women with a CD4 count lower than 350 cells/mm ³ when diagnosed during pregnancy ³ .
Change 3	Information of a change of field supervisor due to the initial supervisor's departure on maternity leave.

As this project involved recruiting vulnerable women with HIV and the handling of potentially sensitive data, due 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 ethical considerations were addressed as follows:

- **Voluntary basis of participation:** Participation in this study was voluntary, with reassurance that decisions about involvement would have no impact on treatment or support from the service.
- **Confidentiality:** anonymity of participants' identities was maintained at all times, and 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 or consult with family members provided.
- **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.

³ Sampling of participants with CD4 counts >350 was originally specified to limit the sample to those who were less physically unwell. It was later decided that a broader range of participants would be informative for this study.

- **Emotional distress:** Clinical backup was put in place at the service if there was any concern over participants' welfare during or following an interview to support that individual.

Data collection

Semi-structured interviews with participants were selected as the method of data collection for the current study, to enable mothers' experiences up to 18 months after birth to be explored. All interviews were audio recorded, and observations about the setting and the interview itself were recorded in a reflective journal at the end of each interview to enrich the data set (Pidgeon & Henwood, 1997).

Interview guide

A draft interview guide was developed at the outset of the research in collaboration with the research and field supervisors (Appendix 8). In line with Grounded Theory methodology, the interview guide aimed to be relatively open-ended to allow participants' own experiences to emerge. Questions relevant to the core research areas were drawn from the existing literature on mother-infant bonding (Bowlby, 1951), HIV in motherhood (Murphy et al., 2010) and literature around diagnosis in chronic illness (Vallido et al., 2010). The interview guide was structured chronologically, starting with the diagnosis during pregnancy, moving onto the birth experience and finally the first 18 months after birth. It was hoped that this chronological structure would allow participants the opportunity to express all aspects which were important to them at different stages of the process of bonding.

Adapting the interview guide

All questions in this study needed to be worded sensitively to encourage participants to reflect openly on their experiences. A service user feedback process was therefore carried out to seek views on the interview guide before data collection began. A small group of 5 mothers with HIV, including 3 who were diagnosed antenatally, were recruited from a voluntary sector organisation in south London. They were consulted for their views on the draft interview schedule in a group context, led by a member of staff who was familiar to them. The organisation decided that the researcher should not be present at this meeting to ensure the service users could speak freely in feeding back on the interview questions. The

researcher provided the group facilitator with a series of prompts regarding the tone, clarity and sensitivity of the language and questions asked. Feedback was then provided via email. Feedback on the interview guide from these service users was largely positive, and conveyed a sense that the questions were clear and appropriate. Some minor edits were proposed regarding the use of the language, such as removing references to 'coping with HIV', which women felt were leading and did not necessarily reflected their experiences. The edited interview guide can be seen in Appendix 8.

A second editing process for the interview schedule followed the completion of the first four interviews for this study. One of the defining features of Grounded Theory 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 four 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 9 for updated interview schedule).

Interviews

All 10 interviews were carried out by same researcher in private consultation rooms in the clinic. The researcher made efforts to book rooms in advance that were predominantly used for research and psychology purposes, so these would feel less associated with HIV diagnosis and virus management for participants. Interviews lasted between 60 and 91 minutes, with a mean interview length of 72 minutes.

The interviews were carried out using the interview schedule in a flexible way, with general topics covered across the interviews but specific questions asked depending on individual participants' responses. The researcher asked prompt questions throughout to encourage participants to expand on their answer and prompt further discussion of key topics. Summaries of respondents' statements were provided at regular intervals to ensure that responses had been properly understood and interpreted (Forrester, 2010). During the course of the research, several participants commented that they had found the interview process helpful in supporting them to reflect on their own experiences. Whilst 3 of the participants were tearful during their interviews and found it emotionally challenging to

discuss their experiences, none were visibly distressed on leaving the interview room. All participants were given contact information for further support if needed.

Analysis process

Transcription

Interviews were transcribed verbatim, and guidelines were followed to ensure a systematic procedure was applied to all transcripts (McLellan, MacQueen & Neiding, 2003). All interviews were transcribed by the researcher, as this process has been found to help familiarise the researcher with the data and further their understanding (Charmaz, 2006). The approach to transcription incorporated verbatim elements of the participants' speech including pauses, emphasis and utterances (Davidson, 2009). This approach suited the present research study as it helped to explore perceptions and constructed meanings in relation to a participant's language and specific experience.

Coding

Charmaz (2006) suggests that Grounded Theory 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 sentence-by-sentence coding was conducted on each of the transcripts, which involved assigning each sentence a label that 'categorises, summarises and accounts for' that piece of data (Charmaz, 2006, p.43). In vivo coding, which serves to preserve participants' meanings in the coding process, was also adopted when the particular word or phrase used by a participant was felt to represent an important concept (Charmaz, 2006). Charmaz (2006) identifies this use of actions in initial coding as enabling the researcher to stick closely to the data and adopt the words and actions of the participant. 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. As data collection and analysis occur concurrently in Grounded Theory, the initial codes applied

to each interview were explored for ideas and analytic concepts which could be pursued with subsequent interviewees.

Second stage: focused coding

The second stage of focused coding involved developing codes to describe larger sections of the data, which were more abstract and conceptual (Charmaz, 2006). The most significant and frequently adopted codes during the initial coding stage formed the basis of focused coding. The constant comparison of data within and between respondents ensured that the codes adequately and comprehensively conceptualised the data into categories, whilst ensuring that they still remained close to the data. The researcher applied Charmaz's (2006) methods of challenging preconceptions, being sure to avoid over-interpreting and being mindful of the tendency to force the data into preconceived categories.

Final stage: Theoretical coding and diagramming

The purpose of this final stage of coding was to describe how the initial categories developed may relate to each other and be integrated into a theory (Charmaz, 2006). Memos were central to this process, and were employed to establish theoretical links and relationships between the codes, leading to the development of an analytical framework. Categories identified in the memos were compared to each other and structured around a timeline which ran through pregnancy, birth and the 18 months following birth. The emergent theory was therefore made up of a small number of overall theoretical codes, with focused codes used to explain different aspects and initial codes and quotations representing their properties. A diagram was used to assist this process and help explain some of the categories, their properties and the relationships between them (Charmaz, 2006). Once this final stage of coding was complete, the emergent theory was compared to research and existing literature in this area.

Writing memos

Memos were written throughout the coding process to summarise and explore thoughts, ideas and concepts arising from the data (Appendix 10). These memos formed a helpful way of capturing and exploring the researcher's tentative ideas, thoughts and insights about the concepts and processes emerging from the data (Birks & Mills, 2011). The process also helped to identify gaps and inconsistencies in the data during the analysis process, thus

directing further data collection (Charmaz, 2006). They provided a vital step between the initial coding stages and the final stage of theoretical coding and the development of conceptual categories. In addition, the memos encouraged the researcher to adopt a reflexive stance to the research, by reflecting on the assumptions and insights made throughout the study to guide the analysis process. This reflexivity has been referred to as 'bracketing', which describes the process by which the researcher strives to retain an objective stance (Dowling, 2006).

Research quality

Criteria for assessing quality and rigour in qualitative research were consulted throughout the study to increase the validity of the emerging data (Elliott, Fischer & Rennie, 1999; Yardley, 2008). Qualitative research can be highly subjective in nature and it is vital that researchers reflect on their own position in relation to the research process. This was achieved through regular reflections in supervision, and a reflective diary on the process of conducting the interviews and the subjective experience of data analysis and generation of constructs and theory (Kazdin, 2003).

To enhance the credibility of the study, validation and triangulation methods were incorporated into the design of the study to allow for independent verification of the categories and the emerging theory. This involved checking the coding of three interview transcripts and resulting themes with other researchers familiar with Grounded Theory techniques, including the research supervisor and another trainee clinical psychologist conducting research using Grounded Theory (Madill, Jordan & Shirley, 2000). The resulting themes were also verified by the field supervisor and the specialist HIV midwife at the service, who provided a credibility check of the analysis and supporting data to confirm that it resonated with their clinical experiences (Elliott et al., 1999). This ensured that the researcher did not miss any important themes, that data were considered from multiple perspectives and that the labels and interpretations fitted the data well (Mays & Pope, 2000). It also helped ensure coherence of the results, that the findings were presented in a way that made coherent sense to others.

This report incorporates examples of themes and categories generated during the analysis process for readers to observe the analytic process, assess the applicability of themes and gain insight into the development of understanding from this process. Quotations from the

data have also been used throughout the reporting process to illustrate the developing codes and memos, and allow the readers to assess the 'fit' between the data and the researcher's interpretations (Elliot et al., 1999). A section of a transcript is included in Appendix 11 to provide transparency through illustrating the interview process, raw data from the study and the initial and focused coding stages.

Chapter 3: Results

An account of the analysis is presented below, with extracts from the transcripts included to illustrate each theme. All identifying details have been removed from the quoted extracts to maintain participants' confidentiality. Participants are referred to using a participant numbers 1-10 to maintain anonymity (see Table 1).

The final stage of analysis produced four theoretical codes, presented in Table 4 below. These theoretical codes comprise nineteen focused codes, each containing a number of specific properties developed during the initial stage of coding. A summary table presented in Appendix 12 documents the presence of themes occurring across participants.

A diagrammatic model is presented at the end of this chapter, showing the inter-relationships between these theoretical codes and properties across a timeline from diagnosis, through to following infant HIV testing 18 months after birth.

Table 4: Theoretical codes, sub-codes and properties

THEORETICAL CODES	SUB-CODES (focused coding)	PROPERTIES OF THE CODES (initial coding)
1 FACING BARRIERS TO BONDING	1.1 Fearing harm to self and baby	Worrying about baby's health and safety Predicting imminent death for self
	1.2 Managing multiple adjustments	Everything coming together at once Adjusting to being on medication for the first time Being abandoned by partner
	1.3 Feeling trapped and alone	Feeling let down/lacking in support Feeling trapped in this country
	1.4 Living with guilt and shame	Blaming self for being HIV positive Feeling responsible for what their child is going through Feeling ashamed of their HIV status
	1.5 Shattered dreams around motherhood	Reduced options around pregnancy, childbirth and feeding Failing to adhere to cultural norms around motherhood Anxiety about having more children in the future
2 FEELING DISCONNECTED FROM THE BABY	2.1 Ambivalence about bringing baby into the world	Uncertainty over continuing with the pregnancy Thoughts of giving up the child
	2.3 Feeling inadequate as a mother	Feeling like a failure for not breastfeeding Feeling inadequate as a single mother
	2.3 Not feeling able to think about the future	Anxiety prior to infant testing Life being 'on hold' during the infant testing process
	2.4 Losing focus on the baby	Protecting self from stigma Anxiety and stress reducing attention on the baby Strains from living in communal situations
	2.5 Worrying about HIV transmission after birth	Worrying about physical contact Limiting food sharing

3 DEVELOPING A SPECIAL BOND	3.1 Enhanced maternal sensitivity and understanding	Sharing of experience between mother and baby Single parenting creating a stronger bond Heightened sensitivity to the baby
	3.2 Maintaining physical closeness	Compensating for lack of breastfeeding Keeping the baby physically safe Seeking comfort from the baby
	3.3 Protecting the baby emotionally	Protecting baby from potential stigma Protecting baby from the impact of own anxiety
	3.4 Reciprocity of life giving	Mother giving life to baby, baby giving life back to mother Looking after yourself so you can look after the baby
	3.5 Baby bringing meaning back to life	Baby bringing happiness and meaning back into mother's life Baby minimising the dominance of the HIV over life
4 STRENGTHENING AND MOVING ON	4.1 Finding meaning in what has happened	Trusting in God to carry you through Being grateful for antenatal diagnosis
	4.2 Living for your baby	Not letting HIV rule your life Not dwelling on your situation Adopting a fighting spirit
	4.3 Being grateful for motherhood	Counting oneself lucky for medication opportunities Comparing oneself favourably to others
	4.4 Accepting HIV implications for motherhood	Looking towards a positive future Growing in strength and confidence as a mother Living every day as it comes

1. Facing barriers to bonding

Fearing harm to self and baby

A prominent fear described by all participants following their antenatal diagnosis related to the health and wellbeing of their unborn child. Women's anxiety stemmed from both the perceived likely transmission of HIV to their baby during pregnancy, and the potential impact of any medication on their infant's antenatal or postnatal development. Fears about HIV transmission were most pronounced for participants prior to receiving information about mother-to-child transmission rates, and were prompted by an emotional response to hearing the news of their diagnosis.

Then I remember screaming out to L [specialist midwife]...and I said 'what about my baby?' ...She was my first and last concern really. (P1)

So I thought 'Well I've got it, so my baby's going to have it, and...then...it's too late to have an abortion, cos I'm so far gone, so my baby is going to die'. (P5)

On learning of their diagnosis, maternal thoughts were dominated by anxiety about foetal death, with powerful negative images of their baby's future living with HIV. Women's early concerns were fuelled by a desire for their baby to escape what they believed they might experience in the future; facing a lifetime of reliance on medication and worry about their health status.

It was a difficult time during pregnancy after I found out about the HIV because I was thinking all the time, I hope the baby is healthy. I hope no harm comes to the baby. I was very worried, because I didn't know whether the baby was going to be in the same position as me, being positive and that, and have a lifetime of medication and worry. (P9)

I think my baby maybe have [HIV]⁴, maybe she's dead before she's born or maybe she never have a good life. I think so many things during this time. The first week, the second week – just thinking bad things all the time. (P3)

⁴ 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.

For the majority of mothers, fears centring on potential harm to their baby from HIV overshadowed any fears of harm or imminent death to themselves. Whilst consideration of their own death *was* a feature of this adjustment stage, these concerns were largely related to the potential abandonment of their baby, and the potential for missing significant future events in their child's future life, such as birthdays and weddings.

I just thought I was definitely going to die...I remember breaking down and thinking 'look at my daughter, she is so small. Am I going to be around for her 18th birthday?'
(P1)

I'm scared— I don't know how far I can live, and whether I'm going to live long enough to see him grow up. Will it be a year, or 10 years? How many years can I live for – will I get to see him getting married or having a baby? It worries me. (P8)

The anxiety experienced by women about their baby's health following diagnosis may have impacted negatively upon their experience of pregnancy. The majority of women were experiencing this anxiety as first time mothers, and perceived this to have a detrimental impact on the antenatal and postnatal period.

It did make a difference to me being a mother I think. Because one, I was worried she might get it, it was at the back of my mind the whole time wondering how I would cope....I was worried about everything in a way I hadn't been before. (P6)

However, maternal fears about harm to their babies were also found to have some positive effects for the mother-infant relationship, in enhancing maternal sensitivity and a desire to protect and maintain physical closeness to their baby. These more positive outcomes are discussed further below.

Managing multiple adjustments

Central to womens' experience of being diagnosed antenatally with HIV was a feeling of being overwhelmed by having to make a number of different adjustments at once. The majority of women received their HIV diagnosis only weeks after they had discovered they were pregnant for the first time, with this diagnosis reported as entirely unexpected for all ten women. This unexpected news disrupted the focus on being becoming a mother for some the participants, transforming pregnancy from a period of excitement to one of

anxiety. For a number of mothers, this was further compounded by significant financial difficulties, insecure housing and uncertain immigration status.

So it was a really tough angle. Everything just came together at the same time. If it was one at a time, the pregnancy and then the HIV, then yes – maybe I would have been able to cope better. But this time it was ‘how do I cope? Where do I sleep?’ I had panic attacks most nights after the diagnosis. Everything felt so out of control.... diagnosis coming at that time, for me, when I was already struggling with the pregnancy symptoms and my financial situation...it was too much. (P6)

The process of adjusting to the HIV positive diagnosis continued throughout pregnancy for many women, until some months following the birth of their baby. This meant that first time mothers were learning how to look after their new baby, whilst also grappling with post-diagnosis anxiety and the new demands of managing their health condition. The experiences of two mothers with children born prior to, and following, their diagnosis highlighted this uniquely challenging combination of factors surrounding their post-diagnosis baby.

The second child was a bit easier for me, as I had had the experience with the first one and I was used to the idea that I was positive...but the first one I had only just found out and I had all these worries ... I’d never been a mother before and so I didn’t know what would happen. (P7)

I think if I’d been a new mum, it might have been harder, because you’re learning all new things about having HIV and being a mum at the same time. (P5)

One of the most notable adjustments for all women following diagnosis was the immediate commencement of medication to increase their CD4 count and reduce their viral load prior to birth. This formed a major physical and emotional transition for several women who had not been on such medication before. A small number of women (3 out of 10) had a negative physical reaction to the medication during pregnancy, which led to difficulties in maintaining adequate nutritional input for their baby.

I’m not a medicine person... So I found it very difficult going on medication every day...And whilst pregnant it wouldn’t stay down, and having a difficult pregnancy, baby not growing well and everything. It was really tough. (P6)

That time, if you saw me, I was like this [pinches fingers] – very thin. The medication made me feel very bad. I didn't eat...They [the meds] make me feel very bad. (P4)

One of the unique factors for this group was the urgency with which it was necessary to start medication after diagnosis, and the consequent lack of time for women to consider their feelings in relation to this. Women described a dilemma at this point, in which they either took medication, with the perception of risking damage to the development of their baby, or they avoided medication and risked transmission of HIV in the uterus. This struggle seemed to add considerably to women's stress and anxiety during the antenatal period.

I was also worried about what it [the medication] would do to my baby, whether it would hurt the baby. I asked the midwife and she said it would not hurt, but I decided to give it all to prayers for protection. (P10)

An additional adjustment for half the mothers was the breakdown of their relationship with their partner following disclosure of their HIV status. For most, this was experienced as a sudden abandonment by their partner, which was never adequately discussed or explained. Women were therefore in the position of adjusting not only to the prospect of being a single mother, and for five of these women to an unplanned pregnancy, but to the perceived rejection of both themselves and their baby due to their HIV status. This seemed very challenging for women to process at such an emotionally vulnerable time.

