A STUDY TO EXPLORE MOTHERS' AND FATHERS' SHARED AND INDIVIDUAL EXPERIENCES OF PREMATURE BIRTH.

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Abstract

This qualitative research project using some of the methodologies of Grounded Theory looked at five couples' experiences of premature birth, in particular comparing and contrasting the experiences of mothers and fathers. Significant themes that were identified were: helplessness, related to parents' belief that they were unable to alter outcomes for their baby; issues of control around the care of the newborn baby; communication and relationships with healthcare staff and the impact on parents' perceptions of inclusiveness in the care of their infants; and for fathers in particular, feeling that they missed out on aspects of the parenting of their newborn. The conclusions were that, due to a number of factors within the NICU environment in conjunction with gender specific methods of coping, fathers tend to be marginalised and excluded from the care of their babies. As a result of this, fathers then distance themselves from contact with their newborns, leading to the cyclic exacerbation of the issues of control and helplessness, which further reinforces their disengagement from the situation. Mothers struggled with the same issues, but not to the extent that they withdrew emotionally and physically from the care of their babies.

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CHAPTER ONE: PERSPECTIVES

The birth of a new baby in a family will in the normal course of events cause changes and stressors of which the parents will have had little true conception prior to the baby's birth. Imagine then if you will the effects on parents when the birth of their baby is too early for it to survive outside a specialised unit. In many cases there will be little advance warning of a premature birth or any idea that the birth is frequently associated with major surgery on the part of the mother. There is the incredibly small size of your infant to come to terms with. The machinery and the sheer volume of noise in the neonatal intensive care unit, plus the number of leads, lines and alarms attached to your baby. Initially there will be little opportunity to touch your child let alone pick it up to feed it. There may be long distances to travel to get to the unit, and there is also in a lot of cases the associated worry of how to cope with other members of your family. On top of this all there is also the fear that your baby may not live.

In any new birth, there has long been an emphasis on the establishment of the mother infant bond. The mother tends to be the parent who is around the baby the most, and traditionally plays the major role in infant care. This naturally has lead to the development of family admission policies in special care baby units that reflect the importance of the mother infant bond. While this is a worthy and necessary goal, it may be that in emphasising the mother/child relationship and reflecting on the psychological and sociological importance of this bond, we have failed to acknowledge that premature births also have a psychological and sociological impact on the immediate and extended

family, and particularly the father. This research project is aimed at attempting to determine some of the effects of premature births not only on mothers but also on fathers and on the couple and to explore the differences and similarities between these experiences.

Reflexive Note. Because this research project is driven in some respects by who I am and what I have experienced it may help to put this study into context by taking a quick look at me. Firstly, I am a pakeha, middle aged woman with a tertiary education. I grew up in a very small town in Central Otago, which perhaps fostered my independence and assertiveness. My dad had nine brothers and we were the first girls to be born into his side of the family in 90 years. My mother also came from a large family, and was an assisted war emigrant, who arrived from Scotland in the early fifties. She trained to be a nurse and then met and married my father who was a farmer. I am the middle daughter in a family of three girls. I attended a very small Catholic school and went from there aged twelve to what was considered a much bigger school for my home town. In my Sixth Form class there were four students, all of whom were girls. My class was the first to gain University Entrance for one student, let alone all four of us. The second precedent we set was that none of us were pregnant at the time.

From school I went to work at Cherry Farm, at that time the local Psychiatric Hospital. I became a registered psychiatric nurse in 1981, having trained in a very large hospital in South Auckland, and over the course of the next 21 years I took papers with Massey culminating in a Bachelor of Science majoring in Psychology in 2002. I now have four children, two of whom were home births.

Our fourth child was supposed to be a home birth as well, but he had other ideas, including the desire to act as the main inspiration for my Masters thesis. Fennec was born 8 weeks

early on the 3rd of May 2000. The fact he was going to arrive early was not entirely unexpected: my waters had broken at least five days prior to his birth. Also though he was our fourth child he was not our fourth pregnancy, as we had had a number of miscarriages that had all occurred within the first trimester. Each baby that had successfully managed to make it to birth had also been born closer and closer to the start of the third trimester. Our eldest was born on his due date; the second was born 11 days early; the third managed to arrive three weeks early; and Fenn, well and truly broke the record for an early birth in our family.

I know looking at Fenn lying in the Neonatal Intensive Care Unit (NICU) with a plethora of tubes, monitors and alarms coming out of his body, that we didn't really think beyond the moment. We were just so pleased he was alive. Other concerns did not percolate past this fact. Certainly in that time spent in NICU it never occurred to me that there was a potential for his early birth to have an impact on his neurological functioning. As far as I was concerned, he was breathing at delivery, he was on oxygen thereafter, and the possibility of neurological damage never entered my thinking. Our days in NICU were about feeding him first through a syringe down a nasogastric tube, then getting him onto the breast and watching his body weight, keeping an eye on his body temperature, holding him in such a way that we didn't impair the oxygen flow to his lungs, listening for alarms, checking monitors, and constantly being in awe of this tiny bright red specimen of babyhood. We picked him up like he was the finest porcelain china. We scrupulously scrubbed our hands before touching him or anything that was going to come into contact with him. We monitored our friends and family about potential coughs, colds and any other bugs they may have come in contact with, before we allowed them to come and visit. The contrast between this regime and the two relaxed and happy home births that had preceded it could hardly have been greater.

Preterm Infants: Description

The following terms and definitions are taken from Bradford (2000). Most babies arrive between 38 and 41 weeks gestation, so a premature baby (prem, preemie, etc) is one born before spending 37 weeks in the womb. There is then a series of terms used to define the actual number of weeks a baby has spent in the womb: extremely premature (24 to 28 weeks gestation); very premature (29 to 34 weeks) and moderately premature (35 to 37 weeks). The next most common terminology used in reference to babies deals with their weight, with a low birth weight baby being one who weighs less than 2.5kg at birth. Most prems are also low birth weight babies. A very low birth weight baby is one born weighing less than 1.5kg, and an extremely low birth weight baby is a baby born weighing less than 1kg.

The earlier on in the pregnancy that birth occurs the greater the risks to the infant and unfortunately there are only a limited number of interventions available to prevent a woman going into full labour. Many of these interventions will involve admission to hospital and at the very least will begin with bed rest although recent studies have shown that this may not be efficacious in preventing premature labour and delivery (Yost, Bloom, McIntire & Leveno, 2005). Depending on the number of gestational weeks passed the option over how the birth will progress may be limited to an emergency caesarean. This option is the preferred method of delivery as the baby is often in a breach presentation and caesarean delivery reduces the stress and damage that can occur during delivery (Weissman, Blazer, Zimmer, Jakobi & Paldi, 1988).

Mothers at risk of delivering before 37 weeks will be given a number of steroid injections. These injections are essential if the baby is to develop surfactant (a lung product) which will allow their lungs to mature; without surfactant premature babies are at risk of developing hyaline membrane disease. Preferably there is 24 hours between the second injection and the baby being born as this is the minimum time available for the injections to produce a change in surfactant production in the baby (Sen, Reghu & Ferguson, 2002).

