

**Bonding Experiences in Mothers of Infants with Severe
Congenital Heart Disease**

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Abstract

Mothers who have an infant with severe congenital heart disease (CHD) face an uncertain and emotionally challenging postpartum period as their baby is hospitalised and undergoes life-saving cardiac surgical treatment. There are many potential risk factors to mother-infant bonding, that is, the emotional tie a mother develops with her baby, in the context of infant illness. Having an infant with a diagnosis of severe CHD could be seen as a threat to the mother's experience of bonding. However, there is limited understanding about the maternal perception of bonding with an infant with severe CHD.

This study aimed to explore mothers' bonding with their infant with severe CHD throughout antenatal, perinatal and postnatal periods and how they coped with any challenges to this bond. Interviews were conducted with eight mothers of infants aged between eight and fifteen months with severe CHD, who were recruited from a children's hospital and who were diagnosed either antenatally or postnatally. Interpretative Phenomenological Analysis was used to identify themes across the mothers' accounts. Four superordinate themes were identified: 'An Emotional Start to Motherhood and the Mother-Infant Bond', 'Losing Control in the Context of CHD', 'Keeping Connected to the Baby' and 'Moving on Together'.

The findings identify mother-infant bonding as a process that can withstand challenges such as maternal-infant separation, potential loss of the infant and maternal feelings of disconnection from the baby. Practical strategies were used by mothers to maintain their bond with their infant following diagnosis and during hospitalisation. These included being close to their infant and taking over caregiving duties from the nurses. Mothers described strength and resilience from the experience and a process of increasingly feeling closer to their infant. Several potential research implications and clinical recommendations for healthcare professionals are suggested.

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Chapter 1: Introduction

Overview

It is a common perception that parenting a newborn can be challenging. However, this is potentially more difficult if the child has a life-threatening condition. It is possible that in this situation the mother-infant bond, that is, the emotional tie that develops between mother and child (Bowlby, 1982), may be affected.

Congenital heart disease (CHD) encompasses a collection of conditions with different prognoses and treatments that affect seven to eight per 1000 live births in the UK (Knowles et al., 2005). They are the most common congenital anomaly at birth and are life-threatening if the condition is severe (Hoffman & Kaplan, 2002). It is recognised that mothers caring for infants with CHD are subjected to many stressors and can be at risk for adjustment and emotional difficulties (Cohn, 1996; Davis, Brown, Bakeman, & Campbell, 1998; Fonseca, Nazaré, & Canavarro, 2012). Whilst the mother-infant relationship has been studied in terms of its impact on the child (Gardner, Freeman, Black, & Angelini, 1996; Goldberg, Simmons, Newman, Campbell, & Fowler, 1991), research on the mother's experience of her relationship with her infant is still accumulating. There is a paucity of studies examining the emotional and psychological aspects of becoming a mother to a child with a severe heart condition and, more specifically, the mother's experience of bonding with her infant or how the process of bonding might change through the antenatal to postnatal periods. In this study, Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was used to explore the experience of bonding for eight mothers with an infant with severe CHD.

This chapter will begin by providing information about CHD, how it is diagnosed and current treatments. Mother-infant bonding will then be defined and specific factors associated with bonding that may be particularly relevant for mothers of infants with severe CHD will be introduced. These include antenatal scans, postnatal depression, maternal anxiety and stress, breastfeeding difficulties, physical separation and infant illness. Following this, quantitative and qualitative literature about the mother-infant relationship in CHD will be reviewed and critically appraised. Finally, a case will be made for further qualitative research to address the shortcomings in the literature and the research aims of the study will be outlined.

Congenital Heart Disease

Congenital heart disease refers to “a heart condition or defect that develops in the womb, before a baby is born” (British Heart Foundation, 2013). A baby’s heart starts to develop shortly after conception and will begin to beat during the third week of gestation (Stauffer & Murphy, 2002). However, during development, structural defects can occur which disrupt the normal flow of blood through the heart. There are many different types of CHD (see Appendix 1 for summary and prevalence) that involve defects in the interior walls of the heart, the valves inside the heart, or the arteries and veins that carry blood to the heart or the body (World Health Organization, 2004). CHD conditions range from simple lesions with no obvious symptoms that do not require treatment to more severe and complex conditions that are life-threatening and require invasive surgical procedures (British Heart Foundation, 2013). Modern open-heart surgery techniques involve closing holes in the heart, repairing or replacing heart valves, widening arteries or repairing more complex defects such as problems with heart development and the location of blood vessels (Goldberg, Morris,

Simmons, Fowler, & Levison, 1990). The psychological adjustment of the child and parents after open-heart surgery has been increasingly researched (for review see Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009).

Severe CHD

Infants with severe CHD are acutely unwell in the perinatal period and often present as medical emergencies, requiring tertiary hospitalisation and invasive surgical intervention, often in the first month of life (Lambert et al., 1966). Severe CHD includes a range of conditions and accounts for approximately 25% of those with CHD, with a reported incidence of two and a half to three per 1000 live births (Hoffman & Kaplan, 2002). Over recent decades, there has been a significant increase in survival rates due to advances in cardiac surgical techniques and post-operative care (Allen, Gauvreau, Bloom, & Jenkins, 2003; Tennant, Pearce, Bythell, & Rankin, 2010). However, for some children with severe CHD, repeated surgical treatment may be necessary. Children with severe CHD can also remain at risk for long-term morbidity and mortality, with increased risk of ongoing developmental concerns (Bjarnason-Wehrens et al., 2007; Wray & Sensky, 2001).

CHD Diagnosis

Antenatal diagnosis

Fetal echocardiography is used to screen, diagnose and monitor CHD during pregnancy. It can be performed after 16 weeks gestation but ideally is done between 18 and 22 weeks when the fetal heart is large enough for adequate resolution, the rib cage is not completely calcified and the fetus can move more easily (Stauffer & Murphy, 2002). Recent advances in fetal ultrasound has allowed experienced obstetric sonographers to detect all forms of CHD, leading to an increase in antenatal diagnoses which, in 2011, accounted for 35% of CHD

cases undergoing intervention in the UK (National Institute for Cardiovascular Outcomes Research, 2012). The majority of malformations detected antenatally tend to be of more severe CHD as they are easier to identify. This trend towards earlier diagnoses has contributed to reductions in early neonatal mortality by enabling immediate cardiac assessment of the neonate post birth and multidisciplinary perinatal management (British Heart Foundation, 2009; Khoshnood et al., 2005). Earlier detection of CHD also allows parents to choose the course of pregnancy and consider termination in the most severe cases or prepare for events post birth if the pregnancy progresses to delivery (British Heart Foundation, 2009). A dedicated fetal nurse specialist can help support parents' preparation for their child's arrival by providing cardiac psychoeducation, counselling, a tour of intensive care and the cardiac ward and help with the birth plan, which commonly includes an induced labour and immediate transfer of the new born infant. The psychological impact for parents of receiving an antenatal diagnosis has been recognised and there is a growing body of research that will be outlined later.

Postnatal diagnosis

As not all cases of severe CHD are reliably detected during pregnancy, the diagnosis for many is made after birth. Although some newborns with severe CHD will show signs of a cardiac problem soon after birth, others will remain asymptomatic (Schultz et al., 2008). Some forms of severe CHD can be difficult to identify by physical examination and can show few symptoms up to 72 hours after birth while the ductus arteriosus, a blood vessel vital for blood circulation in the fetal aquatic environment, is still functioning (Krishnan, 2002). Infants with undiagnosed severe CHD will eventually develop signs and symptoms of cardiac disease such as profound metabolic acidosis (where the body produces too much acid), cardiac arrest (where the normal circulation of the blood has ceased due to the heart failing to contract effectively) and hypoxic-ischemic encephalopathy (where the brain is deprived of

oxygen; Schultz et al., 2008). Thus infants diagnosed after birth often require emergency transfer to the nearest children's cardiac surgical centre and depending on the timing following childbirth and the mother's recovery, there may be a period where mothers are separated from their infant.

The risk of morbidity and mortality increases for infants diagnosed postnatally with delayed diagnosis and treatment. The median age of death in infants with undiagnosed severe CHD is less than two weeks of age (Chang, Gurvitz, & Rodriguez, 2008) and thus CHD is one of the main causes of perinatal and infant death from congenital malformations (Hoffman & Kaplan, 2002; Wren et al., 2012). The Royal College of Obstetrics and Gynaecology (2000) and the National Institute for Health and Clinical Excellence (2010) therefore endorse antenatal anomaly screening and recommend detailed examination of the fetal heart.

Mother-Infant Bonding

A fundamental process for new mothers is the development of an affectionate relationship with their baby. An established mother-infant bond is considered essential for an infant to develop and thrive in their mother's care (Kennell & McGrath, 2005). The term 'bonding' is generally accepted as relating to the parent's emotional tie or feeling of connectedness towards their infant (Bowlby, 1982). It implies a special, enduring and affectionate relationship specific to one's child (Herbert, Sluckin, & Sluckin, 1982), that, for a mother, is gradually established during pregnancy and birth (Fleming, Ruble, Krieger, & Wong, 1997). Thus 'bonding' is from the mother's perspective and relates to her feelings of warmth, devotion, protectiveness and concern for her infant's wellbeing, a longing for contact with her infant and pleasure in their interactions as evidenced by maternal behaviours such as gazing, smiling, touching and vocalising (Herbert et al., 1982; Robson & Moss, 1970). In the

literature, the term 'bonding', as described here and used henceforth, is also synonymous with the terms 'mother-to-infant attachment', 'maternal attachment' or 'mother-infant bonding'. This is not to be confused with a similar concept 'attachment' which is also reported as 'infant-mother attachment' or 'infant attachment'. 'Attachment' refers to the unique and powerful relationship an infant forms with their primary caregiver during their first year of life and is from the infant's perspective (Bowlby, 1969; Bush, 2001).

Much research related to the early mother-child relationship has focused on the child's attachment with their mother. Typically, objective methods such as video observation are used to look at aspects of behaviour in both the child and mother and their interactions with each other. The quality of maternal-child interactions are understood to have implications on the child's emotional and social development; influencing various aspects of the child's later autonomous functioning (Sroufe, Fox, & Pancake, 1983) and attachment security (i.e. the child's internal representation of their caregiver; Britton, Britton, & Gronwaldt, 2006; Coyl, Roggman, & Newland, 2002). However, researchers are increasingly recognising the importance of studying the developing mother-child relationship from the mother's perspective (Borghini et al., 2006; Figueiredo, Costa, Pacheco, & Pais, 2007; Hornstein et al., 2006). A mother's subjective experience of motherhood and her emotional involvement with her child is likely to influence the quality of care and interaction the child receives. Research into the mother's perspective tends to use quantitative design and rely on questionnaire data. Indeed there are several self-report questionnaires designed to capture a mother's subjective view of her baby and bonding feelings. These include the Maternal Postnatal Attachment Scale (Condon & Corkindale, 1998), the Postpartum Bonding Instrument (Brockington et al., 2001), the Mother-to-Infant Bonding Scale (Taylor, Atkins, Kumar, Adams, & Glover, 2005) and the attachment subscale in the Parenting Stress Index

(Abidin, 1986). However, pre-determined responses do not give an understanding of the *experience* of the bonding process for mothers which qualitative interviews can provide.

One study that did use qualitative interviews, explored the process of bonding in 54 mothers of healthy infants who were three and a half months old (Robson & Moss, 1970). Mothers were interviewed about the onset of their feelings toward their infant and how they progressed over the first three months postpartum. They found that mothers' feelings of affection towards their infant gradually increased, becoming more intense as the infant began to fixate and smile at the mother. After three months, mothers felt strongly attached to their infant and found absence from them unpleasant. This study was one of the first to recognise the value in studying bonding from the mothers' perspective.

It is now widely recognised that mothers begin the process of bonding with their baby during pregnancy (Alhusen, 2008; Righetti, Dell'Avanzo, Grigio, & Nicolini, 2005), commonly referred to as 'maternal-fetal attachment'. This initial bond of a mother with their unborn baby has been shown to be a good predictor of the mother-infant relationship after birth. Women who display higher levels of affection and emotional involvement with their baby during pregnancy are more likely to be involved and interactive with their child after birth (Siddiqui & Hägglöf, 2000). Therefore, to thoroughly understand the developing mother-infant bond, it follows that a mother's emotional connection to her baby during pregnancy is important.

Factors Influencing Mother-Infant Bonding

There are many physiological, environmental and psychological factors which are thought to influence mothers' experience of bonding. Attention has been directed towards both

understanding optimum environments for bonding to develop (Kennell & McGrath, 2005) and the risk factors which may hinder a mother's capacity to effectively care for and bond with her infant (Goldberg, 1988). Areas which have received research attention include the mother's own experience of being parented and her attachment style (Willinger, Diendorfer-Radner, Willnauer, Jörgl, & Hager, 2005), support from their spouse and family (Goldberg, 1988), mother-infant separation after birth (Feldman, Weller, Leckman, Kuint, & Eidelman, 1999), breastfeeding (Kuzela, Stifter, & Worobey, 1990), maternal mental health and the health of the baby (Kennell & Klaus, 1984; Morrissey, 2007). There is not the scope in this chapter to cover all of these areas, so only the factors that are particularly relevant to the bonding process for mothers of infants with CHD will be described.

Antenatal scans

Studies have highlighted the benefits of antenatal scans for parents by acknowledging that it can be a pleasant experience to have visual confirmation of the pregnancy, a form of contact with the baby and reassurance that the baby is healthy (Garcia et al., 2002). However, there is also literature exploring parental reactions when the scan identifies a problem. The parents' experience of receiving an antenatal diagnosis in their unborn baby (Catlin, Áskelsdóttir, Conroy, & Rempel, 2008; Hedrick, 2005; Van der Zalm & Byrne, 2006) including CHD (Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007; Rempel, Cender, Lynam, Sandor, & Farquharson, 2004) has been described and commonly includes feelings of shock, anxiety and grief. There is less literature on the perceived impact this has on the mother-infant bond when pregnancy is continued, although positive feelings toward the fetus have been described in one phenomenological study which interviewed 15 pregnant women carrying a child with a non-lethal congenital abnormality (Hedrick, 2005). Related research in women with high-risk pregnancies, due to maternal disorders, obstetric difficulties or complications with the fetus, has described expectant mothers as appearing to hold back

from bonding with their baby for fear of losing their child (Moore, 1983). It has been suggested that these women might therefore be less likely to exhibit nurturing bonding behaviours (Philipp & Carr, 2001). These findings may apply to mothers who receive an antenatal diagnosis of CHD.

Maternal postnatal depression

Maternal emotional well-being is important in the postpartum period to enhance the mother's sensitivity (i.e. ability to respond promptly, consistently and appropriately to one's baby) and consequently to facilitate bonding and effective parenting (Coyl et al., 2002). Postpartum psychiatric disorders, and most commonly postnatal depression, are recognised to negatively impact on mother-infant bonding and mother-child interactions (Hornstein et al., 2006; Moehler, Brunner, Wiebel, Reck, & Resch, 2006; Noorlander, Bergink, & Berg, 2008). Maternal depressive illness and stress is thought to affect mothers' feelings and responses towards their infant leading to unfavourable parenting practices such as spanking (Coyl et al., 2002; Martorell & Bugental, 2006; McLearn, Minkovitz, Strobino, Marks, & Hou, 2006). Maternal postnatal depression has been linked to multiple adverse developmental outcomes for children which can outlast the depressive episode, including compromised behaviour, cognitive, social and emotional development (for reviews, see Beardselee, Versage, & Giadstone, 1998; Downey & Coyne, 1990; Zeanah, Boris, & Larrieu, 1997).

Depressed mothers have been noted to display two types of interaction behaviour: a withdrawn, less engaged and less stimulating style and an intrusive, irritable and controlling style (for reviews, see Field, 2010; Lovejoy, Graczyk, O'Hare, & Neuman, 2000; Reck et al., 2004). Literature related to how mothers perceive bonding in the context of postnatal depression is accumulating. Depressed mothers have subjectively viewed their bonding experience negatively (Hornstein et al., 2006; Noorlander et al., 2008) and stronger reactions

such as absent affection, failure to love, rejection and even neglect or impulses to harm have been described (Kumar, 1997). Ten primiparous mothers with postnatal depression interviewed in a phenomenological study expressed concerns about bonding and described thoughts and feelings of being “a bad mother” (Hall, 2006, p. 257). The author acknowledged that it remains unclear whether such descriptions are an example of negative self-judgment and/or developed as a consequence of depressive illness.

Mothers of newborns with severe CHD are considered vulnerable to depressive illness because they face additional challenges to motherhood with the hospitalisation of their infant, altered feeding and bathing routines and additional care tasks such as administering medication. Indeed, probable depression was found in close to 20% of mothers of infants with severe CHD ($n = 40$) with another 15% reported to have mild depressive symptoms (Rona, Smeeton, Beech, Barnett, & Sharland, 1998). A growing number of studies investigating psychological distress in parents of infants with CHD, have identified high levels of stress, anxiety and depressive symptoms (Doherty et al., 2009) for both antenatal and postnatal diagnoses (Brosig, Whitstone, et al., 2007) and in comparison to parents of healthy infants (Fonseca et al., 2012; Goldberg et al., 1990).

Maternal anxiety

The adverse effects of anxiety on mother-infant bonding is not as well reported in the literature with many studies grouping anxiety together with depression as ‘psychological distress’ (e.g. Doherty et al., 2009). That being said, maternal anxiety has been given some attention in relation to the experience of antenatal scans. Anxiety has been shown to be relatively common during pregnancy with more than half of a sample of 357 pregnant women having elevated anxiety at some point during their pregnancy (Lee et al., 2007). It has been reported that women often feel anxious before antenatal scans and this is

especially true for women in high-risk groups, such as those with a suspected fetal anomaly, complications from previous pregnancies or maternal infections and chronic disease (Brisch et al., 2002). However, pre-scan anxiety has been found to diminish in women whose scans are unremarkable and the baby is reported to be in good health (for review see Garcia et al., 2002) and this can positively influence bonding (Lumley, 1990; Ross, 2012). For women whose scan shows a problem with the fetus, anxiety levels remain elevated (Brisch et al., 2002). There is limited research in terms of the effect this has on bonding, although an inverse association between perceived quality of antenatal bonding and self-reported anxiety has been reported (Condon & Corkindale, 1997).

There is also evidence that maternal postpartum anxiety negatively affects mother-infant bonding. In a study of 91 primiparous women, higher levels of maternal anxiety was found to predict worse emotional involvement with their infant after birth (Figueiredo & Costa, 2009). Anxious mothers have also reported higher levels of worry, vigilance and preoccupation with bonding and may be less capable of self-regulating their negative states and managing their distress (Feldman et al., 1999). However, despite experiencing considerable anxiety, many women successfully bond with their infant during pregnancy and after birth (Figueiredo & Costa, 2009).

Mothers who receive a diagnosis of severe CHD in their infant might, understandably, experience substantial anxiety and concern. The reality for these mothers is that they face hospitalisation of their newborn and their open-heart surgery, which are highly anxiety-provoking experiences that make it difficult for parents to maintain their parent role (Lewandowski, 1980). In addition, parents become responsible for the usual infant care duties as well as an array of more specific ones (for details see Pinelli, 1981). Mothers of infants with CHD have reported increased concerns after discharge from hospital, primarily about recognising and reacting appropriately to their newborn's needs and especially

symptoms of heart disease (Pinelli, 1981). Thus, they may not feel confident in their ability to care for their infant and therefore may show heightened levels of vigilance and greater anxiety during interactions (Carey, Nicholson, & Fox, 2002). Mothers of children with CHD are also likely to have significant uncertainty regarding their child's future (Carey et al., 2002) and may be overprotective of their children. The concern is that an overprotective parenting style, presumably fueled by anxiety, might impact on the overall development of these children (Utens et al., 1994).

Maternal stress

Evidence suggests that maternal stress can impair the developing mother-infant relationship during pregnancy (Hsu & Chen, 2001) and after birth (Crnic, Greenberg, Robinson, & Ragozin, 1984; Muller-Nix et al., 2004). Indeed, parenting stress has been associated with maternal depressive and anxious states which are also understood to influence the mother's quality of care, interaction and responsiveness with her infant (Coyle et al., 2002; Feldman et al., 2009; Murray, Fiori-Cowley, Hooper, & Cooper, 1996). Parenting stress is thought to relate to how parents appraise their role and whether they perceive their child's characteristics as stressors (Abidin, 1992).

There is a wealth of literature recognising increased stress in parents, and particularly in mothers, of children with CHD (Brosig, Whitstone, et al., 2007; Carey et al., 2002; Doherty et al., 2009; Gardner et al., 1996; Goldberg et al., 1990; Majnemer et al., 2006; Moola, 2012; Pelchat et al., 1999). It appears that the constant medical attention, lack of control over treatment and uncertainty regarding the infant's survival contributes significantly to the stress experienced by parents (Goldberg et al., 1990; Lewandowski, 1980; Weinhouse, Weinhouse, & Nelson, 1992). Parents also often face difficult decisions, disrupted expectations and challenges to their parenting role which can lead to doubts and stress

regarding their competence as parents (Brosig, Mussatto, Kuhn, & Tweddell, 2007; Hoehn et al., 2004; Pelchat et al., 1999). This may explain why mothers of children with CHD are more psychologically distressed (Pelchat et al., 1999).

There is conflicting evidence regarding whether there is an association between parents' stress levels and the severity of the child's heart condition. Higher levels of stress have been reported in parents of children with more severe cardiac conditions (Brosig, Mussatto, et al., 2007) but other studies have not found any relationship (Davis et al., 1998; Uzark & Jones, 2003). Studies have generally reported higher stress levels in parents of children with CHD when compared with other populations such as cystic fibrosis, cleft lip/palate and healthy children (Cohn, 1996; Goldberg et al., 1990; Pelchat et al., 1999; Uzark & Jones, 2003) and particularly when children are younger than two years old (for summary see Soulvie, Desai, White, & Sullivan, 2012). A study by Goldberg et al. (1990) reported on parenting stress for families with healthy infants ($n = 30$), infants with CHD ($n = 26$) and infants with cystic fibrosis ($n = 15$). Parents of infants with CHD reported the highest levels of stress which the authors presumed was due to the threat to life and uncertainty in outcome for these children.

Breastfeeding

Breastfeeding is widely recognised to have short-term and longer-term health benefits for children (Horta & Victora, 2013) and is recommended by the World Health Organization (2002) as the exclusive source of nourishment for infants until six months of age. Breastfeeding is considered especially important for mothers who have difficulties bonding with their infants as it provides additional opportunities for close mother-to-infant interactions (Kennell & McGrath, 2005; Kuzela et al., 1990). For mothers of infants with severe CHD, there are practical barriers to breastfeeding such as physical separation due to hospitalisation and therefore difficulties in maintaining milk supply. There are also several

physiological factors related to CHD (e.g. excessively rapid heartbeat and increased respiratory rate) which lead to fatigue and weak sucking in infants with CHD that can impact on breastfeeding (Forchielli, McColl, Walker, & Lo, 1994; van der Kuip et al., 2003). However, the protective benefits of breastfeeding are particularly important in this population as these children are vulnerable to infection (Lambert & Watters, 1998).

Although high rates of breastfeeding have been found in mothers of infants with CHD, they were also shown to wean at a much faster pace than mothers of healthy infants (Tandberg, Ystrom, Vollrath, & Holmstrom, 2010). A study by Lobo (1992) assessed parent-infant interactions during feeding and found that infants with CHD exhibited unclear cues and were less responsive than healthy infants, and mothers of infants with CHD were also less likely to smile, hum, sing or make eye contact with their baby than mothers of healthy infants. Maternal reports in this population offer insight into potential reasons for this difference. The feeding process has been implicated as a source of difficulty, with all eight mothers in a qualitative study describing difficulties in establishing mutuality with their infants with CHD (Gudermuth, 1975). Mothers of infants with CHD have further described fatigue, anxiety, physical separation due to surgery and lack of privacy in hospital as obstacles to breastfeeding (Lambert & Watters, 1998).

Maternal separation from infant

During the first few hours and days after birth, interactions between mother and baby as well as the release of oxytocin and other physiological mechanisms are all thought to contribute to the mother's developing bond to her infant (Kennell & McGrath, 2005). For a mother of a newborn with severe CHD, this period commonly involves physical separation as the baby is hospitalised and requires surgical intervention. There has been considerable speculation about the notion of a 'critical period' in which mother-infant contact is seen as

vital for securing future attachment (Klaus & Kennell, 1976). This, however, has been widely disputed and is no longer the accepted understanding (Goldberg, 1983; Lamb, 1982).

Nevertheless, physical separation and hospitalisation inevitably impacts on early interactions between mother and infant. In an ethological study (Feldman et al., 1999), maternal bonding was investigated using interviews and self-report questionnaires in three groups of mothers: continuous proximity with a term infant ($n = 29$); separation from a healthy premature infant ($n = 30$); and prolonged separation from and potential loss of a premature infant ($n = 32$). Bonding behaviours and thoughts about the infant were found to decline linearly with increasing duration of mother-infant separation. Mothers at-risk for disrupted bonding were highly anxious or depressed and separated from their ill child. These findings are relevant to the CHD population as exemplified in qualitative interviews with 25 parents and 28 grandparents of children with Hypoplastic Left Heart Syndrome, who reported physical separation and hospitalisation as a barrier to early interactions and bonding (Rempel, Ravindran, Rogers, & Magill-Evans, 2012). This study is discussed in greater detail later in this chapter.