After the birth... I call the Dad, and I say 'I've just deliver a baby girl', he said 'congrats' and cut off the phone. It's bad. For a mother to go through caesarean, only to call the father to tell him and for him to say that, that's bad - the rejecting feeling. (P4)

One woman described the devastating impact of her HIV diagnosis on her plans for the future, which had broken down following disclosure of her status to her partner.

When I told him [partner], it was not good.. Still not good now. He left the relationship. So, it was kind of... I got pregnant with the intention of getting married, and thinking things were going to get good now, and all of a sudden everything came falling apart. So it was kind of very tough... (P6)

Other women described being left with unanswered questions about their partner's whereabouts and HIV status.

So at that point I suspected, maybe he knows that I've got HIV. Maybe that's why he doesn't want to know. Maybe he know he have the HIV from before. That is why he ran away. I think I got it from him. Why else would he not to continue with me? I said 'just come and look at your baby', and he said 'I don't want to, I don't want the baby'. (P4)

These unanswered questions about the sudden breakdown of relationships seem to have detracted from a positive experience of becoming a mother for several women, and their ability to feel hopeful about the future for themselves and their baby.

Feeling trapped and alone

Most of the mothers in this study reported feeling lonely and socially isolated in facing motherhood for the first time. Women described feeling let down by family members, who did not provide the level of support they had hoped for after birth. This lack of support was attributed in many cases to family members being unaware of their HIV status and the associated struggles they were facing at this time.

My sister didn't really support me, everyone else had their own problems. So I felt very on my own. I was actually on my own. (P6)

Several women compared their own experience of early motherhood living with HIV to that of new mothers with less stigmatising chronic health conditions, such as cancer or diabetes. Women remarked on how much more support they imagined receiving, had they been able to share such a diagnosis with family and friends.

Yeah, if I'd had cancer and told people, then everyone would have been around you, wanting to help you and look after you, wanting to look after the baby. I didn't have people around me like I would have done if people had a different look on the HIV, or if I had diabetes or another disease. (P5)

Although women did not make a direct link between this lack of support and the developing relationship with their baby, it was clear this isolation formed an additional strain and burden during the first few months after birth. Several made comparisons to their experience of the postnatal period for women in Africa (the continent of origin for most of the mothers), in which a culture of providing greater support to new mothers assisted the mother-baby bonding process. Mothers who felt trapped in the UK due to the perceived

lack of medication in their home continent showed a desire for this kind of support system around them and their baby in the UK.

In Africa, when you have the birth, your mother is there, your sisters and friends, and all of them will be around to help you at all times...If your baby is crying then someone will help you... But here in England, nobody will help you – you are doing it for yourself. That was the most difficult thing for me, comparing with last time [in Africa]. (P10)

Living with guilt and shame

One of the key emotional burdens for women following their diagnosis and birth was their battle with pervasive negative feelings about themselves and their HIV status. Feelings of guilt and shame were reported by nearly all mothers, and perceived in some cases to interfere with their role as a new mother. Anger at themselves for having contracted HIV was initially most notable following diagnosis, and led some women to questioning their previous behaviours and lifestyles.

I thought it was my fault, because I could count two occasions when I was not so careful, so I thought it must have been one of those. I was so angry with myself. (P6)

Self-blame was closely related to a sense of responsibility for what their child was going through during the infant medication and testing process. Maternal guilt was most associated with the first month of having to give daily medication to the baby after birth, and the perception of their innocent child suffering because of them. One mother articulated the paradox that she blamed herself for the situation, even though she knew it was not really her fault.

I hated myself. HATED. You know? For making her going through that. You know, sometimes I'd look at her and I'd just feel hate for myself. Even though it was not my fault but I just felt hate...for myself (P1)

But it was dealing with the fact that I had to be giving medication to my child for a month. The guilt around that was MASSIVE. I felt like 'Oh my God, I've put her through this', but then I thought 'I have to give it to her, to protect her' (P2)

For some women, these negative feelings about themselves appear to have detracted significantly from their enjoyment of the experience of pregnancy and the first few months after the birth of their baby. This may have been exacerbated by a more general feeling of

shame surrounding their diagnosis, which seems to have impacted upon participants' feelings about themselves as a mother.

I didn't feel joyful about the pregnancy after I'm diagnosed. I wondered what I was doing having a child in my situation. It was stupid. I felt stupid. (P4)

Shattered dreams around motherhood

One of the main struggles faced by mothers striving to keep their baby safe from HIV was giving up on long-held dreams around motherhood, such as breastfeeding and having a natural birth. Whilst two women did not feel affected by the restrictions on breastfeeding, the majority faced significant emotional difficulties associated with this. These mothers also described a perceived departure from long-held generational and cultural practices.

I'd always said, once I have my children, I'm gonna breastfeed. That had been my dream, and that suddenly couldn't happen... it was a big thing. My mum breastfed me, so, you know, a lot of people around me were breastfeeding. I weren't able to just give back to my child in the way my mum did to me. (P1)

When I got married, I would just be practicing my steps for when I became pregnant. I would hold a pretend baby to practice breast-feeding, but unfortunately it turned out that couldn't do that. And that hurt. A lot... I had been looking forward to it so much. (P7)

Regarding the birth of their baby, several women reported a dilemma between following what they saw to be a natural vaginal delivery, and maximising perceived safety for their baby through caesarean delivery. This caused distress for those who believed that either option might compromise their baby's safety in some way. Whilst the final choice around birth and feeding was available for mothers themselves to make, many felt in reality these choices had been taken away by their HIV diagnosis. Nine out of ten participants elected to have their baby by Caesarean (Table 2).

I actually didn't want the Caesarean, I had always wanted natural birthing, but I was told that it was safer for the baby, and also I had no other option than 'I am having this Caesarean' when they saw that she wasn't growing at all. So the option wasn't there to choose anymore. (P6)

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

From where I come from, if you give birth naturally it is really important. You have to go through that process to birth your child properly. Otherwise it is like a failure. It is a woman's right to give birth to her child naturally, and to have that taken away...It feels terrible. I wanted it to be natural so much. (P7)

In Africa everybody breastfeeds. It is expected. So I felt bad for this reason. (P10)

Having gone through the anxiety of giving birth following their diagnosis, mothers also talked about the end of their dreams to have more children in the future. A number of women felt they could not put themselves, their partner or future baby through that level of anxiety again. It seemed that the pain of the infant testing and risk of HIV transmission were still prominent for the mothers, even following their own baby's negative results.

But I don't think I can make more baby now. Because I'm scared that if I get pregnant now, maybe the next baby will come with HIV....There is small chance but what if I am the one?... So I pray. I want to baby, but I think it is not possible. (P3)

I don't know if I could go through that again. To put myself and a baby through that. It was horrible. (P6)

2. Feeling disconnected from the baby

Mothers described a range of emotional stressors following their HIV diagnosis, which in many cases led to a perceived distancing from their baby's needs and their parenting role. The development of a relationship with their baby seemed difficult for some women to comment on, even when asked about this directly. Mothers did talk, however, about being distracted, stressed and distanced from their baby in the first few weeks and months after birth, making clear links between this and their recent HIV diagnosis.

Ambivalence about bringing a child into the world

After first hearing of their HIV diagnosis, many mothers described a period of uncertainty over continuing with their pregnancy. Most briefly considered the option of termination, only abandoning these thoughts after reassurance from the specialist HIV midwife about the low risks of mother-infant transmission. Thoughts of termination were most prevalent amongst women whose relationship had broken down following diagnosis and were facing unstable financial and housing situations. The main trigger for these thoughts was the idea that their baby might suffer, alongside maternal uncertainty as to whether they would be around to care for their child in the long-term.

I said to the nurse, "I don't want to die and leave the baby on its own", and so I asked if we could terminate so that the baby wouldn't suffer... I thought that I didn't want it because of the HIV (P10)

I was thinking...thinking, do I really want to bring a child into this world knowing that anything could happen to me at any time?... My fears were mostly about my child, you know, the unborn child. I was very worried. (P1)

Three mothers also spoke about thoughts of giving their child up to care services after birth, feeling overwhelmed and struggling to adjust simultaneously to motherhood and managing their HIV. High levels of maternal guilt stemmed from having had these thoughts, despite a recognition by mothers that it had seemed like the best option for their baby at that time.

I was adjusting to the diagnosis. Sometimes I felt like...you know I want to give her away, cos I can't cope no more. And then I felt rotten....I don't think it if came to it, deep down, I wouldn't have gave her away, but sometimes you think 'I wish I could'. Send her away for a little while (P5).

For one woman, speaking with social services about putting her baby in care was related to wanting to protect him and build a better life for them together in the future.

I went to the social services people, and I said 'I want you to take my son away', because I couldn't cope with the situation and I wanted him to be moved to a better place without my problems. I wanted to protect him...I don't have my place, I don't have any money, people are getting to know about our business. I thought at the time if I give him up to

care for a while perhaps I can sleep on the streets and save money to rent our own house, and get him back again. It is better for the baby that way (P8).

It seems likely these thoughts of termination and residential care for their baby may have impacted negatively upon women's experience of pregnancy and their relationship with their child. For some women, their status as a single HIV positive woman seemed both incompatible with motherhood, and inadequate for bringing up a child. Whilst all mothers were pleased in retrospect to have continued with their pregnancy, a sense of uncertainty over their suitability for motherhood continued to dominate the first year after birth.

Feeling inadequate as a mother

Several mothers saw the breastfeeding of their child as a central part of the maternal role, and their inability to do so led to feelings of self-doubt and maternal inadequacy. The clear guidance from healthcare professionals to avoid breastfeeding presented mothers with another dilemma, with their need to protect their babies from HIV conflicting directly with their strong maternal desire to feed their baby from the breast. Mothers described forceful physical urges to breastfeed, both from themselves and their infant, which they attempted to suppress to keep their baby safe. This felt unnatural for many, and was accompanied by guilt, as if women were failing to perform a central part of their mothering role.

I just so wanted my child to be able to suckle on my breast, your own child to be able to do that. It felt awful not being able to do that. So unnatural to have to stop it. (P7)

I wanted to breastfeed so much... I really wanted to and felt that I had to. But I didn't for protection. I wasn't allowed to. .. Whenever he was hungry, he was searching for the breast.... He was trying to get it and I couldn't give it. (P8)

For mothers who struggled emotionally with bottle-feeding their babies, restrictions around breastfeeding also led to a maternal perception of interrupted bonding with their baby. This was one of the only points at which mothers felt able to articulate a tangible impact of their HIV diagnosis upon their developing relationship with their infant. A perceived disruption to bonding was characterised as a maternal distancing from their baby, and a delay in connecting entirely from birth as they felt a mother and new baby should.

Don't get me wrong, I love her unconditionally and whatever, but I felt like if I'd breastfed, the attachment between herself and me would have been a bit more stronger. A little bit more. From me to her. (P1)

I thought breastfeeding was really important for several reasons – but the most important was for helping bonding. I struggled with this... (P6)

Yeah it was a problem. It was a more...what do you say...distant relationship. But now it is better. Now I understand [her]. But it was hard to comfort her when she was sad because she wanted the breast. (P4)

For some mothers, their inability to comfort their baby through breastfeeding seems to have been further exacerbated by a focus on the nutritional aspects of breastfeeding, which they felt unable to provide for their child. There was a strong sense that their baby would suffer both physically and emotionally as a result of missing out on breast-milk, lacking the comfort and nutrition they needed at this time. The language used by one mother around 'robbing her baby' of nutrition highlights the presence of self-blame within these accounts.

And all those nutrients, especially in the first breast-milk, it felt like a waste. Like I was robbing my baby of something. And I felt so bad about it. (P8)

I was crying all the time because I knew that I couldn't breastfeed my child. I was putting all the blames on myself for being in that situation, and the fact that my children would come out and they would suffer...It's worn me out every day this guilt... I would just be always talking to her, saying 'please forgive me', you know?... 'I'm so sorry if I put you in this awkward situation, not being able to breastfeed'. (P7)

The single status of mothers following the breakdown of their relationships during pregnancy was the other main cause of feelings of inadequacy in the maternal role. For some mothers, it seemed that cultural expectations around marriage had contributed to a sense of hopelessness about being single, with a belief it was not possible to be an adequate parent on your own. Carrying out the maternal role with limited practical and emotional support left some women feeling exhausted, unsupported and judged by those around them for not being married, serving to undermine their confidence as a mother. Levels of anticipated stigma also seemed to be raised for this group of mothers compared to those in relationships.

The HIV makes it hard to find new partner. And it is hard to be good mother on your own. So I am stuck on my own with HIV and a child. Because, this baby. If there is not a man around...they [the child] do not want to listen to you. I am not enough on my own. (P4)

If I had a partner, I would have more confidence in taking care of my baby. Other people wouldn't see me like a question mark, because they suspect things and they now see me as a question mark. And that affects how I am as a mother. (P8)

Not feeling able to think about the future

The majority of mothers struggled to feel hopeful about the next stage of their child's life prior to receiving an HIV negative result from the infant-testing process. High levels of maternal stress and anxiety were described by all mothers during this testing process, with many appearing to focus on the risk of perinatal infection. For some mothers, this anxiety led to physical symptoms such as sickness and sleeping difficulties throughout the first year after birth.

But then at the back of your mind, you still think 'are you going to be the 1% where it could be my baby that does get it?... I was still feeling really rotten about it throughout the first year. It definitely changed that first year for me. Definitely. I was so much more tense than with the boys before and I don't know whether that impacted on her. (P5)

The night before the tests I felt so worried, like I would be sick...there is always a small voice in your head saying that maybe you are the unlucky one. (P10)

Mothers also described this period of infant testing as putting their relationship with their child 'on hold', with some mothers seeming reluctant to start developing a full relationship with their baby until they had greater certainty about their baby's future health and survival. This may have acted as a form of emotional protection for mothers in preparing for the possibility of bad news.

Before the results I was living but I wasn't really living...And after that it was like 'OK, thank God. Now let's be mummy and daughter, and nobody is going to take you away'. (P2)

Yeah, it weren't till her third blood test when they said 'negative', that you knew she was fine. Before that I was worrying constantly...it was like I was waiting for our life together to start, do you know? It had started but it hadn't started too. (P5)

This fear that their baby may be 'taken away' left mothers and their babies in a state of limbo, living one day at a time and feeling unable to think optimistically about their future together.

Losing focus on the baby

All mothers made concerted efforts to avoid disclosing their HIV status to family and friends to avoid discrimination, creating excuses about their reasons for bottle feeding, medication and their Caesarean birth. In most cases, women were supported by the specialist HIV midwife at the hospital in thinking through plausible excuses to help protect their HIV status. Despite this additional support, this was a stressful and draining process for new mothers, bringing an extra burden to carry in the first few months after birth. In some cases, this led to increased social isolation for mothers and their babies, as they distanced themselves from family and friends to avoid exposure to constant questioning about their feeding and birth choices.

My step mum was asking me 'why is it that you're not breast-feeding?' This was a real extra burden in my first few weeks that I really could have done without. And I said to her 'because I don't have any milk, it's dried out' ...But I could tell she disapproved...And this was an additional worry for me as well, on top of everything else. (P1)

It was really stressful, having to make up lies all the time - why I wasn't breastfeeding, why I'd had Caesarean, why she was taking medication - it exhausted me and made me not want to see people. (P9)

Several mothers described the efforts to hide their HIV status from friends and family as distracting them from time focusing on the needs of their baby. Whilst the majority did not reflect directly on whether this had impacted upon mother-infant bonding, awareness of the potential for disruption seemed to add further to levels of maternal stress during this period.

Yes, it was very stressful. When I should have been full time thinking on my baby. There was no way I wanted people to know. (P8)

As I said, it was stressful on both of us. And, I don't know. (Pause). I did bond with her, but there was so much going on and so much to think about with the lies to family and

the medication making me sick and the worry about her results. It wasn't easy to just focus on her. (P5)

In addition to these concerns about disclosure, half the women described financial difficulties as forcing them to live in cramped communal living situations with very little privacy. This was very stressful for mothers, compounding efforts to maintain confidentiality and causing an extra strain on the mothering role. Some women described feeling unsafe in their communal living situations, sensing a high potential for HIV-related discrimination. The suspicious nature of these communal living environments seemed to stand in direct contrast to women's descriptions of the supportive communal systems surrounding new mothers and their babies back home in Africa.

Worrying about HIV transmission after birth

Mothers expressed concerns about the potential for transmitting HIV to their babies after birth, affecting the level of physical contact some felt comfortable having with their newborn baby. A number of mothers were initially wary of any saliva contact with their baby, which led to restricted displays of physical affection, such as kissing.

At first I don't kiss my baby... I would try to keep her away from me as much as possible if I thought I had a scratch or a cut or something...I don't want to sneeze, I don't want to kiss her, I don't want to touch. It was painful cos I wanted to, but I was scared. (P4)

Before that I was worried about kissing and cuddling my daughter – I did cuddle her, but did less kissing until I'd been reassured by the doctor. I'm glad I asked because it's not nice holding back. It feels all wrong. (P6)

Sensitivity to cuts or open wounds on their own bodies also led mothers to limit physical contact with their baby to minimise risk of HIV contamination. Many described a reluctance to share cutlery or food with their child, or engage in cultural African practices around breaking up food in their mouths as their child grew older. These restraints represented another way in which mothers felt they were restricted from behaving in a natural way with their baby, once more having to resist maternal urges and deny their baby what they felt they wanted. Having sought guidance and reassurance from healthcare professionals, most notably the specialist HIV midwife at the hospital, the majority of mothers had later learned that their concerns about sharing saliva were based on misunderstandings about how HIV could be transmitted. This strong desire to protect their baby from their infected bodily

fluids did, however, reflect the extent to which mothers considered their own bodies to be infected. It also presented a potential barrier to bonding between mother and infant, in denying their baby physical contact at this formative stage.