Treatment after birth for a premature infant often means immediate transfer to the special care nursery or neonatal intensive care unit, because of anticipated complications The environment within NICU is designed with the premature infant's particular needs in mind and to reduce the amount of stress placed on the newborn. Premature babies have three specific requirements: warmth, food and an environment where they are protected whilst they undergo the essential growth and development that they have missed in utero (Tunell, 2004; Adan, LaGamma & Browne, 1995; Aucott, Donohue, Atkins & Allen, 2002). As a result of the improvement in neonatal technology over 90% of babies born before 37 weeks and weighing 800 grams or more survive. The chances of survival for those weighing above 500 grams is between 40% and 50%, however their risk of complication is higher (Gomella, 1999).

There are numerous possible causes of premature delivery. It is associated with a number of maternal lifestyle or health factors such as smoking, or not gaining enough weight during pregnancy (Steer & Flint 1999). However, all too frequently the cause is not directly under the mother's control. In particular, preterm delivery is more likely

when a woman is in her teens or above her mid thirties, or where the mother is carrying multiple babies, and sometimes the cause is simply unknown (Martin et al., 2003). Premature infants are more likely to be girls than to be boys. They often have very little body fat and have decreased muscle strength, muscle bulk, and muscle tone and numerous complications may develop, due to birth prior to the completion of development (Boukydis, Bigsby & Lester, 2004). Establishing the baby's actual gestational age can be done on the basis of surveying the infant's physical characteristics (Dubowitz, Dubowitz & Goldberg, 1970), where the amount of creasing on the soles of the baby's feet, genital development, and other characteristics can give an extremely accurate estimate of the number of weeks of gestation. The maternal dates (date of last normal menstrual period) can also give a fairly accurate measurement (Keehn & Lieben, 2004).

As noted earlier the direct result of improving neonatal technology is reflected in the increasing number of babies surviving despite being born early. Over 400,000 prem babies are born annually in the United States, an incidence of 12.1% of all live births in 2002 (Martin et al., 2003). As would be anticipated, the lowest birth weight and frailest babies have the most significant long-term problems and their mortality rates are correspondingly the highest, with infant survival ranging from over 95% for babies born at 30 weeks (with an average birth weight of 1.35kg) down to less than 3% for babies born at 23 weeks (with an average birth weight of 500g) (Gomella, 1999). York and Devoe (2003) outline the potential long-term health implications for premature infants as including chronic lung disease, cerebral palsy, learning disabilities, and vision and

hearing impairments (all of which have since become apparent for Fennec). While doctors have made tremendous advances in caring for babies born too small and too soon, they have yet to find out how to prevent these early births from happening in the first place, despite decades of research. In fact, in the United States of America, the rate of premature birth increased from 9.4% in 1981 to 12.1% in 2002 (Martin et al., 2003).

Preterm Technology

The three most basic requirements for any newborn are breathing, feeding and warmth. These requirements are more of a concern when a baby is born prematurely, because the systems responsible for these three areas have not developed fully in a premature infant. An early baby is often moved to a neonatal intensive care unit where various pieces of technology may be used to assist and monitor the baby. From our own experience, an NICU can be a place of seemingly constant beeping from one monitor or another, with alarms set to go off if a baby's breathing, heart rate, temperature or oxygen saturation falls outside a preset range.

Some examples of the technology that may be employed in the care of a premature baby from our experience and from the experiences of the parents in the current study are as follows. For more detailed descriptions, see Bradford (2000). Different types of monitors include:

- Monitors to measure heartbeat and breathing. These are likely to be attached via soft pads on the baby's chest.

- Oxygen saturation monitors. These measure the level of oxygen in the blood by shining an infra-red light through a baby's hand or foot.

- Blood pressure monitors. These can either be in the familiar form of a pressure cuff around the baby's arm, or may be attached to a line going into an artery.

An incubator will be used to keep the newborn warm and in some cases to control the air the baby is breathing. An incubator in its simplest form is essentially a transparent plastic box on wheels. Depending on the baby's particular needs, a fully enclosed incubator with latching portholes and a lid may be used. For less fragile infants, the incubator may be an open-topped box with a heating pad incorporated into the mattress, or placed over the baby.

There are a number of special pieces of equipment developed to help a baby to breathe, but treatment for breathing will usually have started well before baby was born via the steroid injections mentioned above.

Other methods are employed following the birth of the baby. Essentially there are three different methods.

- For babies who need a little extra oxygen but otherwise can breathe without help, oxygen may be piped into the incubator, or an oxygen mask or head box (that fits over the baby's entire head) may be used. A very common sight in NICU is a baby with a nasal cannula, an oxygen tube leading to two soft prongs that go up each nostril.

- Similar to the nasal cannula is CPAP (Continuous Positive Airway Pressure), a technique where a mixture of air and extra oxygen is pumped through tubes in the baby's nostrils down into the lungs, keeping the lungs partially inflated at all times. This stops the lungs from collapsing inwards, and prevents the inner surfaces (the alveolar sacs) from sticking together. It also means the baby does not have to work as hard to breathe (DePaoli, Morley, & Davis, 2003). One positive benefit of the use of CPAP is that Fennec has the most perfectly formed circular nostrils imaginable, due to the early shaping influence of the nasal prongs.

- A ventilator can either help breathe or completely take over breathing for a baby. A mixture of air and oxygen is pushed down an endotracheal tube, which goes into the mouth, down the throat and into the lungs. As Bradford (2000) describes, there are two main types of ventilator: a positive pressure ventilator, which pushes a mixture of air and oxygen under controlled pressure; and an oscillatory ventilator, which delivers the air oxygen mixture into the baby's lungs but 'vibrates' rather than blows the mixture in. This type of ventilator is very gentle on the lungs.

Many preterm infants have apnoea attacks, where they may stop breathing for 10 to 20 seconds or more. To monitor for this, most babies in NICU will be attached to an apnoea alarm that will monitor the baby's breathing either through a blanket that the baby lies on, or a belt worn around the infant's waist.

There are a variety of methods for feeding premature infants, many of whom will have developed neither the suckling response nor the muscular coordination required to feed from a breast or bottle. An intravenous line may be used to introduce food, hydration or medication directly into the baby's bloodstream. A tube may be used to put food directly into the baby's stomach; this will be either a naso-gastric tube (that enters via the baby's nose) or an oro-gastric tube (that enters via the baby's mouth). In some cases, a transpyloric tube may be used to feed directly into the baby's small intestine.

There are several other pieces of technology that may be used with pre term infants. For example, a common concern with premature babies is jaundice, associated with high levels of bilirubin in a baby's blood, which can lead to brain damage. The treatment for this is to break down the bilirubin by shining bright lights on the baby's skin. This will be done either using a phototherapy unit similar to a suntan bed, or placing the baby on a biliblanket, a special mat composed of brightly lit fibre optic tubes.