Infant illness and congenital malformations

During pregnancy, women tend to develop an idealised image of their baby that has to be reconciled with the reality after birth (Goldberg, 1983; Leifer, 1980). This is likely to be particularly difficult for mothers of infants who are unwell. Indeed, the health status of an infant is another factor thought to contribute to the quality of parenting a child receives (Kazak, 1989). Research has investigated disruptions to mother-infant bonding in the context of infant illness, medical complications and congenital conditions.

Premature infants

Mother-infant bonding has been a common area of study in the premature infant population. Medical complications in premature infants have been found to be a risk factor for the early developing mother-infant relationship (Minde, Perrotta, & Marton, 1985) with less optimal interactions (e.g. being less sensitive to infants' cues) observed in mothers of more unwell infants (Jarvis, Myers, & Creasey, 1989). Maternal psychological distress resulting from the birth of premature infants is thought to impact negatively on maternal-infant interactions (Singer et al., 2003). Indeed mothers who experienced high stress during the perinatal period were rated by researchers in a mother-child play interaction as being more controlling and insensitive than mothers of full-term infants (Muller-Nix et al., 2004). These patterns of interaction are important as they are thought to play a role in later developmental and behavioural outcomes (Beckwith & Rodning, 1996; Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006), which is also reflected in CHD literature (McCusker et al., 2007).

More relevant is a qualitative study investigating mothers' experiences of interacting with their premature infants (Nicolaou, Rosewell, Marlow, & Glazebrook, 2009). Mothers described finding the hospitalisation of their infant as a barrier to interactions and they continued to feel unsure and anxious about interacting with their babies after discharge, although this improved with time. It has been suggested that feelings of guilt, loss, detachment and a sense that the baby was not really theirs are quite common in mothers of premature infants but that these tend to pass with time (Niven, Wiszniewski, & Alroomi, 1993). It is possible that mothers of children with CHD have a similar experience, especially for those who received the unexpected diagnosis after birth and therefore, as with

premature infants, have less time to adjust to having a sick child and face immediate hospitalisation.

Unexpected diagnoses of congenital conditions

There is not the scope for a thorough review of bonding research in other congenital conditions except to say that reacting with shock and distress to the diagnosis is reported in other conditions (e.g. oesophageal atresia; Caplan, 2013) and there are reports of mothers temporarily rejecting their baby during uncertain periods (e.g. following diagnosis of cystic fibrosis; Al-Jader, Goodchild, Ryley, & Harper, 1990). Two qualitative studies, outlined below, used models to describe the adaptation process for parents following an unexpected diagnosis. Both studies have interviewed parents of children with a range of congenital malformations and found their experience to be similar.

Drotar et al. (1975) presented a five-stage model which described parental reactions following birth. They interviewed twenty mothers and five fathers of twenty children, aged between seven days and thirteen years, with congenital malformations including Down's syndrome, cleft palate, microcephaly and CHD. Analysis of the interviews revealed five sequential stages: 'shock', 'denial', 'sadness and anger', 'adaptation' and 'reorganisation' which differed in intensity and duration. Some mothers experienced difficulties loving their child in the third stage where angry feelings were directed towards the baby. Positive bonding feelings were described in the 'adaptation' and 'reorganisation' stages with mothers reporting a strong attachment to their infant and more rewarding interactions and long-term acceptance, respectively. Thus, parents experienced increasing attachment to their children, with some finding their relationship was "closer than normal" (p. 714). However, there are methodological limitations with this study as it used a heterogeneous sample which included both mothers and fathers, a spread of congenital diagnoses from correctable anomalies to

life-limiting conditions and also a wide variation in retrospective recall of participants (i.e. from seven days to thirteen years). The method of data analysis was also not mentioned and there were limited quotes and therefore poor grounding of the model in the data.

The other model, Recasting Hope, presented in a study by Lalor et al. (2009) shows the process of adaptation for mothers following fetal diagnosis. Interviews were conducted pre- and post-birth with 41 mothers (ten mothers terminated their pregnancy, the other 31 mothers continued with their pregnancy, although a proportion of these infants died soon after birth). Grounded theory analysis identified four temporal phases for mothers: 'assume normal', 'shock', 'gaining meaning' and 'rebuilding'. There was less emphasis on bonding processes in this study presumably because some mothers were childless, but in the third phase, there was recognition that some women had difficulty bonding with their fetus to protect themselves from emotional pain if the baby did not survive. The final phase involved moving forward and hoping for quality time with the infant, especially for mothers whose babies were only due to survive for a short time after birth. Whilst this study touched upon aspects of bonding during pregnancy, its primary focus was on the process of adaptation, and therefore it offers little insight into the maternal perspective of bonding over time. There remains a lack of qualitative research with mothers exploring the perceived impact of congenital chronic illness and hospitalisation on the developing mother-infant bond.

Positive experiences

Whilst the majority of the reviewed research focuses on the challenges faced by mothers of children with chronic health conditions, it is important to also note the positive experiences that have been described in some studies. Parents have reported gaining an appreciation for things that really matter and that through the ordeal they discovered inner strength (Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009). Successful bonding and close

relationships are also described despite the turbulent start (e.g. Rempel et al., 2012) with some parents also feeling the experience has brought them closer to their child (Drotar et al., 1975). It is important to consider the potential for socially desirable accounts in this type of research, as maternal responses about parenting practices can be influenced by cultural and societal expectations of motherhood (Durgel, van de Vijver, & Yagmurlu, 2013).

Uniqueness and Challenges of Severe CHD

Despite some similarities between severe CHD and other congenital conditions, there are several defining characteristics of severe CHD which may differentially influence a mother's bonding experience:

Life-threatening diagnosis

Attention has already been paid to the diagnosis of CHD and the repeated fetal scans if the defect is detected during pregnancy. In addition, unlike other congenital anomalies, there may be the option of late termination for the most serious heart conditions (Allan & Huggon, 2004). Another consideration for these mothers is the limited time to adjust and cope with the diagnosis, hospitalisation of their infant, open-heart surgery and subsequent intensive care, all while being aware of the life-threatening nature of their child's condition. Therefore, mothers are susceptible to psychological distress and associated bonding difficulties.

Treatment & prognosis

The treatment for children with severe CHD is uniquely different to other congenital conditions. Indeed, parents of children with CHD identify with the severity of open-heart

surgery and the real threat to life and uncertainty of outcome of having a heart condition (Goldberg et al., 1990). Parents are likened to being in a “survival mode” (Moola, 2012, p. 217) due to the immediate threat to life. Whilst parents may not have ongoing responsibility for treatment, the procedures for their infants always take place at hospital, require intensive care follow-up and if there is cardiovascular failure, the infants are at-risk for neurological sequelae or death (Knowles & Hunter, 2013). Together these may explain the higher levels of stress consistently reported by parents of infants with CHD compared to other populations (Goldberg et al., 1990; Pelchat et al., 1999) and the potential for parenting and/or bonding difficulties with hospitalisation.

Cormorbidity

CHD can be associated with chromosomal anomalies and specific genetic syndromes such as Down syndrome, Goldenhaar syndrome, Marfan syndrome and the DiGeorge sequence (Krishnan, 2002). Thus there may be consideration of these conditions around the time of diagnosis creating additional anxiety in parents waiting for further testing and results.

Identification with the heart and no visible sign of illness

Research has highlighted that parents of children with severe CHD are acutely aware of the fragility of their infant as they understand that the heart is a vital organ and there are serious implications when there is a problem (Goldberg et al., 1991). This threat to life can create distress in mothers and interfere with their capacity to bond. Mothers may even withdraw from their child to protect themselves from a potential loss. It has also been suggested that parents may find it difficult to accept the CHD diagnosis as there is no visible sign of illness (Emery, 1989). A child with CHD often appears completely normal, unlike other critically ill children who have obvious physical deformities such as hydrocephalus or spina bifida. This

difficulty in accepting the diagnosis may consequentially impact on how mothers adjust and adapt at a time also crucial for bonding.

Mother-Infant Bonding in CHD

Quantitative research in CHD related to the early mother-child relationship has focused on the quality of mother-child interactions, attachment and development outcomes for children and psychological distress experienced by mothers. Research has suggested that compared to non-cardiac mother-infant pairs, infants with CHD (mean age 6.3 months) have less secure attachments (Goldberg et al., 1991) and lower levels of positive affect and engagement with their mothers (Gardner et al., 1996). There is also evidence to suggest that parental overprotection is associated with developmental motor deficits in children with severe CHD compared to healthy peers (Bjarnason-Wehrens et al., 2007). Moreover, a study by McCusker et al. (2007) showed that family factors such as parenting style and maternal mental health, were stronger predictors of behavioural outcome for children with CHD than disease or surgical factors. These studies thus demonstrate the implications of parenting on children's development in this population.

Researchers have recognised the importance of understanding the psychological impact on parents. As already mentioned, mothers caring for infants with CHD are subjected to many stressors which may make them vulnerable to adjustment and emotional difficulties, often reported as elevated levels of psychological distress (Brosig, Whitstone, et al., 2007; Davis et al., 1998; Doherty et al., 2009; Fonseca et al., 2012). This is not surprising given that mothers experience strong emotional reactions of shock, grief, loss, fear and sadness at the time of diagnosis, either antenatally or after birth (Brosig, Whitstone, et al., 2007; Leuthner, Bolger, Frommelt, & Nelson, 2003). Due to the unexpected diagnosis, parents of children with CHD

have described disrupted expectations for their child (Rempel et al., 2012) and it has also been reported that they were less likely to perceive their child as a source of positive reinforcement than parents of healthy infants or children with cystic fibrosis (Goldberg et al., 1990). Such findings provide insight into the psychological and emotional challenges for mothers in this situation. There are also studies focused on parenting children with CHD which have emphasised difficulties around feeding (Lobo, 1992), decision making about surgery (Hoehn et al., 2004; Rempel et al., 2004) and parenthood transitions (Svavarsdottir & McCubbin, 1996). Consequently, psychological interventions have been aimed at helping mothers of children with CHD improve their adjustment and coping. A recently developed Congenital Heart Disease Intervention Programme consisting of six sessions of psychoeducation, parent skills training (to improve feeding and care-taking) and emotional processing (for grief associated with the loss of a 'normal' child) has been shown to benefit feeding interactions and maternal appraisal, worry and anxiety (McCusker et al., 2009). By comparison, relatively little research or indeed therapeutic interventions have been devoted to the developing maternal emotional bond in this population.

Qualitative methods can offer valuable insights into a mother's perspective of bonding in the context of CHD which quantitative literature is unable to provide. There is emerging qualitative research in this area exploring the experiences of parents of children with CHD. Nine mothers and seven fathers were interviewed in a grounded theory study about their experience of parenting a young child (aged between two months and five years) with Hypoplastic Left Heart Syndrome (Rempel & Harrison, 2007). Parents were described as engaging in "extraordinary parenting" (p. 827) to ensure the best possible outcome for their child, making extra efforts to encourage the necessary weight gain and protect their child from infections. Parents also found strategies to keep themselves and their partner going by normalising their situation, using distraction to manage worries and trusting and supporting

each other. More recently, Rempel et al. (2012) added to these findings by describing a process of 'Parenting under Pressure' in this population. They identified four overlapping and re-emerging phases – 'realising and adjusting to the inconceivable', 'growing increasingly attached', 'watching for and accommodating the unexpected' and 'encountering new challenges'. The second phase was specific to bonding and facilitated by parents being able to hold their infant. Parents began to see their child as their own and felt a desire to nurture them, despite physical and emotional barriers. Along with the developing relationship, however, were concerns about their child's future and upcoming surgeries.

These studies are clearly informative in helping to provide some insight into parents' ability to cope and bond with their child in the context of a severe heart condition. However, there remains a limited understanding of the developing mother-infant bond as interviews were not restricted to mothers; in fact grandparents were also interviewed in the latter study. Furthermore these studies only focused on one heart condition, reported on experiences after birth and relate more to parental adjustment. Therefore the whole process of bonding throughout antenatal, perinatal and postnatal periods remains unclear.

Rationale for the Proposed Study

The literature described thus far has highlighted the need for further research in the context of several important findings. Firstly, mothers who receive an unexpected diagnosis for their baby have strong emotional and psychological reactions and an anxiety-provoking post-diagnosis period with hospitalisation of their infant which might impact on their experience of bonding. Secondly, mothers of children with severe CHD are physically separated from their new born infants often immediately after birth, and during the necessary heart surgery, which may impact on their experience of interactions and the developing relationship with

their baby. Thirdly, parenting stressors which can disrupt mother-infant bonding have been reported in mothers of children with severe CHD (e.g. postnatal depression, maternal anxiety and stress, breastfeeding restrictions, demanding care schedule). It is possible that these factors might influence mothers' experience of the bonding process with their infant.

Qualitative methods can offer valuable insights into the lived experience of these women who face a challenging start to motherhood. It is hoped that findings can contribute to interventions in this unique parent group, such as the Congenital Heart Disease Intervention Programme described earlier, by facilitating the bonding process in at-risk mothers and normalise the struggles and emotional reactions evident in this population.

IPA is a qualitative analytic approach commonly used in health psychology. IPA researchers aim to understand the complex and interactive processes of the lived world of participants by focusing on the content and meaning in participants' accounts and how they make sense of their experiences (Smith et al., 2009). IPA can be used to explore the bonding experiences of mothers by allowing for idiosyncratic accounts and exploration of the ways they have coped with emotional, physical and psychological challenges.

Research Aims and Questions

In summary, despite CHD being the most widely diagnosed congenital condition in newborns, there remains a limited understanding of the bonding experiences in mothers of these children. As demonstrated by the reviewed literature, there are many factors which influence mother-infant bonding and these might be compromised for mothers of infants with severe CHD. Previous research about mother-infant relationships in the context of CHD has been largely quantitative with few studies examining mothers' lived experiences through qualitative interviews. There are, to date, no studies that outline the process of mother-

infant bonding throughout pregnancy, during hospitalisation and in the later postpartum period for mothers of children with severe CHD. Thus further research is needed to enable a better understanding of these mothers' experiences and to inform interventions that may lead to better bonding outcomes for mothers and children with severe CHD.

This study aims to add to existing research by adopting a qualitative approach to study the phenomenology for mothers of bonding with a baby with severe CHD and explore how they coped with challenges to this bond. IPA was used to identify important themes and capture any similarities and divergences across accounts. The rationale for using IPA is discussed in the following method chapter.

This study will attempt to answer the following research questions:

1. For mothers of infants with severe CHD, what is their lived experience of bonding with their baby throughout their pregnancy, the hospitalisation and post-hospitalisation?
2. How have mothers negotiated any challenges to bonding in the context of severe CHD?

Chapter 2: Method

Research Design

This research used a cross-sectional qualitative design, employing in-depth semi-structured interviews with eight mothers of infants with severe CHD. The interviews were analysed according to the principles of Interpretative Phenomenological Analysis (IPA; Smith et al., 2009), described later in this chapter.

Sampling, inclusion and exclusion criteria

Tight inclusion criteria was used to ensure homogeneity in the sample in line with IPA methodology (Smith et al., 2009). Mothers of children who were patients at a tertiary children's hospital were eligible to participate if they met the following inclusion criteria:

- Their child with a severe heart condition required surgery in their first month of life and was aged between six and eighteen months (the lower age limit ensured some distance from the experiences of hospitalisation to allow mothers time to process events, establish the bond with their infant and settle into motherhood, and the upper age limit prevented extended retrospective recall (Li, Scanlon, & Serdula, 2005)).
- They could comprehend and speak English (to avoid potential bias from interpretation).
- They were over 18 years of age at the time of birth (as the challenges of being a teenage mother might complicate interpretation of findings (Hanna, 2001)).

Mothers who received the diagnosis antenatally and postnatally were included to ensure an adequate sample size and that the themes elicited would represent experiences of bonding at different times of diagnosis.

Mothers of children with severe CHD were excluded from the study if the children were:

- Receiving inpatient treatment at the time of interview or were critically ill.
- Diagnosed with a syndrome or other serious medical condition.

It was anticipated that these mothers would have additional concerns and different experiences which could influence their relationship with their infant and thus affect homogeneity in the sample.

Recruitment

Participants were recruited from a paediatric cardiology department at a tertiary children's hospital. The department provided medical and surgical treatment to children with congenital and acquired heart disease, operated a fetal cardiac service to diagnose and manage prenatal CHD and also had a specialist cardiac psychosocial team with Clinical Psychologists, a Family Support Officer and Social Worker.

Eligible participants were identified by the team fetal sonographer who was experienced in congenital cardiac conditions and well placed to access the cardiology patient database, theatre lists and also the fetal cardiac team's database for antenatally diagnosed mothers. The fetal sonographer screened the databases, cross-checking with theatre lists, to identify mothers and their children who met the inclusion criteria. In total, 26 mother-infant pairs were identified, but it was noted that one family lived overseas. Thus there were a total of

25 potential mothers from which to recruit, 16 of whom were diagnosed antenatally. The details of these women and children were passed onto the researcher in the form of a spreadsheet.

In line with the sampling strategy agreed by the NHS ethics committee, mothers with younger children were invited to participate first to improve homogeneity in the sample and recruitment alternated between antenatally and postnatally diagnosed mothers until a sample of eight mothers was reached.

Mothers invited to take part in the research were sent an invitation letter (Appendix 2) which briefly outlined the study and a Participant Information Sheet (Appendix 3) which contained more detailed information about the research and provided the contact details of the researcher and the field supervisor who was a Consultant Clinical Psychologist from the cardiac psychology team at the recruitment site. The Consultant Cardiologists of these invited families were emailed prior to the letters being sent to inform them of the study and check for any objections to the mothers' recruitment, of which there were none. Mothers interested in being involved in the research or who had any questions were invited to contact the researcher or Consultant Clinical Psychologist by telephone or email. Those that did not make contact were followed up by the researcher with a telephone call, after a minimum of one week, to see if they had any questions and would like to take part.

Over the recruitment period, a total of 13 eligible mothers were sent letters inviting them to partake in the study. Three of these women declined the invite, reporting that they were either not interested or were too busy, and one mother could not be contacted. The other nine mothers who agreed to be involved were interviewed. However, one of these interviews could not be used as the mother no longer met the inclusion criteria as her child was recently diagnosed with a genetic syndrome. The sample therefore comprised of eight

mothers whose demographic characteristics are outlined in Table 1. Table 2 summarises diagnostic information about their infants and their hospitalisation. This information was gathered from the interviews and demographic questionnaire (see Measures) with the exception of the infants' diagnoses and surgical details which were collected from the hospital patient database.

Table 1

Participant Demographics

Participant (pseudonym)	Age	Ethnicity	Marital status	Employment status	Planned/ unplanned pregnancy
Elizabeth	33	White British	Married	Full-time, maternity leave	Planned
Rebecca	33	White British	In a relationship, not cohabiting	Unemployed	Unplanned
Lucy	37	White British	Married	Housewife	Unplanned
Georgina	36	White Other	Married	Housewife	Planned
Hannah	32	White British	Married	Housewife	Planned
Mary	27	White British	Married	Part-time	Planned
Francesca	35	White Other	Married	Full-time, maternity leave	Unplanned
Joanne	31	White British	Married	Housewife	Planned

Choice of Methodology

Qualitative approaches are particularly suited to areas where there is limited research as they facilitate in-depth exploration of participants' lived experiences and perspectives by allowing researchers to elaborate on areas most important to participants (Forrester, 2010).

As experiences related to pregnancy and early motherhood rely on the meanings women ascribe to them, a qualitative approach allows for associated psychological processes to be explored. The reasons for specifically adopting IPA will be outlined in the following sections.

Interpretative Phenomenological Analysis

IPA is focused on detailed examination of personal lived experience and how individuals make sense of and attribute meaning to their experience (Smith, 2011). It has theoretical roots in three philosophical areas: phenomenology, hermeneutics and idiography. Whilst it is beyond the scope of this research to examine these in detail, they will be briefly described (for greater detail please see Shinebourne, 2011; Smith et al., 2009).

Phenomenology

Phenomenology is the study of lived experience and is key to IPA in that the individual's personal experiences are attended to and participants are 'given voice' (Larkin, Watts, & Clifton, 2006). IPA draws on ideas from four of the leading phenomenological philosophers: Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2009). Husserl established the importance of focusing on human experience and conscious reflection. Heidegger (1927, 1962 as cited in Smith et al., 2009) further suggested that one's perceptions and experience are influenced by 'being-in-the-world' and thus dependent on context. Hence, he moved toward a more interpretative position, also shared by Merleau-Ponty and Sartre who respectively described an embodied and social element to interpreting the world. IPA is influenced by these phenomenologists, adopting the view that experience is a lived process with perspectives and meanings unique to each person derived from their relationship with a social world. In an attempt to understand another person's experience, IPA researchers therefore focus their efforts on the meanings people made from the experience whilst acknowledging that it will be an interpretative process (Smith et al., 2009).

Table 2*Child Demographics*

Participant (pseudonym)	Number of siblings of child with CHD	Time of Diagnosis	Age of child at time of interview	Gender of child	Child's heart conditions	Length of stay in hospital	Child's age at surgery
Elizabeth	0	20 week antenatal scan	10 months	Male	TGA, ASD, VSD	14 days	4 days old
Rebecca	4	1 day post birth	11 months	Male	CoA, VSD, PDA	13 days	5 days old
Lucy	3	20 week antenatal scan	8 months	Female	TGA	13 days	5 days old
Georgina	1	2 days post birth	9 months	Male	TGA	9 days	4 days old
Hannah	2	21 week antenatal scan	11 months	Female	CoA, IAA, VSD, PDA, complications post birth	16 days	5 days old
Mary	0	20 week antenatal scan	10 months	Male	TGA, ASD, PDA	17 days	8 days old
Francesca	1	7 hours post birth	10 months	Male	TGA	13 days	5 days old
Joanne	1	6 hours post birth	15 months	Male	TGA, ASD, small VSD	19 days	6 days old

Please note: TGA = Transposition of the great arteries; ASD = Atrioseptal defect; VSD = Ventriculoseptal defect; CoA = Coarctation of the aorta; PDA = Patent ductus arteriosus; IAA = Interrupted aortic arch (see Appendix 1 for descriptions of these conditions)

Hermeneutics

Hermeneutics is the theory of interpretation and formed part of Heidegger's work as well as other writers. Since IPA is an interpretative method, it uses hermeneutics, the premise being that through the art of interpretation and using one's intuition, one is able to understand the intention and meanings of another person and offer insights beyond explicit claims and content. IPA is considered to involve a double hermeneutic in that the researcher is attempting to make sense of the participant who is trying to make sense of their experiences (Smith et al., 2009). IPA also applies the hermeneutic circle through an iterative and dynamic analysis process. This means it considers the dynamic relationship between the part and the whole by moving back and forth between these positions, with the intention of gaining a richer perspective, rather than using a linear approach.

Idiography

The third theoretical underpinning of IPA is idiography which means being concerned with the particular. IPA's commitment to idiography is applied in two ways. Firstly, through detailed analysis where there is in-depth and systematic engagement of transcripts and secondly by using small, purposively selected samples in a particular context to allow for unique and even individual perspectives (Smith et al., 2009).

Rationale for choosing IPA

IPA provides a practical and theoretical framework for exploring participants' perceptions of particular events and how processes unfold over time while being particularly sensitive to the context in which events occur (Brocki & Wearden, 2006; Smith et al., 2009). Advocates of IPA have argued that it can usefully supplement quantitative research by exploring the

processes underlying observed findings, without imposing a hypothesis or focusing on outcomes (Brocki & Wearden, 2006).

IPA is particularly suitable for gathering in-depth individual accounts as it privileges the voice of participants, regarding them as the experts of their experience (Larkin et al., 2006). This fits with the research aim to promote maternal perspectives of bonding and also the growing NHS emphasis on service-user experiences and patient-centred approaches (Reid, Flowers, & Larkin, 2005). As well as focusing on the maternal perspective, this research explored bonding processes in the context of CHD, something not currently represented in the literature. IPA is “especially useful when one is concerned with complexity, process or novelty” (Smith & Osborn, 2003, p. 55) as it does not attempt to fit experience into predefined categories and allows for new perspectives to emerge (Smith et al., 2009).

IPA is also frequently used in health psychology because of its interest in transformative experiences that incite reflection. IPA has been used to examine experiences of illness including heart disease (Senior, Smith, Michie, & Marteau, 2002) and also parental experiences of their child’s illness (e.g. parenting adolescents with chronic pain; Jordan, Eccleston, & Osborn, 2007). It has also been used in studies that have relevance across various psychology disciplines (Smith, 2004) and which involve more complex psychological processes that occur over time. For example, IPA has been used to explore a woman’s sense of identity during her transition to motherhood (Smith, 1999) and also for the experiences of teenage mothers (Seamark & Lings, 2004) and disabled women (Walsh-Gallagher, Sinclair, & Mc Conkey, 2012). IPA was therefore considered an appropriate method for addressing the research questions of the study.

Exploring other qualitative methods

IPA was selected as the most appropriate analytic method after discounting discourse analysis and grounded theory.