3. Developing a special bond

A strong theme shared across mothers was a feeling that, despite the challenges, the bonding process with their baby had been heightened through their experience of being diagnosed antenatally with HIV. The majority of mothers described having moved on from the initial challenges to develop a strong relationship with their baby, achieving this bond in spite of the notable barriers to bonding. One reason for strengthened bonding seemed to be a maternal awareness of early distancing from their baby, which led to subsequent concerted efforts by some mothers to compensate for these shortcomings as their baby developed and their anxiety started to decrease.

Enhanced maternal sensitivity and understanding

The special bond described between mothers and their babies was influenced to a large extent by the infant medication and testing process after birth. Whilst this period was emotionally draining for mothers, it was also perceived to have created a rare connection between mother and child, which may otherwise never have developed. Having been through HIV blood tests and taking medication themselves, mothers felt able to empathise during treatment and testing, feeling closer to their baby through this shared experience.

It [the infant medication and testing] wasn't pleasant for me at all. But it was bonding for me and D [son], because as for me, I knew what he was going through with the testing and medication because I had been there. (P8)

I used to look at her sometimes and I think - 'you and me we are the same - you know how I feel. You know my secret' - when nobody else does. It was just us two in our little world. (P4)

Mothers also related their HIV diagnosis to a perceived heightened sensitivity to their baby, monitoring their movements closely for any signs of discomfort or illness. Whilst this level of sensitivity was initially prompted by HIV-related anxiety, this seemed to bring with it a closer connection between mother and child.

It has made us closer because I make sure anything she does I never cause her illness or anything. So I make sure that I watch her, her movements, the way she plays...In fact it brought me closer to her to monitor her movements and to make sure that she doesn't fall ill unnecessarily, you understand? (P7)

For single mothers, there was also a sense of strengthened bonding with their baby through the constant presence and knowledge that their child was purely dependent on them. As the majority of single mothers perceived their solo status to have resulted directly from their HIV diagnosis, the strengthening of this mother-infant dyad was closely linked to HIV. The challenge associated with fulfilling the role of both parents, whilst also managing their own health condition, was thought to have paid off in bringing a stronger connection to their child.

I've had to be mummy AND daddy, and at the same time having to deal with the fact that I am HIV. When she's crying, it's me. I'm the sole parent and I'm there for her at all times...the fact that I'd been so hands on and without any other support, has helped us to bond ridiculously...It drove me closer to my child. (P2)

Cos for me and my baby, you know, I am the only one who can care for her. It is me for everything. So I am her everything and she is my everything, and that is that. It is us two. (P10)

Whilst the presence of maternal HIV was therefore not directly associated with stronger mother-infant bonding, the indirect consequences of the antenatal diagnosis - such as single parenthood and a heightened desire to protect their child from harm - were more clearly related.

Maintaining physical closeness

Mothers displayed a keen awareness of having brought an innocent child into a world full of danger, leading to an enhanced sense of responsibility to protect their infant from any harm. This maternal protectiveness was heightened in cases in which mothers saw themselves as vulnerable to being ill or dying, and perceived the world to be a dangerous place.

She was so innocent, and I was thinking...I can't believe I've bought her here, to this place of illness, or sadness...I need to keep her safe. (P5)

Mothers drew comfort from physical proximity to their baby when they were feeling low in mood, frightened or alone, with physical closeness bringing reassurance and contentment during the later stages of pregnancy and after birth. This was particularly commented on by the single mothers taking part in the study. Within these maternal narratives was a sense of their baby understanding their pain, and providing comfort in a way that nobody else could at that time.

Just seeing my child growing inside me being pregnant, that was a blessing. That made me feel so much happier. (P1)

When he started to grow up... he would look at me as if to ask why I'm crying...I really felt that he could console me at that time, I would hold him and hug him and hug him and I would feel better. (P7)

A principal driver for mothers maintaining physical closeness to their baby was a desire to compensate for their lack of ability to breastfeed their child. This theme was shared widely across mothers, with many citing skin-to-skin and eye-contact as important factors in helping to overcome any bonding difficulties associated with a lack of breast-feeding. For some mothers, mimicking the physical positioning of breastfeeding itself was thought to be helpful in strengthening their bond with their baby

I made sure we were that close [pinches fingers tightly] as I was giving her the bottle, it was just like I was giving her the breast. Regardless of our short-comings, we still are getting the same amount of closeness and bonding as anyone else...Make even bottle feeding the most bonding moment that you could ever had. Look at your child in the eye during that process, go into them, you know? (P2)

Personally I tried everything I could to make sure we had that connection. I made sure I spoke to her and made silly noises so that she knows her mummy's voice. I gave her lots of hugs and cuddles, kisses, you know? (P1)

Mothers appeared to see these compensatory strategies not only as making up for a lack of breast-feeding, but as creating a stronger bond than would have been there otherwise. The cultural and societal pressures around breastfeeding from many African communities seem

to have further driven this maternal desire for greater physical contact. For those who had struggled with self-blame and feelings of inadequacy around their maternal role, the physical closeness may have served to calm these feelings and create more positive conditions for bonding with their child.

Protecting the baby emotionally

Maternal responsibility to protect their baby from any harm was characterised not only in terms of protection from HIV, but also in protecting their child emotionally against any HIV-related stigma. The majority of mothers felt there was significant potential for their baby to be discriminated against by family, friends and professionals as a result of their own HIV diagnosis. This seemed unbearable for most mothers, reinforcing their wish to avoid disclosure of their diagnosis to family and friends.

With HIV...it's like a dirty thing. And I didn't want nobody to know cos I didn't want it to reflect bad on my children. That was the main thing. If people thought I was dirty they might think they're dirty too. I couldn't do that to them. (P5)

My daughter would have the same treatment – yeah yeah it would have been for both of us. People keep their distance from the parents and from the children too. Even if she is negative... I didn't want that for her. (P10)

One participant reported personal experience of discrimination in the negative attitude of her friends towards her baby following the disclosure of her HIV status. This had led to feelings of maternal guilt and a desire to protect her son from experiencing any further discrimination, which was not always within her control.

There is so much stigma. There are two friends who know about the HIV, and they are not talking to me. They don't want to look after my son. They don't want anything to do with him, and it really hurts. I tried to save him from this but I can't (P8).

The two mothers with children born prior to their diagnosis described feeling more protective towards their post-diagnosis child than their other children. For most mothers who described this desire to protect, they felt this had brought them closer to their baby and supported the bonding process.

So it was very emotional...Because I had brought him into the world, and I needed to take care of him....That was the only thing that mattered to me, and that made us feel tight together (P8)

An additional form of heightened protection described by mothers was in the form of sheltering their babies from the impact of their own maternal anxiety during the first year of life. Mothers showed awareness of the potential for their baby to pick up on their own stress and anxiety, particularly during the infant testing process, and were keen to disguise any such negative emotions from the outset.

The other thing about feeling anxious in the first year was that I was constantly wondering about whether T was picking up on my anxiety. Yes I was. I hoped she wasn't picking up on things, I didn't show it to her...if that makes sense. Cos I've said to myself, I've done enough damage, like...I'm just going to try and be happy every time she is awake, I'm always happy, smiling. You know? (P1)

It felt like P [daughter] knew about the tests as well as she didn't sleep before the tests – we were both awake. Maybe she senses from me my stress. I feel bad for this. I try to hide it. (P3)

Reciprocity of life giving

Mothers described a sense of gratitude and mutual life-giving between themselves and their baby following their antenatal diagnosis. This was characterised by the baby giving life to the mother, through triggering the early antenatal diagnosis of HIV and subsequent treatment; and the mother then giving life back to the baby, through protecting their health in pregnancy and after birth. Mothers expressed gratitude to their baby for triggering an early HIV diagnosis and prompting access to medication, providing the opportunity for survival and freedom from the most severe effects of HIV. This reciprocity in life giving led to a unique bond between mother and baby, with each reliant on the other for survival. This appeared to have contributed to a perception of equality within the mother-infant relationship.

I owe her so much. Without her I would be dead now. For sure. I freed her, she freed me'. (P4)

And sometimes I see it like she helped me...if I wasn't pregnant, I wouldn't have thought of having a test...And it's because I was, and it's because of her, that she's given me life and I need to give her that life...I think I owe it to her. She's the reason I live, I'm the reason she lives. (P2)

Mothers and their infants were also seen as providing each other with mutual support, due to the baby fuelling maternal adherence to their HIV treatment. Mothers described a strong desire to look after themselves so they could look after their baby, citing their mothering role as the main motivator for making positive lifestyle changes and adhering to treatment.

She's the reason why I keep going to my appointments, I don't miss any, and I try to just do the right thing. ..So I think she has helped in that sense. (P1)

I can take my medication, which I do every day, I've never missed it....But that's because I have that responsibility. To be a mother, to live, to be well and to still be here...And I think knowing that I have a child, I need to keep taking it. (P2)

In this sense, maternal responsibility for their baby was seen as directly maintaining health for the mother, bringing with it better life prospects and a more positive sense of the future.

During the period of anxiety about results from the infant testing process, mothers described their own mental health and wellbeing as inextricably linked to the perceived health and wellbeing of their baby. Whilst the idea of being ill themselves was something many could cope with, any pain and suffering inflicted on their baby seemed unbearable in comparison.

I thought 'me being ill, it is OK, I can cope - but my little girl she is only a baby. She is so small. It is no good for her to be sick'. No good no good. (P3)

Baby bringing meaning back to life

Mothers described their baby bringing happiness and meaning back into their lives after the traumatic experience of being diagnosed with HIV. This was particularly powerful for five of the women who had described a sense of hopelessness about the future following their diagnosis. There was a well-defined connection for mothers between the birth of their baby, and the start of new beginnings for themselves. For one mother, the birth of her child elicited positive emotions and feelings of love that she had previously believed she would never feel again.

Being a mother in those first few weeks, it gave me a sense of belonging again. You know? I felt love...again. Cos when I was diagnosed, I just felt numb. You know? So, just seeing her and looking at her face, I just felt – ‘this is my reason to push, this is reason I’m going to pull through’. (P1)

For others, the sense of pride and achievement at becoming a mother overshadowed any negative emotions associated with their HIV status, prompting a sense of disbelief at how happy they could feel. The realisation of a long-standing dream of motherhood for some women minimised the power of HIV over their lives, and the extent to which their diagnosis could impact negatively upon them. With their new baby taking centre stage and requiring their full attention, there was less room for dwelling on the negative aspects of their diagnosis.

I just looked at her and I thought ‘Is she really mine?’ And nothing else mattered in that moment....It was the best time for me. Even though it was tinged with guilt and worry, it didn’t stop it being amazing...It was crazy. It was overwhelming. It was exhausting. But it was amazing. (P2)

I was SO HAPPY! I was very very very happy. I was finally a mother of my own. It was a dream come true, even with all this going on. At that moment, the HIV never got to me. I was just looking at the baby, you know? She was the centre of everything. Yes, I was just very very happy. (P7)

For many mothers, the birth of their baby seemed to bring with it a shift in self-identity, from that associated with disease and ill health, towards a more positive identity associated with motherhood and new life. With this new role came a renewed strength and ability to cope with their diagnosis and related circumstances.

4. Strengthening and moving on

Central to women’s experience of motherhood following their diagnosis was a deep feeling of relief upon hearing that their baby had been given an HIV-negative result from the infant testing process. All ten mothers received a negative result for their baby 18 months after birth, with this news prompting reduced anxiety and a notable shift in how mothers felt about themselves and their relationship with their child. This phase of moving on started in

the latter part of the first year for most mothers, following positive news from the second round of infant testing up to six months after birth.

Finding meaning in what has happened

A strong faith in God was shared across almost all mothers, with prayer and trust in God's protection providing great comfort and support following diagnosis. For many women, this faith enabled them to look back on their experience since diagnosis and find some purpose and meaning in their personal journey. A small number of women understood their experience in terms of their Faith being tested by God, with some feeling they had gained greater resilience and energy as a mother through rising to the challenges they faced during the first year after birth.

My Faith and belief in God helped a lot, it did. Because in the Christian faith there's a saying that 'God doesn't give anything that he doesn't think you can bear or manage'. So I used to hold on that saying and think 'well, if God didn't think that I would be able to cope, then he wouldn't have put me in that situation. (P1)

I do think my Faith has played a key role....I know He didn't put me through this just because he hates me. There's a reason and He thinks I can handle it.... He's given me the strength to push on. (P2)

For mothers reflecting on their experiences in a positive light, the bond developed with their baby was the most notable positive outcome to have emerged. This helped to boost a sense of maternal wellbeing and strengthen women's positive feelings about themselves and their baby's future. Others were able to express gratitude for their diagnosis during pregnancy, with several feeling the antenatal diagnosis had provided them an opportunity to take positive steps to protect their baby from HIV.

It's good to find out about it when pregnant. Because if I don't know...then I would give the baby the breast and the baby will be positive. But now I am so grateful, because I am HIV positive and my daughter would have been HIV positive. (P4)

The ability to draw positive conclusions from a very challenging set of circumstances seemingly brought a feeling of hope and strength for the future. Mothers were able to talk in a more positive way about their relationship with their child in the future, freed from previous uncertainty surrounding their own health and the health of their baby.

Living for your baby

Mothers viewed their lives from this point onwards as defined by a need to survive HIV and continue living for their child. The responsibility to mother and look after their baby was central in helping to overcome anxieties about their health status in the future. This sense of obligation to remain healthy was expressed most clearly amongst single mothers, who felt there was no option but to carry on living.

Sometimes I feel that I wouldn't live that long because of the HIV. But then I remember I have to live for him, you know?... I'm just looking after myself because he won't have anyone if I'm not here. He's got only me. I want to be there for him, and to give him a better life than I have had... You have responsibilities now. So you need to survive. (P8)

For many mothers, this sense of responsibility was accompanied by a strong fighting spirit, with women working hard to diminish the impact of HIV on their lives. Mothers depicted themselves as becoming independent from the disease, with their path towards health separated from any negative associations with HIV. For these mothers, it seemed that a healthy life with their baby involved distancing themselves as far as possible from HIV.

I have it (HIV), it does not have me. It's not because I'm trying to block it off, it's because I'm trying to live. And the living path is the one where I've got a child...now I need to know, what do I do from here? I need to have all the information I need to make the right decisions for myself and for my child. (P2)

This renewed fighting spirit may have also served to raise the general sense of self-acceptance amongst mothers, minimising levels of maternal self-loathing described previously following diagnosis.

Being grateful for motherhood

A recurring theme across mothers was a feeling of being lucky and blessed, with a genuine gratitude for the opportunity to become a mother. This was heightened for some by previous concerns following diagnosis over whether this opportunity might be taken away from them through ill health for themselves or their child. Women drew comfort in comparing their situation to others who did not have the opportunity to become a mother.

I felt happy to be a mother, because he is OK now and he has no problems, and I just wanted to have a child and I achieved that. So I feel lucky really. (P9)

There's a light at the end of the tunnel, you know? The child is a blessing – some people are diagnosed and they are unable to have children – so, be grateful and just live your life as if it's your last, every day, you know? (P1)

Mothers also expressed gratitude for the medical opportunities available within the UK, which they felt had maintained their own health and ability to care for their child. For a large proportion of the sample (8 women) who originated from African countries, there was an acute awareness of the relative lack of opportunities for treatment in their home country.

In Angola - no medication. Every day, people dead. My boyfriend has one son, 12 years old, he is dead. From HIV...There is no help there. That's very serious. So I am lucky to be here. (P3)

The gratitude expressed by women looking back on their diagnosis at the point of interview sat in contrast to their initial feelings of hopelessness immediately following diagnosis. Such gratitude and positive thinking about the future may have served to minimise previous barriers to bonding, such as feelings of guilt and fears about harm to themselves and their baby. The peace of mind for mothers gained through the confirmation of their baby's negative status, coupled with adjustment to their diagnosis and trust in their medical treatment, seemed to bring more physical and emotional energy to focus on being a mother and meeting the needs of their baby.

Accepting the implications of HIV for motherhood

The final theme to emerge for mothers considering their on-going relationship with their child was around accepting their HIV diagnosis and the resulting negative implications for motherhood. Several mothers made a conscious decision to make peace with the perceived restrictions on being a mother, such as lack of breastfeeding, minimising the negative impact over their lives in the process.

I just decided to make peace with the fact that she was a crying baby and I couldn't comfort her with the breast. (P10)

It's still tough knowing I have HIV and will have it always, but then, somehow you get used to it being there. And you learn new ways of coping and making it have less importance in your daily life. (P7)

The ability of women to move on from these limitations appeared to free them up from previous negative emotions to allow a clearer focus on the task of being a mother. The fighting efforts of some mothers to minimise the presence of HIV in their lives were supported by conscious efforts to avoid thinking too deeply about what they were missing.

Don't think too much, because if you think too much – all the time you are thinking 'the sickness will kill me, the sickness will kill me', and it will start killing you little by little.
(P10)

I had to get a lot of things embedded in my head... so I thought 'I can't do this', and because I knew I couldn't do it, I didn't want to think any other way. And I think that's what's kept me sane, cos if I really thought about 'Oh my god I should be breast-feeding'...it would be have been even harder. (P2)

Mothers described a steady growth in self-assurance in their role as a mother following the results from infant testing, as they felt more accepting of their diagnosis and were able to let go of some of the associated feelings of guilt and shame. This shift in maternal attitude highlighted the extent to which women had felt inadequate as mothers during the first few months after birth. Mothers also recognised a growth in their physical, mental and spiritual strength having come through this period of uncertainty following diagnosis, and linked this to more positive views of motherhood in the future.