CHAPTER TWO: IMPACT OF PREMATURE BIRTH

The Family

In recent times, "family admission policies" have been developed for special care baby units, as well as ordinary maternity units. When we are defining family, or who constitutes a family, it rapidly becomes obvious that this can mean different things to different people; and this great diversity of meaning is nowhere better demonstrated than within the health arena. Medalie and Cole-Kelly (2002, p 1277) argue that "family practice implies that 'family' is the focus of care." McWhinney (1989) states that "the definition of family varies with the clinical situation and has important clinical implications." A General Practitioner may be responsible for the health of a family who can range in age from newborns to older parents and in some instances they may be involved with grandparents. An approach used in the past was to focus on the individual and not to see them in relation to his/her family of origin. This approach has been questioned by some health practitioners and there is an increasing focus being placed on how the patient lives within the structure of their family environment. Another alternative has been to see the "family" as the patient (Medalie, Zyzanski, Langa, & Stange, 1998). Lang et al. (2002) state that working with a family as the patient introduces interesting and diverse possibilities into the realm of general practice, and can introduce ethical dilemmas that might not have been apparent at the outset.

There are many ways of defining the concept of family. In the United States of America the U.S. Census Bureau's description of a family is "a group of two or more people

related by blood, marriage or adoption" (United States Department of Commerce, Bureau of the Census, 1982, cited in Medalie and Cole-Kelly, 2002). Medalie and Cole-Kelly (2002) argue that the benefit of this definition is that it allows for families that are composed of people who do not fall within the paradigm of mother, father and their biological child. It allows for the inclusion of same sex couples, single parent families, families who are parented by grandparents and families where members are adopted. Because this definition allows for a greater breadth in the definition of family, Medalie and Cole-Kelly (2002) argue that it has become the basis for family charting. However as they point out the clinical situation presents practitioners with a broad range of potential problems. For example, care may have to be focussed on a number of factors relating to the family. These will be dependent on age, position in the family, the particular illness and the degree of illness. Medalie and Cole-Kelly also identify the fact that the composition of family does not necessarily just include those who are kin related.

Medalie and Cole-Kelly (2002, p. 1278) argue that it is important to identify the "functional family (i.e., the group involved in dealing with the everyday affairs of the patient and family)" particularly when the focus is on a long term illness. They talk about how the functional family does not just include those who are immediately related by blood, but extends to those who work with the family, such as nannies, carers, meals on wheels, cleaners, and those who help with home maintenance, for example. The range of people who can potentially become involved in a long term illness demonstrates the impact chronic illness may have on a family. Rolland (1994) describes the

alternation, during the course of a chronic illness, between periods of crisis and relative stability.

Premature birth is highly correlated with chronic disability; therefore the family group dealing with a premature birth are likely to have to deal with chronic health problems, as well as the crisis or series of crises surrounding the birth itself. (Wood, Marlow, Costeloe, Gibson, & Wilkinson, 2000)

Medalie and Cole-Kelly (2002, p. 1278) have broken the presentation of family down into two discrete groupings. They refer to the family that responds to a crisis or death and has cultural and kinship ties as the "crisis family". They recognise this grouping as a "secondary conceptual definition" that emerges from the "primary family type". It is this family that can become the "central focus of care" when a crisis happens. They found that the composition of this family may have little to do with kinship bonds: it relates to the people involved in the immediate crisis intervention. In many cases, the birth of a premature baby will also fit the criteria of a crisis, and the crisis family will be all those people involved in dealing with the effects of the premature birth. Medalie and Cole-Kelly (2002, p. 1279) have also identified the "bereaved family". They found that this family appears as a response to a sudden death or can be tied to the emergence of a chronic illness. Medalie and Cole-Kelly note that bereavement or grieving usually becomes an active part of the family structure when the family recognise that death is imminent, and will continue to occur following the death of the family member. Bereavement however is also a serious issue for families who are confronted with premature births and the possibility of an ongoing chronic disability as a result of that

premature birth. Bereavement may encompass such issues as the reappraisal of the importance of health and of the unspoken expectation of what the birth of this child means to each family member.

Jackson, Ternestedt and Schollin (2003) found that the experience of having a premature baby has far reaching consequences for both parents. They describe differences between mothers and fathers that are centred round stress and adjustment issues. Their research found that these factors were more significant for mothers than fathers. They also discuss factors that can modify parents' abilities to cope, and that can have both negative and positive influences on parents. The two most common domains they refer to are the state of the family and the well being of the child. They also found the research that examines fathers' experiences to be meagre, and it appears that studies on the experiences of other members of the wider family are similarly lacking.

McFadyen (1994) looked at how the mother child relationship is affected by time spent in a special care unit. However McFadyen acknowledges that her research essentially looks at the relationship between the primary caregiver — the mother — and the special care infant. Her research touched on the relationship between fathers and their special care offspring, but this was not a primary focus.

There are two studies that have looked at the impact on older siblings of premature infants, but these date from the 1980s and offer conflicting reports. Breslau, Weitzman and Messenger (1981) looked at families where a child was born with a range of disabilities and found that siblings within these families, though not demonstrating

overall higher levels of disturbance than a control group, were found to have higher levels of interpersonal aggression with peers. This contradicts a study by Lavigne and Ryan (1979), who found that siblings of children with acquired and chronic congenital birth issues had a higher level of disturbance, which manifested itself as irritability and social withdrawal.

Linden, Paroli and Doron (2000) produced a very readable and informative book that drew on the experiences of two of the writers having given birth to premature infants in the late 1990s. The third author is a neonatologist and sister to one of the other writers. This combination of mothers who have experienced premature birth first hand and a sister who works exclusively in the field of premature births has allowed them to examine many areas of concern to parents who have had little or no prior experience of early births. However, their book also has only a very limited area devoted to the effects on the wider family experiencing an early birth. Little notice is paid to fathers, siblings or grandparents, who have limited opportunity to discuss their perceptions and fears, or to explain the positive and negative aspects of their experiences.

Impact on Mothers

O'Hara and Swain (1996) have found from their analysis of postnatal research that approximately 10% to 15% of post partum mothers will experience depression at a level high enough to gain them a clinical diagnosis of depression within the DSM IV criteria. Studies by Brooten et al. (1988) and Thompson, Oehler and Catlett (1993) found that mothers are still experiencing high levels of stress, despite them having greater access to

their preterm infants than in the past, and levels of communication having improved between them and health professionals in NICU. It could be argued that the nature of the NICU environment is quite frightening and out of context of what mothers expect to experience following the birth of their baby. But Brunssen and Miles (1996); Miles (1989); and Raeside (1997) suggest that it is not the technologically advanced and intrusive machinery of NICU that mothers find frightening, but rather the sight of the baby, and its smallness and fragility. Lindsay et al. (1992) and Raeside (1997) comment that parents tend to see fragility as being aligned with illness, and Meck, Fowler, Claflin & Rasmussen (1995) also argue that it is the constant spectre of death that mothers find the most stressful. This combined with the severe alteration in their expected parental roles and the fact that they are separated from their newborn affects their coping state (Hughes, McCollum, Seftel & Sanchez, 1994; Moehn and Rossetti, 1996; Shields-Poe & Pinelli, 1997). All of theses studies discuss the higher levels of depression to be found in mothers who have a baby in NICU, but it is extremely difficult to find any comparable studies on the levels of depression experienced by fathers or other affected family members.