Discourse analysis and IPA are seen to overlap in that they both involve close reading of participant accounts and are focused on language (Smith, 2011). However, discourse analysis takes a constructionist position and focuses on the function of language within specific contexts (Potter & Wetherell, 1987). Discourse analysis is therefore less interested in the experience, emotions and meanings conveyed by what participants have said (as would be the case in IPA), but rather how participants construct their role through the language they use. As this research was concerned with the former aspects of maternal experience, IPA was deemed more suitable.

Grounded theory is often seen as a viable alternative to IPA (Smith et al., 2009). This methodology seeks to generate theories about a particular phenomenon of interest and requires theoretical sampling, ideally to the point of saturation (Willig, 2008). Grounded theory is therefore most suitable for research which aims to present a theoretical model grounded in the data of a large sample that can draw on individual accounts (Lingard, Albert, & Levinson, 2008). However, the focus of this study was not to make a theoretical claim but rather explore bonding experiences in a small select group of mothers given the limitations of previous research in larger heterogeneous samples (Drotar et al., 1975). Therefore IPA's focus on individual experience was felt to be more compatible with the aims of this study.

Measures

Data collection

Face-to-face semi-structured interviews were conducted individually with participants, as considered by Smith et al. (2009) as an optimal data collection method. All interviews were audio recorded and a personal reflective journal was completed before and after each interview to record observations and important reactions which were hoped would enrich the data set. A demographics questionnaire and two self-report measures, outlined below, were also completed with participants to help situate the sample. Table 4 provides participants' scores on the two self-report measures.

Semi-structured interview schedule

An interview schedule (Appendix 4) was developed with input from the academic and field supervisors, published IPA guidance (Smith et al., 2009), relevant CHD and bonding literature and discussion with service users (see Service User Involvement). In line with IPA methodology, the questions in the interview schedule were open-ended, structured in an appropriate sequence, in this case chronologically, and contained prompts to allow for expansion of answers (Smith & Osborn, 2003). The order of the interview questions followed mothers' experience of bonding from pregnancy, through the diagnosis, birth, hospitalisation and discharge home, up until the time of interview. There was some variation in the order of questions for women diagnosed postnatally whose infant's birth was discussed prior to diagnosis. The length of time spent on each stage depended on individual experience. It was hoped that the chronological structure allowed participants to reflect on their experiences of all aspects of the bonding process and any changes that happened over time.

Demographics questionnaire

A demographic questionnaire (Appendix 5) was used to capture characteristics of the participant sample including details specific to the mother and her family, and also the relevant cardiac information about the infant and their hospitalisation.

The Depression Anxiety Stress Scales-21 (DASS-21; Lovibond & Lovibond, 1995)

The DASS-21 (Appendix 6) contains 21 self-report items to assess the frequency and severity of symptoms of depression, anxiety and stress in the past week. These three subscales each have seven statements (e.g. "I felt that I had nothing to look forward to", "I felt scared without any good reason", "I found it difficult to relax") which are rated using a four-point Likert scale from 0 (did not apply to me at all) to 3 (applied to me very much or most of the time) with a score range of 0-63. The DASS-21 subscales have been shown to have high internal consistency (depression: $\alpha = .94$, anxiety: $\alpha = .87$, stress: $\alpha = .91$) in a combined clinical ($n = 258$) and non-clinical ($n = 49$) sample and high convergent validity with other measures of similar constructs (Antony, Bieling, Cox, Enns, & Swinson, 1998). The DASS-21 is considered a useful measure for women in the postpartum as it offers broader assessment of postnatal distress over and above depression by also including anxiety and stress (Miller, Pallant, & Negri, 2006). The DASS-21 has been used to assess maternal mood in the context of preterm birth (Evans, Whittingham, & Boyd, 2012), having a child with Downs Syndrome (Norizan & Shamsuddin, 2010) and breastfeeding duration (O'Brien, Buikstra, & Hegney, 2008). Whilst DASS-21 does not provide a categorical measure of clinical diagnoses, it can usefully assess level of disturbance with the following cut-offs categorising the full range of scores in the population:

Table 3*DASS-21 Cut-off Scores (adapted from Lovibond & Lovibond, 1995)*

	Depression	Anxiety	Stress
Normal	0-4	0-3	0-7
Mild	5-6	4-5	8-9
Moderate	7-10	6-7	10-12
Severe	11-13	8-9	13-16
Extremely Severe	14+	10+	17+

Note: A score in the ‘mild’ range means the person is above the population mean but likely to be below the typical severity of someone seeking help (i.e. it is not a mild level of a disorder).

The Maternal Postnatal Attachment Scale (MPAS; Condon & Corkindale, 1998)

This self-report scale (Appendix 7) assesses the intensity of a mother’s subjective emotional response to her infant. It comprises of 19 statements grouped into three subscales: quality of attachment (nine items); absence of hostility (five items); and pleasure in interaction (five items), which respondents complete using two-, four- or five-point answers. Example items include “When I have to leave the baby, I usually feel rather sad(5)-relieved(1)” and “When I am not with the baby, I find myself thinking about the baby almost all the time(5)-not at all(1)”. Scores are given equal weighting and range between 1 (low attachment) and 5 (high attachment). The psychometric properties of the MPAS were established by Condon and Corkindale (1998) in a sample of 260 women, assessed at three different time points in the months following birth. The global scale was shown to have high internal consistency (four weeks: $\alpha = .78$, four months: $\alpha = .79$, eight months: $\alpha = .78$) and high test-retest reliability (r

= .86). The MPAS is commonly used in studies related to maternal aspects of bonding (e.g. Maas, Vreeswijk, Cock, Rijk, & Bakel, 2012) including in high risk populations (Evans et al., 2012). There are no cut-off scores for this scale but higher scores are indicative of a higher quality of maternal attachment.

Table 4

Participant Scores on the Self-report Measures

Participant (pseudonym)	Depression Anxiety Stress Scale-21			Maternal Postnatal Attachment Scale		
	Depression (0-21)	Anxiety (0-21)	Stress (0-21)	Quality of attachment (9-45)	Absence of hostility (5-25)	Pleasure in interaction (5-25)
Elizabeth	0	4	8	39.4	17.5	25
Rebecca	2	3	6	42.2	22.6	25
Lucy	4	0	4	43.6	20.2	24
Georgina	2	2	8	34.3	19.9	19
Hannah	0	2	1	43.6	24	23
Mary	0	1	0	42.2	23	23
Francesca	0	1	2	42.6	16	22
Joanne	1	1	7	43.6	21.6	22

As can be seen in Table 4, the sample as a whole had low scores for the DASS-21 subscales indicating an absence of symptoms of depression, anxiety and stress and the mothers had high attachment scores on the MPAS, indicating good mother-infant attachments.

Procedure

Ethical approval

The research first gained approval by an internal scientific peer review committee at the recruitment site. Following this, full ethical approval was granted from the North West Liverpool Central NHS Research Ethics Committee (Appendix 8) and the Departmental Ethics Committee at Royal Holloway, University of London (Appendix 9). NHS Research and Development approval was also gained from the recruitment site where the research was registered (Appendix 10).

Consideration was given to the possible ethical implications of the research for participants as it was recognised that potentially sensitive information might be discussed due to the nature of the topic. A summary of how these ethical considerations were addressed follows, with full details included in the Participant Information Sheet.

Voluntary participation and informed consent

Invited mothers were given time to consider their voluntary participation after receipt of the invitation letter and Participant Information Sheet. Mothers were made aware in the Participant Information Sheet and before the interview of the purpose of the research, their right to withdraw at any time and that decision about involvement would not impact on their or their child's future healthcare. Participants were also given the opportunity to ask questions and choose the interview location if they agreed to take part. Participants also gave written informed consent (Appendix 11) which the researcher countersigned, and both parties received a copy.

Confidentiality

Participants were notified in the Participant Information Sheet and during consent that all information gathered was confidential with the exception that they disclosed anything that suggested a risk to themselves or their child. The anonymity of participants was maintained at all times by using a participant number or pseudonym to identify personal information and transcribed material. Verbatim quotes were edited to preserve anonymity. Audio-recordings of the interviews were destroyed after transcription and all data was stored securely in line with data protection protocols and NHS confidentiality standards.

Risk

It was hoped that participants would benefit from the interview by having a space to share their story, reflect on their experiences and have it validated. However, it was anticipated that the interview might be emotive and therefore steps were taken to minimise any potential distress for participants. The researcher used her therapeutic skills to respond sensitively and empathically to any distress in participants and ensured they were comfortable, had breaks and were reminded that they could terminate the interview. The researcher debriefed mothers at the end of the interview and provided them with contact details of support groups and the hospital's cardiac psychology team (Appendix 12). The researcher was open to referring mothers to the Cardiac Psychosocial Team (which included Clinical Psychologists, a Family Support Officer and Social Worker) if there were concerns about the participant's or child's wellbeing but no mothers required this support.

Service user feedback

The interview schedule was developed with input from service users to ensure that questions were relevant, asked sensitively, enabled rapport building and encouraged

mothers to speak openly about their experiences. Two mothers of an older child with severe CHD (and therefore not suitable for participation in the study), who were known to the field supervisor were separately consulted for their views on the draft interview schedule. They agreed to review an electronic version of the draft schedule and comment on its structure, the clarity and sensitivity of each question and whether any questions should be added or removed. One service user provided feedback via email and the other over a telephone call with the researcher. Feedback on the interview guide was largely positive; however there were suggestions to simplify and combine some questions and add an initial and final question about how the mother was feeling. Thus the final interview schedule was shortened and made less formal which the women felt would be more engaging for mothers and allow them to relax into an open dialogue.

Interviews

Mothers were interviewed separately between August and December 2013. All eight interviews were conducted by the researcher, in a private clinical room at the children's hospital ($n = 1$) or in the participant's home ($n = 7$), whichever was more convenient for the participant. The researcher made efforts to meet mothers alone without their child/ren present, by arranging the interview when the child/ren were sleeping or in childcare. However, this was not possible for four mothers who were interviewed with their infant present for part of the interview. Interviews lasted between 59 and 104 minutes, with a mean interview length of 79 minutes.

The interview schedule was used flexibly, to guide the interviews and ensure that the main chronological events were covered. As the interviews were semi-structured, there was variation in the questions asked and the prompts used, depending on the responses given by participants and what was important to their experience. The researcher encouraged

participants to expand on their answers and prompted further discussion and clarification of relevant areas for the research questions. The participants' answers were regularly summarised to ensure that the responses were understood and that the researcher was not making assumptions (Forrester, 2010). At the end of the interviews, several mothers reported that they had not had the opportunity to discuss their experience in detail and although four participants were tearful in the interviews, they also felt it was helpful to reflect upon. None of the mothers were visibly distressed at the end of the interview and none took up the offer for psychology support. However, all participants received contact details of further support for related charities and the Psychosocial and Family Services at the children's hospital.

Analysis Process

Transcription

Interviews were recorded using an Olympus WS-750M digital recorder and later transcribed verbatim by the researcher, removing identifying information. IPA does not require the prosodic aspects of the conversation to be recorded (Smith et al., 2009) however pauses and expressions such as laughter and crying were recorded in parenthesis throughout the text. The words mothers spoke to their children among dialogue with the researcher were transcribed and breaks in the interview, such as when mothers left to attend to their child, were noted. The transcripts were manually typed in a landscape orientation document with wide margins for annotations and page numbers to locate important quotes.

Data analysis

The interview transcripts were analysed according to the principles of IPA with guidance taken from the academic and field supervisors who are familiar with qualitative research and also two experienced researchers who co-facilitate the London IPA peer support group. The following guidelines for IPA analysis, as detailed by Smith et al. (2009), were applied to the transcripts. Given IPA's idiographic stance, analysis began with examining a single case in detail before moving on to the next one.

Reading and re-reading: The first transcript was read a number of times and the audio-recording was also listened to closely. This created familiarity with the account and a sense of being immersed into the world of the participant. An open mind was maintained to allow for new insights to be revealed with each reading.

Initial noting: Initial thoughts and notes about the transcript were recorded in the right-hand margin of the word document. These annotations included three different focuses: (1) descriptive comments about the content and subject of what was said; (2) linguistic comments about the use of language, tense, pauses and repetition and (3) interpretative or conceptual comments at a more interrogative level drawing on personal reflections and asking questions of what was said to think about the meaning for the participant. Thus the comments included summaries, pointed out connections that came to mind and highlighted where there were similarities, differences and contradictions in the text. The researcher attempted to maintain a clear phenomenological focus with descriptions staying as close as possible to the participant's intended meanings.

Developing emergent themes: The initial notes of the transcript were then transformed into concise themes and phrases to capture the essence of what was important for the participant. These themes were noted in the left-hand margin. Identifying emergent themes

related to a higher level of abstraction, included more psychological concepts and reflected both the participant's original words and the researcher's interpretation. The premise was to find expressions that would allow for connections within and across cases while keeping grounded in the text.

Searching for connections across emergent themes: Emergent themes were then listed in a spreadsheet and, through a process of searching for patterns and connections, were arranged into related clusters. Some themes were discarded in this process with the intention to convey the most interesting and important aspects of the participant's experience. The resulting clusters of emergent themes were given a descriptive superordinate theme title and listed together in another spreadsheet with supporting verbatim quotes. This ensured an iterative process whereby the connections were evidenced by the source text.

Moving to the next case: This process was then repeated for the other seven transcripts, analysing each in turn. Whilst each transcript was treated as much as possible as a separate account, the researcher was aware of convergences and divergences between cases.

Looking for patterns across cases: Superordinate themes were compared and contrasted across cases. Attention was paid to more potent themes, concepts which were shared and also how a theme in one case illuminated aspects of another account and thus data was prioritised and reduced. The final result of this process was an organised master table of themes (Table 5 in Results) illustrating how themes were contained within superordinate themes and which were related to each participant.

Quality in IPA

It is recognised that quality and validity are important considerations in qualitative research which cannot be assessed using traditional quantitative criteria. This has led to the development of general guidelines to assess validity in qualitative research (Elliott, Fischer, & Rennie, 1999; Yardley, 2000, 2008) and these have formed the basis for criteria specifically applied to IPA studies (Smith et al., 2009; Smith, 2011). The following framework proposed by Yardley (2000) and cited in Smith et al. (2009) as applicable for IPA research was used to promote the validity and quality of the study.

Sensitivity to context

This was demonstrated from the start of the research process by using collaboration with clinical staff at the recruitment site and conducting a thorough literature review to inform the study and research aims. Sensitivity to context was also shown by attending to the perspectives of participants through service user involvement, open-ended questions in the interview and keeping close to raw material with verbatim extracts. Attention was also paid to the characteristics of the researcher and how she may have influenced the research process (see *Situating the Researcher's Perspective*).

Commitment and rigour

Commitment was demonstrated by in-depth engagement and understanding of the topic, attentiveness to the participant during data collection and systematic and thorough data analysis with input from experienced IPA researchers. To ensure rigour, the researcher developed her knowledge and skill in IPA by attending lectures (on IPA theory, interviewing and data analysis), an IPA support group and consulted IPA literature. Of importance in IPA is sufficient idiographic engagement and ensuring analysis is interpretative (Smith, 2011)

which was achieved by attending close to individual accounts, illuminating convergences and divergences and engaging with a double hermeneutic (making sense of the participant making session of their experience). Finally, with a sample of eight participants, extracts from at least half of the participants were represented in each theme as suggested by Smith (2011) as a characteristic of rigorous IPA (see Table 5 for the prevalence of themes).

Transparency and coherence

This was addressed by comprehensively describing the research process, grounding interpretations with verbatim examples, having regular consultation with the research supervisors and using peer supervision. To provide a credibility check of the analysis using multiple perspectives, the supervisors reviewed two analysed transcripts, ensuring there were no overstatements and that interpretations resonated with participant's accounts (Elliott et al., 1999). Supervisors and peers also checked that themes were mutually exclusive, coherent, grounded in the data and there was clarity in the fit between quotes and the assigned title. An example of the analytic process has been included for readers to enhance transparency (Appendix 13). As IPA is inherently interpretative and influenced by the researcher's preconceptions and experiences (Smith et al., 2009), a reflective journal (Appendix 14) was kept throughout the research process and explicit attention paid to the role of the researcher (see *Situating the Researcher's Perspective*).

Impact and importance

This aspect concerns whether a piece of research is "interesting, important or useful" (Smith et al., 2009, p. 183) and has empirical and clinical relevance. The contribution of this research and its novelty in relation to the current evidence base was discussed in the Introduction. The findings are also examined in relation to existing theories and literature and attention is paid to how the accounts of mothers' experience of bonding in the context

of severe CHD may inform clinical practice to better meet the needs of families in this situation.

Situating the Researcher's Perspective

It was important for the researcher to own her perspective and reflect upon her role in the research process by disclosing aspects of her background and personal experiences that may be relevant to the research (Elliott et al., 1999). It was also felt important for her to specify any preconceptions that could influence how the research was conducted and interpreted.

The author is a female White Australian Trainee Clinical Psychologist of child-bearing age. She had no personal experience of pregnancy or being a mother, although is interested in having a family in the near future. She is an aunt to two nephews and has increasingly more contact with babies and conversations about motherhood as her friends become mothers. It is likely that witnessing this transition in her sister and friends has led to an understanding of the varied experiences mothers have during pregnancy and in the early stages of motherhood.

The researcher also has no personal experience of heart disease or acute or chronic illness and nor does her family. Therefore her interest in the research was mainly from a clinical and academic perspective. The researcher has an interest in psychodynamic approaches, specialising in this in her final year of training and is therefore familiar with theories of attachment and the implications of early mother-child relationships on later developmental, social and interpersonal outcomes. It is possible that the researcher's interpretations may therefore consider unconscious processes and inner conflicts for mothers.

The researcher also had an interest in early mother-child experiences prior to her clinical psychology training. She used to work clinically in an ophthalmology department at a children's hospital assisting with the diagnosis of retinal conditions and visual pathway dysfunction. In this role she witnessed the impact unexpected diagnoses had on mothers and families and the struggles mothers experienced with disrupted eye contact with their infant. Often these children had other chronic conditions which led to the researcher developing an appreciation of the complex lives for these families. However, the researcher had little knowledge or experience in cardiology prior to undertaking the research which was thought would enable her to approach the topic with few preconceptions and a degree of neutrality. However, during the interviews, the researcher was surprised by certain aspects of participants' accounts which raised awareness of her implicit assumptions. These were reflected upon in the research diary and kept in mind during analysis to ensure that the researcher stayed as close to the accounts as possible.

Participants were made aware that the researcher was not part of the clinical cardiology team and did not have experience in cardiac disease. However the personal circumstances of the researcher were not disclosed. Her childlessness led the research to have genuine curiosity and naivety during interviews, and thus allowed mothers to take the expert position regarding bonding experiences.

Chapter 3: Results

Interpretative Phenomenological Analysis revealed sixteen subthemes, grouped into four superordinant themes, as presented in Table 5. A full summary table and representation of themes across participants, with additional extracts is provided in Appendix 15.

A narrative account of the data is presented below with descriptions of the mothers' experience and higher level interpretation and analytic commentary. Verbatim extracts from the participant transcripts are interspersed throughout, to evidence each theme and highlight the different and particular lived experiences of the mothers. Some quotes have been edited to ensure the confidentiality of participants and to maintain clarity. Explanatory comments added by the researcher are written as [text] and the omission of less relevant material is indicated by '...'. Pseudonyms have been used to maintain anonymity of participants.

Superordinant Theme 1: An Emotional Start to Motherhood and the Mother-Infant Bond

The mother-infant bond was portrayed as an evolving journey that began with confirmation of the pregnancy. This first theme captures the beginning of this journey, as mothers developed feelings towards their baby throughout pregnancy and with their first meeting following birth.

The mothers' bonding experience predated the CHD diagnosis and began in the early stages of pregnancy. During this time, mothers imagined their future life with their infant and family and, for primigravida women, their new identity as a mother. During the antenatal

Table 5*Master Table of Themes*

Superordinant Theme	Subtheme	Mothers contributing to the theme
1. An emotional start to motherhood and the mother-infant bond	Antenatal excitement and impatience for the new baby	6
	Growing bond during pregnancy	7
	Overwhelming first encounter with the baby	7
2. Losing control in the context of CHD	Shattered expectations	8
	Suffering with physical separation	7
	Confronting the reality of uncertainty and potential loss	8
	Feeling disconnected from the baby	5
	Feeling useless with the loss of caregiving role	8
	Losing confidence and feeling inadequate as a mother	7
3. Keeping connected to the baby	Maintaining closeness	6
	Taking back control and rebuilding confidence	7
	Prioritising and protecting the baby	8
	Persevering with support and focusing on recovery	8
4. Moving on together	Looking forward as a stronger mother	8
	Devotion to the baby at home	8
	Seeing the baby as both normal and special	8

period, mothers were not only aware of physical changes to their body and the physical connection to their baby but also the growing emotional bond with their baby. This emotional connection was strengthened with antenatal scans and fetal movements, even though some women received an antenatal diagnosis of CHD. With the birth, most mothers described overwhelming love as they identified with their babies, but for one mother her intense feelings related to unexpectedly having a critically unwell baby. Thus, this emotionally vulnerable time was not only the start of the mother-infant bond and motherhood but also the start of the challenges of parenting a child with CHD.

Antenatal excitement and impatience for the new baby

It was clear in participants' accounts that pregnancy was welcomed and elicited positive reactions. This was the case for all mothers, regardless of whether they had previous children or the pregnancy was planned:

I was so excited, so excited. And then-because me and my husband were trying for two and a half years and we just thought that we were never gonna have a child. So when we did, obviously we were over the moon. (Mary)

It's main-mostly excitement really, I'm gonna have two kids, that's really nice to say. (Joanne)

In response to this excitement, the pregnancy and growing baby seemed to become the focus for several women. Mothers spoke fondly of their pregnancy and baby, despite their having a challenging time due to illness, housing stress, an antenatal diagnosis of CHD or bereavement.

I was excited about having a [baby] and I didn't mind being ill because I was happy I was pregnant. (Hannah)

At first, I just wanted him to stay in there until I knew what was going on. But I did just want to meet the baby. I just wanted to be a mum really. (Mary)

For mothers, pregnancy also highlighted an imminent change to their circumstances and led to them imagining their future, which for some involved an expanding family:

I was looking forward to my little boy having someone to play with....I thought about them together a lot. (Hannah)

For the two primigravidae women, who had both longed to be mothers for many years, the imagined future was focused on their new identity and role as a mother:

I couldn't wait to just love this little baby and just, you know, do its nappies and feed-like, you know, do the feeding and being up at night and I know that sounds ridiculous. (Mary)

I was just really looking forward to being a mum and you know, couldn't wait really....I had wanted to be a mum for such a long time. (Elizabeth)

These extracts highlight the mothers' impatience for motherhood and enthusiasm for the maternal caregiving role. There is a sense of fulfilling their dreams and looking forward to a special and intimate relationship with their baby. The other women also expressed an impatience to meet their baby and be a mother again:

I just wanted him here, in my arms....it was just excitement and impatience. (Joanne)

Just wanted [the pregnancy] to be over with, really, and have the baby with me and, you know, be a mother already. (Georgina)

Growing bond during pregnancy

The antenatal period was important to the bonding journey as mothers were starting to develop feelings for their babies and communicate with them. This time was savoured by the women. They were aware of their unique role carrying the baby and being privy to intimate moments:

It's just like that connection you make because you are carrying that baby....he can hear me, all the time, he can-he can hear my heart beat all the time, you know, he can hear my voice and-and so he's starting to recognise me already, um and although I can't see him and I can't hear him, I can feel him, so I can, so I'm recognising him already. (Joanne)

Joanne describes an early reciprocity in her relationship with her infant as they begin to recognise, communicate and become familiar with one another. This developing relationship was very personal and very hard to describe for some women. For Francesca, the developing connection with her baby was instinctual and was sensed internally, with herself as the provider of love:

I think the connection, it's not about like talking to the baby constantly and giggling with the baby, it-I think the connection is um, inside. You feel it, you just feel it, you know it's your baby, it's yours, you put all love into the baby. (Francesca)

Mothers commonly experienced a growing love for their baby throughout pregnancy that began when the pregnancy was visually confirmed during the first antenatal scan. Thus, mothers found the antenatal scans an emotional experience:

When I first saw him as a blob, you feel that love straight away....you see them on that screen, you know, you can feel your body-you can feel your heart just kind of melt a bit....you feel that connection. (Joanne)

Every time I would get a scan I would be emotional. You know, I would get tearful and um just to see their heart beating and see them moving and see um that they have all their fingers and their toes, you know, it was just, you know, exciting and emotional as well....happiness, um excitement for the future, I think, um yeah, and love. (Georgina)

As well as this emotional aspect to the bond, mothers were aware of the physical connection to their baby. Mothers spoke fondly of the physical changes to their body and pregnancy shape and saw this as a reminder of their growing baby. The fetal movements were exciting and meaningful for the women as they signalled a thriving and nourished baby:

When you just feel them move, it's-it's just special cos it re-again it reminds you that there's something growing in you and you-you're making-you're creating a life and you're-you're growing that life. (Joanne)

I could feel more sort of flutters and-and I was excited about it....I knew it was baby and I was excited about looking pregnant. (Hannah)

For Hannah “looking pregnant” seems to indicate not only a growing baby but also a social aspect as pregnancy is visible to others. There was also evidence of mothers’ commitment to their baby during pregnancy as they adhered to nutritional recommendations and showed affection by speaking to their baby and rubbing their belly. For some women, this focus had a protective quality. Rebecca was at risk of a premature labour due to complications during pregnancy and four other women received an antenatal diagnosis of CHD. There was a

sense of these mothers prioritising their baby and becoming very dedicated and protective of them:

As soon as I found out she was gonna be poorly, I was just concentrating on making sure that I had her and she was fine and doing everything I could for her. Everything else went out the window. (Hannah)

I was bonding towards him, and you know, obviously with them having to then do the surgery and then put the stitch in, that scared me and obviously made me more-more protective over him. (Rebecca)

These mothers were focused on giving the baby the best chance of survival and were strongly against termination, which was offered to Hannah who received the diagnosis overseas:

I felt like they were trying to, um, get me to have a termination. I felt-I couldn't believe anybody would even, um, let that come out of their mouth. I couldn't even believe they suggested it. (Hannah)

The protective response of Hannah is evident in this quote as she guards her baby from others and gives her baby a chance at life.