As time went on I became more and more of a mother as I felt more confident, and I think that's how it has led to where I am today...where I would do anything for my child. So just being HIV, I believe it has really really made me a very very strong person. I never thought I was THIS strong. (P1)

I think I am a strong lady, I am stronger than I was before. I'm getting better, and I feel strong in the head. I feel strong for being a mother to my child. And strong in my Faith.
(P10)

Mothers showed a renewed ability to look ahead towards their future as being long-lasting, trusting in treatment to keep them safe. A sense of living every day as it comes was supported by a wish to appreciate all the time they had with their children.

Let your child be your child and enjoy every moment of having them around.. you need to be positive and need to know that this is not the end, but a new beginning. You've

just been given a new lease of life, and grab onto it and live every day like there's no tomorrow. You've got it [HIV], but live on the fact that it doesn't have you... And crucially, it does not have my child. My child is so free. And that is the most important thing. (P2)

5. MODEL OF MOTHER-INFANT BONDING

The final aim of this study was to develop a model of mother-infant bonding, and assess how this model relates to previous findings from the literature. Figure 4 below outlines how the main themes interact in relation to mother-infant bonding following an antenatal HIV diagnosis. The focused themes occurring most frequently across individuals under each of the four theoretical themes are included within the model.

This model uses a chronological and developmental structure, with themes plotted across a timeline from antenatal diagnosis through to following the completion of infant testing 18 months after birth. The main stages in this timeline are displayed at the top of the model, with the corresponding infant age for each of these stages displayed across the bottom. The second stage, entitled 'Medication', refers to the month following birth in which medication is given to the infant orally by their mother. The width of each of the theme bands across this timeline indicates at which stage in the process each theme is most prominent for mothers.

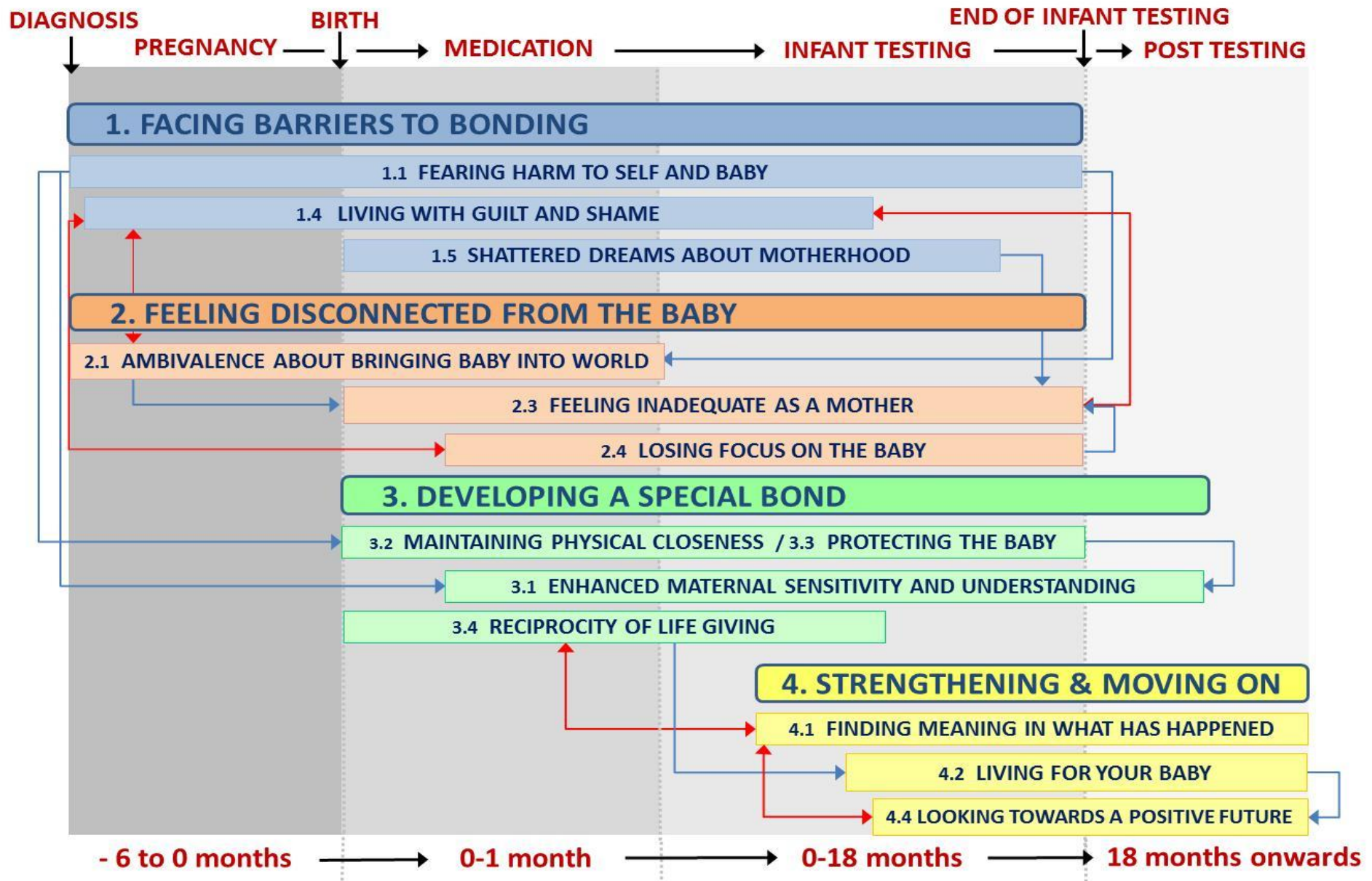
The model starts at the point of antenatal diagnosis, and shows that barriers to bonding and feelings of maternal disconnection from the baby begin during pregnancy, before the birth of the baby. The model shows how women move developmentally through different stages from diagnosis through to after the end of infant testing. The challenges with bonding are primarily experienced in the first 18 months, before the completion of the infant testing process. Maternal strengthening and positivity about the future develops towards the end of infant testing, and particularly following the confirmation of negative infant HIV status.

The arrows in the model show how one factor may feed into and influence another. The **blue arrows** indicate a one-way relationship between themes (in the direction of the arrow), whilst the **red arrows** indicate a circular relationship, in which both themes feed into and influence each other. An example of a circular relationship is 'Living with guilt and shame', which fuels 'Ambivalence about bringing a child into the world'. Many women reported

further feelings of guilt and shame as directly resulting from this ambivalence about their pregnancy, leading to a circular relationship between the two processes.

There are also examples in which a theme is shown to lead to both positive and negative implications for mother-infant bonding. An example of this is 'Fearing harm to self and baby', which leads to both an initial ambivalence about continuing with the pregnancy (and consequent disconnection from the baby), and a later enhanced maternal sensitivity and desire to protect their baby from harm (fuelling the development of a special mother-infant bond). Some themes in the model are therefore shown to have both a positive, and a negative, impact on mother-infant bonding. These positive and negative bonding processes can occur at the same time for some mothers, such as 'feeling disconnected from the baby' and 'developing a special bond'.

Figure 4: Model of mother-infant bonding



Chapter 4: Discussion

This study explored the experience of mothers in bonding with their baby following an antenatal diagnosis of HIV. Ten mothers diagnosed antenatally with HIV were interviewed about their experiences. Data were collected and analysed according to the principles of Grounded Theory (Charmaz, 2006), and aimed to answer the following questions:

- c) What is the experience of mothers diagnosed antenatally with HIV in bonding with their baby?*
- d) What are the main challenges to bonding, and what helps women to manage this process during pregnancy and the first year after birth?*

Four overarching themes emerged from the analysis, which were mapped onto a model outlining the chronological and developmental process through from diagnosis to the end of infant HIV testing 18 months after birth. These themes related to:

- 1) Facing barriers to bonding;
- 2) Feeling disconnected from the baby;
- 3) Developing a special bond; and
- 4) Strengthening and moving on.

Overview of findings

The findings suggest there are a number of systemic, relational, cultural and psychological factors which can impact upon a woman's experience of bonding with her baby following an antenatal diagnosis of HIV. Mothers described a series of mutually interacting processes, occurring concurrently from diagnosis through to following the infant HIV testing process. During this period, mothers reported facing a number of initial barriers to mother-infant bonding, which led to feeling disconnected and distanced from their baby. No mothers described having started to develop a relationship or bond with their baby prior to birth. Significant feelings of maternal guilt and shame regarding their HIV diagnosis were coupled with a perceived loss of control over their birthing and feeding choices. For some mothers,

these factors contributed to initial ambivalence about motherhood, and feelings of inadequacy in the role of a mother. Maternal anxiety and stress around the baby's health during HIV testing led to a perceived loss of focus on their baby, feeding back into feelings of guilt and maternal inadequacy and creating a circular relationship.

In spite of these initial challenges to bonding, most mothers described moving on subsequently to develop a uniquely close and special bond with their baby. This related to maternal efforts to compensate for a lack of breastfeeding and a desire to protect their baby from harm. A reciprocally positive relationship between mother and baby developed in some cases, whereby the baby was perceived to bring life to the mother through antenatal testing and consequent early access to treatment. A mutual inter-dependence was also described between some mothers and their babies, with both mother and baby bringing comfort and support to each other after birth. The confirmation of negative HIV status for all infants at 18 months led to a strengthening stage for mothers, who were able to adjust and find spiritual meaning in their diagnosis. This led to a greater maternal confidence and self-efficacy, maternal acceptance of the implications of HIV for motherhood and a more positive focus on their future with their child.

Key findings

Facing barriers to bonding

Participants described a number of situational and psychological processes which have been associated with delayed or disrupted mother-infant bonding in the general population. Financial instability, communal living conditions and high levels of anxiety about their baby's health were perceived to have the greatest negative impact on mental health and wellbeing after birth. In several cases, this was perceived to have disrupted effective early mother-infant bonding by creating additional stresses and distracting the maternal focus away from the baby. These findings are consistent with previous research with HIV positive mothers diagnosed prior to pregnancy, showing links between disrupted mother-infant bonding and financial deprivation (Martins & Gaffan, 2000; Cooper, 2008), social isolation (Cooper & Murray, 1998; Hagen, 1999) and high levels of maternal stress during the antenatal period

(Muller-Nix et al., 2004). The current findings suggest that the maternal stress and anxiety associated with these factors may have served to detract mothers' energy from the task of focusing on the needs of their baby.

Participants described a strong emotional response to receiving their antenatal HIV diagnosis, including disbelief, panic and fears of death for themselves and their baby. These emotions were consistent with those documented in previous research with groups of women diagnosed with HIV across resource rich, and resource limited, countries (Stevens & Hildebrandt, 2006; Sanders, 2008). For many women in this study, an HIV positive diagnosis at this early stage of pregnancy led to a notable disruption to personal relationships, emotional well-being, social identity and plans for motherhood. This maternal distress led to ambivalence about their pregnancy for some, and temporary thoughts of termination. At the centre of this disruption to maternal wellbeing was the antenatal timing of the diagnosis of HIV.

The management of multiple adjustments in tandem for these mothers reflected the findings of Kelly and colleagues (2012), who reported that HIV positive mothers diagnosed antenatally faced anxiety about their own health, worry about the health of their unborn child and concerns over their suitability for motherhood. However, these processes seemed to be intensified for women diagnosed antenatally in the current study, due to time pressures around adjustment to diagnosis prior to the birth of their baby. The maternal fear of dying from HIV before their baby had grown up was also consistent with studies with mothers diagnosed with HIV prior to pregnancy (Wilson, 2007). This highlights that, despite significant reductions in the actual risk of death from HIV in the UK over the past 10 years (HPA, 2012), maternal fears of death following diagnosis are still present.

Research has also shown the potential for antenatal maternal anxiety around the health of their unborn child following an antenatal HIV diagnosis prior to pregnancy (Oswalt & Baisini, 2010). The fear of infant ill-health seems to have been heightened amongst the current group of recently diagnosed mothers, with less time for adjustment and to process information about risks of MTCT than for mothers diagnosed prior to pregnancy. Whilst this anxiety provided early challenges to bonding for some mothers, it also contributed to greater maternal sensitivity and a desire for infant protection associated with stronger bonding.

For women in the current study, the sudden realisation of their own health vulnerability appeared to clash with images of becoming a mother, a role that traditionally invokes images of strength and stability (Waltzer, 2007). This perceived incompatibility of HIV with motherhood was consistent with previous research with women diagnosed prior to pregnancy (Wilson, 2007). Participants in Wilson's study reported HIV to be irreconcilable with 'good mothering', threatening the self-concept of mothers with HIV. Becker's 'Theory of Disruption', (1997) provides a useful framework for understanding the distress experienced at the point of the antenatal diagnosis. Becker's theory asserts that distress occurs for people when they experience disparity between their cultural ideal of how life is supposed to be lived, and the reality of their actual experiences. For women in this study who had grown up with positive images of motherhood, alongside negative images of HIV, it may have been particularly challenging to reconcile the two.

Participants reported pervasive feelings of guilt and shame following their antenatal HIV diagnosis, which were closely related to a perception of personal responsibility for their baby's suffering. This type of shame has been described previously in terms of 'internalised stigma' (Earnshaw & Chaudoir, 2009), which can lead to women endorsing the negative beliefs and feelings associated with HIV about themselves (Link, 1987). Maternal self-blame was heightened by a perception that women were failing in their role as a mother and losing focus on the needs of their baby. These negative maternal emotions are consistent with studies with chronically ill mothers, in which women's maternal identity has been threatened through a perceived inability to care for the baby due to illness, and the guilt associated with this (Wilson, 2007; Vallido et al., 2010).

This maternal experience of guilt and shame can also be considered in terms of Jackson's (2000) concept of 'Disrupted Mothering', which proposes that mothers experience significant guilt and distress when their plans for mothering become disrupted. This concept helps to explain the circular relationship in this study between maternal guilt and shattered dreams about motherhood, in which mothers' inability to breastfeed and birth naturally led to increased feelings of self-blame and responsibility for harm to their baby. Reichert & Foote (2009) found that HIV positive mothers in the USA who compared themselves to an idealised image of motherhood, often culturally formed, experienced an undermining of self-identity and feelings of self-worth. This may also help to explain why the participants of African origins

in this study, with strong cultural ideas about the importance of natural delivery and breastfeeding (Fourquier, 2011), experienced such distress at not being able to meet these expectations.

A lack of social support for mothers in the general population is a risk factor for difficulties with mother-infant bonding (Catz et al., 2002). This has been associated with higher levels of maternal stress and fewer adaptive coping strategies. Most mothers in the current study reported feeling lonely and socially isolated in facing motherhood for the first time, intensified by a distancing from family and friends due to fears of discrimination for themselves and their baby through disclosure of their HIV status. Many women felt this isolation added significantly to their feelings of anxiety after birth, feeling alone with their baby outside of any supportive family structure. Theories of coping in HIV suggest that individuals tend to engage in either 'approach coping strategies' (e.g. seeking social support) or 'avoidant coping strategies' (e.g. social isolation or denial) (McIntosh & Rosselli, 2012). Both these strategies have been associated with short-term relief from HIV-related emotional difficulties, with avoidance strategies potentially leading to greater distress in the longer-term.

Social isolation appeared to lead to an additional undermining of confidence for mothers in developing a relationship with their baby. This is consistent with Bandura's (1997 cited by De Montigny & Lachante, 2005) description of 'Efficacy and Competence Beliefs', which proposes that efficacy beliefs are influenced by four sources of information. These include enactive mastery experiences (e.g. achieving goals), vicarious experiences (e.g. learning from others), verbal persuasion (e.g. feedback from others) and psychological states (e.g. emotional wellbeing). The sense of isolation and abandonment experienced by mothers in the current study following their diagnosis may therefore have contributed to low self-efficacy beliefs in their role as a mother, due to a lack of opportunity for observing and modelling others' mothering styles (vicarious experiences) or receiving corrective or affirmative feedback on their parenting skills (verbal persuasion). In addition, Bandura (1997) asserts that feelings of personal anxiety may be interpreted as further signs of personal inefficacy. This is consistent with mothers' negative interpretations of their own anxiety from this study, including concerns over the likelihood of their anxiety impacting in a negative way upon their baby.

Quantitative research with mothers in the general population has reported a significant negative relationship between maternal perinatal anxiety and feelings of control over the birth experience and subsequent childcare options (Cheung, Wan-Yim & Chan, 2007). Mothers in the current study reported having few options with regards to medication, childbirth and feeding, leading many to feel they had limited control over decisions around the delivery and care of their baby. Women from West African countries have been reported to have strongly held beliefs about vaginal deliveries being safer and more socially acceptable than Caesarean births (Adageba, Danso, Aduso-Donkor & Ankobea-Kokroe, 2008). These findings are relevant in showing the extent to which cultural beliefs could raise levels of anxiety during the birth process for mothers who feel their only choice is to have a Caesarean delivery.

In line with research carried out with mothers diagnosed prior to pregnancy (Pauli-Pott, Mertesacker & Beckmann, 2004; Vallido et al., 2010), restricted opportunities for breastfeeding were also associated with feelings of maternal disempowerment, anxiety and inadequacy for mothers in the current study. 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.