Researchers such as Easterbrooks (1988) recognise that these are the moments when mothers especially are going to need extra support while they come to terms with the uncertainty and shock associated with their newborn. There are a number of studies that have examined how parents cope and what strategies they use to reduce their levels of stress. Studies such as that by Lau and Morse (2001) have identified that mothers cope better when they believe that they have adequate support networks in place. Also,

increased proficiency in parenting and reduced levels of maternal depression are strongly related to strong social and family support networks (Gowen, Johnson-Martin, Goldman & Appelbaum, 1989). What is not clear from any of this work, however, is where those people who make up this social network find their own support, and what mechanisms for ensuring good psychological health are being used. Again, the studies focus on the networks of support that surround the mother, and not on the support networks that may exist for the wider family coping with premature births.

Davis, Edwards, Mohay and Wollin (2003) acknowledge the dearth of research that surrounds the possible variables relating to mothers of premature infants and their depressive symptoms. They surveyed mothers of very preterm infants at one month post delivery. In their study they found that 40% of mothers of very premature infants reported depressive symptoms, this is much higher than the population norm of 15%. They argue that this is not surprising given that these mothers are experiencing a series of crises related to the early birth of their baby. Factors that this study identified as having an influence on the scores on a depression rating scale were: worry about the baby's expected life span, uncertainty over ongoing health problems related to premature birth, and any crisis that arose in their day to day care in the unit. This result reflects other studies which show that mothers of premature infants suffer significant depressive symptoms during the time the baby is in NICU (Logsdon & Davis, 1997; Miles, Holditch-Davis, Burchinal & Nelson, 1999). Some mothers find that their level of depression increases after their baby is discharged from NICU and this may be related to the perceived loss of support of NICU (Ahn & Kim, 2004).

Davis et al. (2003) in their research identified that maternal stress was the single most significant variable associated with maternal depression. They point out that the mother of a premature infant assumes the role of a parent in some of the most stressful conditions possible, with neither the mother nor the premature infant being ready to assume their role. They add that mothers with newborns in NICU are nearly always separated from their baby, often by multiple pieces of equipment, with some mothers not being in a position of being able to physically care for the baby. Alternatively, the baby may not be in a stable enough condition to allow the mother to handle it. Combined with this is the constant fear for the mother of the baby dying. Davis et al. (2003) make the argument that it is not surprising that the mother reports feelings of depression. Again, this begs the question of what the same situation is like for fathers and other family members.

Davis et al. (2003) did not look at other aspects of life that could be expected to produce stress. NICU staff may be oblivious to external stressors, but needless to say these external factors can have an impact on how parents perceive events in NICU and their subsequent interactions (Hughes & McCollum, 1994). In the study by Davis et al. (2003), a number of mothers reported external occurrences of stressful incidents such as deaths, occupational and income worries that could have acted as eternal influences on the mothers' level of depression.

The perception of the nurses' presence also played a significant role in the level of depression mothers reported in the Davis et al. (2003) study. Where nursing staff were seen as supportive mothers reported lower levels of depression. Similarly, Hughes and

McCollum (1994) found that if a mother felt that she was not getting a great deal of support from the nursing staff there was an associated rise in the reports of depressive symptoms. Parents and other family members are confronted with a continually changing array of medical staff during their time in NICU, and this is further complicated by the fact that the mother is often not in the same department as the premature newborn. Davis et al. (2003) noted that mothers end up repeating their story to a wide ranging audience and this can happen many times throughout the day. It is unsurprising then that some mothers do not feel that they have developed a trusting relationship with the staff assigned to the care of their child (Affleck, Tennen & Rowe, 1991; Redshaw, Harris & Ingram, 1996).

A large number of mothers (97%) in the study by Davis et al. (2003) reported that their partner was very supportive in emotional needs as well as supportive in ensuring day to day material needs were met. The researchers make the comment that this level of support probably had a significant effect on abating the more distressing aspects of having a baby in NICU. Other studies also identify the baby's father as an essential support person in relation to the mother (Affleck et al., 1991; Miles, Carlson & Funk, 1996). Davis et al. (2003) found that the strategies developed by mothers did not have a relationship with their depressive symptomatology. McCubbin et al. (1993) have defined coping as "the specific efforts by which individuals or families attempt to reduce the effect of a stressor on the family and to manage the situation". Other studies have identified the two most common methods employed by mothers with babies in NICU were to reinforce social support networks and to talk to others (Affleck et al., 1991;

Crnic, Greenberg, Robinson & Ragozin, 1984; Hughes et al., 1994). This emphasis on the mother's familial support structures that enable her to continue functioning despite the increased levels of stress does not address the question whether the other people who make up this support structure remain well and can successfully deal with the stress that they may also be experiencing.

Impact on Infant

Apart from the physical and physiological problems that may be encountered by preterm infants, there is also the possibility that the parents' mental state may have adverse effects on their baby. In particular, maternal depression has been related to delays in infant intellectual, emotional and developmental achievement (Field, 1995; Murray & Cooper, 1997). Field (1995) points out that all infants may have a vulnerability to the effects of maternal depression, however the premature infant's risk factor is even higher given its greater need for stimulation and the fact that it is already operating at a level of lower responsiveness. Information is lacking again on whether fathers' levels of depression also have an effect on the psychological health of a premature infant. This combined with the literature on levels of depression in women experiencing a premature birth, may give those involved with mental health issues an indication that we may need to be more proactive in supporting families who experience a premature birth.

Finkelman (2003) argues that the mental health status of parents (and in this article she was referring to mothers) has a direct impact on the health of their children and newborn babies; she goes on to point out that this fact does not receive the attention it deserves. In

an attempt to deal with these issues the New Freedom Commission on Mental Health was established in the USA in 2002. Finkelman (2003) says this was in answer to the pervasiveness of significant mental health issues surrounding the areas of pregnancy, childbirth and parenting, and the recognition that the current health care system was incapable of meeting these needs. Her analysis of National Comorbidity Survey data concerning the incidence of psychiatric ill health and parenting showed that about 31% of American women and about 17% of men have a 1 year occurrence of at least 1 psychiatric disorder (not including substance abuse), and significant numbers of these people are mothers (65%) and fathers (52%) (Substance Abuse and Mental Health Services Administration, 2000). She found that the most frequently noted disorders are the affective type, including major depression, bipolar disorder, and anxiety disorders, and argues that the figures for psychiatric disorders are likely to be underestimated, based on the idea that many people are reluctant to acknowledge a psychiatric illness.

Nicholson, Sweeney and Geller (1998) looked at long-term child outcomes when a child has a parent with mental illness. They found the incidence of such children with a psychiatric diagnosis was between 30% and 50%, a marked increase from the 20% that is seen in the general child population. The researchers also noted that children of parents with a psychiatric disturbance may demonstrate developmental delays, poor academic achievement and disrupted social relationships. The United States Department of Health and Human Services (1999) report also noted that the probability of these children developing depression was three times greater than that of children whose parents are not depressed. Finkelman (2003) identifies a range of other potentially

negative factors to which these children are often exposed, such as sub-standard maternity care, low economic status, sole parenting, accommodation issues, divorce, environmental stressors and custody issues.

Impact on Fathers

In contrast to the comparative wealth of information on mothers of premature infants, research into the impact on fathers is extremely sparse. This may be due in part to practical issues. In many countries women get maternity leave, and although in some countries men get paternity leave, the length of stay in NICU may often exceed the number of days allocated for paternity leave. Some employers may be willing to continue to pay a father while his child is in NICU, but sooner or later a father's sick leave will run out, or he will have exceeded the number of annual leave days he may have accrued. Eventually an employer will expect a father to return to the workforce. Fathers in many cases then may not take as large a part in caring for their premature babies, and may also be less available to take part in research studies, for example.