Overwhelming first encounter with the baby

All mothers found childbirth an emotional and overwhelming experience but there was divergence between accounts when they met their baby. For the two first-time mothers seeing their baby for the first time seemed to come as a shock:

When he was delivered it was amazing just seeing this baby like-like I knew there was a baby in my tummy but just seeing it there was just incredible. And then having him for a cuddle was just-yeah it was absolutely lovely. (Elizabeth)

I was shocked when he was born, how much I loved him.... everyone says to you, you never know love until you have a child, and that saying is so true. So it-I-when he actually come out I couldn't believe how much I loved him when I thought I loved him in my tummy but that was nothing. (Mary)

The experiences of Elizabeth and Mary are overwhelmingly positive. For other women, there was a sense that they could recognise and identify with the experience and their new born infant:

As soon as I saw her, I felt like she looked like my baby....I knew she was mine. (Hannah)

As soon as you hold them in your arms it's just you know, through your whole body you just feel, so much love and a connection....I can't really say that I've had that feeling ever in my life except for childbirth. (Georgina)

It is magical cos you can just, again, you feel your heart melt straightaway and it's just-it's just an amazing feeling that a baby's now here and he's yours. (Joanne)

These accounts all highlight the birth of a child as a unique and special moment drowned in love as though the antenatal bond is not only consolidated but becomes more tangible. This moment seemed particularly overwhelming for the antenatally diagnosed mothers who were expecting their baby to be unwell and rushed away:

I just thought, oh my god, this is amazing, cause I thought she was gonna come out blue and they were gonna rush her off and, you know, like, I thought she was yeah, you know, gonna be in some terrible trouble and [she] wasn't, she was absolutely fine and she looked perfect. (Hannah)

This moment seemed particularly special for Hannah as her efforts to prioritise her baby during pregnancy were rewarded and she was proud of herself:

I felt like I'd done exactly what I needed to do and so I felt pretty good about my part in it. You know, like cause she come out and she was big and-and healthy and, well, looked healthy enough to not rush her away, I felt good about my part. (Hannah)

In contrast, this theme played out differently for Rebecca. While Rebecca also felt connected to and protective of her baby during pregnancy and had looked forward to his arrival, she did not identify with him after birth:

He came straight onto me and I sort of looked and I sort of quite shocked myself and....I wondered why, you know what was wrong with him? Had he been starved of oxygen or something for him to be that colour?...just looking at him, he just didn't seem-he weren't really sort of moving and thrashing about as much as you know normal babies do, he sort of just lied there sort of grunting, basically....I just didn't feel right with him. Um, sort-sort of mother's instinct. Something's telling there's something not right. (Rebecca)

Rebecca's son had not yet been diagnosed with a heart condition and she was presented with an oxygen-starved baby who, to her, did not look 'normal'. There is a sense that her baby did not match the one she had imagined from pregnancy or her previous children and she struggled with this discrepancy.

Superordinant Theme 2: Losing Control in the Context of CHD

Mothers experienced a range of emotional stressors as a result of the CHD diagnosis and subsequent hospitalisation of their baby. This theme captures the lack of control felt by mothers, as they faced the unwanted and uncertain reality of having a critically ill baby.

The women experienced a challenging and traumatic start to motherhood in what they perceived as a deadly, miserable and alien hospital environment. This setting symbolised a threat to the developing mother-infant relationship as mothers struggled to bond and care for their infant in the usual ways. Mothers lost a sense of control in this setting as they experienced separation from their infants, had limited physical touch, faced uncertainty with the life-threatening nature of their baby's condition and lost their caregiving role as the hospital staff took over. The experience was possibly more difficult and overwhelming as it was in stark contrast from what, for most women, was a safe and controlled pregnancy experience and a contrast with their previous children. Thus, this theme highlights how the mother-infant bond was an evolving process that could be threatened by challenging circumstances.

Shattered expectations

Receiving the CHD diagnosis was very difficult for all participants. Mothers described feeling shocked, devastated, numb and in disbelief at the news and some found speaking about it in the interview upsetting. It appeared to have such a profound impact as it was a serious diagnosis and was completely unexpected. Mothers reported expecting a similar outcome to their other healthy children and/or had not considered the possibility of a problem (including postnatally diagnosed mothers who all had unremarkable antenatal scans):

It was really yeah a big shock and everything cos you don't imagine that anything's wrong. (Elizabeth)

Horrible. Yeah, getting emotional now (tearful)...you think you got sort of normal healthy baby to then all of sudden be told he's got a, you know, problem with his heart. (Rebecca)

For postnatally diagnosed mothers, the shock of the diagnosis was followed by a sudden and somewhat frenzied transfer to the cardiac unit which made the whole experience dramatic and left mothers in disbelief:

When you go from you know, lunch time "oh you know, we're sorting you out to go home"....to then suddenly you're in [children's hospital] at 9 o'clock at night. It's just mad, absolute madness. (Joanne)

Me and [husband] just didn't even know what to say to each other, it was just that stunned silence of, you know, what the bloody hell's going on?! (Joanne)

It appeared that the CHD diagnosis marred a potentially positive start to their child's life and turned it into something more ominous:

There was such dark sadness when it came to [infant]'s birth and beginning of life. (Georgina)

For Hannah, who had an antenatal diagnosis, the birth was associated with an expectation of loss:

It felt more like um that might be the end of something, rather than the beginning. (Hannah)

I didn't ever feel like I was gonna actually have her and-and she was gonna stay alive and everything was gonna be fine. (Hannah)

Hannah's association of CHD with loss may help to explain why there was a sense of dreading the arrival of her baby, as exemplified in her following quote, in which she makes a comparison to other mothers:

I couldn't look forward to [having a baby] like they were gonna look forward to it and I couldn't plan like they were gonna plan. (Hannah)

Several mothers described searching for an explanation or reason for the diagnosis. Five participants blamed themselves and found faults in their actions during pregnancy, such as taking anti-sickness medication, smoking, having limited sleep, being stressed and not eating carefully enough:

It must be something I've done, something wrong, and I remember just blaming myself. (Joanne)

I just blamed myself, and I kept saying to my husband, like it's my fault....and that's all I kept saying. (Mary)

These mothers appeared to feel responsible for the diagnosis as they were carrying the baby. This guilt was so powerful that some mothers did not let go of the idea until they had researched the causes of their child's heart condition or were reassured by hospital staff. For Hannah, the diagnosis was so difficult to accept she seemed to be in denial:

I convinced myself that [the sonographer] was wrong and that again we were all gonna be alright. (Hannah)

In summary, the CHD diagnosis shattered mothers' expectations of a healthy baby and highlighted an unpredictable reality.

Suffering with physical separation

Mothers were separated from their infant on many occasions and found this unbearable. Antenatally diagnosed mothers knew that they would be separated immediately following birth and some had very limited contact:

He was only on me for five seconds, then they had to rush him away. (Mary)

Despite the forewarning, these mothers found the separation very difficult. It is possible that they were so focused on their baby's survival after birth, they did not consider their own feelings. Being separated from their husband, who went with their baby to the children's hospital, made the situation worse:

Completely on my own, with no baby, no husband. It was just horrible. (Mary)

I found that really stressful because they didn't-I don't think we really thought about that-that I would be left on my own. (Lucy)

The separation was exacerbated for those recovering after birth in a maternity ward with other women who had their babies:

I was just crying, I was a mess....they took me to a ward that was full of babies and I just went mental at all-at all the nurses. "How can you take me to a ward when everyone's got their babies and I haven't?!" (Mary)

When I was in [local hospital] and [infant] was in um [children's hospital] was yeah the really hardest bit. Um, especially as I was in a ward with lots of other mums who had their babies with them and who, you know in the night were

crying and they were getting up and feeding them and I didn't, you know, I had an empty cot. (Elizabeth)

There is a sense of mothers being angry and struggling with exposure to a more desirable experience. Elizabeth uses powerful imagery of her separation by expressing how she is alone in the wrong hospital. The "empty cot" is also symbolic of her worst fear, returning home after losing her baby, and indeed for her at this time, this outcome could not be disconfirmed. Elizabeth, and the other mothers in this situation, felt trapped and were desperate to be reunited with their infants and relieve themselves of this anxiety and uncertainty about what was happening with their babies:

I was desperate to go but they wouldn't discharge me. (Elizabeth)

I just-just wanted to go to [children's hospital], you know, that was all I could keep thinking about doing. (Lucy)

Mothers described being angry about their separation and gave a sense of the powerful hospital against them and their baby. They were desperate to be with their infant following birth, to offer special protection and care for them:

I wanted to be there because, you know, I felt like I could probably do a lot more than what [partner] could, you know, with being mother. (Rebecca)

I don't wanna really leave him....he's my baby, he isn't, you know, he's only just over 12 hours old, I don't wanna-I don't wanna walk away from him now and just leave him with strangers. (Joanne)

These quotes highlight something special and unique about being a mother. Mothers continued to struggle with separation for the entire hospital stay and often stayed by their

baby's bed all day, finding it difficult to leave to sleep, eat and express milk, especially before the open-heart surgery. For some, the separation became near impossible:

You just want to say "no, sorry, I'm not leaving her, you can't have her!"

(Hannah, referring to the cardiologists)

I have to leave him and I can't leave him. (Francesca)

It was also apparent that some women were mindful of how their infants were experiencing the separation and limited touch, expressing concern for how it might impact on them:

I wanted to be near him, just be near him so that he knew I was close. I didn't

want him to think that I had abandoned him. (Rebecca)

This extract is indicative of Rebecca having an instinctively protective and nurturing bond. She is mentalising, thinking about her baby's mental state and how he might be feeling, and she acts accordingly.

Confronting the reality of uncertainty and potential loss

Fundamentally, for mothers, the diagnosis of CHD meant a threat to their baby's life as they identified with the seriousness of a heart condition. The death of the infant would also be the ultimate threat to the mother-infant bond and mothers were tormented by this persistent fear of losing their baby:

I just kept thinking that she wasn't going to survive. That-that was the main-my main thing. I just kept thinking, I don't think she's gonna live. (Lucy)

My whole brain was just playing all these horrible images....all of my thoughts were to him dying. (Georgina)

Several of the mothers described vivid memories of witnessing the consequences of their baby's heart failing and being confronted with a blue baby, beeping alarms and a rush of urgent medical assistance:

I'm totally freaking out, I'm absolutely like crying my eyes out....he was turning blue, his whole body was going blue at this point. I was, oh my God, he's gonna die-he's gonna die....I just remember like begging the doctor, I was be-begging her going "please, please don't let my baby die." (Mary)

It was really scary-really scary to sit and watch. I-I then had to leave because I then thought he was going to die. (Rebecca)

Mary uses emotive language, partly in the present tense, to communicate one dramatic moment of sheer panic, distress and terror at the possible loss of her baby. Rebecca was similarly fearful of losing her child, and later refers to being haunted by feelings of loss related to a previous child of hers who died after being born prematurely. She described anticipatory grief for her son with CHD, as she did not expect him to survive such life-threatening moments:

Knowing the hurt feeling of losing a child before, you know, I kept getting them feelings back even though I knew [infant] was still there....I felt like I was grieving for [infant] but I knew-I knew that what I was feeling was a grief, if you get what I mean....I think I felt like I'd lost him, even though I hadn't, that was just that feeling I had-I had in there, which was strange for me to be feeling that-that, even though he was still there but, unless it was my body trying to prepare me for something that could've happened. (Rebecca)

Rebecca speaks of this grief as her way of preparing for the potential loss of her son. The reaction seems to be a form of self-protection so that the reality of facing bereavement will

be less painful. This was a similar reaction for Georgina who found herself tormented with imagining her child's death:

You just constantly play the worst scenario in your-in your head. I think it's protecting yourself cos....if you have a better outcome than the worst then you won't be disappointed in a way. (Georgina)

For Rebecca and Georgina this reaction seems to be a way of coping with an intolerable, uncertain situation. Indeed, mothers were acutely aware of the fragility of their infant and commented on them being covered in tubes and not looking like a baby should. Some mothers expressed how they felt sorry that this was happening to their infant, seeing them as undeserving of this situation. For Hannah this was epitomised with the open-heart surgery as she reflected on the resulting permanent scar:

The thought of them cutting her and-and it almost felt like she would never be the same. She would never be, um, I want to say perfect....I thought....she's gonna have this big scar and she's never gonna be like she is now again. (Hannah)

This description evokes powerful imagery of a mother having to expose her daughter to trauma and losing a 'perfect' child. Just as the "cutting" permanently changes the physical form, the mother is emotionally severed from her imagined child. The scar also serves as a permanent reminder of the heart condition and the challenging start to life.

Feeling disconnected from the baby

Five participants reported a feeling of being disconnected from their infant. Although these distressing experiences tended to be short-lived, they served as surprising reminders of the mothers' uncontrollable reactions to the hospitalisation of their infants. Elizabeth's baby

was unrecognisable and strangely unfamiliar when she was reunited with him following their separation overnight after birth:

I was like, is that him? Like, I'd only seen him so briefly, there were lots of other babies and I couldn't really remember what he looked like. Is that [infant]?
(Elizabeth)

For other mothers, there was a distancing in their relationship due to the absence of reciprocity and any reactions when their baby was sedated in intensive care:

I didn't really have a relationship with her at that time, I suppose. (Lucy)
It felt like everything was just on hold then, she was paralysed under sleep.
(Hannah)

Mothers struggled with the lack of interaction and understanding about what their infants could feel, hear or smell at this time which is vastly different from expectations for new mothers to learn to decipher their newborns' reactions to meet their needs. Joanne felt that during intensive care, she was losing the bond she had already developed with her infant. She spoke of needing to rebuild this bond and found the lack of physical contact particularly difficult:

Him being in a-a cot....[touched by] a finger or a hand is not the same as a whole body cuddle you know, so, you do-you do feel a bit disconnected. (Joanne)

In contrast to the other women, Rebecca experienced a more severe detachment from her infant and even temporary rejection, possibly related to her previous experience of losing a child:

I had er a bit of a breakdown where I couldn't go near him, I couldn't touch him.

I didn't want to touch him, I couldn't look at him. (Rebecca)

To be honest, I didn't-wasn't really feeling like a mother, I weren't feeling like a mum standing there. I-I felt he was sort of alien towards me....I suppose I was making myself feel like it was somebody else's baby and I was just there just-looking-you know looking after him, just watching him. (Rebecca)

Rebecca experienced these feelings for several terrifying hours before she “snapped” out of it. She reported receiving some psychological input around this time. Similar to her feelings of grief for her baby presented earlier, she linked this strong detachment from her baby as a way to protect herself from the hurt she would suffer if he died.

I think I felt that if I didn't-didn't bond with him then the hurt wouldn't be as bad if something was to happen. (Rebecca)

Feeling useless with the loss of caregiving role

There was a strong sense from all mothers of losing their caregiving role at the hospital and feeling like a “bystander” as the nursing staff took over:

Once you're there, for me, it's all sort of taken out of your hands....the nurses....tell you what's happening....and you just-you just stare at your baby. That's it. (Lucy)

Being unable to care for their baby ultimately led mothers to feel useless and helpless:

You feel a bit useless....you can't look after your baby. Somebody else is looking after your baby for you. (Lucy)

You just want to be able to do everything but you feel helpless cos you can't.

(Georgina)

Mothers also had to reluctantly accept that, as well as not being able to provide the care, they did not know what was best for their baby. There is a sense of mothers relinquishing control to the hospital staff and having to ask their permission to do anything.

I didn't feel like I was the one who was her main caregiver because even once we got to the-the hospital, once we got her into intensive care, I asked them if I could change her nappy and I asked them if I could give her a dummy and I felt like they knew better than I did....I felt like I didn't know best, I needed to let somebody else um be the person who was in charge because they knew more of what she needed than I did. And I wouldn't say that meant that I didn't feel like her mum because I definitely felt like her mum but I didn't feel as though I knew what was best for her. (Hannah)

This evocative description highlights how Hannah seemed to have to redefine her place, after losing her caregiving role to the nurses, although she still identified as a mother. It seemed that her role was conditional on the understanding that she was not in control of making or acting on decisions about her child's care. This is also portrayed in her reference to seeking permission from a nurse to put some soft toys in her baby's cot:

[The nurse] was like "look, she's your child, you can do what you want." But I didn't feel like that. It was their bed, it was their medicines and....they were doing it all. (Hannah)

Hannah felt her personal freedom was constrained in an unfamiliar environment where nothing belonged to her. Joanne also described challenges in negotiating her identity and

place in the hospital after losing her caregiving role but in her case, she was unable to affirm her role as mother:

I really wasn't doing anything for him, I wasn't changing-even like changing nappies....[I was] literally doing nothing. So you just kind of think, well what-what am I doing here? So you feel a bit-bit helpless and a bit like-like you're twiddling your thumbs, and, you know waiting for something to happen, so don't really feel a-a mum. (Joanne)

Joanne could not identify as mother, a role that is usually not disputed and taken for granted. There is a clear indication of her and others' struggle in being unable to care for their infant at the mercy of the medical condition and hospital staff.

Losing confidence and feeling inadequate as a mother

Most mothers expressed a desire to breastfeed their infant and considered this an important part of their role. However, mothers were unable to put their incubated babies to the breast and were encouraged to express instead. This was very stressful and disheartening for the women who struggled and was compounded by them knowing that their breast milk was one of the only things they could offer their baby. This led to feelings of inadequacy, especially when the women saw other mothers being able to express:

Breastfeeding was another stress and at the beginning, in particular, when I was going into the expressing room and some ladies like-were like coming out with bottles full of milk and there was me with like a few drips. Oh, why can't my milk get going? So I did find that hard. (Elizabeth)

I just felt like I was worthless, I think, at that point, because I know he needed it. (Mary)

Most mothers also reported genuine fear about harming their fragile babies with physical contact in intensive care:

Every time we held her, her sats would drop. We'd pick her up and her sats would drop, so we just didn't want to hold her. You didn't want to pick her up, you know, because you were just so frightened that something was-you weren't doing the right thing. (Lucy)

I didn't wanna change his nappy because yeah, I was too scared I'd pull a tube out and something would go wrong. (Mary)

Lucy and Mary show sensitivity to risk and decided to err on the side of caution by placing limitations on their involvement. It seemed that mothers' diminishing responsibilities led to them feeling insecure, inadequate and deskilled and they lost confidence which, for some, continued until discharge and into their home. Unsurprisingly, mothers were nervous of leaving the hospital and being solely responsible for their child:

I was worried to go home, actually, with him, because I was like, I don't know how to look after him. I'm like maybe he needs something, maybe I-I'm not gonna be able to do what I ne-what I have to do. They gave us some medicine we had to give him and I was like, oh my God, it's so much, um, I'm all by myself. (Francesca)

This is one of the more evocative descriptions of the participants' fear at the prospect of returning home and offers a succinct portrayal of an experience observed across most of the sample. Mothers feared taking over the care alone as they felt unable to match what had been provided at the hospital. For one mother, the discharge was so anxiety-provoking that she requested to stay another night as she did not feel ready or prepared. The fears expressed by mothers before their transition home highlight some ambivalence as, despite

longing for a caregiving role at home, they felt daunted by this prospect and responsibility when it became reality.

Superordinant Theme 3: Keeping Connected to the Baby

This theme arose because of the commitment mothers demonstrated to their baby despite the difficult circumstances. Mothers endeavoured to savour their bond with their baby and kept their baby in mind, even losing focus on themselves in the process.

This theme captures how the women gave meaning and purpose to their time in hospital despite feeling overwhelmed and not in control. The participants experienced a maternal desire to overcome the obstacles they faced and maintain a connection with their infant. Thus this theme highlights an active side to the bonding process, as mothers employed a range of strategies to keep connected to their baby and regain some control. They ensured physical and emotional proximity to their baby, reclaimed their maternal caregiving role, prioritised their baby and found ways to cope and focus on a successful outcome. It seemed that contact with the baby and engaging with caretaking tasks, no matter how small, allowed the bond to develop.

Maintaining closeness

Throughout the interviews, women reported how important it was for them to be close to their infants and how they sacrificed their own needs:

I spent most of my time at [infant]'s bedside. I was up over there every morning about half-past five in the morning, I weren't leaving until one in the morning either so I was living on lack of sleep. (Rebecca)

More than just physical proximity was a desire for mothers to be able to touch their infant. Physical contact was restricted in intensive care but mothers described ways to make contact by touching with just their hand, singing and speaking to their infant:

When he was in, um, intensive care, you couldn't hug him at all. So you're just tryna hold his hand or just stroke his head or you're tryna get any sort of contact that you could and that's really hard not having the contact. (Joanne)

However, for mothers, the most memorable moments came when they were able to hold their infant:

Obviously with him being all strapped up all the time we were limited to err, cuddles. So when we did get cuddles, so it was, yeah....big special moment. (Rebecca)

As soon as I got him back in my arms, my heart melted again and I was-it-it was a relief as well, you kind of do that big like "Ah (breathed out), I got him back". (Joanne)

It seems that just as separation was considered a barrier to the mother-infant bond, regaining contact seems to help with reconnection, for both mother and infant:

I think [physical touch] was ah, just something I-I know I definitely needed and I felt like he needed it. Again, it's that reassurance thing for him [to have his mother close]. (Joanne)

Another intense desire was the recovery of their baby:

I felt close to him, I felt, you know, bonded to him, I felt-like I loved him so much and I needed him, um, I just needed him to get through it. (Georgina)

Mothers continued to be close to their baby for the rest of their hospital stay and were mindful of their baby also developing an attachment to them. One mother spoke of exchanging each other's clothing and sleeping with the item to assist bonding and another mother savoured other reciprocal interactions:

When he was awake and alert that was nice sort of to make-like try make eye contact with him and just-just give my-my scent to be honest....that was lovely, that was really-I loved every part of that. (Rebecca)

It seemed that just like the lack of physical contact had been a barrier to the mother-infant bond, resuming physical touch and having intimate and close moments clearly facilitated the bond and strengthened mothers' feelings towards their infant.

Taking back control and rebuilding confidence

To re-establish their perception of their role as primary caregiver, it was crucial for mothers to take back caregiving responsibilities from the nurses. This view was shared by most women and tended to coincide with a more robust, stable and less machine-dependent baby.

When they were swabbing her mouth out and stuff I'd, you know, I'd say "ooh, can I do it? Is there anything I can do?" Um, and that was nice, just-just to do the little things, wipe her eyes and put some scratch mits on her. (Hannah)

As well as giving some control back to mothers, the involvement in care tasks assisted with bonding and reinstating their identity and role as mother:

All those little things just gave me that bit more of a connection. Like holding his syringe and giving him his drugs and just being, made me feel like a mum again, like I was doing all the things that I should be doing to a newborn. (Joanne)

Once you were able to help out with her care a little bit more and you can go in and you can pick her up....and she was able to feed like a normal baby and that was nice because once you can start feeding her and changing her and you know putting clothes on her, it definitely [strengthened our relationship]. (Lucy)

Despite nurses offering to do the care, mothers became more vocal, insistent, assertive and confident that it was their “job” as aptly described by Rebecca:

I did feel like [the nurses] were....still trying to do my job, if you-you know. I’m there trying to do things and they are “oh no, we’ll just quickly pop it down his tube” and I’m like “no, I don’t want him being tube fed, I will sit here and I will feed him!” (Rebecca)

This role reversal and regained control was a powerful transition for mothers and felt completely natural for some women when it continued at home:

It was lovely not feeling like I had to ask anyone anything, I just did it all on my own and-and it was all my responsibility. And that’s what I wanted. (Hannah)

Prioritising and protecting the baby

There was continual evidence across the mothers’ accounts of dedication to their child. This encompassed their reactions following the CHD diagnosis, the hospital stay and also home life. For some mothers, this focused attention on their children was all consuming:

I didn’t think about me. Not really. You just don’t. You’re thinking about-all I was worried about was her, my other children at home....I didn’t really think about-about myself at all. Um, I just did what I had to do. (Lucy)

For many mothers, to give their infant the best possible care, meant providing breast milk as they were aware of the nutritional benefit for their fragile infant and it was a way to show their commitment to their child and help with their recovery:

I'd started um-err on the breast pump, so that was making me feel a bit more motherly....it meant everything, yeah, it meant that I was trying to give him the best, if you get what I mean, you know trying to, eh, build him up, make him stronger, so he could sort of get better quicker. (Rebecca)

One day I managed to get like four ounces out and I came back and....it was best thing in the world. I was like that (puts her hands in the air), yeah! He's gonna eat well tonight! You know, so it was-it was my-my way of helping him....I was doing something for him, you know, I was helping him get stronger. (Joanne)

For these mothers, providing breast milk was a huge triumph and boosted their confidence, made them feel more motherly and it also symbolised an ideal nurturing relationship between mother and child:

I was so desperate to have this ideal you know like relationship with him and you know being able to breastfeed him, it was so important to me. (Elizabeth)

Many women also felt a strong desire to protect their infant from professionals and the hospital environment and saw this as part of their role as mother:

I wanted to make sure that I was watching everything everyone was doing....to make sure that the people who were giving her the care were watching her and- and I think when you have a baby, you are the person sitting, watching them the whole time making sure they're alright. (Hannah)

You just think, I'm his mum, I should be protecting him, he shouldn't be going through [heart surgery] at six days old. (Joanne)

For Joanne, it is as though handing her son over for heart surgery meant she could no longer offer him safety and protection. She indeed expressed a protective and nurturing quality to holding her infant, as though her arms formed a sanctuary of safety and healing:

You think if I've got him in my arms, I'm gonna keep him safe. That's-that's what you-what you feel, like, you-you can make him better just by holding him. (Joanne)

The concept of protection was also shared by Mary who refers to the unique importance of a mother to their infant:

I just think, this little thing, it needs you, like more than anyone in the whole world, even more so than the dads, and then I think if it needs you then, you need to be there. (Mary)

What is striking about these accounts is the transition for mothers from being helpless and dependent on hospital staff to taking charge.