Feeling disconnected from the baby

The majority of mothers in this study described feelings of ambivalence about their pregnancy following their antenatal diagnosis, with many temporarily considering terminating their pregnancy. Thoughts of termination were most prevalent amongst women whose relationship had broken down following diagnosis, and were facing unstable financial and housing situations. These findings relate to studies exploring decision-making around termination amongst pregnant women with HIV diagnosed prior to pregnancy, which cite the key influencing factors as socio-economic hardship and a maternal fear of inflicting suffering on the baby after birth (Orner, de Bruyn, Harries & Cooper, 2010). One qualitative study reflected the core dilemma described by women in the current study, who felt torn between significant societal expectations to become a mother, and anticipated stigma around child-bearing whilst HIV positive (London, Orner & Myer, 2008). For several women in the current study, there was also a conflict between the idea of termination and their religious beliefs and guilt about

this, which has been widely documented in the general population literature (Omer, de Bruyn & Cooper, 2011). The findings of this study suggest this period of maternal ambivalence may have caused a temporary disturbance to women's perceptions of their path towards motherhood, and sense of bonding with their unborn baby during pregnancy.

Women's desire to avoid disclosing their HIV status to family and friends reflect findings with newly diagnosed HIV groups, regardless of age, gender, ethnicity and sexuality (Green and Smith, 2004; Visser et al., 2008). Avoiding disclosure was particularly challenging for newly diagnosed mothers in this study, however, who felt largely unprepared for the continuous questioning from friends and family about their birthing and feeding choices. These events are consistent with Holzemer et al.'s (2006) conceptual model of stigma, which outlines the stigmatising behaviour 'pestering', defined as a continual questioning of someone about their diagnosis or behaviour (p.547). The anxiety and stress associated with hiding their HIV status led many women to feel they were losing focus on their baby's needs at this early stage after birth. These findings are consistent with a study involving mothers with severe and enduring mental health problems (Montgomery et al., 2006), whose constant struggle to provide a façade of good mothering skills to friends and family was reported to deplete their emotional reserves and exacerbate their condition. The experiences of antenatally diagnosed women in this study are comparable with this group due to shared concerns around disclosure of a highly stigmatising condition and the potential impact on bonding with their baby.

The maternal concern around losing focus on one's baby also ties in with literature outlining the relationship between maternal sensitivity and perceived mother-infant bonding in the general population (Bowlby, 1982; Bakermans-Kranenburg et al., 2003). In a study by Forcada-Guex and colleagues (2006), mothers who were less distracted by stress and anxiety in the first few months after birth reported themselves as more able to respond to their baby's needs and focus on developing a close relationship with their baby. Whilst it is important to retain the distinction between maternal *perceptions* of the mother-infant relationship and *actual attachment*, these studies help to explain why mothers in the current study may have lost confidence in their mothering abilities following high levels of postnatal stress and anxiety.

The infant HIV testing process after birth provided an additional set of anxieties for mothers in this study, many of whom were unable to think about the future with their baby until they

received a negative result from the infant testing process. This period of uncertainty was perceived by some mothers to prevent their fully entering into a relationship with their baby until they gained further clarity about their child's future health and survival. These findings are consistent with the literature showing that threatened infant ill health (e.g. through premature delivery) may be associated with disruptions to effective and timely mother-infant bonding (Waters et al., 2000; Hoke, 2001). Mothers of babies born prematurely have reported feeling that life has temporarily been 'put on hold', until they have more certainty about any long-term health difficulties their baby may face (Lazarus et al., 2009).

Whilst some researchers have attributed bonding difficulties in the context of threatened infant ill-health to an overly controlling and insensitive maternal style (Muller-Nix et al., 2004), the findings from the current study suggest there may be an element of maternal self-protection in preparing for the possibility of their baby being HIV positive. This relates to the 'escape-avoidance' strategies set out in Lazarus and Folkman's model of 'Emotion-Focused Coping' (1984), in which people are found to distance themselves emotionally from difficult situations to reduce or eliminate the associated distress. Researchers have found people are more likely to engage in such denial or distancing strategies when they perceive a situation must be endured and cannot be changed (McCrae, 1984).

The significant emotional challenges experienced by mothers unable to breastfeed their baby in the current study were consistent with those reported in qualitative research with HIV positive mothers diagnosed before pregnancy (Wilson, 2007; Murphy, 2009). Observational research has concluded that breastfeeding elicits positive and intimate social interactions between mothers and their infants (Fouts, Hewlett & Lamb, 2012). The majority of mothers in this study felt the bonding process with their baby had been disrupted due to this absence of breastfeeding, and experienced resulting guilt and low mood. This is consistent with findings that a lack of breastfeeding is associated with disrupted mother-infant bonding in the general population (Boyd et al., 2006). The lack of choice around such maternal behaviours has also been associated with maternal reports of less positive mother-infant relationships amongst HIV positive populations (Murphy, 2009).

It is likely, however, that the emotions experienced amongst this group of antenatally diagnosed women were more complex than for women who were unable to breastfeed for other reasons (e.g. lack of milk production or inverted nipples) due to high levels of self-blame

reported by mothers in this study. Eight out of ten of the women in this study were also exposed to the widely documented pressures from within Sub-Saharan African communities around the importance of breastfeeding (Airhihenbuwa, 2007). The internalisation of such cultural expectations for women from these countries may have contributed to the feelings of maternal inadequacy described. The average duration of breastfeeding for women in Africa is of relevance to these findings, with the median duration across Africa ranging between 16-28 months (Dop, 2008). This compares to figures from the UK, where under 50% of mothers are still breastfeeding at six weeks following birth (NICE, 2010). This highlights an extended period during which the African mothers in this study may have been experiencing negative emotions from the pressures of failing to meet societal norms.

One of the key concerns for mothers in the current study focused on the potential for HIV transmission to their infant through physical contact or the passing of saliva after birth. A study by Lazarus et al. (2009) reported that many mothers with HIV hold incorrect beliefs around the ease with which HIV can be passed from mother to child. Some mothers described having reduced their preferred levels of physical contact and affection with their baby because of these fears. These reports replicated a study from the USA showing that maternal misconceptions around HIV transmission can limit behaviours such as kissing and the sharing of utensils between mother and child (Schuster, Beckett, Corona & Zhou, 2005). Research also suggests that limited physical contact between mother and baby after birth has the potential to impact negatively upon the development of the mother-infant relationship (Pauli-Pott et al., 2004; Boyd et al., 2006).

The majority of mothers sought advice about transmission from healthcare professionals within the first couple of months after birth, learning that their concerns were based on misunderstandings about how HIV could be transmitted. It seems likely that these early misunderstandings may have been enhanced amongst this recently diagnosed group of women, with less time to learn about their HIV infection than those diagnosed prior to entering motherhood. As the majority of women in this study were also first time mothers, levels of anxiety around potential risks to their baby may have been higher than for more experienced mothers, as seen in non-HIV contexts (Green & Baston, 2003). This was reinforced by the two women in this study who had children prior to being diagnosed with

HIV, who commented on how much more challenging they would have found having their first child following their diagnosis.

Developing a special bond

Despite the various challenges faced in bonding with their baby following their antenatal HIV diagnosis, most mothers described having developed a special bond with their baby during the first year after birth. This strengthened bonding was attributed to maternal empathy during infant medication and testing; a heightened focus on protecting their baby physically and emotionally; and a sense of reciprocal life-giving and mutual inter-dependence between mother and infant. Research has reported a complex inter-relationship between motherhood and HIV, echoing the theme of reciprocal life-giving and mutual support between mother and baby. In a study involving mothers with other chronic health difficulties (Grue & Laerum, 2002), mothers reported feeling reliant on their baby for emotional support from birth, whilst also reporting significant efforts to shield and protect their children from anxiety or worry.

It seems possible that mothers in the current study may have become emotionally reliant on their baby in the absence of other sources of social and familial support. A strengthened 'exclusive' mother-infant bond was emphasised predominantly by single mothers, who described feeling emotionally entwined with their baby during the first year after birth. This replicates findings from qualitative research with single HIV positive mothers diagnosed prior to pregnancy (Hebling & Hardy, 2007), who described themselves and their baby as 'standing alone against the world' (p.50). It therefore seems the close interdependence fostered by mothers in this study may have served to meet specific needs, including overcoming barriers to bonding such as maternal loneliness and reducing maternal guilt.

Mothers described employing a number of compensatory strategies to help forge a closer relationship with their baby in the absence of breastfeeding and a vaginal delivery. These included mimicking the physical act of breastfeeding whilst bottle feeding, maximising eye contact and maintaining physical closeness to their baby at all times. This behaviour reflects the findings of Rempel and Harrison (2007) in their study with mothers of children with life-threatening heart conditions. Mothers in this study were reported to engage in 'extraordinary parenting', actively working on developing a closer relationship with their child whilst using distraction and denial techniques to manage their worry and anxiety about their child.

'Problem-focused' coping strategies of this type are effective in reducing psychological distress through supporting feelings of efficacy and situational mastery (Coetzee & Spangenberg, 2003). These maternal efforts to forge a closer relationship to their baby highlight the extent to which mothers in the current study had been aware of the early barriers to bonding associated with their antenatal diagnosis, and been active in overcoming these barriers.

As part of the mother-infant bonding process, mothers described an overwhelming desire to protect their baby from any potential HIV-related discrimination. Levels of maternal anxiety seemed strongly affected by an anticipation of how their baby *may* be treated by others, rather than the actual experience of discrimination. In line with the framework outlined by Earnshaw and Chaudoir (2009), these findings suggest that mothers may have experienced enhanced 'anticipated stigma' on behalf of themselves and their baby. This is consistent with previous research suggesting that anticipated stigma may be enhanced by motherhood (Sandelowski & Barroso, 2003; Wilson, 2007).

Whilst anticipated stigma has been noted across all groups with HIV (Mak, Poon, Pun & Cheung, 2007), the maternal preoccupation with infant protection in this study suggests that antenatally diagnosed mothers may experience heightened levels of anticipated stigma compared to other groups, including mothers diagnosed with HIV prior to pregnancy. This may be explained by the fact antenatally diagnosed mothers experience stigma associated with their HIV positive status for the first time during pregnancy, and may therefore not have had the chance to build up strategies for coping with this (Joachim & Acorn, 2000). This group will also have had limited opportunities for positive experiences of disclosing their HIV status to others, possibly leading to increased levels of anticipated stigma in the community. Research also suggests that this group may be particularly vulnerable to anticipated stigma associated with continuing their pregnancy as an HIV positive woman (Kelly et al., 2012), possibly due to cultural expectations around motherhood discussed.

Strengthening and moving on

The final stage of mothers' experience following the completion of infant HIV testing involved a positive shift in perspective on their diagnosis and on-going relationship with their baby. Looking back on their experiences in a positive light brought feelings of strength and hope

for a healthy future with their child. Participants also reported feeling strengthened as a mother following testing. Women particularly reported having gained confidence and gratitude for their situation in comparison to women without access to treatment or the opportunity to become a mother. The shift towards a more positive emotional state following infant testing also appeared to be linked to a more relaxed approach to motherhood, and a greater perceived responsiveness to their baby's needs.

These findings are in line with Taylor's (1983) 'Cognitive Adaptation Theory', which views people as adaptable, self-protective and functional in the face of adversity such as a chronic health diagnosis. This theory suggests that stressful events challenge core beliefs, and people are then motivated to restore a sense of meaning (achieved by positive growth); a sense of mastery (achieved by changes in controllable aspects of life) and self-esteem (achieved through downward social comparison to others). The findings are also consistent with the strategies of 'Positive Reappraisal' (Folkman & Moskowitz, 2000) and 'Benefit Reminding' (Affleck & Tennen, 1996), in which people learn to reappraise challenging situations in a positive light. Features of these strategies are clearly present within this study, and have also been found in studies with African women living with HIV in the UK (Flowers et al., 2006; Ndirangu & Evans, 2008). Women's ability to employ such strategies and reframe their role as a mother played a clear supportive role in further strengthening the mother-infant relationship following infant testing.

Spiritual perspectives and religious-based practices such as prayer have been found to provide psychological relief from aversive experiences for women living with HIV/AIDS, especially amongst women of African descent (Morse et al., 2000). The shift in emotional well-being of mothers in this study following the completion of infant testing was attributed by many to a renewed trust in God for their future health and wellbeing. For some mothers, their faith allowed them to understand their HIV as forming part of a greater spiritual journey or plan. The 'handing over' of their health status and future wellbeing to God can be understood in terms of Rotter's (1966) 'Locus of Control', related to Attribution Theory (Weiner, 1986). In line with Rotter's theory, mothers showed a shift towards a more 'external local of control' (e.g. believing their situation was guided by God), reducing earlier feelings of self-blame associated with an 'internal local of control' following diagnosis (e.g. believing their situation was due to their own personal decisions). This is also consistent with research suggesting that

one's internal or external locus of control can change depending on circumstances (Hans, 2000). For many women in this group, this shift took place relatively late in the infant testing process, as previous concerns around infant health began to subside.

Mothers in this study saw their responsibility to look after their child as central to helping overcome anxieties about their own health in the future. To achieve this, women employed active coping strategies to distance themselves emotionally from HIV and move on with being a mother. This reflects the findings of Joachim & Acorn (2000), who described HIV positive women as engaging in 'stigma management', using cognitive strategies to enhance normalisation of their situation and disavow identities as diseased or dying people. For many mothers in this study, their baby gave them the strength they felt they needed to fight HIV and bring hope for a long life together. Whilst achieving this sense of hope has been found amongst HIV positive mothers in previous studies (Sandelbowski & Barroso, 2003), this process may have been affected for this group by the relatively short period of adjustment to their diagnosis, and the implications for motherhood, prior to the birth of their baby.

Strengths and limitations

Strengths

One of the key strengths of this study was the recruitment of a specific group of antenatally diagnosed women, whose experiences have rarely been explored in isolation from the wider cohort of mothers with HIV. The majority of participants in this study were from African countries (80%), with 29.5 years the average age of antenatal diagnosis. This sample appears to be representative in terms of age, ethnicity and country of origin when compared to the total population of mothers diagnosed antenatally with HIV at the study hospital site.

Another strength of this study was the incorporation of various credibility checks and triangulation methods to maintain quality and allow for validation of the categories and the emerging theory (Madill, Jordan & Shirley, 2000). The use of internal and external supervision alongside peer-support and feedback through the Royal Holloway Grounded Theory Trainee Support Group provided validation of the initial coding table for sense and clarity (Charmaz, 2006). This ensured that the researcher did not miss important themes and that the labels and

interpretations fitted the data well. Internal supervision focused on ensuring that codes were not overlapping and that higher order themes captured lower order themes. An additional phone consultation was carried out with the specialist HIV midwife at the hospital sexual health service who had supported all participating women through their pregnancies and births. This was conducted following initial analysis of data to validate the key themes and draft model to help increase the quality and clarity of the findings. These processes also helped to ensure the coherence of results, which is thought to be important in the design of good quality qualitative research (Patton, 2001). Service-user feedback on the interview schedule prior to data collection ensured greater clarity and sensitivity around the questions being asked. Whilst the use of email feedback may not have been as informative as a face-to-face discussion with service-users, this process was carried out within the constraints on time and confidentiality set out by the participating organisation.

Kvale and Brinkmann (2009) further suggest that asking participants about their experiences of being interviewed can strengthen the validity of a qualitative study. Feedback from participants at the end of interviews suggested they largely appreciated the opportunity to reflect on their difficult experiences, and identify what had helped them to manage during this period. The use of a reflective diary (Appendix 4) and the writing of memos (Appendix 10) throughout the research process strengthened this study in shaping the editing of research questions. This process also helped in capturing early concerns about researcher influences on the study findings, such as the potential undue influence of knowledge gained from prior clinical experience with this group.

Limitations

The study may have been compromised by the completion of a literature review for course and ethics committee requirements prior to the collection and analysis of data (Charmaz, 2006). To counter this limitation, the author attempted to 'bracket' existing knowledge by capturing prior assumptions before data collection and watching for when questions might have been leading. 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). However, validation of the study findings with participants would have

further enhanced quality checks of the study (Elliot et al., 1999), and was not carried out due to time restrictions.

The participants for this study were recruited from one inner-city hospital site, potentially limiting the external validity and generalisability of the findings to other sites across the UK. The majority of the sample (8 out of 10 women) were first time mothers, suggesting that the emergent model may not be relevant to all mothers diagnosed with HIV during pregnancy, such as those with previous and subsequent children. Although Grounded Theory aims for the emergent model to be relevant to the population sampled (Corbin & Strauss, 1990), it would have been clinically useful for the model to be applicable to a larger group of mothers.

From the pool of participants meeting the inclusion and exclusion criteria, 16 (out of 50) patients were marked as being lost to follow-up, having disengaged from the service at some point following diagnosis. The final recruitment rate for this study was 40% (10 out of 25 approached), with over 40% of those approached (11 women) declining to take part in the study. These patients stated that their experience was either still 'too raw' to speak about, or that their partner did not want them to take part. It is therefore possible that the present sample may have been limited to those with more positive experiences, with additional challenges potentially not captured within this study. Ethical approval for this study did not allow for details of mothers who had disengaged from services, or those who declined involvement in the study, to be explored. This therefore forms a significant limitation for the study findings in terms of generalisability to the wider pool of women who are diagnosed with HIV during pregnancy.

The retrospective design of this study led to reliance on women recounting recollections of their experiences of bonding with their baby. It is possible the data collected may have been subject to recall biases (Kazdin, 1998), which may have compromised the reliability of the study. The researcher attempted to limit the potential for such bias, by narrowing the inclusion criteria to include only those with a post-diagnosis child under 4 years of age. Previous studies have also shown that mothers participating in research are likely to be strongly influenced by cultural and societal expectations of motherhood (Paulson et al., 2006), with a high potential for social desirability within this type of qualitative research (Crowne & Marlowe, 1960). The author attempted to reduce these biases by emphasising

confidentiality, ensuring anonymity and outlining the purpose of the research for helping mothers diagnosed antenatally in the future.