Of the limited literature in this area, a study by Lundqvist and Jakobsson (2003) described eight Swedish men's experiences of becoming fathers to their preterm infants. The study identified six categories where these men were affected: concern, stress, helplessness, security, support, and happiness. Lundqvist and Jakobsson identified the major influences on the men's experiences of the premature birth of their child as being in the areas of control and non-control. They found that when the fathers' experiences included concepts such as support, security, and happiness, fathers felt that they were in

control and able to handle the situation. On the other hand, when the fathers' experiences included emotional states such as concern, stress, and helplessness, and these states were accompanied by feelings of unhappiness, lack of support, and feelings of insecurity, they experienced non-control. This is the only published study that I have found that is focused solely on fathers' experience of preterm birth.

However, also of interest is a study that was done by Goodman (2004), which discusses the relationship between mothers and fathers with post-partum depression. Following a literature search from 1980 to 2002, Goodman identified twenty research studies which had data on the prevalence of paternal depression occurring through the first year of the baby's life. She found that during the first post delivery period of a year levels of depression in fathers were between 1.2% and 25.5%, however the levels of depression in fathers who had a partner with post partum depression rose to between 24% and 50%. Goodman (2004) makes the argument that mothers with postpartum depression become a very strong marker for fathers with depression during the postpartum period. Goodman argues that the strong correlation between paternal postpartum depression and maternal postpartum depression has important clinical implications for the continuing functioning and wellbeing of the family.

Fathers have an important role in contributing to and maintaining a child's well being, but the number of studies that examine a father's involvement in their child's health care are few. A study by Moore and Kotelchuck (2004) was designed to explore the extent of fathers' involvement and to identify the key factors that had positive and negative influences on that involvement. They found that factors associated with high attendance

at WCVs (well children's visits) included being present at the child's delivery; a young child; an older father; health insurance that included the child; and having more than one child.

Tiedje and Darling-Fisher (2003) found in their research that fathers in the late 20th and early 21st century are more actively involved in their children's lives and healthcare than fathers from the earlier part of the 20th century. As a result of this move in fathers' roles, they suggested that those who provide health care to families need to be aware of and actively respond to fathers' inclusion in health provision. The researchers commented that there is very limited literature on healthcare provider inclusion of fathers, and what has been written tends to focus on strong recommendations to include fathers, or reflects on occasions where fathers have been treated as invisible. Tiedje and Darling-Fisher (2003) say that where healthcare providers are not overtly hostile to fathers, they do have unfortunate tendencies to minimise their presence and to trivialise their input, therefore the authors recognise that the major issue for providers is no longer to question whether to include fathers, but how to include fathers as active and participating parents.

Another important aspect of the interactions between the health system and fathers is when a child is dying. For fathers of very premature infants, this is a very real possibility. Despite medical advances made in the last twenty years, very small babies have a higher risk of death than do their full term counterparts. In a study by Davies et al. (2004) that specifically looked at fathers dealing with their dying child it was reported by participants that the experience was such that there was not a single aspect of their life that was unaffected by the process of dealing with their child's terminal

illness. The authors used grounded theory to examine the fathers' experiences, and to best encapsulate this experience arrived at the term "living in a dragon's shadow" (Davies et al., 2004, p111), indicating the uncertainty and hopelessness that develops when a parent is confronted by events where they have no control or ability to change or influence outcomes. The way that fathers dealt with the child's illness was to fight, being categorised in the study under the term "battling" (Davies et al., 2004, p111) and the descriptors that the study used in relation to the fathers were "conscious", "active", and a "continuous process" that called upon the father's "strength", "willpower", and "work". The researchers' use of the term "battling" occurred when the fathers felt that their parenting role was challenged and this was identified in three particular aspects of being a father in the face of a terminal illness: "...uncertainty, ...responsibility, and ...everyday disruption." (Davies et al., 2004, p111). They found those fathers who reported having strong supportive networks at their place of work and who also identified as having good communication with their child's medical team related more positive aspects in relation to the experience. They also found that conversely when fathers experienced difficult and unsatisfactory relationships with their child's health care providers they found that this heavily influenced the negative aspects of "battling with life in the dragon's shadow" (Davies et al., 2004, p111).

There do appear to be differences in the ways that mothers and fathers deal with their experiences of having a child with a disability, which could have some relevance in the context of looking at parents dealing with a premature baby. One qualitative study by Pelchat, Lefebvre, and Perreault (2003) used focus groups to identify these differences

and similarities. Two major premises became apparent within the groups, demonstrating the manner in which parents are similar and dissimilar. One premise arose around roles, where the family is made up of a number of smaller systems, and the roles seen within that context can be real or expected. The second premise was related to the issues that can arise in relation to a child's disability; these issues are related to normalisation and stigmatisation. The focus groups found that fathers' outlooks are attuned to the external world - their priorities are not tied to the day to day functions of the child's care - whereas mothers have far fewer demands and their outlooks and needs are more self orientated. Mothers also appeared to do better in interpersonal relationships and group communication. These findings are similar for families without a child with a disability, but the problems they encounter are emphasised when they are accompanied by the birth of a child with a disability.

Having a premature baby admitted to NICU causes anxiety, and how staff deal with information dissemination can have a huge impact on fathers' levels of anxiety. This was clearly demonstrated in a study by Singh, Singh, Pooni, and Soni (2003), where fathers were either talked to at their infant's cot side, or were talked to outside the unit. There was a statistically significant difference in levels of anxiety between the two groups at 7 days after admission. They concluded that talking to fathers at their baby's bedside significantly reduced the level of fathers' anxiety.

CHAPTER 3: THE PRESENT STUDY

The Research Question

The aim of the proposed study is to explore both mothers' and fathers' shared and individual experiences of premature birth. One of the major aims of this research is to look at the contrasts and similarities between a father's and a mother's experience. This is important in that the research to date looks at the impacts on mothers and largely fails to consider the impact on the father or the couple.

Some of the ideas of Grounded Theory were used as a framework to analyse a number of interviews with parents who had experienced a premature birth of their babies. Babchuk (1997) states that a key concept of grounded theory is that it needs to be a mutually interactive occurrence. This is important as the theory needs to reflect internal triangulation as well as peer evaluation. Basically this means that the researcher has to be able and willing to collaborate in ongoing dialogue at all times throughout the research period. As a result the methodology has an emphasis on memoing, constant comparison, coding, selection of a core category, etc. which the researcher needs to come back to again and again. While it has not been possible in the current study to take a fully collaborative approach, many useful insights and ways forward have been gained through discussions with my two supervisors.

Grounded Theory is appropriate for this study in that it enables the researcher to have an initial question that enables one to focus upon a particular interest (Willig, 2001). In this

instance what are the parents' psychological experiences of premature birth, and how these differ between mothers and fathers. Willig (2001) makes the point that when you are formulating a research question, that this need to be an open question, one where participants are invited to discuss their experiences and what it meant for them, which is the case in this instance. A research question is orientated towards discovery and understanding (Rowan & Huston, 1997).