Persevering with support and focusing on recovery

Mothers drew on several sources of individual and social support to manage after the initial diagnosis. The four mothers who received an antenatal diagnosis appeared to cope well during pregnancy, stated how they researched their child's heart condition and prepared practically for the arrival of their baby and hospitalisation. Professional support also helped with this process with mothers finding it helpful at the time of diagnosis to receive information about their child's heart condition, details of the surgical treatment and the

operation success rates. Elizabeth found the fetal nurse specialist, who gave her a tour of the cardiac ward at the children's hospital, particularly helpful:

I can't emphasise enough really how-how important it was to have that kind of person....having somebody who really kind of understood and just had-seemed to have all the time that we needed, to talk to us and reassure us. (Elizabeth)

Thus it seems that a therapeutic and understanding professional was helpful by alleviating the concerns and worries of Elizabeth at this uncertain and emotionally difficult time. During the hospitalisation, mothers described getting support from other families who had a child with CHD and were reassured by other children's recovery and not feeling isolated. The mothers' partner also provided essential support, being a constant companion to help absorb the difficult news, managing other children at home and staying strong when the mother was struggling. For many mothers, this experience with their partner strengthened their relationship:

I feel like we've come through something you know and it took a lot of strength to get there and-and love, really for my husband....I think we worked well together and it brought us a lot closer. (Georgina)

During the whole process, mothers were also helped and supported by their family and friends:

I've got a very supportive family, my mum and dad. I've got quite a big family, brothers and sisters-in-laws and um friends and yeah just having other people's support as well is really, is crucial, I think. (Lucy)

I just then turned to my friends and I think if it weren't for them I would never of got through it. (Mary)

It appeared that having a positive mind-set and refusing to be defeated was a huge aspect of coping for some mothers:

I wouldn't let myself be in the mind-set that she wasn't gonna be ok....I wasn't prepared to um to let go of the idea that everything was gonna be ok. (Hannah)

Significant improvements in their infant's health and appearance helped facilitate a positive outlook as the likelihood of recovery increased. Understandably this brought a sense of relief to all mothers as they saw their frail infant transform into a 'normal' baby:

Gradually day-by-day [all the wires and tubes] start to come away and that's lovely. That, you can't-you can't understand how nice that is....she starts to look like a baby again as opposed to this poor little thing. (Lucy)

Some mothers described feeling closer to their baby as a result of the experience and that their child had fought to be with them. It seemed that being so focussed and emotionally invested in their child for an intense period of time helped to strengthen their bond and allowed them to appreciate their child more:

He's so much more precious to us, going through what he's been through. Yeah, I just love him so much more, I really do. (Mary)

Superordinant Theme 4: Moving on Together

This theme captures the changing circumstances and attitudes of the mothers as they moved on with their baby and focused on their future together. Across participant accounts, it was clear that the hospital experience had influenced mothers, affecting their relationship and interactions with their infant at home and how they viewed themselves.

Mothers were profoundly reflective and many experienced personal growth and re-attributed their experiences in a positive light. This theme also highlights mothers' altered parenting and interaction with their infants at home and the continuation of the mother-infant bond. The experience led to a more protective parenting style, with some women being hypervigilant for health problems and giving their infant extra attention and affection to make up for the limited contact in their first month of life. Finally this theme captures the mothers' resulting acceptance of their child as normal but with an awareness of their uniqueness to have survived a traumatic start to life.

Looking forward as a stronger mother

Most mothers reflected on their experiences positively, expressing gratitude that their baby had recovered, feeling they had overcome the difficulties together and could look to their future. The reattribution of their experience in a positive light is succinctly expressed by Elizabeth:

My memories a bit-are more positive because we had this amazing new child, new baby, it was so exciting. (Elizabeth)

Elizabeth's transformative shifting of a traumatic experience into positive memories is remarkable and highlights the possibility of post-traumatic growth. A similar attitude was shared by other mothers who gave positive reflections of themselves and their resilience and strength:

I feel good actually. I feel good that we came through it all and that I didn't just completely capitulate at any point. (Hannah)

Although I did do a lot of crying, it amazes me how strong I was. Thinking-but I think that was just mum instinct coming through. That protection

instinct....because I-I had bonded with him for nine months previous...[it] was just natural. (Joanne)

I feel strong....I guess strong is the only word I can really-can really explain because err to go through that and to err come out. (Georgina)

There is also a sense for mothers of coming through the experience united with their infant which enhanced their bond and relationship. Joanne also acknowledged her maternal instinct as a driving force to get through the experience. The mothers' ability to draw positive conclusions from very challenging circumstances, seemingly brought feelings of contentment with their situation:

I have kids right now, I feel much more happier, ah, I feel like I achieved something and I can see that I can look more forward-look forward to the future. (Francesca)

Francesca shows how mothers could positively imagine their future again with their child, freed from previous uncertainty regarding their child's survival. For the two primiparous mothers, this future meant a change of plans and staying at home:

I've decided that I'm not gonna be going back to work. I'm going to be a stay-at-home mum for a little while which I'm really delighted about. (Elizabeth)

However, for Hannah, as well as having a positive reflection, the experience also had some unwanted reactions, illustrating divergence in the experience:

I'm much more afraid of things now than I was before. I worry about things now that I would've never worried about before. I worry about silly things like getting in a car crash and I lay in bed at night and think what if-what if there's an

earthquake....and I would never ever of thought about things like that before.

But I am worried about bad things happening now. (Hannah)

It seemed that Hannah had learnt from her experience that the world can be dangerous and unpredictable and was bothered by worries of this nature.

Devotion to the baby at home

The experience in hospital led to striking changes in how mothers cared for their infants at home and highlighted their continual dedication and love for their children. Several mothers described “spoiling” their infants with affection and being less strict as compensation for their time in hospital.

I think because we couldn't hold him so much when he was in hospital, we held him more and we-if he cried we'd pick him up straight away rather than, you know, letting him deal with it for a bit. (Joanne)

I feel um I'm more soft on her. I'm, you know I-I will pick her up. I still let her have feeds in the night and she's a year (chuckles), you know, I think that I would have been more um not-not strict but I would've made her sleep through. I still carry her until she falls asleep. I just-I desperately want to make sure that she has all of that, you know, that she has cuddles and-and things because I feel like she had such a rough start. I feel sorry for her a bit. (Hannah)

Mothers also reported an overprotective parenting style, being hypervigilant around their infant and finding separation from them difficult:

I did find myself just like lying awake watching him and making sure he's breathing and all that kind of thing. (Elizabeth)

We didn't wanna like leave him so between me and [husband] we'd take turns and one of us would sleep downstairs with him so that we had all of the bottles and all the formula and everything and all his medicine. (Joanne)

The mothers saw their behaviour as protective and expressed heightened concern for illness and catastrophic thoughts when their baby seemed unwell. Two mothers reported involving emergency services when they were concerned about their child's blue lips, but were informed their baby had wind. Mothers were clearly continuing to view their child as fragile and were fearful of further health problems. Several mothers highlighted that dealing with another serious heart scare would be worse as they felt a stronger bond to their infant:

I love him so much more now and that-the love does grow every day- if I wouldn't, I don't-I don't know how I would cope if he had to go through that again. (Mary)

Mary also noticed her child's developed attachment to her:

He was helpless as a newborn baby, so, and he didn't need me as a newborn baby but he needs me now. He crawls to me now and gives me a cuddle, you know, he, obviously he didn't do that when he was newborn, he definitely knows I'm his mum, he didn't when he was first born. (Mary)

Mary highlights the progression in her experience of motherhood, and reciprocation, reaffirming her mother role. In contrast, Rebecca, who experienced some detachment from her infant in hospital, expressed awareness of some difficulties in regaining her maternal role at home, despite feeling a close, protective bond to her infant:

I felt more of nurse to him to what I did a mother, if you get what I mean, sort of administering his medication and keeping an eye on [him]. (Rebecca)

I did feel like I wasn't bonding very well with [infant] and I was-yeah I even asked my health visitor for, um if I could go and do like a special baby massage, for just me and [infant] so then that was just mine and his time. (Rebecca)

Rebecca's awareness of the nature of her bond and relationship with her infant is striking and more so for her insight to try to rectify it. She also reflects on her mixed role, feeling confused at administering medication to her son as presumably this does not match her perception of the mother role but rather is more fitting for a nurse. However, this perception and awareness nevertheless show how Rebecca was devoted to her infant.

Seeing the baby as both normal and special

This subtheme tended to emerge towards the end of the interviews and captures how the mothers came to view their baby. All of the women reported that in time they came to see their child like any other child, as "normal":

I don't look at him any differently. I don't look at him and think like he's got a label, he's got congenital heart disease and will have that for the rest of his life. I don't look at him like that. He's a normal little boy to me. (Mary)

Apart from obviously, you know, the-the-the scar on her chest and things like that. She was just like any other normal baby. (Lucy)

Being "normal" meant their children no longer required different care from other children.

For Hannah this normality was established with being able to breastfeed:

She breastfed and was perfectly fine and that was a real triumph for me because then I felt like, you know, she was then like any other baby. (Hannah)

For other mothers, normality meant their child slotting into family life at home. Seeing the family together perhaps assisted in mothers viewing their love for their children as equal:

I've been thinking that I should maybe love him more than her but....I don't feel I should be doing that....I have to love them exactly the same way equally.

(Francesca)

However for some of the mothers, whilst caring for their baby with CHD was seen the same as another child, they felt that they were still special:

I feel like she's more special. I feel-I think if I'd had any baby I would've been pleased with them, of course. But with her, I just feel like she's a miracle.

(Hannah)

Hannah expresses proud feelings towards her daughter and her fighting spirit and journey of survival. She refers to a special relationship which was also expressed in other mothers' descriptions of feeling closer and more committed to their infant as a result of the experience. It is as though the bond is strengthened by the mother and child surviving the difficult circumstances together.

Chapter 4: Discussion

This study explored the bonding experiences of eight mothers of infants with severe CHD. Data were analysed according to the principles of IPA (Smith et al., 2009) and aimed to answer the following research questions:

1. For mothers of infants with severe CHD, what is their lived experience of bonding with their baby throughout their pregnancy, the hospitalisation and post-hospitalisation?
2. How have mothers negotiated any challenges to bonding in the context of severe CHD?

This concluding chapter will address the research aims by describing the study findings and how they relate to and inform the CHD and bonding literature. Attention will be paid to a number of relevant psychological factors in the context of bonding, coping and positive growth theories. These will be summarised according to the four superordinant themes revealed from the analysis:

1. An Emotional Start to Motherhood and the Mother-Infant Bond
2. Losing Control in the Context of CHD
3. Keeping Connected to the Baby
4. Moving on Together

This chapter will also present the strengths and limitations of the study, suggestions for future research and personal reflections of the researcher. Finally, the clinical implications of the study will be outlined.

Overview of Findings

The findings suggest that mother-infant bonding in the context of severe CHD is an evolving process influenced by early challenges associated with the diagnosis and hospitalisation of the infant. The experience of participants in this study revealed that successful bonding can be achieved despite potential risk factors for motherhood and challenges to the bonding process. All mothers reported forming close relationships with their infants, irrespective of the timing of diagnosis, which was also consistent with the mothers' self-report attachment questionnaire responses. There are many potential reasons for the positive mother-infant relationships that developed which will be discussed in more detail later in this chapter. However, three possibilities are evident that relate specifically to the characteristics of women in this study:

Firstly, there was an absence of current maternal mental health difficulties in the sample as indicated by the DASS-21 responses, although it is not clear if the responses would have been similar at diagnosis or in hospital. As presented in the introduction, maternal postnatal depression, anxiety and stress are all risk factors for bonding difficulties and can be common in mothers of children with CHD, but they were not present in this sample at the time of interview. Secondly, all of the mothers reported their child to be in good health at the time of interview and therefore they were not experiencing ongoing uncertainty and fear about losing their child. This is likely to be related to the type of heart conditions represented in the sample (i.e. Coarctation of the Aorta and Transposition of the Great Arteries) in which the heart is anatomically normal and the arterial problems can be successfully repaired in one major operation, unlike Hypoplastic Left Heart Syndrome where several operations are required over a number of years. Thirdly, it is also possible that the time-limited disruptions and the relatively short-term hospital stay (i.e. maximum of 19 days) for these mothers

allowed for more straightforward adjustment to the diagnosis and adaptation to motherhood. The successful bonding described by mothers is consistent with suggestions that the majority of mothers of chronically ill infants show sufficient resilience to adapt successfully to their situation without major disruption to the mother-infant relationship (Goldberg, 1988).

Key Findings

An emotional start to motherhood and the mother-infant bond

The perceived journey of bonding that participants described fits with an understanding in the literature that the mother-infant bond is not an all-or-nothing phenomenon but best described as a dynamic, dimensional continua of maternal loving and nurturing features and behaviours (Herbert et al., 1982). This maternal perception of the bond as a developing process was also evident in a qualitative study of preterm babies (Niven et al., 1993).

The women in this study described a developing relationship with their babies, beginning with confirmation of the pregnancy. This maternal affection towards the developing baby is consistent with widely accepted views of maternal-fetal bonding as the start of the mother-infant relationship (Siddiqui & Hägglöf, 2000). Indeed, Phillipp and Carr (2001) propose three psychologic maternal stages of pregnancy that fit with the experiences of mothers in this study. The first stage involves women initially discovering and accepting their pregnancy. The second stage encompasses the undeniable realisation of and emotional affiliation with their growing baby which is initiated with the antenatal scans and fetal movements. The third stage is predominantly concerned with the baby's arrival and involves maternal worries about childbirth and more intense maternal-fetal bonding in anticipation of meeting the

baby. These stages were experienced by mothers in this study, characterised by initial excitement and impatience for motherhood, then a growing bond during pregnancy and finally the mothers' preparation and anticipation of the arrival of their infant.

Phillipp and Carr (2001) also highlight how the stages of pregnancy might be compromised with a high-risk pregnancy. They define high-risk as involving obstetric difficulties, maternal factors such as gestational diabetes and HIV and congenital malformations in the fetus. It is proposed that in these cases, mothers might have prolonged ambivalence in early pregnancy, altered or delayed bonding with the fetus and diminished preparatory and protective health behaviours before birth. However, whilst these could potentially have applied to the women with antenatal diagnoses of CHD in the current sample, they were not reported. This might have been due to a period of adjustment for mothers following the diagnosis resulting from developing an understanding of CHD and its treatment. Indeed, studies have highlighted that receiving an antenatal diagnosis of congenital anomalies in pregnancy does not prevent the developing bond between mother and infant (Brosig, Whitstone, et al., 2007; Hedrick, 2005; Kemp & Page, 1987).

The antenatally diagnosed mothers also demonstrated commitment to their child by prioritising and protecting them during pregnancy, for example by refusing termination. Indeed, maternal vigilance about keeping one's baby safe from harm begins in pregnancy, exemplified by mothers who follow health and dietary recommendations (Eswi & Khalil, 2012). Childbirth and meeting the baby also helps to consolidate the mother-infant bond (Fleming et al., 1997), which was the experience of women in this study.

This study also supports the accepted understanding that there is no 'critical period' after birth in which skin-to-skin contact must occur for mothers to be able to successfully bond with their baby. Successful bonding was reported by all women in the sample, including

those who were separated from their infant after birth. This is also indicated by adoption studies in which there is a much later start to mother-infant bonding (Herbert et al., 1982).

Losing control in the context of CHD

Mothers experienced several situational and psychological stressors related to the CHD diagnosis and period in hospital which have been associated with disrupted mother-infant bonding. Physical separation from the infant, difficulties with breastfeeding, a compromised caregiving role and high levels of anxiety and stress around their baby's health were all perceived by mothers to impact on their sense of control and ability to protect their infant.

All mothers were emotionally distressed at receiving the CHD diagnosis and described feelings of shock, disbelief and fear around losing their baby. These reactions have been previously reported in this population and for both antenatally and postnatally diagnosed women (Brosig, Whitstone, et al., 2007). The CHD literature also highlights parental guilt around the diagnosis, grief with reconciling the loss of their imagined healthy baby (Brosig, Whitstone, et al., 2007; Hedrick, 2005) and adjustment to a seemingly inconceivable reality (Rempel et al., 2012). The women in this study had similar experiences as they described shattered expectations with the realisation of their child's fragile health and guilt and self-blame around the diagnosis.

The mothers' distress around the diagnosis can be contextualised by Becker's (1999) Theory of Disruption. Becker describes life phases and events as being structured by expectations and cultural meanings and that when these expectations are not met, people experience inner chaos and distress which leads to re-evaluating the self and world. It appeared that mothers in this study were particularly challenged by the CHD diagnosis as it shattered expectations of a healthy baby and the cultural ideal of adopting a maternal caregiving role after birth.

The postpartum period often involves adjusting and settling into a new routine (Herbert et al., 1982) which for many mothers involves breastfeeding. Breastfeeding is understood to facilitate mutuality and bonding behaviour in this early period as it elicits positive and intimate social interactions between mothers and infants (Lobo & Michel, 1995; Thompson et al., 2005). This opportunity was disrupted for mothers in this study and the difficulties experienced were consistent with previous reports. Mothers of children with CHD have reported feeding as one of the most difficult caretaking tasks (Svavarsdottir & McCubbin, 1996), commonly experiencing fatigue and worry about infant weight gain (Lambert & Watters, 1998). In line with research conducted by Lambert and Watters (1998), difficulties in maintaining milk supply during hospitalisation have been associated with feelings of maternal inadequacy and diminished confidence as a mother. It appears that restricted opportunities for and control over breastfeeding, led women to feel inadequate as a mother.

The women in this study also described a loss of control over the care of their infants in hospital which is consistent with reports from parents of infants who were on a neonatal intensive care unit (Charchuk & Simpson, 2005). It appears that the loss of control comes from an inability to perform a normal parenting role as mothers face a vastly different situation from what they expected prior to the diagnosis. The hospital was perceived as an unfamiliar, alien environment where mothers were not in charge of their child's care.

The feeling of being in or out of control seemed to play a pivotal role for mothers in terms of their sense of maternal identity and confidence in their ability to mother. There is much research about the importance of perceived control for psychological and emotional wellbeing. Difficulties coping with the loss of control is indeed implicated in some psychiatric conditions and relates to feelings of stress, anxiety and depression (Lachman, Neupert, & Agrigoroaei, 2010). Mothers in this study found the hospital period stressful and emotionally overwhelming, especially regarding the potential loss of their child. The relinquishing of

their infants' care to hospital staff was described as unbearable and left them feeling useless and inadequate in their maternal role. The lack of normal maternal caregiving seemed to create a disruption to their experience of bonding which has also been reported in mothers of pre-term babies (Niven et al., 1993).

For women in this study, the reluctant realisation and acceptance of the hospital staff as best placed to care and provide for their infant, undermined their culturally influenced perception of the mother as provider and primary caregiver who always knows best and can protect, nurture and care for their baby. This incompatibility between what mothers felt they should be providing and what they were able to, was consistent with findings from a review about the parental experience of having an infant in intensive care (Obeidat, Bond, & Callister, 2009). It was revealed that with hospitalisation, mothers felt powerless, insecure and like an outsider but their strong desire to be close and in contact with their infant remained, as it did with the women in this study.

Mothers reported struggling with the uncertainty in their child's health and the threat to life resulting from the CHD diagnosis. Uncertainty has been acknowledged in studies of mothers of infants with CHD for many decades (Glaser, Harrison, & Lynn, 1964; Gudermuth, 1975) and was a key finding from two more recent studies. Rempel et al. (2012) found that parents were watching for the unexpected with their child with Hypoplastic Left Heart Syndrome and Carey et al. (2002) suspected that persistent uncertainty regarding a CHD diagnosis accounted for mothers' sustained vigilance and monitoring of their child's health compared to mothers of healthy children. The fear around the infant's uncertain health seemed to have been heightened amongst the current group of mothers, who had limited time to adjust, process the diagnosis and faced a real threat to their baby's life.

Whilst the current understanding is that short-term mother-infant separation after birth does not significantly impact on bonding (Lamb, 1982), most mothers in this study *perceived* separation as disruptive to their developing relationship. Mothers found the limited contact with their infant following birth and during hospitalisation unbearable and they longed to have normal interaction with their infants. Indeed, it is understood that mothers come to recognise and respond to their baby through sight, touch, auditory cues and olfactory senses and this early discrimination depends on contact between mother and infant (Pederson et al., 2005). Therefore, separation and limited sensory input will make the early relationship harder to establish. Mother-infant interaction is not only shaped by maternal behaviour but also the responsiveness of the infant (Feldman & Eidelman, 2007) and therefore infant sedation may be another contributing factor to why the bonding felt disrupted for many of the mothers.

Although the majority of mothers did not experience significant disconnection from their baby, it is important to consider the experiences of one participant who felt detached from her son. Researchers suggest that bonding difficulties can be attributed to a controlling and less sensitive caregiving approach in mothers (Muller-Nix et al., 2004). This study, however, highlights the importance of historical context (such as previous bereavement) and that emotional distancing from one's infant might be a preparative strategy for self-protection from loss. Rebecca reported withdrawing from her "alien" infant, not being able to go near him, touch him or look at him. This reaction can be understood as an escape-avoidance strategy described by Lazarus and Folkman's (1984) emotion-focused coping, in which people attempt to alleviate their distress by emotionally distancing themselves from difficult situations. Evidence suggests that it is more effective in the short-term but maladaptive in the long-term and tends to be related to stressors that are uncontrollable (Ben-Zur, 2009). A reliance on emotion-focused coping strategies has been found one year after diagnosis in

mothers of children with CHD who find the child's care demanding and who generally tend to be avoidant in relationships (Berant, Mikulincer, & Florian, 2003).

Keeping connected to the baby

Mothers engaged in a number of compensatory strategies to keep connected to their infant in response to the challenges they faced within the confines of the hospital. These included maintaining closeness with any form of touch, speaking and singing to their infant, engaging with caretaking duties and remaining positive about a good outcome. These maternal behaviours reflect the findings of Rempel and Harrison (2007) who described parents as engaging in 'extraordinary parenting' with their children with Hypoplastic Left Heart Syndrome. This meant actively making extra efforts in parenting their children and managing their own worries, despite overwhelming uncertainty about their child's health outcome. Similar maternal efforts and dedication were evident in the current study which can be conceptualised as problem-focused coping in Lazarus and Folkman's (1984) model. It is theorised that these strategies are used in situations perceived to be amenable to change and will reduce distress through active management of the stressor (Frey, Greenberg, & Fewell, 1989; Miller, Gordon, Daniele, & Diller, 1992). It is possible that, as time passed and the infants became more robust and more likely to survive, mothers were able to engage with problem-focused coping. Thus the mothers' coping strategies changed depending on the fragility of the child. It could be proposed that it was adaptive for mothers to engage with emotion-focussed strategies when they had limited control, but problem-focused strategies were more useful when mothers began to have more control.

Problem-focused coping was also evident in the ways mothers sought crucial support from their family, friends and hospital staff to adjust to the challenges and remain focused on their baby. Several women were particularly appreciative of their partner containing their

emotional distress, remaining strong and being a constant companion. The results suggest that having supportive relationship between parents is central to positive adaptation. The emotionally supportive role of infants' fathers has been previously reported in the CHD literature from both self-report questionnaires with parents (Svavarsdottir & McCubbin, 1996) and qualitative interviews with fathers (Clark & Miles, 1999). The current study also suggests that this positive alliance helped to bring couples closer and it is possible this moderated the mothers' experience of bonding with their children.