Grounded Theory suggests that sampling should be purposeful and explore new areas of interest emerging within the data (Charmaz, 2006; Glaser & Strauss, 1967). From this perspective, it may have been beneficial to sample increasingly purposively as the study progressed, such as focusing recruitment on mothers without religious faith, or those who had chosen to breastfeed. This may have provided further insight into the specific challenges or facilitating factors that were present for different groups of mothers. It is also unlikely that all categories in this study reached saturation, due to the relatively small sample size and the participants' difficulties at points in articulating their own experiences in relation to bonding (Levitt, Butler & Hill, 2006).

A final limitation of this study is the level of demographic information collected, which could have been more systematic to provide more context for the sample. Data that may have been useful includes the continuing use of medication for mothers, the location of family members (in the UK or abroad) and more systematic recording of mothers' living conditions, both antenatally and postnatally.

Suggestions for future research

There are several potential avenues for future research arising from this study. Firstly, the findings highlight the importance of the systemic context in which mothers receive their diagnosis, and the emotional difficulties associated with partner abandonment during pregnancy. A valuable area of future research would be to explore the perceptions and experiences of partners who are in a relationship with a women diagnosed with HIV during pregnancy. Women in this study whose partners remained present following their antenatal HIV diagnosis reported feeling more able to manage the demands of new motherhood than newly single mothers. Quantitative research has shown that single mothers in the general population show poorer emotional involvement and bonding with their new-born infants than new mothers who are married or cohabiting (Figueiredo, Costa, Pacheco & Pais, 2009). It would therefore be helpful to learn more about the experience of partners in the context of a maternal antenatal diagnosis of HIV, and what enables fathers to adjust and support their

partner through this difficult process. Of particular relevance would be exploring the type of support or information that would be most helpful in understanding their partner's diagnosis, establishing their own HIV status and preparing for parenthood (Ramchandi, 2005). It may be beneficial to carry out a dyad study involving both women and their partners to explore more about their joint experiences following a maternal HIV diagnosis during pregnancy.

Another potential area of interest for future research would be a deeper exploration of the 'anticipated stigma' experienced by newly diagnosed mothers in this study during the antenatal and postnatal periods. Anticipated stigma is known to limit social interactions and impact on negative feelings about the self for people with HIV (Earnshaw & Chaudoir, 2009). This study suggests that recently diagnosed mothers feel the potential for HIV-related stigma most acutely on behalf of their child, rather than themselves, with mothers avoiding disclosure of their status to protect their baby from discrimination. It may therefore be useful to conduct a longitudinal study exploring how anticipated stigma changes over time for new mothers following an antenatal diagnosis, and what helps in reducing the experience of this stigma for mothers. Such research could lead on to considering ways to better support newly diagnosed women in managing disclosure and coping with the experience of HIV-related stigma and discrimination, as set out in the BHIVA (2012) guidelines for HIV in pregnancy women.

Personal reflections

Throughout the process of conducting this research I have reflected my own social and cultural background as a white, middle-class, female professional, whilst interviewing a predominantly socio-economically disadvantaged group of HIV positive women from Sub-Saharan Africa. My reflections drew on the work of Russell (1996), who stresses the need for an anti-discriminatory research model when working as a white female researcher with a black female participant group. I also reflected on issues of similarity and difference regarding religious beliefs, views on breastfeeding, age and relationship status. I have 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.

I was aware of my dual role as researcher and clinician whilst interviewing, and found it challenging during early interviews to balance my remit of exploring women's experiences, whilst desisting from engaging in a therapeutic style and encouraging participants to move forward in their thinking (e.g. through challenging dysfunctional assumptions). I also became aware in some interviews with women whose partners had left them following diagnosis, that I was feeling anger on behalf of these women for the perceived unfairness of their situations. I have found the use of both internal and external supervision to be invaluable in helping me to reflect on these challenges and maintain awareness of the potential impact of my own background, and the emotions aroused within me during interviews, upon different aspects of the research.

A prominent area of reflection throughout the data collection, analysis and reporting stages of this study has been the fact I myself became pregnant half way through carrying out the research. From one perspective, I feel this has provided me with a beneficial level of insight and understanding when discussing pregnancy details with mothers, such as blood tests and scans. On the other hand, I realise it may potentially have reduced aspects of my objectivity as a researcher, through any impact of my pregnancy experience upon my interpretation of the findings. Dwyer and Buckle (2009) suggest there are advantages and disadvantages to the researcher sharing 'a direct experiential base' with their participant group in qualitative research (p.8). Some studies have shown that sharing an identity or experience with research participants may allow the researcher more rapid acceptance by their participants (Asselin, 2003). Others have suggested there may be biases in the interpretation and analysis of findings, with personal experiences providing undue influence and compromising objectivity (Armstrong, 2001). With this in mind, I have tried to maintain awareness of how my own experience of pregnancy might affect my interpretation of findings, and separate my own feelings from those of participants.

My own pregnancy became visibly identifiable half way through the completion of participant interviews, following a one-month gap in recruitment between participants 5 and 6. This meant that the latter group of participants would have been aware of my pregnancy, whilst the first group were not. I found the majority of participants to be open in sharing their personal experiences with me from the outset, but felt the latter group of women more immediately open and trusting of me within interviews after they had noticed my pregnancy.

I reflected on whether this could be connected to women seeing me as more of an 'equal', with a shared experience of pregnancy breaking down some of the pre-existing barriers of ethnicity and professional status.

It felt challenging at points in this research for women to talk directly about developing a relationship with their baby. Women spoke openly about a range of difficulties they had faced since their antenatal HIV diagnosis, but seemed less inclined to specify details relating to bonding with their baby. This was despite direct questioning such as 'How would you describe your relationship with your baby in the first few days after birth?' There are several possible explanations for this. One relates to the ethnic and cultural backgrounds of eight of the ten participating women, originating from Western and Eastern African countries (see table 1). Nuclear family structures are much less common in Africa, with less focus on the dyadic relationship between mother and infant, and more emphasis on the extended family system around the child (Kimani & Kombo, 2010). The influence of cultural backgrounds could, therefore, have affected the extent to which participants were already primed to think about the dyadic relationship and bonding between mother and child.

Another explanation is that mothers may have been reluctant to discuss any difficulties in bonding with their baby due to concerns about how this might be perceived or acted on by myself as a researcher. 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. This could have been further exacerbated due to my own pregnancy, and concerns about how their experiences may be interpreted by me. This can also be linked to recent research on self-disclosure in personal therapy (Cruddas, Gilbert & McEwan, 2012), which has linked fear of personal disclosure to anxiety, feelings of shame and negative social comparison (e.g. feeling inferior to the therapist). For women who faced significant challenges in bonding with their baby, the reluctance to discuss this process could also be understood in terms of psychoanalytic theory (Freud, 1933; as cited in Stratchley, 1940). Such theorists would propose that women may employ unconscious defensive strategies to minimise having to engage with the emotional pain of certain memories or experiences (Lindeman, 1944).

Clinical implications of the findings

The findings highlight a number of factors which may be relevant to practitioners supporting women diagnosed antenatally with HIV in the future.

1. Psychological support: The findings highlight the importance of providing effective and timely psychological, social and practical support to women following an antenatal diagnosis of HIV (Segurado & Paiva, 2007). Existing BHIVA guidelines (2012) for working with HIV positive women antenatally focus almost exclusively on the medical management of HIV prevention of mother-child transmission, with limited focus on psychological needs during this period. The BPS guidelines for addressing the psychological needs of adults living with HIV (2011) suggest that antenatal and postnatal psychological support should be made available through manualised approaches (e.g. motivational interviewing) provided by Level 2 practitioners, trained to provide information and support but not psychological interventions. This study shows that women diagnosed antenatally may experience a complex range of emotions following diagnosis, including ambivalence about pregnancy, anxiety about the future and fears about HIV medication. The findings also suggest the need for psychological intervention which focuses specifically on women's emotional and psychological transition to motherhood and developing a relationship with their baby in the context of adjusting to their recent HIV diagnosis. Whilst all women in this study appear to have eventually adjusted to their diagnosis, it is arguable that psychological intervention from level 3 practitioners at an earlier stage could have minimised unnecessary distress sooner.

Whilst the BHIVA (2012) and BPS (2011) guidelines recognise the importance of psychological support during this period, there is little detail about which psychological approaches may be most useful for women. The following approaches may be beneficial for addressing the specific challenges raised by mothers in this study:

- Specific psychological interventions designed to prevent low mood and boost maternal wellbeing following birth (e.g. postnatal support outlining by Dennis, 2005) could be adapted for use with this group;
- Compassion Focused Therapy (Gilbert, 2009a; 2010) may be beneficial in working to address the pervasive experience of maternal guilt and shame described during the infant testing process;

- Cognitive Behavioural Therapy (CBT) may be appropriate for helping manage maternal anxiety and support the positive cognitive reframing (e.g. regarding thoughts about the future) which was found to help many of the women in this study (Beck, 1995);
- Acceptance and Commitment Therapy (ACT) approaches may be beneficial in helping women to come to terms with their diagnosis and the implications for maternal role and identity (Hayes, Kirk & Kelly, 2011).
- Behavioural interventions to enhance mother-infant bonding could be adapted from existing interventions for at-risk families (Zeanah, Strafford & Zeanah, 2005), which involve one-to-one and group support around mother-infant bonding and relationship development in the first year after birth.
- Interventions to facilitate the disclosure of HIV status following an antenatal diagnosis (Dass-Brailsford, 2012). The 'Model of HIV Disclosure' (Bairan et al., 2007) provides an example for healthcare practitioners in supporting people with HIV to disclose to friends, sexual partners and family members.

2. The role of the specialist HIV midwife: The majority of women in this study found the continuity of support and reassurance provided by the specialist HIV midwife at the hospital to be invaluable. Specialist HIV midwives allow for continuity of care through from diagnosis until the end of the infant testing process, and have psychological training to carry out an important role in assessing feelings of maternal isolation, anxiety, ambivalence and distrust of treatment (BHIVA, 2012). This professional can also play a key role in supporting women to disclose their HIV status to their partner following diagnosis (e.g. through role play and being physically present when they tell their partner), which guidelines state is a process that should be closely supported by professionals (BHIVA, 2012). The study findings suggest this individual could also be central in helping to boost a sense of maternal empowerment and control over decision making around childbirth and feeding. A greater sense of control may become more realistic as increasing numbers of HIV positive women are able to elect a vaginal birth delivery (BHIVA, 2012).

3. Timely information and psycho-education: The findings suggest that mother-infant bonding may be at risk of disruption in some cases, due to maternal misunderstandings about the mother-infant transmission of HIV. This suggests that clear information from healthcare professionals about HIV transmission would be beneficial at a point at which mothers are able

to understand and absorb this information. It is important this is repeated more than once to allow for adjustment following diagnosis, including during the first few days after birth and at the two week check-up. Clear statistical information and reassurance about mother-child transmission rates is also likely to be informative for women who are considering pregnancy termination due to fears of infant infection (BHIVA, 2012). Research shows that written information produced in accessible formats can help in normalising the experiences of mothers with HIV and encouraging support-seeking during this vulnerable time (Murphy et al., 2002).

4. Support in mother-infant bonding: Specialised services currently exist within the NHS to support mothers who are struggling to bond with their baby for a range of reasons. Services such as Perinatal and Infant Mental Health Services (PIMHS) are located within Child and Adolescent Mental Health Services (CAMHS) in the NHS, using both psychodynamic and systemic interventions. Research shows, however, that these services have increasingly limited capacity and extensive waiting lists (Barlow et al., 2010). Psychologists, psychotherapists and other mental health workers in such settings could provide targeted support to this group of antenatally diagnosed mothers who are reporting difficulties with relating to their baby. The study findings suggest that support for the following may be helpful:

- managing emotions related to breastfeeding restrictions;
- coping with feelings of distance from their baby;
- managing anxiety around HIV transmission; and
- engaging in behaviours that support effective mother-infant bonding, such as skin-to-skin contact between mother and baby (Svanberg, 2009).

Research shows that such support is most beneficial in cases in which the mother, baby and partner (or close family member) are all involved and engaged in the process (Edge, 2011). This may be challenging for mothers who have not disclosed their HIV status, or whose partners are no longer present following the birth of their baby.

5. Social support: Research has shown the effectiveness of peer support, both in helping women to adjust to a diagnosis of HIV (Simoni et al, 2011), and in helping new mothers in the general population to manage maternal anxiety and isolation following the birth of their first

baby (Dennis et al., 2009). The levels of social isolation reported in this study suggest that specific support groups for women diagnosed antenatally may be particularly useful at key points, such as post-diagnosis and commencing the infant testing process. The strong levels of religious belief described amongst this study sample also suggest a role for faith groups in providing such support for new mothers (Siegel & Schrimshaw, 2002). BHIVA (2012) guidelines suggest that midwives, health visitors and social workers can play a role in supporting mothers to forge links with key organisations and facilitate the development of supportive peer relationships. The study findings also suggest these professionals could play a key role in supporting women to disclose to their partners, supporting the partners through adjustment to the diagnosis and providing targeted support to women whose partners leave them following disclosure of their diagnosis.

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Appendix 1: Participant Information Sheet

Version 2, 21.03.12

What is the experience of mothers getting to know their infants after a diagnosis of HIV during pregnancy?

We are carrying out a study exploring women's experiences and memories of getting to know their babies after they have been diagnosed with HIV during pregnancy. This is a student project being carried out by me, a Trainee Clinical Psychologist, as my doctoral thesis.

I would like to invite you to be interviewed by me at XXXXXX Department of Sexual Health about your experiences and memories of getting to know your baby after being diagnosed. The interview will last no longer than 1 ½ hours, and will include some questions about how you felt during the first few weeks and months after your child was born, and what helped you to cope during this time.

Before you decide if you want to take part, it's important that you understand why I am 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 spouse, partner or family before you decide whether or not to take part, please feel free to do so and to ask me any questions you may have.

Why am I doing this research?

I would like to find out more about what it is like for women bonding with their new-born babies after being diagnosed with HIV during pregnancy. I am particularly interested in people's different experiences, how they felt about themselves at the time and what helped them to get to know their babies during this time. I am also interested in looking at whether these specific experiences are similar or different to the experiences of other mothers following the birth of their infants.

Why are you asking me to take part?

I am asking you to take part in this study because you are a mother who was diagnosed with HIV during pregnancy at the XXXXXX Department of Sexual Health in the past 3 years.

What will happen in the interview?

The interview will include a number of questions that have been planned in advance. You will not have to fill out lots of forms at the interview, but some open questions will be asked at the beginning about when you were diagnosed with HIV, your general wellbeing at the moment and how many children you have. You will be welcome to ask me any questions you have about the project at the point before we begin. If you agree to take part, I will also look at your medical records to collect information about your health at the time of diagnosis and birth.

Where will the interview take place?

The interview will take place in a quiet and private room at the Clinic within the Department of Sexual Health, XXXXXXXX Hospital. We will reimburse your time for taking part in the interview to the value of £20. To allow you to be able to speak freely, we would ask that you arrange for your child/ren to be looked after elsewhere during the interview.

Do I have to take part?

No, you don't. 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?

I will treat the information from interviews as highly confidential and keep it in a locked and secure location. Only you and me, Kate Willcocks, will know that you have given the answers you have. My supervisor, Dr Michael Evangeli, will have access to the anonymised information but not to any other information that might identify you. In very rare cases, if you tell me something during the interview that suggests that you or someone else might be at risk of serious harm (for example, if you tell me that you are planning on harming yourself), I may need to speak to your clinical team so that they are able to provide you with support. I 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 only people who will have access to the consent forms are Kate Willcocks and Ms Sarah Zetler (or her replacement), Clinical Psychologist at the Department of Sexual Health. Ms Zetler is involved in supervising the study. The interviews themselves will be recorded on a Dictaphone and will be kept in a safe place, and then transcribed in full and stored as word documents in password protected computer folders. The consent forms you sign will be destroyed 12 months after the study has ended.

Who will be writing up the research?

Kate Willcocks will look at the information carefully and use it to write a thesis as part of a professional qualification to become a Clinical Psychologist. We hope that these findings will

be used to plan health services for the future. Before the thesis is written, 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 don't wish to have any further involvement at this stage, there is no need to do so. The data collected may also be used to write academic papers for publication or may be presented at conferences. No identifiable information will be included in these papers or the conference presentations.

Are there any disadvantages or risks of taking part?

Some people find talking about HIV and their diagnosis difficult, sensitive or in some cases upsetting. I will ask the questions in a sensitive, tactful and non-judgemental way. I do not believe that any question has a right or a wrong answer; I am interested in hearing about your experiences. You don't have to answer any question that you don't want to. If you want to talk to anyone from your clinical team about things that you've discussed in the interview, I could help facilitate this, or you could approach someone of your own accord. At the end of the interview I will give you details of organisations you may wish to contact should you wish to speak to someone outside of the clinic.

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 following a diagnosis of HIV during pregnancy. This knowledge could help to develop better services for people in your situation in the future.

Will I get anything personally for taking part?

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

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

Before I begin the research I have to get approval from the Royal Holloway University of London research committee and an NHS 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. The London Bloomsbury REC committee has also reviewed this research project (reference number: 12/LO/0339).

If you are unhappy with anything to do with the research, please contact me on the email address is provided below). If you are still unhappy, or you don't wish to talk to me about it, please contact The Patient Advice and Liaison Service (PALS) at The XXXXXX Hospital who will be happy to listen to you and will help you make a formal complaint. Their number is XXXX XXX XXXX. Best wishes, Kate Willcocks Trainee Clinical Psychologist

Kate.willcocks.2010@live.rhul.ac.uk Thank you for taking the time to read this letter.