The types of question that were posed to the participants were open ended, for example: "How did you view the experience of having a preterm birth?" Research questions in a grounded theory-based study need to be open and general rather than formed as specific hypotheses; this should ensure that the emergent theory will account for a phenomenon which is relevant and problematic for those involved (Becker, 1993).

Grounded Theory is a "general method of comparative analysis" (Glaser 1978, p 116) to discover theory, with four central criteria, i.e. work, relevance, fit, and modifiability, and is an interpretive method (Glaser & Strauss, 1967). Glaser and Holton (2004) discuss Grounded Theory in terms of it being a systematic generation of theory from data that arises out of qualitative work. They say that one of its most basic tenets is that it is used to arrive at a discovery about information rather than used to force relevance on a work. In addition to this they acknowledge that one of the characteristics needed to be able to work with grounded theory is a tolerance for confusion and regression.

There are a number of concepts that are used in Grounded Theory; these terms are used throughout the literature when discussing the methodology. Willig (2001) lists them as follows:

Categories: Willig (2001) states that grounded theory involves the progressive identification and integration of categories of meaning from data. Categories are defined by Strauss and Corbin (1990, p. 7) as being "higher in level and more abstract than the concepts they represent.... Categories are the "cornerstones" of developing theory". An example of this is the initial analysis of the interview data which grouped together items that have some uniformity with other similar items; for example statements that included descriptions of a baby's size, skin colour, fragility and so on were grouped together. These could then be given the category "baby's appearance". The researcher can then move from using labels that describe the phenomena to interpreting and analysing the content thus moving toward developing theory.

Coding: In Grounded Theory the analysis of data is often referred to as coding. Strauss and Corbin (1990) describe three forms of coding: open, axial and selective. Willig (2001), on the other hand, does not distinguish between these three forms of coding; she refers only to coding in general. However Strauss and Corbin (1990) and Willig (2001) appear to be talking about the same construct. In brief, it is the process whereby the researcher reads the data and looks for concepts and themes that may emerge from the interviews. Using Strauss and Corbin's ideas axial coding is the step where the researcher looks for connections between the categories identified. This is a process whereby the researcher is examining more deeply the concepts that have emerged.

Willig (2001) identifies the importance of the requirement that coding needs to reflect the constructs used by the participants; in other words it should use the specific words used by the participants. In the current study the coding categories were initially developed from the analysis of one interview, which was then used as the basis for coding the other interviews.

Constant comparative analysis: Willig (2001) describes constant comparative analysis as the process by which each item is checked or compared with the rest of the data. In this way the researcher is rebuilding and breaking down the information that arises from the categories. The importance of performing this task is to be aware and investigate instances where data conflicts among the emerging codes. By repeatedly investigating the material the researcher hopes to become cognizant of what it means. Any information that does not fit into the existing categories will give the researcher the opportunity to integrate this information into the emerging theory (Glaser & Holton, 2004). This technique was used to ensure that the final themes that emerged from the analysis were complete and consistent. The themes that were finally identified did indeed differ markedly from the initial coding scheme.

Negative case analysis: Willig (2001) and Glaser and Holton (2004) state that the researcher needs to actively look for negative cases that run counter to the emerging theory, and where these are found they can be examined to see whether the theory should be modified to accommodate them. This will allow the theory to become coherent, whole and well developed. In practice, the number of negative cases identified

in the current study was small, and where these were significant, they are noted in the detailed analysis.

Theoretical sensitivity: As described by Willig (2001), this is the process of asking questions returning to the data, and seeking further clarification or more data, in order to check for consistencies or opposites. Willig states that this is only achieved by the researcher becoming immersed in the data, and that interaction with the data should add to the researcher's emerging theory. The purpose of the current study was to examine the experiences of parents, without necessarily being designed to develop theories as such. An attempt was made to link the themes that were identified in the study to possible theoretical causes drawn from previous research, however.

Theoretical sampling: The researcher after carefully scrutinising the data that they have already collected and in the light of the categories that they have identified will need to go back to the data yet again (Glaser & Holton, 2004). This time they will be actively seeking information that can both support and attack the views that they have formulated. This is very different to the open method used in the earlier part of theory generation. Now the researcher is focussing on incidents where they can find supporting evidence for theory generation. In incidences where they find it adversely affecting their theory they look for the reasons this might be so (Willig, 2001; Glaser & Holton, 2004).

Theoretical saturation: This is the process by which the researcher needs to keep on coding and categorising until they exhaust all potential concepts (Willig, 2001). Willig points out that this is a potential goal rather than an achievable one. In practice,

although all the interviews were fully coded, complete theoretical saturation was not achieved due to practical limitations; further lesser themes may still remain to be identified.

Memo writing: is an essential and fundamental part of grounded theory. The process begins with the conceptualisation of the research question and active records are kept of every step of the process from this stage onwards. Glaser and Holton (2004) argue that memos allow the researcher to keep a record of the ideas and directions of insight that evolve from the reading of the transcripts through to the development of theory. They say that without memos there would be no definable track for the researcher to follow their progress from codes to categories, and that it allows the researcher to speculate and search for both conflicting and supporting evidence amongst the data. Memo writing and note taking were a fundamental part of the current study, tracking the process of analysis through all stages of work.

CHAPTER 4: METHOD

Participants

Five couples were interviewed for this study. Participants in the study were identified through word of mouth in Surrey, England. They were parents whose babies were premature, and had required a stay in the intensive care unit. Those who showed interest in the study were given the contact details of the researcher, and invited to participate if they wished.

The information given to the potential participants made it clear that both mothers and fathers would be interviewed. The only requirements placed on participants were that they must have a good understanding and use of English, that they must not be suffering from mental health issues, and that both members of the couple must be equally willing to talk about their experiences of preterm birth. The participants were therefore self-selecting for the study on the basis of meeting these requirements.

The couples interviewed were as follows (all names are pseudonyms):

Mother	**Father**	**Prem baby**	**Other children**
Caitlin Tree	Cary Tree	Christopher	Catherine
Mary McFoley	Michael McFoley	Marissa	
Rita Street	Richard Street	Rex	Randal
Anita Mulholland	Andrew Mulholland	Amber	Anna; Alexis
Terri Summer	Ted Summer	Tim	Trent

All the interviewees were relatively well-educated, articulate middle class people. All participants were over 30 at the time their premature babies were born, with the majority being over 35 years old.

Procedure

In order to gain as much insight as possible into mothers' and fathers' differing experiences and also their shared experiences of the preterm birth, they were interviewed both individually and together, with the couple interviews being conducted after both individual interviews had taken place. The structuring of the interviews in this way was done in particular to address two concerns on gaining information from interviews involving couples:

1. Within relationships there may sometimes be one member who is more articulate than the other in social situations. To avoid getting a biased picture based on the information given by a more verbally dominant member of the couple, the participants were interviewed both as couples and also as individuals. By seeing the participants individually, this gave both parents an opportunity to discuss their own perspective of the experience. It also enabled people to be as open and as frank as they wished without being inhibited by their partner's presence.

2. The couple interviews were conducted after each of the individual interviews had taken place to ensure that the shared account which was constructed between the couple was not overlaid onto the individual's experience.