For all mothers, physical touch was an important way to show affection and feel connected to their infant. This sense that physical touch was crucial for bonding is supported by bonding literature. Skin-to-skin touch is understood to help regulate infant behaviour and affect by providing comforting effects (Harrison & Woods, 1991; Prodromidis et al., 1995). Caregiving practices such as hugging provide an exemplary illustration of how close physical contact helps to reduce infant distress and promote mutuality between mother and child (Zeifman, Delaney, & Blass, 1996). Such distress-soothing responses are understood to be highly rewarding for both mother and baby and help solidify the mother-infant bond. Thus, tactile stimulation is seen to be a normal and important component of caregiving and can improve infant wellbeing (Zeifman, 2013).

Insight into the benefits of tactile stimulation for infants' wellbeing and successful bonding has led to massage and kangaroo-carrying interventions which promote early skin-to-skin contact. These interventions have been successfully applied in the context of postnatal depression (O'Higgins, St. James Roberts, & Glover, 2008) and prematurity (Field, Diego, & Hernandez-Reif, 2010; Tessier et al., 1998) and are likely to also benefit mothers of hospitalised infants with CHD. Perhaps the positive bonding outcome for mothers in this study can therefore be partly explained by the mothers' insistence on staying close to and having physical contact with their infant.

Another key concern for mothers was to protect their infants during hospitalisation. They stayed by their infant's bedside, monitored staff and were concerned about harming their infant with caretaking tasks. Similar vigilance and protectiveness, described in a qualitative study with parents of hospitalised critically ill infants, was thought to be triggered by perceptions of being in an alien environment (Hall, 2005). This commitment and attention towards the infant is also consistent with findings of Holditch-Davis et al. (2003) where mothers of medically fragile infants were found to be more responsive to their infant and provide more social stimulation than mothers of infants without acute medical problems. It is possible that having an unwell and less responsive baby, as with hospitalised infants with severe CHD, leads mothers to compensate by giving more attention to their infant.

Mothers expressed increasing confidence throughout the hospital stay, which seemed to coincide with the improved health of their baby and gaining control of caregiving. Having more interactions, helped to develop the bonding connection and mothers' perceived competence in her role, consistent with previous findings (Jackson, Ternstedt, & Schollin, 2003). It has been suggested that a thriving infant who is gaining weight and progressing developmentally provides the mother with positive feedback, enhances her confidence and validates her ability to care for her infant (Gudermuth, 1975).

This maternal reappraisal may be understood in terms of Rotter's (1966) concept of internal versus external locus of control (LOC; i.e. the degree to which a person believes their lives are controlled by themselves or external forces). The mothers' ability to gain a sense of control or mastery over their situation, as concerns around the infants' health subside, is in line with developing an internal LOC. Mothers were able to influence their situation and bonding by proactively engaging with caregiving duties, interacting with their infant and seeking help from their family and staff when needed. This internal LOC is in contrast to previous more externally focused perceptions when their infants were more fragile. Whilst

LOC is generally considered to be a fairly stable personality characteristic, there is a suggestion that life-altering events affect a person's sense of control and therefore it can change depending on one's circumstances (Legerski, Cornwall, & O'Neil, 2006).

In health psychology, the type of LOC is thought to influence psychological adjustment to illness and one's coping resources. Adopting an internal LOC is associated with positive health behaviours and a sense of personal control over health outcomes (Eswi & Khalil, 2012). It is also thought to be a common indicator of one's coping resources and is associated with greater individual competency and ability to successfully adapt in difficult situations (Thoits, 1995). Thus, having an internal LOC may help explain the successful bonding and adaption for mothers in the sample.

Moving on together

The mothers described a positive shift in their perception of the hospital experience with their transition home. They expressed gratitude at having a healthy child and reunited family and reflected positively on their own personal strength. They relished in their newly regained parental responsibilities and more natural interactions with their infant. Most women also felt that surviving the hospital experience as a family had brought them closer to their infant and partner. It is likely that engaging with problem-focused coping strategies and an internal LOC allowed for this cognitive reappraisal of previous difficulties and enabled them to reaffirm the value of motherhood.

The personal growth, resilience and positive effects on motherhood reported, are consistent with features of Cognitive Adaptation Theory by Taylor (1983), which suggests that people can successfully withstand threatening events including chronic illness by shifting focus to something that is controllable. Hence people are viewed as adaptable, self-protective and functional. The theory proposes an adjustment process whereby people who experience

personal setbacks or threatening events can respond with cognitively adaptive efforts that allow them to return to their previous level of psychological functioning or even surpass it. This is thought to be possible through adaption centred on restoring meaning (by understanding why a crisis occurred), gaining a sense of mastery (by feeling some control over the threatening event) and enhancing the self (by restoring self-esteem). These ideas are akin to cognitive coping strategies such as benefit-reminding (Affleck & Tennen, 1996) and positive reappraisal, used in Cognitive Behavioural Therapy (Folkman & Moskowitz, 2000), which allow for appraisal of a difficult situation in a more positive light. It has been suggested that people engage in such positive thinking strategies when they perceive a situation as a challenge rather than a threat (McCrae, 1984). Therefore this was potentially only possible for mothers in this sample when the child was safely out of intensive care away from the threat of death.

Research has also suggested that post-traumatic growth (Tedeschi & Calhoun, 1995) is associated with coping strategies such as acceptance, positive reframing, seeking social support and problem solving (Joseph, Murphy, & Regal, 2012). The theory of post-traumatic growth explores how an individual might adapt to traumatic events and experience some positive change from their struggle (Tedeschi & Calhoun, 1996) with three broad domains noted in the literature. The first includes enhanced relationships of both friends and family, increased compassion for others and longing for intimacy. The second involves growth in the self and includes learning about one's vulnerabilities and developing enhanced self-efficacy and self-reliance. The final is growth in one's philosophy of life, for example by gaining a new perspective or stronger spiritual beliefs (Joseph et al., 2012; Tedeschi & Calhoun, 1995). Indeed, the women in this study experienced changes in these areas through closer relationships, feeling stronger and more confident as a mother and having more perspective by not taking health for granted and being grateful for their situation.

Several mothers in this study also described great devotion to their child with CHD, as they continued to build a special connection and look to the future. It is not known whether this dedication would have been their natural response or whether it resulted from the child's heart condition and hospitalisation. There is suggestion that the hospital experience may have played a role as there have been previous reports of devotion and a positive future perspective in a study interviewing mothers returning home after their infant was discharged from a neonatal unit (Murdoch & Franck, 2012).

Some mothers in this study engaged in protective parenting practices at home due to ongoing anxiety about their infant's health. Mothers described watching their infants, checking on them frequently and exaggerating health concerns in comparison to their other children. It has been acknowledged that checking behaviour and preoccupation with creating a safe and secure environment for infants is common following birth. Leckman et al. (1999) found that 90% of new parents reported repeatedly checking their baby at three to four months postpartum. It seems that this heightened level of vigilance can continue in mothers of children with CHD aged two to five years (Carey et al., 2002). It is worth highlighting that children with CHD (and in particular Hypoplastic Left Heart Syndrome), can have surgery up to four years of age and therefore the mothers may continue to be alert and vigilant as there are ongoing experiences of their child's fragility.

For one mother, the heightened sense of risk did not just apply to health concerns for her infant but also a general perception of the world as being more dangerous and unpredictable. This unwanted reaction from the CHD diagnosis is consistent with research suggesting that the psychological impact of a traumatic experience can negatively affect an individual's assumptions about the world and self for several years (Janoff-Bulman, 1989).

A key finding from this study was also how mothers came to view their child as normal, despite also being concerned about their fragility in having CHD. Mothers acknowledged the strength in their infant for having survived but they were also aware of their infant's vulnerabilities, thus highlighting contradictory views and the possibility of an internal conflict within mothers. Indeed some women tried to enhance the normality of their infant by seeing their child as equal to their other children and treating them the same. These behaviours could be understood by Cognitive Dissonance Theory (Festinger, 1962) where someone experiences distress by holding two contradictory beliefs. Therefore to reduce the incongruence, mothers try to focus on seeing their child as healthy and normal. Normality has been a theme in other qualitative studies about mothering a child with a disease or disability (for review, see Nelson, 2002). Mothers have searched for signs of normalcy in their infants through caregiving, trying to maintain normal feeding and noticing the development of their child's progress. This view of mothers relating to their child as 'normal' has also been reported in the preterm (Murdoch & Franck, 2012) and CHD population (Pinelli, 1981).

More than just perceptions of their child as normal, some women also came to view their child as 'special' and 'a miracle' for having survived which led to them establishing a closer relationship with their infant. This is consistent with previous reports of parents of children with congenital anomalies (Drotar et al., 1975). Mothers spoke positively about their child's future with a perception that they would grow up like any other child. This seems to again highlight the mothers' ability to maintain a positive perspective. However, there is also an understanding that positive thoughts about the baby and the parenting role have been found to increase over time (Kim, Mayes, Feldman, Leckman, & Swain, 2012). Parents are thought to be more capable of focusing on positive and rewarding aspects of parenting, as preoccupations about their infant's health wane and they witness their babies developing

over the postpartum months and becoming more interactive. It is also thought that mothers find it easier to care for their infant as the parenting experience become more pleasurable and rewarding (Kim et al., 2012) and their confidence increases. Interestingly, Leckman et al. (1999) found that, at three to four months postpartum, 73% of new mothers report their healthy infants as “perfect”, which is the time mothers in this study would be settled back at home with their infant.

Strengths and Limitations

Strengths

One of the strengths of the study was the homogenous sample of participants as required for IPA. The resulting sample of mothers were close in age, identified as either White British or White Other, were in hospital for a similar period of time and had infants between eight and fifteen months of age with similar heart conditions. This homogeneity strengthens confidence in the conclusions that can be made for this select group and contributes to the novelty of the study. Whilst the inclusion criteria allowed for greater variability, the infant sample has been reported by clinicians to be representative of the population of children seen at the hospital site (S. O’Curry & V. Kelly, personal communication, April 2, 2014). This suggests that the findings are potentially generalisable to this hospital group, although it is unclear what proportion of these children have comorbid conditions. Furthermore, there was a good response rate for participation in the study with nine out of the thirteen mothers approached, taking part.

Another strength of the study was the service user involvement for feedback on the draft interview schedule which served to maximise effective data collection by ensuring questions

were clear, sensitive and relevant. The researcher also made concerted efforts to be reflective throughout the research process by keeping a reflective journal to capture personal concerns, thoughts and influences (Morrow, 2005). This was used to help with interview technique and bracket out specific biases during the analysis that could have impacted on the findings.

Another key strength of the study was using credibility checks of the data to maintain the validity and quality of the analysis and final themes (Yardley, 2008). To gain multiple perspectives and enable cross-validation, internal and external supervisors, as well as the London IPA support group, all provided feedback on the organisation of themes and their titles in relation to key extracts. Input centred on whether the themes were mutually exclusive, coherent and grounded in the data. In keeping with good qualitative practice, the final themes were deemed to be central to the mothers' experience, prevalent across accounts and illustrated convergence and divergence in the data (Smith, 2011). The resulting themes were not validated with participants as the analysis is specific to the researcher's interpretation of participants' account of their experience. This is theoretically consistent with IPA's double hermeneutic (Smith et al., 2009).

Limitations

Due to the retrospective design of the study, there was reliance on mothers recollecting their bonding experiences which introduced the possibility of recall bias. However, the researcher made attempts to minimise this by imposing an upper limit of 18 months for the infant's age as part of the inclusion criteria and also using a sampling strategy to invite mothers with younger children first, to also encourage a tighter age range and thus greater homogeneity in the sample.

Due to the nature of the research topic, this study had the potential for socially desirable accounts. Indeed, social desirability has been suspected in research relying on maternal self-reports of parenting practices (Durgel et al., 2013). The researcher attempted to reduce this bias by emphasising confidentiality and anonymity for participants and exploring mothers' idiographic experience in a non-judgemental, trusting and empathic manner. It is possible this was achieved as mothers appeared to be open and honest with their accounts, as they spontaneously discussed sensitive and upsetting issues with one mother describing negative feelings towards her infant.

There is also the possibility that the method of recruitment introduced bias, as mothers for whom bonding was particularly positive may have chosen to take part, whilst others who had a less positive experience did not. However, this is speculation as ethical approval to gather information about the mothers who declined was not obtained. Furthermore, by excluding mothers of children with genetic syndromes and/or critical illness, the generalisability of the findings to a wider pool of mothers are limited. As the participants were also recruited from one hospital site, the generalisability of the findings to other locations across the UK is also potentially limited.

Whilst the results show some divergence in mothers' accounts, all mothers in the study identified as White British or White Other and therefore there is no representation of maternal experiences from an ethnic minority group, despite this not being an exclusion criterion. Greater heterogeneity has been lost with the lack of representation of mothers from different ethnic backgrounds as there may be differences in the way these mothers view their relationship with their infant. Indeed, the dyadic relationship between a mother and her infant and the nuclear family structure are much less common in collectivist cultures (Woodhead, Faulkner, & Littleton, 1998).

Future Research

There are several possibilities for future research arising from this study. Firstly, in view of the limitations, future studies could aim to include other populations of mothers who were not represented in the current sample, in particular, mothers from ethnic minority groups, younger women and mothers of children with additional genetic syndromes. Bonding has been considered in terms of a Western cultural perspective, where a nuclear family and mother-infant relationship can be idealised (Woodhead et al., 1998). However, it would be interesting to explore how different cultural background and complexity in health issues impact on bonding experiences. In addition, mothers known to the psychology service could be recruited to elicit the different experiences when there are maternal mental health problems or recognised bonding difficulties. However, this is likely to be a small and hard-to-recruit population.

To further the understanding of the bonding experience, future research could also use follow up interviews, to explore the mother-infant relationship through later developmental milestones in the children. This longitudinal methodology would allow for a more complete picture on how the CHD diagnosis and early hospitalisation is associated with the mother-child relationship longer term.

Another valuable area of study would be to explore the father's lived experiences of bonding with their infant. The paternal role is generally an under-researched area but is increasingly recognised to be relevant particularly given the increasing caregiving role of fathers in modern society (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000). Women in this study reported their partner as a huge support throughout the process and most fathers had the role of accompanying their infant during the transfer to the children's hospital when mothers were recovering from childbirth. Furthermore, research suggests that men have a

different role in hospital, providing emotional support for their partner (Svavarsdottir & McCubbin, 1996) and thus it would be important to explore whether the sense of inadequacy as a parent, difficulties with physical separation, the threat to life and coping strategies, reported by mothers in this study, is also experienced in a sample of fathers. It would also be interesting to explore father-infant bonding as unlike mothers, fathers do not experience pregnancy and cannot express milk for their infant, which were both important for the mothers' bonding experiences in this study. Although the experience of fathering a child with severe CHD has been explored to some extent (Clark & Miles, 1999), there are limited studies about father-infant bonding.

It would also be interesting to carry out a dyad study with both partners to explore their joint experiences and the impact on their relationship (and reciprocal interactions). Many mothers reported becoming closer to their partner throughout the experience but research has also suggested links between less marital satisfaction and infant illness severity (Berant et al., 2003) which lends itself to further exploration about the impact of CHD on the parental relationship.

A final possibility for future research would be to further explore the impact of hospitalisation and particularly intensive care recovery from the heart surgery on the mother-infant bond. This study suggests that this period was particularly disruptive to the mother-infant relationship. Therefore, it may be useful to interview mothers during this period to capture their perceptions at this time. Such input could lead to an indication of what would help mothers during the hospital stay and allow for better psychological and nursing support.

Personal Reflections

I have experienced my own journey throughout this research process, encountering both challenging and rewarding moments that have left an impact on me both personally and professionally. I was genuinely interested in the experiences of the mothers I interviewed and felt privileged to hear their accounts of a personally traumatic and intimate time in their life. I was humbled by their honesty and openness, especially as they were recounting painful and upsetting memories. I have reflected on how my childlessness might have affected how I conducted this research and thought that I was possibly more open to mothers' bonding experiences by not having personal experience of it. The mothers were not aware of my childlessness but I wondered whether they might have made assumptions about this and if their knowing would have enhanced or hindered the interview. Although I could not identify with the mothers' experience, I reflected on our similarities in age, ethnicity, relationship status and the theoretical possibility of me being in a similar situation in the future. I have wondered whether my future experience of pregnancy, antenatal screening and life with a new born baby might be influenced by this research.

In conducting this research, I was aware of my dual role as a therapist and clinician and the challenges this posed for the research interviews. The skill was finding the right balance in gaining a rich, in-depth and meaningful account from participants without intervening therapeutically and making interpretative links from a psychodynamic perspective as I would do clinically. This approach allowed me to develop an appreciation of other important clinical skills such as sitting with distress, allowing silences, re-orientating conversations when mothers spoke about tangential topics and eliciting emotions and reflections when mothers gave factual accounts. I also wondered about how the interviews might have been helpful for the mothers, as well as me. Even though I think mothers' primarily participated

to give back to the hospital and help future mothers (which presumably were important reasons due to the high response rate), I hope mothers benefitted from telling their story to a willing listener.

During the interviews, I was surprised by my assumptions related to certain aspects of participants' accounts. For example, I had anticipated that mothers would find the experience incredibly distressing and have little positive reflection, but I was struck by the mothers' resilience and reappraisal of events. I was especially surprised to hear that some mothers did not feel the CHD impacted on their relationship with their baby and that it, in fact, brought them closer. Obviously this was good news, but it highlighted my preconceptions about traumatic situations leading to difficulties which I think might partly be explained by my clinical work in severe and enduring mental health. This experience has encouraged me to be more aware of my own preconceptions and influences of my clinical work but also given me a refreshing view and hope for the people I work with.

Finally, this was my first experience of qualitative research, and therefore was a steep learning curve which tested me at times but ultimately allowed me to develop skills in designing an explorative study, conducting research interviews and interpreting transcripts. Supervision was invaluable in helping with these aspects and encouraging me to develop as a qualitative researcher. However, being a novice to IPA meant that I frequently struggled with being unsure about what to do and whether what I was doing was correct. Thus, at times, I found the process demanding and difficult, especially during the analysis stage. However, when I was able to embrace the chaos and become immersed in the data, I found the interpretative aspect of the process interesting as it helped me make sense of the mothers' experience. I feel it has given me an appreciation of the service users' voice and I would advocate for this in future clinical research.

Clinical Implications

This study offers some helpful contributions to the current understanding of the developing mother-infant bond in the context of life-threatening infant illness. As the mothers in this study adapted to the CHD diagnosis and bonded well with their infant, and all but one did not require psychological input, a stepped care approach would be most appropriate for supporting this population:

Psychoeducation

Mothers responded well to clear and timely information from health professionals and therefore, as a first line approach, clinicians should be educated to support and reassure mothers in the following ways, if they are not already being done:

- Provide mothers with written information (including diagrams) of their child's heart condition and the course of treatment to aid their understanding.
- Prepare antenatally diagnosed mothers for hospitalisation with a tour of intensive care and/or the cardiac ward, details of the birth plan and highlight the need for extra support in the case of separation from the infant following childbirth. Fetal nurse specialists are particularly suited to providing this information and continuity from diagnosis to surgery.
- Encourage mothers to speak to other parents and seek support from their family and professionals during hospitalisation, especially if they have concerns about bonding, or their adjustment.
- Develop a psychoeducational leaflet with details of relevant charities and a description of maternal reactions following the diagnosis, during hospitalisation and of the bonding process to normalise the challenges mothers' experience.

Emotional distancing and grief reactions could be highlighted as adaptive responses and a form of self-preservation to a traumatic event. Staff should be educated and trained to normalise such reactions in mothers, but also recognise when there are more concerning bonding problems such as with rejection of the baby (Jackson, Power, Dean, Potgieter, & Cleary, 2013).

Supporting mother-infant bonding

The results of the study offer practical examples of what helped mothers keep connected to their infants in hospital and provide ideas with how professionals can facilitate mother-infant bonding at this time, if needed. It is important to educate hospital staff to promote maternal empowerment and provide mothers with a sense of control and choice in the following ways:

- Inform mothers separated from their babies following childbirth about the health of their infant and, where possible, avoid placing these mothers on a maternity ward to recover with other mothers who have their baby (or give them a choice). It is likely that some maternity wards would need to be educated about this.
- Inform mothers of their baby's ability to feel, hear and smell and support skin-to-skin touch and interactions between mother and infant.
- Praise mothers for their efforts at expressing breast milk and provide breastfeeding advice and support, if needed.
- Reassure mothers that they will be most helpful to their infant if they attend to their own needs (e.g. take breaks, eat regularly, rest) and that they will be phoned if there are any concerns about their infant.
- Negotiate a caregiving role for mothers in hospital (e.g. bathing, feeding, nappy changes of their infant) in line with mothers' preferences and safe practice. Explain

that this role is likely to change depending on the circumstances of their baby's health. With recovery, encourage mothers to take back control and reassure them that their baby is robust, to reduce maternal anxiety so that the usual caregiving tasks can resume.

Psychological support

Specialist psychosocial services in children's hospitals are best placed to support mothers with the adjustment to their infant's illness, mental health problems, parenting skills in the context of CHD and also address any early mother-infant bonding problems. If difficulties continue to persist at home, there are additional specialised Perinatal Services in the NHS which offer support for mothers and their infants. Whilst most mothers in this study did not require specialist psychological support, the following recommendations are likely to be helpful for those who present with adjustment and bonding difficulties:

- For concerns around adjustment to the CHD diagnosis and persistent psychological distress, ideas from Compassion Focused Therapy (Gilbert, 2009) could be helpful to address maternal self-blame and guilt and Glenda Fredman's (2004) systemic and narrative approach could be used to encourage conversations about emotions and introduce alternative/expand existing narratives.
- Cognitive Behavioural Therapy (Beck, 1979) or narrative therapy (White & Epston, 1990) could help mothers who continue to negatively interpret the loss of caregiving role and feel inadequate as a mother, by helping with reappraisal and reattribution of experiences. These approaches are also likely to be useful for anxious and hypervigilant mothers, to help with challenging and reframing their perceptions of their baby as 'fragile' at discharge.

- Early psychosocial interventions such as the Congenital Heart Disease Intervention Programme (McCusker et al., 2009) would be useful for mothers who require parenting skills and psychoeducation around caring for a child with CHD. This intervention could be also adapted to include aspects specific to mother-infant bonding.
- Mother-infant support, using baby massage or video-interaction guidance, as recommended by the National Institute for Health and Clinical Excellence (2012), would be appropriate for mothers who had persistent difficulties to help normalise their struggles and boost maternal wellbeing and confidence.

Finally, cardiac liaison nurses have an important role for this group of mothers as a port of call when mothers have concerns. The New Congenital Heart Services Review (Holden, 2014) proposes a network model of care, with liaison nurses regularly going out to the network to educate and support staff.

Summary and Conclusions

The results of this study provide a detailed account of mothers' lived experience of bonding with their infant with severe CHD. Eight mothers took part in the interview and the transcripts were analysed using IPA. Existing literature suggests that mothers may be at risk of bonding difficulties when their child is born with a severe heart condition; however the findings from this study revealed that successful bonding outcomes can be achieved. Bonding is a process that can withstand disruptions such as infant illness, breastfeeding difficulties and restricted mother-infant interactions due to hospitalisation. This study highlights how mothers kept connected to their infant and re-established their maternal role by engaging with various practical strategies in hospital and adaptive ways of coping. The

mothers demonstrated resilience and experienced personal growth following the transition home and were able to reaffirm the value of motherhood and develop a positive relationship and bond with their infant.

Suggested further research includes investigating the bonding experiences in mothers from ethnic minority backgrounds and also in fathers. It would also be interesting to further explore the impact of CHD in a dyad study involving the parental couple. The study helps to inform clinical practice by suggesting a stepped care approach for how professionals can support mothers and the bonding process.

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APPENDIX 1: Summary of Congenital Heart Defects and their Prevalence (adapted from Knowles et al., 2005)

Name of congenital heart defect	Description	Median prevalence per 100,000 live births (<i>lower quartile, upper quartile</i>) (Hoffman & Kaplan, 2002)	Prevalence per 100,000 live births (Hoffman & Kaplan, 2002; Leonard, Derrick, O'Sullivan, & Wren, 2000; Wren & O'Sullivan, 2001)
Aortic (valve) stenosis	Narrowed aortic valve.	26 (16,39)	20
Atrial septal defect	Hole in atrial septum allowing blood flow from left to right atrium.	56 (37, 106)	28
Coarctation of the aorta	Narrowing of the distal aortic arch.	36 (29, 49)	35
Complete atrioventricular septal defect	Lower atrial septum, inlet ventricular septum and atrioventricular valves are all malformed.	34 (24, 40)	27
Hypoplastic left heart syndrome	Aortic valve atresia, possible mitral atresia and small left ventricle.	23 (15, 28)	14
Interruption of the aortic arch	Part of the aorta fails to develop. Always associated with another major heart defect.	Not cited	8
Persistent (patent) ductus arteriosus	Fetal connection between pulmonary artery and aorta persisting after 6-12 weeks of age.	57 (32, 78)	50
Pulmonary atresia	Pulmonary valve is closed. May have ventricular septal defect or intact ventricular septum.	8 (8, 15)	21 (5 with intact ventricular septum; 10 with ventricular septal defect; 7 complex pulmonary atresia)
Pulmonary stenosis	Narrow malformed pulmonary valve.	53 (35, 84)	65
Tetralogy of Fallot	Subaortic VSD with anterior displacement of aorta and right ventricular outflow obstruction.	35 (29, 58)	31
Total anomalous pulmonary venous connection	Pulmonary veins do not connect with left atrium and blood flows directly into systemic circulation.	9 (6, 12)	9
Transposition of the great arteries	Pulmonary artery arises from left ventricle and aorta from right ventricle.	30 (23, 29)	30
Ventricular septal defect	Hole(s) in the interventricular septum. Often associated with other heart defects.	Over 4000 (including studies involving routine echocardiography at birth)	197 (echocardiography not used to screen)

APPENDIX 2: Invitation Letter

Dear _____,

**RE: Bonding Experiences in Mothers of Infants with Severe Congenital Heart Disease
Research Project**

You are invited to be part of the above research project. Please find attached an **Information Sheet** which will tell you more about the research and what you will be asked to do if you take part.