Appendix 2: Participant Consent Form



Version 2, 21.03.12

Title of the project: The experience of mothers diagnosed antenatally with HIV

Names of Investigator: Ms Kate Willcocks

Ethics Committee Reference number: 12/LO/0339

**Please
initial box**

1. I confirm that I have read the information sheet dated 21st March, version 2 for the above study and have had the opportunity to ask questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected

3. I agree to have my interviews with Ms Kate Willcocks audiotaped.

4. I agree to take part in the above study.

5. I agree to having my anonymous quotations used in the reports produced for this study.

6. I agree to my medical notes being looked at for the purpose of this study.

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 XXXX Hospital. They may be able to provide support directly or refer you on for additional support. You may also wish to contact your GP.

If you feel at 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:

Positive East:

“Here to help anyone affected by or living with HIV in East London. Looking for information about our services in a hurry? Positive East can provide confidential and impartial help, support and information services for anyone living with or affected by HIV, or accessing HIV services in east London.”

- Website: www.positiveeast.org.uk
- Email: advice@positiveeast.org.uk
- Phone: 0207797 2855

Positively UK:

“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.”

- Website: www.positivelyuk.org
- Phone: 020 7713 0222

Terrance Higgins Trust:

“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.”

- Website: www.tht.org.uk
- Phone: 0808 802 1221

Women for Positive Action:

“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.”

- Website: www.womenforpositiveaction.org
- Email: WFPA@litmus-mme.com

Best wishes, Kate Willcocks

Appendix 4: Excerpts from Research Diary

Wednesday 9th May, 2012

I delivered a presentation this morning to the whole of the sexual health service about my study as part of the service CPD programme. It was quite nerve-wracking beforehand, but I'm really glad I've done it and hope it will help people to know my face and remember the study. The presentation seemed well received, but there were some questions I may need to consider. The issue over childcare was raised again and it was difficult to answer, with some disputing that £10 was enough to cover childcare costs. There was also a question over culture, for example breast-feeding is thought about very differently in different parts of Africa and this may impact on the mothers' experience of not being able to breastfeed. I explained to the group that I would be around in the next couple of months recruiting, and would be happy to answer any questions that anyone has. I need to make sure that cultural implications around breastfeeding are properly addressed in my introduction and discussion sections. The seemed to go well generally, and I feel positive about recruitment at the Homerton that the clinicians are on side and see the point of the project. Things I need to follow up on after today:

- Circulate copies of participant information sheets to clinicians, as promised
- Follow-up email to the team, outlining my days of recruitment over the next month
- Email to XXXX (lead clinician) summarising presentation and queries.

Monday 18th June, 2012

One of the concerns at the moment is that recruitment and interviewing is charging on (five interviews completed, another two booked) but I haven't yet made any changes to the interview guide. I'm going to Grounded Theory training in Bournemouth for two days this week, so hopefully that will help with planning the rest of the data collection and analysis. This is one of the problems with carrying out a GT project for a student doctoral thesis – that you can't actually properly follow the format intended, and this includes having done a literature review before you even begin data collection. I am concerned that my knowledge of the literature has influenced some of the ways in which I'm asking questions and coding the data. It's impossible for what I know about the challenges not to seep into my questioning, and it has been a surprise that many of the challenges raised through previous studies have not been raised yet as part of this project. I must remember to refer back to my paragraphs

outlining my 'prior assumptions' when analysing data and writing the results section.

Thursday 5th July, 2012

I think it's probably important to reflect on my pregnancy, and how this may be impacting on my research and researcher role. Having previously not had children, I was coming to this research fresh with some preconceived ideas of what it might be like to be pregnant, but no direct knowledge. I am now 12 weeks pregnant and will be 6 months by the time data collection is completed. I already feel that I am getting a small sense of what it must have been like for these women finding out that they had a chronic illness that is potentially transmittable to their unborn child at this stage of pregnancy. You feel an unbelievable level of protection towards your child, born or not born, and it is your maternal role to protect that child and ensure that they don't come to any harm. I feel that through my pregnancy I am going to get a new perspective on this research, and that I have to make sure that I am still able to occupy the objective position of a researcher during the process. I think it is also important to note that for some of my final participants, it is likely that I will be starting to show my pregnancy, and that will not have been the case with the first group. I wonder whether this will have an impact on how they relate to me, and whether this might alter the quality of the information at all. I need to talk in supervision about how I handle this, and whether I introduce my pregnancy to them or let them notice or not.

Friday 10th August, 2012

I completed interview number X today, and realised during the interview that I was feeling very angry on behalf of the participant, whose partner had disappeared and never contacted her again following her disclosure of her HIV status. She has no idea whether or not he is HIV positive or not, but feels this is likely to be how she contracted HIV. It just felt so unfair that this woman was placed in a position of having to go through pregnancy, birth and being a single mother just because of her HIV status and the fact that men are more able to leave. She had so many unanswered questions, and was clearly very hurt by his sudden abandonment of herself and of their child. I think it is important to recognise when I am feeling angry, and how these emotions may impact upon my interviewing style and the way in which I interpret the data. This is something I should take to supervision to discuss further.

Appendix 5: NHS Research Ethics Committee (REC) approval letter



Health Research Authority

National Research Ethics Service

NRES Committee London - Bloomsbury

HRA NRES Centre Manchester
Barlow House 3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7815
Fax: 0161 625 7299

20 June 2012

Miss Kate Willcocks
Trainee Clinical Psychologist
Department of Psychology, Clinical Doctorate Programme
Royal Holloway University of London
Egham
Surrey
TW20
0EX

Dear Miss Willcocks

Study title:	How do mothers experience bonding with their infants following a maternal diagnosis of HIV during pregnancy?
REC reference:	12/LO/0339
Protocol number:	N/A
Amendment number:	Substantial Amendment 1
Amendment date:	11 May 2012

- The amendment proposes to change the recruitment procedure. It is also proposed to broaden the inclusion criteria.
- Finally, there is a change in the local collaborator.

The above amendment was reviewed at the meeting of the Sub-Committee held on 19 June 2012.

Ethical opinion

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
Investigator CV	Penny Petrak	
Protocol	2	08 May 2012
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1	11 May 2012

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.

12/LO/0339:

Please quote this number on all correspondence

Yours sincerely



Signed on
behalf of: **Dr
Joe Brierley
Chair**

E-mail: ashley.totenhofer@northwest.nhs.uk

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

Copy to: Ms Linda Legrand (nee Stephenson) - Homerton University Hospital
NHS Foundation Trust

Professor John Wann – Royal Holloway University of London

Appendix 6: Email approval from the Departmental Ethics Committee (DEC)

From: Blackman, Carol [Carol.Blackman@rhul.ac.uk]
Sent: 04 April 2012 14:57
To: Willcocks, Kate (2010)
Cc: Pote, H; Evangeli, Michael; Lock, Annette
Subject: Ethics Proposal 2012/037

Dear Kate,

Ethics Proposal 2012/037: How do mothers experience bonding with their infants following a maternal diagnosis of HIV during pregnancy?

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 7: REC Approval of Ethics Amendment



Health Research Authority

22 March 2012

Miss Kate Willcocks
Trainee Clinical Psychologist
NHS (Camden and Islington Foundation Trust)
Department of Psychology, Clinical doctorate programme
Royal Holloway University of London
Egham, Surrey, TW20 0EX

Dear Miss Willcocks

Study title: How do mothers experience bonding with their infants following a maternal diagnosis of HIV during pregnancy?
REC reference: 12/LO/0339

Thank you for your letter of 21 March 2012, 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](#).

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).

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>
Advertisement	2	21 March 2012
Covering Letter		10 February 2012
Evidence of insurance or indemnity		05 July 2011
Interview Schedules/Topic Guides	1	02 February 2012
Investigator CV		02 February 2012
Letter from Sponsor		25 March 2010
Other: CV: Michael Evangeli		
Other: CV: Helen Pote		
Participant Consent Form	2	21 March 2012
Participant Information Sheet: Dear Participant	1	02 February 2012
Participant Information Sheet	2	21 March 2012
Protocol	1	02 February 2012
REC application		
Referees or other scientific critique report		12 January 2012
Response to Request for Further Information		21 March 2012

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

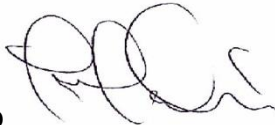
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

12/LO/0339	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



pp
Dr Joe Brierley Chair
Email: taki.austin@imperial.nhs.uk

Copy to: *Miss Kate Willcocks, NHS (Camden and Islington Foundation Trust)*
Ms Linda Legrand (nee Stephenson), Homerton University Hospital
NHS Foundation Trust

Appendix 8: Interview schedule

Version 2, 18th May 2012

Interview process

1. Introductions

- The purpose of this research study is to find out more about the experiences of women getting to know their babies after receiving a diagnosis of HIV during pregnancy.
- The study aims to gather information to help professionals to better support these women, their babies and their families following birth.
- This interview will include some open questions about your personal experience and memories of getting to know your baby, and what helped you to cope during this time.

2. Confidentiality and consent

- Explain standard confidentiality procedures
- Remind interviewee that she has the right to withdraw from the study at any point, without need for explanation, and that this will have no impact at all on the healthcare they receive from the Homerton Hospital.

3. Any questions?

Interview schedule

Warm up questions

- Tell me a bit about your family
- Where is your child/children today?
- How are you feeling health-wise at the moment?

Diagnosis and pregnancy

I'd like to start, if you feel able, by going back to the time you first heard about your HIV diagnosis.

- Do you remember how you felt at the time?
- What thoughts did you have about your pregnancy following the diagnosis?
- What thoughts did you have about yourself as a mother?
- How did you share the news with others?
- What were their reactions? Did you have support from a partner/friends/family?

- What helped you during that time?

The birth and immediately following

Now I'd like to go back to thinking about when your child was born...

- What was the birth like for you?
- How did you feel immediately after birth?
- Can you remember how you felt about your baby?
- How did you feel about yourself?

(If participant was worried/had negative thoughts and feelings) –

- What did you make of these thoughts/feelings?
- Did anything help you cope? Did anything make you feel worse?

Early stages (first few days)

- How did you feel when you first saw your baby, after being born?
- What were the first few days like after your child was born? What was it like getting to know your baby?
Probes: What was it like being with your baby in hospital? Who was with you when you first brought your baby home?
- How would you describe your relationship with your baby in the first few days after he/she was born?
- How did you feel about yourself at this time?
- Who else was around at that time? What would they have said about your baby/about you as a mother?

Possible probes:

- What were the positive things about getting to know your baby? What things helped with this process?
- Were there any things that made getting to know your baby difficult?
- Were there any things you felt, or thoughts you had at the time, which you didn't feel able to share with other people?
 - PROBES – Did you have any difficult feelings towards your baby during this time? Did you have any feelings or thoughts that surprised you?

Middle stages (up to 6 months)

- Can you remember what the first few weeks were like after your child was born?
 - How would you describe your baby in those first few weeks? Probes: How was sleeping, feeding, crying etc?
- Who else was around at that time? What would they have said about your baby/about you as a mother?
- How did you feel about yourself as at this time?
- How did you manage with those first few weeks and months? What or who helped you?
- Did anything make things more difficult?

Later stages (6-12 months)

- Can you remember what it was like as your baby started to become more interactive with you?
- How did you feel about yourself during the second half of this first year?
- How did you manage with those first few weeks and months? What or who helped you during this time?
- Did you feel that anything helped or got in the way of you getting to know your baby better as he/she started interacting more?
- Did anything make things more difficult for you?

PROBES:

- Were there any things you felt, or thoughts you had at the time, which you didn't feel able to share with other people?
- Did you have any difficult feelings towards your baby during this time? Did you have any feelings or thoughts that surprised you?

Final questions

- If you were going to describe your experience to someone of being a mother with HIV, and particularly having a baby after an HIV diagnosis in pregnancy, what would you say?
- Is there anything else which you think might be important for me to know about your relationship with your child following their birth?

Thanks for participation and close

Appendix 9: Edited Interview Schedule

Version 3, 27th July 2012

Warm up questions

- Tell me a bit about your family
- Where is your child/children today?
- How are you feeling health-wise at the moment?

Diagnosis and pregnancy

I'd like to start, if you feel able, by going back to the time you first heard about your HIV diagnosis.

- Do you remember how you felt at the time? Do you remember how you felt about yourself/other people (e.g. partner)?
- What thoughts did you have about your pregnancy following the diagnosis?
- What thoughts did you have about yourself as a mother?

Disclosure

- How did you share the news with others? If not, what stopped you from telling them? Did you think people not knowing about your HIV impacted on your experience of being a mother in any way?
- If yes - What were their reactions? Did you have support from a partner/friends/family?
- What helped you during that time?

The birth and immediately following

Now I'd like to go back to thinking about when your child was born...

- What was the birth like for you?
- How did you feel immediately after birth?
- Can you remember how you felt about your baby?
- How did you feel about yourself?

(If participant was worried/had negative thoughts and feelings) –

- What did you make of these thoughts/feelings?
- Did anything/anyone help you during this time? Did anything/anyone make you feel worse?

Early stages (first few days)

- How did you feel when you first saw your baby, after being born?
- What were the first few days like after your child was born? What was it like getting to know your baby?
Probes: What was it like being with your baby in hospital? Who was with you when you first brought your baby home?
- How would you describe your relationship with your baby in the first few days after he/she was born?
- How did you feel about yourself at this time?
- Who else was around at that time? What would they have said about your baby/about you as a mother?

Possible probes:

- What were the positive things about getting to know your baby? What things helped with this process?
- Were there any things that made getting to know your baby difficult?
- Were there any things you felt, or thoughts you had at the time, which you didn't feel able to share with other people?
 - PROBES – Did you have any difficult feelings towards your baby during this time? Did you have any feelings or thoughts that surprised you?

Infant screening process

Can you tell me about the infant testing process in the first year after birth?

PROBES: How did you find it? What helped you during this process? Did anything make it more difficult? Did you have any difficult thoughts or emotions during the process? Did you feel that the process affected your bond with your baby in any way?

Breastfeeding

Did you breastfeed you child after birth?

(If not) Can you tell me about you found the experience of not being able to breast-feed?

PROBES: Did anyone/anything help you with this? Did you feel this affected your bond with your baby in any way?

Faith

(If ppt. expresses faith in God)

Can you tell me about the role your faith played in your experience of being diagnosed and becoming a mother?

Middle stages (up to 6 months)

- Can you remember what the first few weeks were like after your child was born?
 - How would you describe your baby in those first few weeks? Probes: How was sleeping, feeding, crying etc?
- Who else was around at that time? What would they have said about your baby/about you as a mother?
- (If nobody else around) – how did you find being a mother for the first time on your own? Do you think this affected your relationship with your baby in any way?
- How did you feel about yourself as at this time?
- How did you manage with those first few weeks and months? What or who helped you?
- Did anything make things more difficult?

Later stages (6-12 months)

- Can you remember what it was like as your baby started to become more interactive with you?
- How did you feel about yourself during the second half of this first year? Do you think the way you felt about yourself as a mother changed at all during the first year? If so – why?
- Did you feel that anything helped or got in the way of you getting to know your baby better as he/she started interacting more?
- Did anything make things more difficult for you?
PROBES:
 - Were there any things you felt, or thoughts you had at the time, which you didn't feel able to share with other people?
 - Did you have any difficult feelings towards your baby during this time? Did you have any feelings or thoughts that surprised you?

Final questions

- If you were going to describe your experience to someone of being a mother with HIV, and particularly having a baby after an HIV diagnosis in pregnancy, what would you say?
- Is there anything else which you think might be important for me to know about your relationship with your child following their birth?

Thanks for participation and close

Appendix 10: Example Memos

Memo on strengthened mother-infant bond (13.07.12)

Most of the interviewees so far have spoken about the ways in which they feel their bond with their child has been strengthened and heightened through their experience of being diagnosed with HIV antenatally. A strong sense of gratitude has come out for the fact that pregnancy has led to an HIV test that would never have been taken otherwise. This seems to have led to a feeling that there has been some form of reciprocity in life-giving between mother and child – the mother gives life to the child, and the child in turn has given life back to the mother. Or the other way round – the child has given life to the mother through diagnosis, so the mother is then able to give life to the child through birth. This life for the mother comes through an early diagnosis and access to medication, which in turn has given these women ‘freedom’ from HIV and given them a life they may not have had. This reciprocity in life-giving has been perceived to help develop a very close and unique bond between mother and daughter. It is as if they have been reliant on each other for survival in a way that may not be typical of non-HIV mothers.

‘She led to me being diagnosed and being saved and I’ll always be grateful for that.... Every day I get up, and I look at her and I think that’s why I’m living’. (P1)

‘She’s given me life, and I need to give her that life where...she’s learning and I’m instilling so much in her.’ (P2)

‘Because as a baby you have given your mum an opportunity to be free from something else. So you are now just giving life to them’ (P2)

‘I owe her so much. Without her I would be dead now. For sure. I freed her, she freed me’ (P4)

‘She’s the reason I live, I’m the reason she lives’ (P2)

‘Having her made my HIV less important too. She gave me reason to live.’ (P10)

There is also a strong theme about the mothers’ awareness of bringing an innocent child into world that is damaged and full of disease, and the sense of obligation and responsibility for protecting the infant from those dangers. This is perhaps something that all mothers naturally feel in their maternal role (link to literature on maternal protection), but it seems to be heightened in these cases in which mothers know that they themselves have a disease, that they themselves are vulnerable to being ill and dying, and feel that the world is a dangerous place. The guilt expressed about bringing a child, unrequested, into this world perhaps heightens these feelings further:

‘I was thinking ...do I really want to bring a child into this world knowing that anything could happen to me at any time?’ (P1)

‘I’d bought her into this world, and I needed to protect her from it...’ (P2)

‘She was so innocent, and I was thinking...I can’t believe I’ve bought her here, to this place of illness, or sadness...I need to keep her safe’ (P5)

The infant testing process seems to have formed another stage in which mothers feel they have developed a bond to their child that has been uniquely strong in some way. There is another memo on the anxiety and difficulties experienced in this year-long testing process (which were huge), but in line with this memo - mothers spoke of a particular bond that developed between mother and child

through knowing that their child was going through this testing because of them and their HIV status. There was a connection described which came from empathy and understanding of a shared experience of on-going HIV screening, which they themselves were also having to undertake.