The interviews were recorded on video, with the aim that the interview would be restricted to one hour in length (in practice this limit was broken for one or two of the interviews). A semi-structured interview format was used, which enabled the participant to tell their own story about their experience of premature birth, while ensuring that as much common ground as possible was covered between the different interviews.

The taped interviews were transcribed onto paper. Only the soundtrack of the tapes was transcribed; no effort was made to record the visual aspect of the interviews.

A week prior to the interview each participant was given a letter containing an explanation of the overall purpose of the study, the setting and format of the initial interview, and the fact that they would be asked to discuss their own personal experience of premature birth. They were also informed that the initial interview may lead to a request for more information to be obtained from the participant in a follow-up interview (in practice, no follow-up interviews were conducted). Participants were informed about what would happen to their data at the end of the research period, and that they would have the option of having their personal interview tape returned to them. The introductory letter also included the information that they had the right to withdraw from the study at any point during the initial interview, but that after they had completed their interview there would no longer be an option to withdraw. This was to ensure that the researcher had a reasonable opportunity to complete all interviews in a timely fashion, and that transcription and analysis effort was not wasted on interviews that might later be withdrawn. The participants also had the right to request that all information given to the interviewer by them would be returned to them if they so requested. It was pointed

out in the information letter that some distress could be experienced by the participants when recalling the events surrounding their preterm child's birth, and they were reminded that at any point they may terminate the interview for whatever reason. A consent form was included with the introductory letter.

This type of work meant that more than one person saw the interviews and transcribed data, potentially introducing problems with confidentiality. Therefore in the letter which explained the nature of this research paper there was an acknowledgment of the possibility of more than one researcher reading the transcripts, and that the transcriber had signed a confidentiality agreement. However it was also made clear that all participants' original names would be changed in the transcripts.

The guideline for the semi structured interview process was to ask questions about the following areas:

- Ask about the child who was born early: name, sex, birth weight etc.
- Was this their first baby?
- Was the baby expected to be early, if not how did it feel going into the birth?
- Describe the relationships with health professionals, in particular Midwife; GP; Hospital staff.
- What memories of NICU did they have? What memories did they have of the staff there?
- What were their memories and emotions regarding the baby?
- What were their memories and emotions regarding their partner during this time?

- What other family members, if any, were involved directly or indirectly, and what was the impact on the family?
- What was the impact on the parents as a couple?
- What was the social, economic, and emotional impact of the premature birth?
- What maternity leave/paternity leave was available, and what effect did this have?
- What was the reaction of friends of the parents?

Interviews began in July 2004, and were conducted in the participants' homes. As planned, no couple was interviewed before their individual interviews had been completed. Also following each parent interview, if the other parent was not immediately available for their individual interview the first parent was asked not to discuss their interview with their partner. This was an attempt to ensure that the second parent was actually talking about their experience as they remembered it rather than as a memory that had been overlaid by their partner's experience.

Each interview was individually video taped. These tapes were then transferred to individual DVDs. A transcriber, using voice recognition software, transcribed the spoken word into written format. The transcriptions were then printed out and sent back to the participants. Included with their transcriptions was a form that gave authority for the release of the tape transcripts and also recognition that the transcript was acceptably accurate. When participants returned their signed validation of accuracy forms the researcher began coding each line of print.

Unfortunately, two of the interviews, those involving Terri Summer, could not be transcribed, due to acoustic problems with the recording (the microphone being too far away from a very softly spoken person in an echoing room). However, some comments from these interviews that were clearly recalled by the interviewer were used, in particular where her recollection differed from the way in which her partner remembered the experience. Terri was sent a specific individual form to indicate her consent for her comments to be used in this way.

Coding and Labelling

After reading each transcript a number of times I was struck by the number of emotions each parent went through. This prompted my first coding decision: to code each line where some type of emotion was stated. When every instance of emotion was coded then I looked for some commonality amongst the emotions being expressed. Keeping in mind the importance of seeking conflicting instances I also looked for emotions that had little commonality with other transcripts.

Following the coding I started labelling. Labelling is a result of reading all of the words that have been coded and looking for categories to put them under. Having already made the decision to look at the emotions expressed by the parents this drove my labelling categories. It was at this point that I realised that I had set myself an impossible task. With over four hundred words coded in just the first interview and another fourteen interviews still to go, a change of approach was needed.

So I returned to the coding and established a much broader network of codes. For the Tree couple interview I restricted my coding to less than twenty categories. These ranged from the emotions of parents to codes such as help, certainty and size of baby. After completing the Trees I then used the seventeen codes that had emerged as a template for the other fourteen interviews. This worked very well and kept the coding in manageable proportions. Below are the seventeen codes used in the analysis of the interviews:

1. Baby's appearance	*"he looked like a little old man"*
2. Size of baby	*"I thought she is very small"*
3. Physical problems	*"he started to get really bad jaundice then"*
4. Emotions for baby	*"you do feel sorry for them that they have to go through that"*
5. Emotions of parents	*"well you feel a bit scared, don't you"*
6. Emotions for partner	*"we got very stressed with each other over it"*
7. Description of partner	*"she is not into the political issues"*
8. State of mother	*"I have got an autoimmune disease"*
9. Help/support	*"I had people bringing things in"*
10. Uncertainty	*"I am not sure whether she did or not"*
11. Certainty	*"I don't need any analgesia"*
12. Past Experience	*"because we have been married so long we have actually been through worse"*

13. Unit set up/Environment/Staff relationships *"we developed a rapport with her, in the short space of time"*
14. Communication *"he kind of said, oh, come back next week"*
15. Family concerns *"it was also routine with the other two children as well, to see that life carries on"*
16. Work *"I felt from my head of department that I was under pressure to get back to work"*
17. Positive/Negative aspects

The last category, Positive/Negative aspects, was used for comments where a negative or positive aspect of the experience was stated or implied, but no overt emotional response was expressed by the interviewee, so that it could not necessarily be inferred that the comment was emotionally significant. Statements in this category were very numerous. Examples are comments such as *"I didn't know the consequences of what could happen after my waters went"; "they had taken us round the unit before she was born, they had actually shown us round"; "I don't really remember my midwife, quite honestly"; "I don't understand about the reasons why they give you till x weeks and then you should have a baby"*. Inferences could be made from these comments that the speaker felt uncertainty; certainty; lack of communication or helplessness, for example, but these cannot be conclusive without a lot of supporting context, or a definite

statement by the participant. In many cases statements within this coding category could be coded under a different heading as well.

CHAPTER 5: FINDINGS

Themes

The mechanisms involved in moving from the coding groups to themes were varied. The most simplistic approach was to gather all the comments that were within a given code, and examine them to see if they formed a unified and consistent whole. The first coding groups to be analysed were those that had been numbered first: those to do with the baby's appearance, size, and physical problems. This was in a sense the simplest of the themes to emerge from the analysis: the comments regarding physical appearance turned out to be intimately tied up with parents' concerns about the baby's medical problems, for example. In this case, there were not sufficient differences between the comments made in these coding groups to justify separating them from each other, and in large part they ended up in the single theme of Baby's Appearance.