In brief, the study hopes to explore how mothers find the experience of forming a close emotional bond with their baby with congenital heart disease. Mothers will be interviewed on one occasion about their experiences throughout pregnancy and after birth.

The researcher, Tessa Mellow, will be in touch soon to answer any questions you may have and to find out if you would be interested in participating. However, if you have any questions in the meantime please do not hesitate to contact her by e-mail or telephone:

E-mail: nwjt085@live.rhul.ac.uk

Telephone (answering machine): 01784 414012 (Royal Holloway University of London, Doctorate in Clinical Psychology office – **please leave a message for Tessa Mellow**)

Thank you for your time and consideration of this research project.

Best Wishes,

Tessa Mellow
Trainee Clinical Psychologist
Royal Holloway University of London

APPENDIX 3: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Study title: Bonding experiences in mothers of infants with severe congenital heart disease

Invitation to participate in the study

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study if you wish.

Please contact us if there is anything that is not clear or if you would like more information [see end for contact details of Tessa Mellow, researcher, and Dr Sara O'Curry, Consultant Clinical Psychologist].

What is the purpose of this study?

The main aim of the study is to explore how mothers of infants with congenital heart disease (CHD) experience bonding with their baby (i.e. forming the initial relationship). It hopes to explore this bonding process for mothers during pregnancy, at the time of diagnosis and after birth. It is hoped this study will increase our understanding about how the bonding process may change and/or develop over time in these circumstances. This is important because if we can understand this, it will help clinicians provide mothers of infants with CHD with the best support.

Who is organising and conducting the research?

The research is being overseen by Dr Sara O'Curry, Consultant Clinical Psychologist. The study is being carried out by Tessa Mellow who is a Trainee Clinical Psychologist at Royal Holloway, University of London. It will also be supervised by Dr Michael Evangelii, who is a Clinical Psychologist and Clinical Lecturer at Royal Holloway University of London.

Why have I been invited to take part?

We would like to speak to mothers of children with CHD to find out more about their experience of bonding with their child and dealing with challenges associated with caring for a child with CHD. We hope to interview both mothers who received the diagnosis before birth and mothers who received the diagnosis after birth.

Do I have to take part?

No. Taking part in this study is entirely your decision and will not affect the care you or your child receives from the NHS. Your or your child's clinical care will not be affected if you decide not to participate. If you decide that you would like to take part, you will be asked to sign a consent form to show you have agreed to be involved and you will be given a copy of this. You can change your mind about taking part at any time and stop participating in the study. You do not need to give us a reason for this. This would also not affect the standard of care you or your child receives or any future treatment.

What will happen to me if I take part?

If you decide that you would like to take part, you will need to meet on one occasion for 1-1.5 hours with the researcher (Tessa Mellow). The length of the interview is likely to vary depending on how much you wish to say. The interview will take place either at your home or in a clinic room at XXX at a time that is mutually convenient. If the interview is at XXX, it can be arranged to take place before or after your child's scheduled outpatient appointment. If possible, it would be best for you to be interviewed alone and have care arranged for your child for the duration of the interview (i.e. 1-1.5 hours).

At the interview, you will be asked for some background information, such as your age, your child's diagnosis, when they were diagnosed and details of any other children you may have. You will also be asked to fill out two brief questionnaires about how you are feeling and your interactions with your child. An interview will also take place, in which you will be asked questions about your experience bonding with your child throughout pregnancy, at the time of diagnosis and up until the interview. You may also be asked what it has been like having a child with a cardiac condition. There are no right and wrong answers, and you are free to decline to answer any question you do not feel happy to answer. With your consent, the interview will be audio recorded. The recording is used to help the researcher remember what has been said, so that nothing is missed, and will be destroyed after the research is finished. After the study has finished, the researcher will send you a summary of the findings from the research, if you opt in.

Any information collected from the study will not be fed back to clinicians, unless there are concerns about your or another person's safety. If this happens, the researcher is obliged to act in accordance with NHS protocols. If the researcher felt that additional support would be beneficial, this would be discussed with you and Dr Sara O'Curry, Consultant Clinical Psychologist. The researcher would help facilitate a referral to the psychosocial services at XXX and any other appropriate persons at the hospital if necessary. The researcher would always try to discuss these concerns with you first, before doing anything.

Expenses and payments

Taking part is voluntary and you will not be paid for taking part. However, you will be reimbursed for travel expenses related to attending the hospital for the interview at a time that does not coincide with a scheduled appointment.

What are the possible risks and benefits of taking part?

Risks: There are no direct risks from taking part, although some people may feel uncomfortable or become upset talking about their experiences. This is an understandable reaction to discussing a sensitive topic. However you will not have to say anything you do not want to. If you become distressed at any time, you can take a break or decide to stop the interview altogether. The researcher is a Trainee Clinical Psychologist and has experience in talking to people about sensitive issues. She will give you time at the end to compose yourself if you need. If you feel you need to speak to someone after the interview, suggestions will be made to help you with this. The researcher will discuss whether a referral to your GP or to see someone from the psychology team at XXX would be helpful.

Benefits: We cannot promise the study will help you directly but it is hoped that by taking part in this research, you will be providing valuable information regarding your experiences of caring for an infant with CHD. People often find it interesting to take part in research and can find it helpful to get their experiences 'heard'. This would be extremely beneficial, because if we can understand more about your and others' experience of receiving an unexpected diagnosis and how it may impact on your early relationship with your child, it will help us know what we can do to support other mothers in the future who are in a similar situation. It may also help develop treatment approaches for those who have difficulty bonding with their child in these circumstances.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to either Tessa Mellow (Researcher) or Dr Sara O'Curry (Consultant Clinical Psychologist) who will do their best to answer your questions [contact details provided at the end of this information sheet]. If you remain unhappy and wish to complain formally, you can do this: please contact the XXX Patient Advice & Liaison Service (PALS) via email at pals@XXX.nhs.uk or by telephoning 020 7829 7862. The normal NHS complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

All the information collected is kept strictly confidential in accordance with the Data Protection Act (1998). All of the data (e.g. questionnaires, audio recordings, transcribed interviews) during the study will be anonymised and identifiable only by a number, not by your name. Some of your comments may be directly quoted when the research is written up for a doctorate thesis or journal article; however, each comment will be completely anonymised such that it will not be identified as coming from you. Any information collected in this study will be stored on a secured network drive that is encrypted. On completion of the research, the audio recordings will be deleted.

What will happen to the results of the research study?

The results of the study will be written up as part of a Doctorate degree in Clinical Psychology. Anonymised quotes from your interview may be used in the final report to help explain the key findings. The research may also be published in a journal or presented at a scientific conference. You will not be able to be identified in any of these. You will also be sent a summary of the research findings, if you opt in.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people to protect your safety, rights, wellbeing and dignity. This study has been approved by the North West –Liverpool Central National Research Ethics Service Committee and the Research Ethics Committee at Royal Holloway, University of London.

Contact details for further information:

Tessa Mellow, Researcher, Trainee Clinical Psychologist

Email: nwjt085@live.rhul.ac.uk or Telephone: 01784 414012 (Royal Holloway University of London, Doctorate in Clinical Psychology Administration Office – please leave a message for Tessa Mellow)

Dr Sara O’Curry, Consultant Clinical Psychologist

Email: Sara.O’Curry@XXX.nhs.uk or Telephone: 0207 405 9200 x0434

If Sara is not available please call 020 7829 8896 and ask for someone from the cardiac psychology team

If you are interested in taking part?

If you would like to take part, please contact Tessa Mellow or Dr Sara O’Curry using the contact details above. Alternatively, Tessa Mellow will make contact with you by telephone to answer any questions you may have and find out if you are interested in participating.

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

APPENDIX 4: Interview Schedule

INTERVIEW SCHEDULE

Version 8, 14/08/13

Introductions

- Study aims and purpose of interview
 - This interview will include some open questions about your personal experience and memories of getting to know your baby.
 - Purpose - to find out about the experiences of women getting to know their babies throughout pregnancy, after receiving the CHD diagnosis and following birth.
 - Aims - to gather information which can be used to help professionals support mothers and their babies during pregnancy and/or following birth.
- Explain confidentiality and its limits and remind mother 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 her or her child's healthcare
- Consent form
- Any questions?

Semi-Structured Interview

Warm up Question

- 1) How are you today?
- 2) Tell me what [child's name] is like?

Pregnancy

I am really interested in your experience of how your relationship with [child's name] has developed and may have changed over time.

- 3) Please could you think back to when you found out that you were pregnant and tell me about this?
- 4) How did you feel about your baby at that time?
PROMPT: Thoughts, images (of being a mother and of your baby)?
- 5) Could you please tell me about the scans?
PROMPT: What were your expectations? How did you feel towards your baby at this time?
- 6) [*postnatal diagnosis*] How did you prepare for the arrival of your baby? What were you feeling at this time?
- 7) [*postnatal diagnosis*] What was the birth like? Do you remember what you thought and felt about [child's name] when you first saw him/her?

Diagnosis

Now I'd like to ask about [child's name]'s diagnosis...

- 8) Can you tell me what it was like when you first heard about the diagnosis?
- 9) What did you think and feel about your baby at this stage? Did any images come to mind?
[antenatal diagnosis] Do you remember if you were given any options when you heard about the diagnosis?
- 10) Research suggests that mothers have a range of feelings at these times, some of which are very difficult. What feelings did you experience?
- 11) Can you tell me what helped at this time?
PROMPT: What would have been helpful? Were you able to talk to anyone about it?
- 12) Did anything make you feel worse?
- 13) *[antenatal diagnosis]* How did you prepare for the arrival of your baby? What were you feeling at this time?
- 14) *[antenatal diagnosis]* What was the birth like? Do you remember what you thought and felt about [child's name] when you saw first saw him/her?

Post birth – first few days

- 15) Did you spend any time with your baby after s/he was born?
- 16) What was it like getting to know [child's name] in these first few days and weeks?
- 17) Were you able to breastfeed? What was this like?
- 18) How did you feel about yourself as a mother?

Post birth – first surgery

It would be very helpful to hear about your experience of your child's first heart operation...

- 19) Can you tell me about your experience of [child's name]'s first operation?
PROMPT: [if relevant] experience of seeing child go under anaesthesia?
- 20) What were your thoughts and feelings about your baby at this time?
- 21) How long was [child's name] in hospital for? Did you feel this affected your relationship with [child's name]? How? *Check mother understood question related to bonding!!*
PROMPT: [if relevant] Other surgeries?
- 22) Thinking about this experience of [child's name] being in hospital, can you tell me what helped and made it easier?
- 23) Did anything make you feel worse?

Post surgery

I'd be really interested to hear about how your relationship with your baby has developed.

- 24) Can you tell me about coming home after surgery and getting to know [child's name]?
- 25) How did you get to know [child's name] during this time?
PROMPT: What helped with this process? What were the positive things about getting to know your baby?

- 26) Were there any things that got in the way of you getting to know [child's name]?
- 27) Was there anything you felt or thought which you didn't feel able to share with other people?
- 28) Do you feel that your relationship with [child's name] has been affected by him/her having a heart condition? How so?

PROMPT: How have you felt about yourself as a mother since surgery?

Other pregnancies/children

- 29) *[if other children]* Was getting to know [child's name] different from getting to know your other children?

PROMPT: How? Did congenital heart disease play any part in this?

Future thoughts

- 30) Given what you know now, was it helpful to know the diagnosis when you found out?
- 31) What are your hopes and fears for [child's name] future?

PROMPT: And how do you see your relationship with [child's name] in the future?

- 32) Is there anything else important to your experience that we have not spoken about?

Administer Self-report Questionnaires

- Depression Anxiety and Stress Scale-21
- The Maternal Postnatal Attachment Scale

Final word

How are you feeling now after our conversation?

If this interview has brought up anything that you weren't expecting or you think it might be helpful for you to speak to someone else about things we have discussed, I would be happy to organise a referral to the psychology team. Would you like me to do this?

APPENDIX 5: Demographics Questionnaire

Demographics Form, VERSION 2, 14/02/13

Date completed: _____

MOTHER Identification Number: <i>(to be completed by researcher)</i>		
DOB:		
Ethnicity		
<input type="checkbox"/> White British	<input type="checkbox"/> Black African	<input type="checkbox"/> Pakistani
<input type="checkbox"/> White Irish	<input type="checkbox"/> Black Caribbean	<input type="checkbox"/> Asian Other
<input type="checkbox"/> White Other	<input type="checkbox"/> Black Other	<input type="checkbox"/> Other (specify) _____
<input type="checkbox"/> Black British	<input type="checkbox"/> Indian	
➤ 1 st language: _____ Country of Origin: _____		
Marital Status		
<input type="checkbox"/> single	<input type="checkbox"/> in relationship (not living with partner)	<input type="checkbox"/> divorced/separated
<input type="checkbox"/> married	<input type="checkbox"/> cohabiting (living with partner)	<input type="checkbox"/> widowed
Family members living at home (tick all that apply)		
<input type="checkbox"/> father of child	<input type="checkbox"/> grandmother of child	<input type="checkbox"/> other children (how many) _____
<input type="checkbox"/> step-father of child	<input type="checkbox"/> grandfather of child	<input type="checkbox"/> other _____
Employment Status		
<input type="checkbox"/> employed full-time	<input type="checkbox"/> unemployed	<input type="checkbox"/> retired
<input type="checkbox"/> employed part-time	<input type="checkbox"/> housewife	<input type="checkbox"/> other (specify) _____
<input type="checkbox"/> voluntary employment	<input type="checkbox"/> student	
Education (highest level)		
<input type="checkbox"/> primary education	<input type="checkbox"/> A-level, 18yrs	<input type="checkbox"/> post graduate degree
<input type="checkbox"/> GCSE (O-level), 16yrs	<input type="checkbox"/> undergraduate degree	<input type="checkbox"/> other (specify) _____
➤ Years spent in education: _____		

CHILD with CHD	
DOB:	Gender:
Heart condition: <input type="checkbox"/> Hypoplastic left heart syndrome	Time of diagnosis: <input type="checkbox"/> antenatal scan _____ weeks

<input type="checkbox"/> Transposition of the great arteries <input type="checkbox"/> Coarctation of the aorta <input type="checkbox"/> other _____	<input type="checkbox"/> post-birth (when?): _____
Other condition/s:	
Date of first cardiac surgery:	
Other surgeries? (including dates)	

ADDITIONAL INFORMATION
Any other children (D.O.B. & gender)?
Do any of these children have cardiac malformations? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, details:
Do any of other children have congenital problems? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, details:
If yes, were they picked up at the antenatal screening?
Have you been involved in another research study within the past year? <input type="checkbox"/> Yes <input type="checkbox"/> No

APPENDIX 6: DASS-21 Questionnaire

<h1>DASS₂₁</h1>		<i>Name:</i>					<i>Date:</i>
<p>Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <i>over the past week</i>. There are no right or wrong answers. Do not spend too much time on any statement.</p> <p><i>The rating scale is as follows:</i></p> <p>0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time</p>							
1	I found it hard to wind down	0	1	2	3		
2	I was aware of dryness of my mouth	0	1	2	3		
3	I couldn't seem to experience any positive feeling at all	0	1	2	3		
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3		
5	I found it difficult to work up the initiative to do things	0	1	2	3		
6	I tended to over-react to situations	0	1	2	3		
7	I experienced trembling (eg, in the hands)	0	1	2	3		
8	I felt that I was using a lot of nervous energy	0	1	2	3		
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3		
10	I felt that I had nothing to look forward to	0	1	2	3		
11	I found myself getting agitated	0	1	2	3		
12	I found it difficult to relax	0	1	2	3		
13	I felt down-hearted and blue	0	1	2	3		
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3		
15	I felt I was close to panic	0	1	2	3		
16	I was unable to become enthusiastic about anything	0	1	2	3		
17	I felt I wasn't worth much as a person	0	1	2	3		
18	I felt that I was rather touchy	0	1	2	3		
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3		
20	I felt scared without any good reason	0	1	2	3		
21	I felt that life was meaningless	0	1	2	3		

APPENDIX 7: The Maternal Postnatal Attachment Scale (not included due to copyright restrictions)

APPENDIX 8: NHS Ethics Approval



Health Research Authority

National Research Ethics Service

NRES Committee North West –Liverpool Central

3rd Floor

Barlow House

Telephone: 0161 625 7434

29 April 2013

Ms Tessa Mellow
Royal Holloway University of London
Egham, Surrey
London
TW20 0EX

Dear Ms Mellow

Study title:	Bonding experiences in mothers of infants with severe congenital heart disease: An Interpretative Phenomenological Analysis
REC reference:	13/NW/0336
Protocol number:	n/a
IRAS project ID:	122601

Thank you for your email of 24 April, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

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

Confirmation of ethical opinion

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

Ethical review of research 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).

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

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	2	11 April 2013
Covering Letter		17 April 2013
Evidence of insurance or indemnity		01 August 2012
Interview Schedules/Topic Guides	3	11 April 2013
Investigator CV	Tessa Mellow	
Investigator CV	Dr Michael Evangelini	
Investigator CV	Sara O'Curry	
Letter of invitation to participant	3	24 April 2013
Other: Approval		09 April 2013
Other: Demographics Form	2	14 February 2013
Other: RHUL Approval		31 January 2013
Participant Consent Form	2	23 April 2013
Participant Information Sheet	3	23 April 2013
Protocol	2	11 April 2013
Questionnaire: Maternal Postnatal Attachment Scale		
Questionnaire: DASS21 Self Report Questionnaire		
REC application	3.5	17 April 2013
Response to Request for Further Information		24 April 2013

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

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

13/NW/0336

Please quote this number on all correspondence

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

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

Yours sincerely



Mrs Julie Brake
Chair

Email: nrescommittee.northwest-liverpoolcentral@nhs.net

Enclosures: *“After ethical review – guidance for researchers”*

Copy to: *Ms Tessa Mellow*
Ms
Foundation Trust &

I NHS

APPENDIX 9: Email approval from the Departmental Ethics Committee

From: Psychology-Webmaster@rhul.ac.uk
Sent: Fri 17/05/2013 17:52
To: nwjt085@rhul.ac.uk; Evangeli, Michael;
Cc: PSY-EthicsAdmin@rhul.ac.uk; Leman, Patrick;
Subject: 2013/040 Ethics Form Approved

Application Details:

Applicant Name: **Tessa Mellow**

Application title: **Bonding experiences in mothers of infants with congenital heart disease**

APPENDIX 10: R&D Approval



Joint Research and Development Office
Division of Research and Innovation

Direct Line:
Email:

07/05/2013

Dr Sara O'Curry

London

Dear Dr Sara O'Curry

PROJECT TITLE	Bonding experiences in mothers of babies with congenital heart disease
Protocol version	2
Protocol date	11 th April 2013
REC Reference	13/NW/0336
R&D Reference	13CC07
Sponsor	Royal Holloway University of London
Chief Investigator (CI)	Tessa Mellow

Notification of NHS Permission.

The research approval process for the above named study has been completed successfully. I am pleased to issue approval on behalf of NHS Trust for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DoH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- The Principle Investigator (PI) must ensure compliance with protocol and advise the Joint R&D Office of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the Joint R&D Office in line with the study

Joint Research and Development Office
Division of Research and Innovation

protocol and Sponsor requirements. Adverse Incidents (AEs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.

- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.
- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.
- The PI must allow monitoring and auditing by the Sponsor and the Joint R&D Office.
- The PI must report any cases of suspected research misconduct and fraud to the Joint R&D Office.
- The PI must provide an annual report to the Joint R&D Office for all research involving NHS patients, staff and/or resources. The PI must notify the Joint R&D Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Joint R&D Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,



Dr
Research Management and Governance Officer
Joint Research and Development Office

APPENDIX 12: Additional Information for Participants

Thank you for taking part in the research. After all the interviews are completed, I will listen to the recordings and analyse them. The results will be written up as a thesis and could also be presented in other forms such as a journal article. A summary of the results will be sent to you once the project is finished.

Further support

If you would like further support or help, you can contact the Psychosocial and Family Services at XXX and ask for someone from the **cardiac psychology team**. They can be reached on the following number: **020 7829 8896**

If you ever feel that you need immediate help, you can call your **local GP** for help or visit your local hospital **Accident and Emergency department**.

If you feel that you need extra support or advice then the following organisations may be helpful:



Children's Heart Federation

Parent-led charity with support for parents

Information Line: 0808 808 5000

Website: www.chfed.org.uk



Little Hearts Matter

Offers support and information for children with half a heart

Telephone: 0121 455 8982

Website: www.lhm.org.uk



British Heart Foundation

Telephone (Heart Help Line): 0300 330 3311

Website: www.bhf.org.uk



Heartline

Voluntary organisation which supports children with heart disorders and their families

Telephone: 0330 022 4466

Website: www.heartline.org.uk

APPENDIX 13: Example Interview Transcript showing Emergent Themes

Emerging themes / Conceptual ideas	Interview Transcript Hannah [P= participant, I= interviewer]	<u>Exploratory Comments</u> (Descriptive; <i>Linguistic</i> ; <u>Interpretative</u>)
<p>Instant bonding – she is mine</p> <p>Protecting baby</p> <p>Comparing between children</p> <p>Loss of caregiving role</p>	<p><i>I: And, so you were saying before about the word “bond” [P: Mmm] and do you feel like that was-that was happening for you?</i></p> <p>P: Yeah, I felt-I felt-I did feel as soon as I saw her, I felt like she looked like my baby...I, you know, I absolutely, I instantly, you know, um...I wanted to get up and run away with her is what I wanted. But um...I knew she was mine...I-I absolutely, you know, [I: Uh huh]...I felt all those same feelings that I felt for [name of older child] except that I didn’t feel like...um I didn’t feel like now this is for me to take care of her. I felt like I needed to give her...</p>	<p>Description of bonding – instant, absolute, she looks like mine, she is mine, want to be with her</p> <p><i>“get up and run away with her” – to protect her from other, separate love affair</i></p> <p>Same bonding feelings as with older son although need to pass care to someone else – <u>losing her caregiving role</u></p> <p>Give her over – <u>learning to separate early on but sounds like this requires strength and is awful experience</u></p>
<p>Devastating loss of role</p>	<p><i>I: Uh huh. And what was that like to have to give her-</i></p> <p>P: It was awful. It was absolutely awful. Because it-it just felt as though I couldn’t do everything for her.</p> <p><i>I: And that’s what you wanted?</i></p>	<p>Awful to feel that can’t provide everything for your child</p>
<p>Desire for maternal role</p> <p>Devastating loss of</p>	<p>P: Yeah, and that’s what I wanted to do. I wanted then to feed her and get her dressed and clean her up and you know, and hold her...and-and not being able to hold her and not being able to feed her was-was</p>	<p>Desire to do everything for daughter (feed, dress, bathe, hold her) and devastated as can’t</p> <p><u>Loss of touch devastating – sense that intimacy is important between mother and</u></p>

intimacy	devastating. <i>I: Mmm. Do you feel like it affected your relationship with her?</i>	<u>child</u>
Making up for lost intimacy/experience	P: No. I-I only to the extent where now I let her be held all the time (laughing) and-and I...um...you know, with [name of older child] I was strict in making him be put down and go to sleep on his own and all of those things. And now, um...I don't feel like that with her. I feel like she-she still needs loads extra.	No lasting impact on mother-infant relationship <u>Sense of making up for lost contact – creating more intimacy</u>
Special child/rules		
Changed parenting	 <i>I: Oh, ok. Because-because she miss...?</i>	Special rules apply to child with CHD, does not have to be alone at bedtime in same way as older child. <u>Special child?</u>
Making up for lost intimacy	P: Yeah, because she missed out on it. <i>I: Ok. And so how were you feeling about yourself as a mum, when you were in, say in hospital with her?</i>	
Resilient/proud mother	P: I felt that because she came out and everyone said she looked good and she was so big. I felt like I'd done the best that I could do and I felt good about it.	Proud/feel good to deliver big, healthy-looking baby – done her best (i.e. did not have epidural although wanted one) – <u>daughter's needs were put first and this is role of mother</u>
Mother prioritised child	And they just said to me, you know, try not to have an epidural. I felt like I'd done <i>exactly</i> what I needed to do [I: Mmm] and so I felt pretty good about my part in it.	
Approval needed from others	You know, like cause she come out and she was big and-and healthy and, well, looked healthy enough to not rush her away. I felt good about my part. Yeah. <i>I: Uh huh. And so how were you able to get to know her then in the days following birth?</i>	 <i>Repetition in words "she was big" "I felt good about my part" to highlight this as important for me to understand and people to know - <u>Sense that people will then agree and not judge her and she will get approval</u></i>