'And I think that process has made us very very close to be honest with you. Just me knowing that she had to go through that, because of me having to be HIV, helped me to be so close to my daughter'. (P2)

'We were going through the same thing. Just that hers was more scary.' (P5)

Again this experience of watching the infant go through this seemed to be tinged with a huge degree of guilt, and feeling of responsibility for pain caused. Mothers again felt responsible, like it was something they themselves had brought on and inflicted on their child.

'Watching your child go through that is unimaginable.' (P5)

'It was dealing with the fact that I had to be giving medication to my child for a month. The guilt around that was MASSIVE.. I felt like 'Oh my God, I've put her through this', but then I thought 'I have to give it to her, to protect her from anything'. (P2)

'Nobody blames you for having cancer': Brief memo on Stigma (20.07.12)

There has been a real sense in which the experience of living with HIV is made so much more difficult due to having to hide the diagnosis from those around you. The majority of interviewees had disclosed their status to very few people, especially not those in their communities who they thought were likely to judge them for their HIV status. Some compared HIV to other chronic diseases such as diabetes and cancer, and said they would much prefer to have these diseases that didn't carry with them such negative connotations. The guilt and shame of having brought this on themselves was something that seemed to sit with people in a very real way.

Stigma has been experienced in quite different ways by people, and I wonder if there is something about how others' actions are interpreted, and also about the perception of fear of stigma before it has actually happened. I need to think this through in a bit more detail. But made me think of the model of stigma by Earnshaw and Chaudoir and colleagues, where it is separated into anticipated stigma and enacted stigma etc. Does having a child, and feeling protective towards that child, make the anticipated or predicted experience of stigma even more notable for women? Does it make mothers more sensitive to the idea that people might blame them for being HIV positive and bringing a child into this world?

There is some research by Sandelowski and colleagues (2004) showing anticipated stigma to be particularly prevalent in the lives of mothers with HIV, but I'm wondering from the interviews so far whether there is something about an antenatal diagnosis that might enhance this for women. This could be linked to the lack of opportunities women have for positive experiences around disclosure of their HIV status prior to the birth of their baby, or the fact they are likely to be experiencing all types of HIV-related stigma during the vulnerable period of pregnancy, following their recent diagnosis.

Appendix 11: Example Interview Transcript (open coded with comments)

Participant 2	Open coding	<i>Comments/thoughts for memos</i>
<p>Int: So how have you been feeling health-wise at the moment?</p>		
<p>286. I'm good. Apart from – I don't know if it's hay-fever or a cold – but I think I caught a cold from her. But, I'm good.</p>	<p>Feeling good healthwise</p>	
<p>Int: Good stuff. So, I'd like to start, if you feel able, by going back to when you first heard about your HIV diagnosis. Do you remember how you felt at the time?</p>		
<p>287. I was in shock, obviously...er...because I had not been unwell at all.</p>	<p>Feeling in shock</p>	
<p>288. And, I was just my normal, my normal self. Before I went in.</p>	<p>Feeling normal prior to diagnosis</p>	<p><i>There's a suggestion here that the diagnosis brought with it a sense of 'not being normal anymore'</i></p>
<p>289. And, you know, to be told – firstly, the nurse when she came to the house took the blood, and I said 'yeah yeah go ahead', because I just didn't think I would be, I mean just like anyone would, you know, I didn't think I would be.</p>	<p>Not thinking she was at risk</p>	<p><i>Wanting me to understand what she's saying.</i></p>
<p>290. Cos obviously my partner at the time, he said he wasn't and he'd tested and he wasn't, so it was one of those when you're just not really thinking anything. I stupidly believed him and I shouldn't have done.</p>	<p>Believing that partner was negative</p>	
<p>291. So, I remember when I got the phonecall to say I needed to come in, I mean, my initial reaction was 'why do you want me to come in?' you know. There's nothing wrong with me.</p>	<p>Feeling stupid. Feeling of betrayal?</p>	<p><i>Having HIV means there is something 'wrong' with you. This sense of HIV being something bad that happens to people, flows through this interview.</i></p>
<p>Int: OK, so you were feeling quite positive before going into the meeting at the hospital. Can you tell me what happened then?</p>	<p>Feeling she was healthy, nothing 'wrong'</p>	
<p>292. Well then, I thought, OK, maybe it could be bad news, because obviously my partner lives in Zambia, and Zambia is kind of high with the HIV rating at the time.</p>	<p>Questioning potential risk Starting to doubt partner's</p>	

<p>293. So, that went through my mind. So I rushed down, and it just kept nagging at me, you know, sitting there in the waiting room thinking ‘Oh my God, what could it be?’.</p>	<p>negative status</p>	
<p>294. And, er, when I saw the nurse, the midwife who was a specialist in HIV women, and she came with a doctor and I thought ‘OK, this is going to be bad news for two people to be there.’</p>	<p>Feeling concerned about potential diagnosis</p>	<p><i>This feels like the first stage of acceptance that something is going to be wrong. Before diagnosis is formally given, there is a shift from ‘I’m normal and healthy’ to ‘this is going to be bad news’.</i></p>
<p>Int: And can you remember how you felt at the time?</p>	<p>Questioning what the results could be</p>	
<p>295. So when she did tell me, I mean... I cried and cried, - I was so upset and so scared - but then I just had to say ‘It is what it is, now, get on with it’.</p>	<p>Fearing bad news</p>	<p><i>Jumps very quickly to acceptance and moving on from the diagnosis. She doesn’t really appear to have given herself time to grieve.</i></p>
<p>296. I think just the positive attitude I had from that moment, it was a shock, but I just said ‘At least I know, and I can deal with it’.</p>	<p>Crying, feeling sad and frightened</p>	<p><i>Not knowing is worse than knowing? Information helps bring power in coping.</i></p>
<p>297. I am NOT gonna let it bring me down.</p>	<p>Accepting the diagnosis and moving on.</p>	<p><i>Emphasis of speech – feels very forceful and fighting in spirit.</i></p>
<p>298. It doesn’t have me – I think that was my first initial thing, I said ‘OK, I have it, but it doesn’t have me’.</p>	<p>Early positive attitude</p>	<p><i>Switch to calling HIV ‘It’ – potentially part of a strategy to distance herself from the disease, as if it is something that is not part of her, and doesn’t own her.</i></p>
<p>Int: It sounds like you were very strong and positive from the outset. Can you remember what helped you think in this way?</p>	<p>Knowing what you’re dealing with helping</p>	
<p>299. I think that was just my thinking, and from then they told me ‘take your medication’, and I remember her saying ‘you have to make sure you take them at the right time, in the morning as well as in the evening’.</p>	<p>Not letting it bring you down</p>	
<p>300. And, initially I was worried that there would be a lot of side-effects’ but I didn’t have no side-effects whatsoever. I was grateful for this, it was a blessing.</p>	<p>Not being owned or dominated by the illness</p> <p>Accepting and refusing to be affected negatively</p> <p>Fearing side-effects at the</p>	<p><i>Seeing all good things about the HIV as gifts from</i></p>

<p>301. So that was pretty, OK, you know.</p> <p>302. But it was just like, OK, there's something I've got to remember. This is my responsibility now.</p> <p>303. I'm pregnant now, I've got to take medication, and that was tough.</p> <p>304. Because, firstly I had to digest the information myself, and then not tell anybody.</p> <p>305. I had to know how to handle it before I could tell anyone else because I didn't think I could handle other people having to know, and me having to deal with <i>their</i> emotions as well as my emotions.</p> <p>306. So I thought let me deal with my emotions first, once I'm strong enough to kind of know the ins and outs and how I feel before I can explain to someone else.</p> <p>307. Because I know the first thing someone will say is 'oh my god you're going to die tomorrow', and that would be the first thing somebody <i>would</i> say, you know what I mean, and I didn't want that.</p> <p>Int: And how did you feel about keeping this information to yourself?</p> <p>308. And...um...for a long time it felt like the only option, it took me two years just knowing to myself and keeping that, and obviously, after giving birth, my CD4 count was pretty stable.</p> <p>Int: What helped you to adjust during those two years?</p> <p>309. Um, I'm not sure. So immediately after giving birth I wanted to make sure that now I was concentrating on my child, in the sense where she...um...firstly I didn't</p>	<p>beginning</p> <p>Feeling a new responsibility</p> <p>Pregnancy bringing responsibility</p> <p>Spending period of digesting information alone</p> <p>Dealing with own emotions</p> <p>No resources to deal with others' emotions</p> <p>Drawing on inner strength.</p> <p>Waiting to share with others</p> <p>Not wanting negative attitudes from others</p> <p>Taking 2 years to adjust to news of diagnosis</p> <p>Having a stable CD4 count</p> <p>Desire for focus on child</p>	<p><i>God – Faith associated with coping for this lady.</i></p> <p><i>Sense of realisation – situation sinks in</i></p> <p><i>She clearly didn't have anyone around who she felt she could rely on for emotional support – and who wouldn't make this worse for her. She had to rely on herself...</i></p>
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<p>know that she was gonna take the HIV test herself, it came out negative, and I didn't know cos I was not told at the birth at the time.</p> <p>Int. You didn't know that she would have to take the HIV tests?</p> <p>310. No, I don't think I knew that she would have to. That was a shock for me.</p> <p>311. So, when um...I came in for her appointment, and the doctor said that 'Oh, you do know that her first bloods were negative'.</p> <p>312. And I'm like 'what bloods'?</p> <p>313. And the doctor said 'yeah, they were negative, and the second ones are also negative'.</p> <p>314. So I think they had to do it three times after she was born, so the third time was obviously going to be 'OK so she's clear'.</p> <p>Int: How did you feel when you found out she was negative?</p> <p>315. Massive relief. Yeah. So it was....I stopped taking my meds immediately after giving birth, but it was dealing with the fact that I had to be giving medication to my child for a month. The guilt around that was MASSIVE.</p> <p>316. It was taken through the mouth, orally.</p> <p>317. I felt like 'Oh my God, I've put her through this', but then I thought 'I have to give it to her, to protect her from anything'.</p> <p>318. And she was my soul, do you know what I mean? I felt this close to her (pinches fingers tight).</p>	<p>Lacking knowledge about infant HIV screening</p> <p>Shocked about infant HIV screening</p> <p>Negative first infant tests</p> <p>Having to give infant meds in first month</p> <p>Guilt for what she's going through</p> <p>Feeling guilt vs a desire for protection of baby from any harm</p> <p>Her baby is part of her soul</p>	<p><i>Sense of confusion at this time. Didn't quite have all the information and feel informed – things happening as a surprise.</i></p> <p><i>Suggestion this was an unhelpful shock – would have been more helpful to feel prepared perhaps.</i></p> <p><i>Interesting informal colloquial use of language about something very serious. Sense that she is not wanting to revisit how anxiety provoking this period was for her.</i></p> <p><i>Big word – emphasis in voice and sense of relief in the voice.</i></p> <p><i>Reassuring herself about what she is having to do by reminding herself that is for the baby's protection.</i></p>
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<p>319. I'd bought her into this world and I had to protect her from it.</p> <p>320. So, whatever way you could help her to do it. Even if it's really painful to watch her go through it.</p> <p>321. So I did it for the month, and thankfully, after all the tests were done, you know we come in – everything's good, everything's positive, you know it was just going the right way. I was so bloody relieved.</p> <p>322. And I remember the final day when we were told that she is very clear and...you know...no need to come back.</p> <p>323. That was like 'Amen'. You know, now we could start living. Do you know what I mean?</p> <p>324. Because, before you kind of...you're living, you're trying to live, but you still having to go back maybe after three months or whatever it is (I can't remember exactly when it was she had to go for her bloods) and you're not free in your mind.</p>	<p>Needing to protect child from dangers</p> <p>Responsibility for protection of baby</p> <p>Pain of testing and infant meds process</p> <p>Relief over negative infant HIV status</p>	<p><i>Sense of bringing an innocent child into a dangerous world, and being responsible for this and having to protect her.</i></p> <p><i>Pain is necessary to protect child – but the pain is worth it.</i></p> <p><i>Emphasis on relief</i></p> <p><i>Prior to the all-clear they didn't feel like they were free. Felt trapped and imprisoned by the HIV hanging over them?</i></p> <p><i>Wish to be understood and heard</i></p>
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Appendix 12: Reference table of themes across participants

THEORETICAL CODES		SUB-CODES		Themes raised across participants (page and line number of quote)									
				1	2	3	4	5	6	7	8	9	10
1	FACING BARRIERS TO BONDING	1.1	Fearing harm to self and baby	1:7 2:7		3:9 6:9 11:13	2:6 9:10 10:7	2:13 2:17 3:4	8:10 16:4	3:5 4:8	1:13 8:6 9:16	4:12 5:4 9:12 18:12	1:12 3:14 9:10 14:3
		1.2	Managing multiple adjustments	7:2		2:13 6:10	4:17 8:9 14:2	4:12 11:3 25:8	3:12 4:11 8:1 16:13	4:16	3:16 5:6 8:3	2:16 3:10 9:3 14:16	15:9
		1.3	Feeling trapped and alone	15:3	30:12	13:11	12:4 13:7 14:3		8:17 17:14 24:5 25:14		7:2 17:18 22:3	9:5 10:2	6:8 10:1 15:4 20:14
		1.4	Living with guilt and shame	3:4 11:8 22:9	21:3		5:16 9:14 18:14	11:11 12:14 29:3	6:1 29:17	2:17 4:2 6:6 12:8	3:7 10:14 13:8 17:7	6:9 15:9	10:9
		1.5	Shattered dreams around motherhood	12:4 17:17		16:14	7:9		18:12	5:14 16:3	2:1 11:3	10:10 13:13 16:13	10:9 19:16
2	FEELING DISCONNECTED FROM THE BABY	2.1	Ambivalence about bringing baby into the world	2:4		6:2	1:18	2:17 14:13 16:2	23:12		3:9 5:11	4:13	4:8
		2.3	Feeling inadequate as a mother	6:2			6:14	15:1		3:15 5:8 6:8	5:15 11:7 17:5		10:9
		2.3	Not feeling able to think about the future	7:11	5:1 20:19	11:13 12:10		3:8 17:1	19:14 24:15	4:5 8:14 8:17	14:18 15:1 19:14	12:4 15:9 20:3	
		2.4	Losing focus on the baby	6:6 21:15		19:4	14:1	11:15 12:4	19:7 22:6	9:9 17:9	2:9 8:14	6:11	14:1 13:16

							20:4	24:10		15:5			
		2.5	Worrying about HIV transmission after birth				14:13 15:6	16:14 24:6	21:9 24:10	7:17 8:5 19:7		11:6 19:17	19:4
3	DEVELOPING A SPECIAL BOND	3.1	Enhanced maternal sensitivity and understanding	13:12	6:4		6:3	24:9		6:11 12:15	12:13 14:9 22:11		19:11
		3.2	Maintaining physical closeness	4:4 8:7	6:3 18:8 23:8			21:10 21:14		6:14 7:5 22:2	12:15 23:5	10:16 13:10	9:12 10:14 11:16
		3.3	Protecting the baby emotionally	25:4	18:15	21:8	14:9 17:7	12:17 23:2	10:5 28:5 30:8	5:17 10:3 14:14 15:7	3:13 15:11 20:4	18:3	5:10 6:13 14:11 15:1
		3.4	Reciprocity of life giving	18:12	7:13 8:5 24:9		21:16	11:7 22:12		14:16	22:16 23:2	16:10	19:11
		3.5	Baby bringing meaning back to life	2:13 9:12	7:13 17:10	11:7	18:8 9:1			14:13	22:16	5:10 20:14	
4	STRENGTHENING AND MOVING ON	4.1	Finding meaning in what has happened	4:6 15:12 16:1	33:10	9:13 21:11	9:1 20:9	6:9 22:10	15:3	11:10 19:14	21:3		3:7 14:14 21:9
		4.2	Living for your baby		2:19 7:13 21:17 24:9	3:13 21:5	18:3 18:8	23:17 27:10	5:5	14:9 15:17 21:15	5:10 20:14 21:14 23:5	13:5 16:10	19:10
		4.3	Being grateful for motherhood	19:5	34:15 35:1	9:14		28:14	30:15	12:2 15: 21:15	21:3	13:17 14:2 20:11	20:10
		4.4	Accepting HIV implications for motherhood		23:3		7:8 20:10	27:14	3:14 18:12	16:5		10:5 17:14	10:9

Appendix 13: List of countries in Sub-Saharan Africa

Angola
Benin
Botswana
Burkina Faso
Burundi
Cameroon
Cape Verde
Central African Republic
Chad
Comoros
Republic of the Congo
Democratic Republic of the Congo
Cote d'Ivoire
Djibouti
Equatorial Guinea
Eritrea
Ethiopia
Gabon
The Gambia
Ghana
Guinea
Guinea-Bissau
Kenya
Lesotho
Liberia
Madagascar
Malawi
Mali
Mauritania
Mauritius
Mozambique
Namibia
Niger
Nigeria
Rwanda
Sao Tome and Principe
Senegal
Seychelles
Sierra Leone
South Africa
South Sudan
Sudan
Swaziland
Tanzania
Togo
Uganda
Zambia
Zimbabwe