Bonding more difficult in hospital	<p>P: Um...it was hard cause I felt rough and usually you're allowed to lay in bed and hold the baby. Um...but obviously, I had to go and get showered and get dressed and go and sit by her bed and I just wanted to lay down so badly. I felt really awful...um... [I: What do you mean?] I-I mean I felt bad as in I felt faint, [I: Right] I felt ill...um...but I-I definitely I didn't leave her side cause I wanted to make sure that I was watching everything everyone was doing and like a guy came in to give her a blood test and she was crying and I was like "no, you're too rough, go away" (laughs) you know, like, I wanted to make sure that I was there to make sure that the people who were giving her the care [I: Uh huh] were watching her and- and I think when you have a baby...you are the person sitting, watching them the whole time making sure they're all right and when they go off to someone else – they look after babies all day long – they're not sitting watching each child, like, constantly, they just leave them for a bit if they cry and, you know, they're seeing to all the other babies so I didn't want to leave her because I didn't want her to not have an eye on her at all times.</p>	Hard to get to know baby after birth when not in maternity ward
Conflict between own and baby's needs		Mother required to get on with things and not able to rest – <u>prioritise baby's needs</u>
Prioritise baby		<u>Conflict in responsibility to self and baby</u> - felt physically unwell so wanted to rest but felt needed to be by baby's side
Protect baby		Protecting baby from others
Hypervigilant – constant monitoring of others		Mothers role is to monitor other people's care of her child – <u>hypervigilant</u>
Special role of mother (care more than staff)		Mother cares more than staff do, mother has more time to monitor. <u>Special role of mother</u>
Threat of CHD		Concern about baby's wellbeing – threat of CHD

List of emerging themes from Hannah's full interview:

Superordinant themes	Emergent themes	Page, Line number
Bonding as an active and developing process	Normal/perfect baby	p:1 22-22 / p53: 3-4
	Antenatal excitement	p2: 11 / p11: 6 / p13: 4-6 / p19: 6-7 / p20: 2-3
	Preconceptions about pregnancy/baby	p11: 23-29 / p.13: 31-33

	Antenatal bonding	p12: 6-8 / p18: 24-25 / p19: 13-14, 30-32
	Fragile baby	p21: 1, 12-14 / p49: 7-14, 22-24
	Imagined vs actual baby	p34: 7-12, 15-20
	Bonding with first meeting (savour in case of loss)	p34: 32-33 / p35: 2-10, 16-17
	Protective bond	p37: 3-7 / p51: 1-3, 10-14
	Bonding on hold during intensive care	p46: 5-7
	Miracle/special child	p53: 10-19 / p55: 29-32
	Hopes for future	p54: 2-5, p55: 13-19, 24-25
	Fears for future	p54: 25-26
Coping in the face of adversity	Coping with knowledge	p4: 17-18 / p10: 7-8 / p16: 18, 29-30 / p17: 5 / p41: 25-26 / p42: 31-32 / p46: 31-33
	Life is precious - termination last option	p4: 5-9, 22-24 / p7: 31-33 / p8: 1-2, 6-9 / p10: 21-24
	Positive attitude	p14: 21-29 / p15: 28-30 / p16: 16 / p17:15-16 / p27: 1-2, 5-6
	Denial	p17: 7-9 / p18: 8-10 / p28: 1-2
	Supportive relationship with husband - mobilising resources	p27: 29-33 / p29: 20-21 / p32: 15-17 / p51: 8-9 / p.53: 31-32
	Supportive family	p29: 1-3 / p57: 18-20, 32
	Gratitude	p30: 27-29
	Dealing with experiences step-by-step	p31: 10-12 / p39: 21-24 / p46:7-9 / p48: 7-8
	Coping through avoidance	p39: 24-26 / p42: 2-4, 16-18
	Coping– emotional and practical preparation	p59:32-33, p60: 8-10, 15
Impact of CHD	Disbelief at diagnosis- seeking certainty	p2: 18-20, 30-32 / p3: 15-16, 20-21 / p4: 16 / p6: 17 / p16: 17-18
	Professionals vs patients	p18: 2-5 / p24: 1-5, 12-15 / p45: 28-30 / p46: 29-33
	Traumatic dreams/memories	p21: 16-17, p54: 9-14, 17-19
	Surgery distress	p40: 19-21 / p41: 3-11

	CHD- Real threat to life	p47: 4-5, 19-22
	Scar as badge of honour	p55: 15-17
	Antenatal diagnosis helpful	p57: 12-16 / p59: 29-31 / p60: 21-26
Changing experience of motherhood	Resilient/proud mother	p4: 9-10 / p34: 1, 11-12 / p38: 12-20 / p53: 27-29 / p56: 10-26
	Mother in control	p6: 31-32/ p28: 2-9 / p48: 19-21, 30-33 / p49: 1-2
	Protecting and prioritising baby	p18: 1-2, 6-8 / p22: 14-21 / p25: 31-33 / p26: 1-3, 14-16 / p37: 5-6 / p38: 32-33 / p39: 1 / p45: 17-19
	Comparing pregnancies	p18: 28-33 / p19: 14-15, 24-25
	Making sacrifices	p26: 7-9
	Determination/fighting a battle	p26: 21-23, 27-28
	Loss of role/ nurses know best	p36: 12-29 / p37: 9-11 / p44: 4-8 / p48: 28-30 / p49: 15-17
	Making up for lost intimacy/experience	p37: 29-33 / p38: 1-2, 6 / p40: 26-31
	Taking control (establishing caregiving role)	p43: 22-23 / p48: 19-21 / p49: 32-33 / p50: 1-2, 4, 9, 20-22 / p51: 19-22
	Regaining confidence & restoring normality	p49: 24-27, 32 / p50: 25-29
	Good parenting – mentalising	p58: 19-20
	Feeling powerless/helpless	p58: 32-33 / p59: 1-12
	Barriers to bonding in the context of CHD	Shock at termination option
Struggling with uncertainty		p9: 9-11 / p17: 16-20, 29 / p58: 17-19
Medicalised experience of pregnancy		p14: 14-26 / p24: 23-24 / p28: 26-28
Anticipating grief/loss		p28: 14-16, 18-21 / p31: 25-26 / p42: 20-24
Hospital/separation as barrier to bonding		p33: 28 / p37: 20-24 / p38: 26-27
Hypervigilant– monitoring of baby/others		p39: 1-9, 14-15

APPENDIX 14: Extracts from Research Journal

19th September, 2013 – before 4th interview

This interview is in London so it is nice that I do not have to travel as far. I am looking forward to trying to be more flexible with my interview style after the IPA meeting last night and their encouragement to build on what the participant says and open up the dialogue by allowing silences and asking them to elaborate and expand on what they have said. I had been feeling that previous participants have described *what* happened and therefore given me facts but there was a lack of emotional content. I have decided that this may have been a combination of my interview technique (i.e. not asking enough “tell me more” questions), the child being in the room the whole time and also mothers propensity to answer factually (as with doctors). So, I’m feeling that I need to keep this in mind for this interview and perhaps rely less on the schedule so I can follow up on emotions. I will also try to enable more silences and keep questions very open. I will use the tube journey to familiarise myself with the interview schedule so that I can be more flexible with it. I really need to also focus on their experience of bonding and elicit any thoughts, feelings and images they have about this. I am looking forward to trying again and making the most of the time I have with this mother.

I also know that her baby will be having a nap during the time of the interview so I hope he does not wake up and I can conduct the interview without distractions. I just think that after my last experience, having the child in the room is not the best conditions for helping the mother tell her story. It seems to limit what she will say and there is a rush to finish so she can attend to him. I am curious how this postnatal experience will compare to the previous interview I did with a postnatally diagnosed mother. There seems to be so many more unknowns when interviewing someone with a postnatal diagnosis as I have no idea how or when they came to find out about the diagnosis.

19th September, 2014 – after 4th interview

That felt like a really good interview. The mother was lovely and really able to tell her story. She spoke a lot and said that she copes by speaking about it so had told her story before which I think helped. I left what seemed like lots of silences and tried to just follow up what she said. She had a lot to say about her relationship and the love she felt for her son. This was the first time I had heard the word “love” which I think is rather surprising considering that the interview are about bonding with a newborn. It was not something I had really noticed before now though but it does seem quite striking. I wonder whether the other mothers just assumed that I would know it was one of their emotions towards their infants or whether it is was not in their repertoire of what they tend to talk about to professionals.

I think that I have some rich data from this interview with the mother voicing that she had felt it was her “fault” the baby was born with “something wrong” (self-blame) and she also

spoke about how her husband was helpful (making me think of systemic factors). Her baby also remained asleep for the duration of the interview which I think allowed her to really open up and even become tearful.

The mother spoke more after we had finished the interview and she was completing the questionnaire (so I wasn't recording) and talked about how she felt the experience would be different if it was her first baby. She wondered how these mothers would manage when they fell pregnant again because she thought that she would be so concerned the next time around. This is a good point and possibly something for me to further consider to see if there are different experiences between primiparous and multiparous mothers and also to consider if any mothers have other children with congenital anomalies.

APPENDIX 15: Table of Themes with Additional Extracts

Subtheme	Participant	Quotes
Superordinant Theme 1: An emotional Start to Motherhood and the Mother Infant Bond		
Antenatal excitement and impatience for the new baby	Elizabeth	I was delighted when I found out I was pregnant cause I'd been keen to have a baby for a long time.
	Georgina	I was just, you know, excited to be pregnant and to be able to have another child.
	Hannah	I knew I was having a girl as soon as I was pregnant and I, um, when it was confirmed, I was so excited.
	Mary	I did just love being pregnant....I had this small little bump and I did, I just loved it.
	Francesca	It was good news for me, it was good news....I was happy with my pregnancy.
	Joanne	Oh. Really happy cos I was like oh that's a nice age gap between the two of them and it'll be nice to have- have another little one and I was praying to have a boy cos I wanted to have one of each....I was really happy and [husband] was happy too.
Growing bond during pregnancy	Rebecca	Oh well obviously I was bonding towards him ... and obviously made me more-more protective over him.
	Lucy	We also been told that she was a girl, at the 20 week scan, so your-your feeling, you know your bonding aren't you, you've already, you know, the baby's moving
	Georgina	I'd say it is, very emotional. It's, you know, every move, every, um, iiiiee (indecipherable), it's almost like an obsession, you know, where, you know, you're um "oh at this time they're gonna start moving again" or like I used to get these, ahh, hiccups every hour and I'd be like "oh they're coming now" you know you're just like-you're constantly aware of your body.
	Hannah	I was always, you know, I was always thinking about how she was growing
	Mary	Oh, it was amazing. When you felt all like the flutters, and yeah and- having just knowing that I could only feel it and no one else could, that was like extraordinary ... and then when it's- when my belly started growing that was just- yeah, amazing
	Francesca	I would just rub my belly and um, just feel like, nice and um, I think I did-I did speak to him a few times, um, like when I was feeling bubbles
	Joanne	My feelings for him started as soon as I saw the blob um but yeah, it does progress as, um, as it goes, as the pregnancy develops, and you know, different you know, like when your feel him move and that, it becomes

		stronger, the feelings become stronger because he becomes more and more real
Overwhelming first encounter with the baby	Elizabeth	Yeah, just excited and over the moon that he was finally here and that he looked good and that he was lovely and pink and chubby looking and yeah he looked-he looked great.
	Rebecca	I just didn't feel right with him. Um sort-sort of mother's instinct. Something's telling there's something not right.
	Georgina	I guess the connection is love and just- wow, you know, almost proud of yourself, like, I can't believe umm, you know an-and also it brings me closer to my husband each time. Just you know the togetherness of-of all of- you know of us coming together and creating - life. I don't know, it's just all these feelings and hormones and just the best feeling.
	Hannah	I felt that because she came out and everyone said she looked good and she was so big. I felt like I'd done the best that I could do and I felt good about it.
	Mary	I don't remember seeing him for the first time ... when he come out, he- they put him on me, I don't- I-I don't-I've got a picture of it. I don't remember.
	Francesca	He was given to me straight after, I saw him, he was like, he was fine as everyone. He was so cute.
	Joanne	That's amazing cos the- his heat, you can feel him and although he's all smelly and, you know, covered, it's-it's-it's magical
Superordinant Theme 2: Losing Control in the Context of CHD		
Shattered expectations	Elizabeth	My first thought was is it something that I've done, particularly because I was so sick and I had to have the anti-sickness medications so I thought well was it a side effect of the medications
	Rebecca	I don't know if I was feeling anything to be honest, I think I was just numb. Absolutely just numb with shock
	Lucy	I just don't think you know whether your, I don't know, it's very, it's a bit surreal really, I think.
	Georgina	I kind of forget about this beginning when it um-I was first told that, um, cause that was um, the hardest day of my life and it's so-so vivid still in my head
	Hannah	I hadn't really let myself think about it cause I knew it was just gonna be so awful.
	Mary	Devastating. It was just devastating. I just, I-w-we-I just- I was in so must shock. Then I just wouldn't stop crying.
	Francesca	What is happening to him because um it wasn't expected and it wasn't picked up on the scan.
	Joanne	It was just a bit of a shock, you know 6 hours after giving birth, ab-absolutely exhausted, your emotions are running crazy cos that's what happens and then get told that- that was a shock.

Suffering with physical separation	Elizabeth	I had to stay in [name of local hospital] overnight while [name of infant] was in London. So that was the hardest bit.
	Rebecca	Just worried about him, just now come to a complete alien place with nothing, you know, no clothes, no money, nothing at all just me and [father of infant] on our own
	Lucy	That was horrible, because I was then stuck in [maternity ward] and they'd gone to [children's hospital].
	Hannah	I couldn't have left her unless I felt 100% sure that the nurse there was who I would be confident leaving her with.
	Mary	I was just wanted him. I just wanted to be – once I sort of calmed down, yeah I just wanted to be with him.
	Francesca	I was thinking I have to go, I have to go and see him
	Joanne	I just wanted to get to [infant]. I just, didn't, you know, I just wanted to be in the same place as him, I didn't wanna be so far away from him
Confronting the reality of uncertainty and potential loss	Elizabeth	Our first thought was, you know, will the baby be ok?
	Rebecca	We were told that he could stop breathing at any time
	Lucy	It was quite nerve-wracking to be fair, it was, because I just kept thinking that they were going to tell me that she wouldn't live.
	Georgina	Thought of-of how could I ever be around anything that's ever going to remind me of him, you know, because I thought that I-that I was gonna lose him
	Hannah	The morning of the surgery, they let us sit and hold her and it made me feel so sad cause I felt like they were-they were giving me the chance to say goodbye just in case anything happened and I-it just was devastating. It was awful.
	Mary	Thinking oh what if he dies? What if something goes wrong? You know they've- he's on a-he's- they're cut his whole entire body open- he's on a bypass machine
	Francesca	I could lose baby, I could lose the baby ... I didn't want to lose the baby. I didn't want to lose the baby
	Joanne	You just think the worst straight away. You-you think oh it's his heart, that's quite an important part of your-your body to-to not be working and although they-they said I think he's got this, we didn't have any definite answers, so I didn't know what it was, so that-that was frustrating and upsetting cos like you do, like I say you do think the worse.
Feeling disconnected	Elizabeth	I did go and see him so that was great but it was a bit strange cause like I'd been apart from him
	Rebecca	I felt that, you know, me keeping away would sort of make it hurt, you know, not hurt as much ... Yeah,

from the baby		because of me also having a child that's passed away previous, you know that brought back a lot-a lot of emotions and feelings
	Lucy	I never had her. Do you know what I mean? I was used to life without her.
	Hannah	To watch her gagging all day and her eyes welling up and struggling – that was unbelievably bad. And I went to the toilet and I thought - I've got to get out of here. I-I could've ran. Like I felt like I wanted to run away – it was just too much to bear
	Joanne	Between him having his surgery and him then being allowed to cud-cuddle him again, I think was 5 days or so, you know, you feel like your connection is getting lost. Um, because ok, your touching him and your stroking him and-and things like that but again, cos he's sedated, you don't know how much he can feel of that
Feeling useless with the loss of caregiving role	Elizabeth	I felt that things were out of my control
	Rebecca	Yeah literally from him being yeah being quite you know sort of taking bottles and taking his feed and everything to then all of a sudden bang – no feeds, nothing, weren't allowed to touch him
	Lucy	You know and the nurses come around and do what they have to do and you-and it is really taken out of your hands. You-you just-you just sort of a bystander, if you like
	Georgina	I felt pretty helpless, you know, like you almost w-wish that you could be the surgeon and, you know, do it for him
	Hannah	You don't feel as though you could question anyone, but you feel like everyone knows better than you do.
	Mary	They done everything. They fed him, they chang- I did change his nappy but- but they did-they did the full care of looking after him ... I weren't there doing his night feeds and his whatever else
	Francesca	You couldn't control err what milk the, you know, they take out. Whether it's the one you brought in the morning or whether that the one that you brought um in the evening
	Joanne	I knew we were in the hands of the doctors and-and the nurses and the surgeons
Losing confidence and feeling inadequate as a mother	Elizabeth	[Infant] got so upset and wound up and like was crying and like he just really didn't enjoy it and umm and that really upset me because I wasn't able to do anything.
	Lucy	you've got so many wires that you're concerned that you're going to pull something out of somewhere
	Georgina	We were nervous about you know, taking care of him and you know, leaving the hospital. They were um, they were gonna dismiss us-discharge us and then we asked to stay one more night (laughs) because we just felt like oh, we're not ready. You know, is he ready? Are we ready?

	Hannah	It was awful. It was absolutely awful. Because it-it just felt as though I couldn't do everything for her. Yeah, and that's what I wanted to do. I wanted then to feed her and get her dressed and clean her up and you know, and hold her and-and not being able to hold her and not being able to feed her was-was devastating.
	Mary	There were so many tubes coming out of his- everywhere, there were tubes ev- and we were so scared that we would pull a tube out that we said um "no, we don't wanna do it, we don't wanna risk any harm coming to him"
	Francesca	My other worry was what's gonna happen to my milk?
	Joanne	I think when he was in the hospital, it was-it was different it was harder to create that bond cos you can't have as much interaction as you would with him at home.
Superordinant Theme 3: Keeping Connected to the Baby		
Maintaining closeness	Elizabeth	I did get a cuddle, I insisted on a cuddle
	Rebecca	I then stayed with [infant] continuously until we left. I didn't leave him....Oh, that was lovely
	Georgina	I would do my best not to cry, and talk to him ... I would sing to him
	Mary	I had to sleep in a top, give him my top and then I had to sleep with his baby grow to try and get milk and to also make us bond apparently ... they kept telling me to have skin-to-skin with him
	Francesca	We came and we supported him all the way. All the way, well, you know, cuddling him, all the time, 24-7 my husband and myself
	Joanne	We were having a conversation and including him so we were saying his name over and over again
Taking back control and rebuilding confidence	Elizabeth	I could just stay with him and like do all his care even through the night and everything and even though the nurses offered to do it, I was just like well I just want to get into the routine of how I'll be doing things when I get home.
	Rebecca	[I was feeling] more protective and me wanting to do everything ... wanting to do it all. I mean the nurses really didn't have to do anything other than keeping an eye on his things cause I was just taking over and doing it all.
	Lucy	We were really able to start taking care of her then, you know, once the wires and everything were coming off.
	Georgina	They kept telling us, you know. "He's fine, he's doing everything on his own, just as we want him to" So, so, yeah, I mean we-we did feel confident when we brought-brought him home
	Hannah	I said "I don't wanna stay, I wanna go home" ... I can feed her, let me take her home and do it."

	Francesca	For me it was just all natural things happening. I didn't question myself, what should I do? Um, this is better, this is worse, I just-I just got to learn how to use medicine and um, it was just for a little while, it wasn't for long and um, all went fine.
	Joanne	We had started being able to give him his food through, well through a syringe ... holding him like this (demonstrates cradling a baby), holding his syringe, you feel like you're giving him a bottle, you know, it's um, that was amazing
Prioritising and protecting the baby	Elizabeth	I was sitting with him all the time I didn't have much sleep and I was getting up and expressing and everything so it was really, really exhausting time.
	Rebecca	We see everything, yes, sit there watching, I-I couldn't sleep, I just sat there beside him, didn't want to leave him
	Lucy	As opposed to feeling anything for myself, I just wanted to make sure that they were all oh-, you know, that they-that they were all ok.
	Georgina	I just kept feeling like oh, I just want to take him-I just want to take him home. I just want all of this to go away and I just want to take him home
	Hannah	I wanted to get up and run away with her is what I wanted
	Mary	All I kept thinking was he's poorly, he needs that first, you know like the clu- colostrum, he needed that bit of milk, from me.
	Francesca	It is just giving a kiss when he is crying. Um, hugging when he is crying or not happy. Make sure that ah he is looked after ah, his nappy is clean, um she is fine, her teeth are brushed, um, they going for a walk, they happy, they make friends. It's just all about them.
	Joanne	It was important to me to give him something cos I felt like I was helping that little bit more
Perservering with support and focusing on recovery	Elizabeth	That's why we coped as well as we did cause we knew exactly what was going to happen
	Rebecca	Ah, that-that was amazing, jus-cause he just completely different again. He looked like a completely different child.
	Lucy	I don't think at the time you really think about it, you just-you just-you're on autopilot, you just get on with it. You just have to. And I am quite a person that gets on with things, I don't, I try not to dwell too much.
	Georgina	My husband ... was my rock, like, because I was more of a zombie and just like ... plugging through the day. Where he was, like on the nurse, like "why is that-what's that number mean? What's this, you know, in here for?" Like, he constantly asked every-like questions

	Hannah	I thought of everybody that I could think of that might be able to-to help
	Mary	I just then turned to my friends and I think if it weren't for them I would never of got through it.
	Francesca	If you're all by yourself, you don't know what's going on, it's very difficult and if you don't have anyone, and my husband, he always supports me so that-that was very helpful
	Joanne	We spoke to, um, a couple of people that had had- their kids had had similar things and that w-that was nice to talk to them. It's always good to talk to people who've been in the same situation
Superordinant Theme 4: Moving on Together		
Looking forward as a stronger mother	Elizabeth	I think [CHD] probably made [our relationship] stronger because of the time that we had a the hospital and I think because I'm so grateful that he's healthy
	Rebecca	You learn to now deal with this heart condition and things go on.
	Lucy	I felt like when we brought her home, the last two weeks, the couple of weeks that we'd been there had just sort of disappeared. They'd gone. It was over now. Um and it was just time to get on with our lives now really.
	Georgina	It makes me feel closer to my husband, my mum- mu mum was a huge support- everybody who- even my friends
	Hannah	For me, it was-it wasn't a sacrifice at all. It was-I was just so lucky to have it.
	Mary	Closer together definitely. Yeah. No definitely. He was my rock going through the whole thing in hospital ... But yeah, he was my rock, he defi- well it's definitely made us stronger.
	Francesca	Why should I worry right now and panicking about something that is not happening yet.
	Joanne	It does put your life into- puts everything into perspective.... I was actually sitting there thinking how lucky we were
Devotion to the baby at home	Elizabeth	I might be slightly more cautious. Umm, I hope I'm not too like over-protective cause I did say at the beginning that I didn't want to like wrap him in cotton wool but I probably do take him to the GP more than other mums do and I worry that they think I'm a bit neurotic
	Rebecca	I am more, sort of overprotective. He sleeps night times, I have alarms and stuff on his cot, and I will keep them on there.
	Lucy	I think we spoil her (laughs) ... I pick her up all the time.
	Georgina	Second guessing everything and just, you know, not wanting to bring him out too much and be around too many people and just didn't even want him to get a cold or anything. Just very, really protective

	Hannah	Now I let her be held all the time (laughing) and-and I, um you know, with [older child] I was strict in making him be put down and go to sleep on his own and all of those things. And now, um, I don't feel like that with her. I feel like she-she still needs loads extra ... because she missed out on it.
	Mary	I wouldn't wanna put him him into childcare and miss all that
	Francesca	I devote all my time to them
	Joanne	You automatically think there's something wrong, is he hurting? Is he in pain? Is it cos he needs something, you see, so you pick him up straightaway and check
Seeing the baby as both normal and special	Elizabeth	Learning how to look after him and you know it's the same as with any baby really (laughing) like developing the skills that you need to look after a little one
	Rebecca	That did stop us doing the normal mother and child bonding things obviously but then that also gave us more of a special bond, I think.
	Lucy	She just became part of the family and that was that.
	Georgina	I see it being just like any other child ... I do feel like he's a normal baby
	Hannah	She doesn't need any-anything different to any other child now
	Mary	But you never know looking at him, you'd never know. He's just so, so good. He's developing exactly how he should be, he's just, yeah, he's just perfect. Uh huh (smiling). He's just perfect.
	Francesca	He's just a normal baby
	Joanne	The longer you're at home, and the longer- and the more check-ups he has "oh he's doing really good", the more confident you get to going back to having just a-a normal relat- bond.