Other themes did not present themselves so simply. While some of the themes discussed below have titles similar to some of the original coding groups, the understanding of the themes, their emphasis, and the comments relating to them differ very widely from the original codings that gave rise to them initially. The coding category of communication, for example, gave rise with part of another coding to the theme of Communication and Relationships, with a specific emphasis on the parents' experiences of hospital staff that was not apparent in the original coding.

Another technique that was used was to look at all the comments made by a father, for example, in the "Emotions of parents" coding, as he moved through his interview, seeing whether similar comments involved similar states of mind or a consistent pattern of emotion that might indicate a theme. The interviews were also examined to see if specific patterns of coding groups occurred consistently together, with an attempt to understand what might be behind a related sequence of statements.

In some cases, themes that seemed initially to be complete and coherent in their own right were modified as other complementary themes emerged. A good example of this was the theme of Helplessness, which emerged quite naturally early on, in part because it was consistently signalled by parents using the word "helpless" to describe their feelings at certain points. However, when the important theme of Control emerged at a later point, it became evident that some issues of Control really belonged more accurately in the theme of Helplessness, and vice versa. These were also the two final themes that were most closely related, and further analysis was required to clearly delineate the separation between them, and even that they were separate themes. In the end it was not simply the content of the parents' comments themselves that led to the realisation of the separation of these two themes, but also the situations in which the different comments were made, and the different emotions that were related to them.

Although there were limited opportunities for collaborative working during the analysis, the value of the collaborative process was amply demonstrated during a conversation with one of my supervisors about the Control theme. When discussing how parents were in the position of having to ask permission to interact with their newborns, my

supervisor commented that parents must have been missing out on contact with their babies if they had to ask permission. This was a light bulb moment in the analysis, as that single comment immediately led to the realisation that many of the parents' comments were indeed about Missing Out, which became a major theme in its own right.

Below, the final themes that emerged from the analysis are described with background information on the types of comments that fit in each theme, and the emotions and situations that they relate to. Some reflexive notes are also included, in cases where a theme resonated particularly strongly with my own recollections and experiences.

Missing Out

The theme of missing out emerged from comments in all of the fathers' interviews. This is where the father feels that he has missed out on aspects of the experience of having a new baby, and was a theme which was of much greater significance for fathers than it was for mothers.

For example, Cary Tree mentioned that he probably didn't have the same access to his second born child because the environment of NICU meant that he had to be aware what his first born was doing when they were in the unit. He said: *"yes, I mean, as a result, you know, perhaps I didn't have the access to Christopher that I probably would have had in a normal birth environment."* He goes on to add: *"I saw him a lot, I didn't get to hold him a lot."*

Andrew Mulholland stated: "*then it was sort of, well, she's been out once today, really we don't want to move all her tubes so I tended to miss that bit. I felt a bit left out at times on that*". He adds: *"In fact, to start with I missed out because she always seemed to come out for Anita"*. As a consequence Andrew felt he didn't bond with his baby in the same manner as his wife: "*I suppose, I had bonded with her but not in the same way that Anita... had bonded with her*". *"I felt I'd missed out on some things because some things had already been done but I, I was working so I knew... that was part of the reason why I had missed."*

Andrew Mulholland talked about feeling that some staff members in NICU had taken activities and responsibilities away from him. He said of one nurse: "*because you used to go in to change, change Amber, and she had already changed her. She would take things off you. So I didn't trust her.*" He expanded on this comment: "*Well it was just a couple of times when I had gone in after school to change... because I thought Oh, I will go in and change Amber, and I found out that she had already been changed, so that was like... that was taken away from me. Just little things."* He summed up the essence of missing out: *"I felt like they have taken away one of my roles as the father.*"

The Missing Out theme is also present where Michael McFoley talked about his role of feeding the baby: *"as opposed to expressing and then bottle feeding her, which I used to do quite a lot of bottle feeding, which was enjoyable, which I sort of miss to a certain extent"*. Michael also talked about how he felt men were viewed in the NICU: *"I don't know, sort of general feeling, initial feeling of both places is, I don't know, it is, it is probably more to do with me than to do with them, was like men aren't wanted."*

Ted Summer also talked about feeling distanced from his child: *"Because... well I suppose in a way, being in the special care unit, being in an incubator as well, you feel that... a bit of a distance I suppose... between you. I suppose you can't bond with someone initially anyway". "Because you can't touch them that much."* He attributed part of this problem of bonding issues to the environment of the NICU: *"Even special care unit didn't... you don't... you feel there is a distance. You know, you have the incubator between you anyway, but you can bring them out but it is a controlled environment, it is not an environment where you can really bond".*

The only father who did not feel he missed out on interactions with his baby during its stay in NICU to the same extent as the other fathers was Richard Street. Richard was working at least an hour's commute away down the M3, when he talked about only seeing his baby in the afternoons, as he would be out of town each morning. His wife Rita asked him: *"Did you feel left out?"* Richard said in reply: *"I didn't feel left out, no..."; "I felt it was a good time to come..."; "you had better time... with, um...Rita and Rex. Then, there wasn't, you know, loads of activity going on, etc and..."; "Yeah, rather than... you know, things going on like bathing and feeding and... everything else."*

It seems very likely that Richard not feeling that he was missing out in the way the other fathers did may have been due to the differences between baby Street and the other babies in this study. Rex Street was born five weeks early, but he was six pounds at birth, and therefore significantly less in need of health care intervention than the other babies in the study. He did not require any form of ventilation, nor any leads or monitors. His parents were able to pick him up and hold him from day one of being in

NICU. Though there were major concerns about his feeding and bilirubin levels, and these contributed greatly to his parents' anxieties, they did not have an adverse impact on the degree of parent/baby contact. This is in marked contrast to the other babies, where the opportunities for parental contact were significantly reduced.

Fathers consistently commented on missing out with their newborns, from the birth right throughout their baby's stay in NICU. The theme of missing out did not appear nearly as much when mothers talked about their experience once their baby was established in NICU. However, with only one exception, all the mothers made similar comments about their first night on the maternity ward when their newborn had been taken to NICU. Mary McFoley said: "*Well it is like a nightmare. You are like going I can't believe this, I can't believe this is happening, you are like what... this is like, I can't believe that I am in a ward with crying babies.*" Rita Street described an identical experience: "*I ended up on the ward, you know, in the, in the maternity ward or whatever, and he was upstairs, and I remember I was just awake all night. Wide awake all night thinking... what has just happened, it was really odd. Just lying there reading a magazine listening to other babies crying thinking this is just... kind of not supposed to be like this, you know. Really weird*". Rita used the description "missing out" to describe the way she felt about not getting to hold her son in the same way that fathers talked about missing out with their newborns: "*Well I feel like I missed out a bit on... because I had... because I had him, so physically delivered him, and then I held him for a period of... you know, a few minutes, if that*".

Caitlin Tree had the same experience as well: "*I was very very upset, as I say, on the night, and I remember calling my husband and I was in tears, because I hadn't... I wasn't able to see him, it just seemed very strange that he wasn't...I was in this room all by myself, I had just spent, you know, the last nine months, and I had just gone through a kind of surreal experience of it all happening.*" Michael McFoley commented on Mary's experience: "*that is a really bad experience where you are separated from your baby but you have to share a ward with mothers with babies, yeah.*"

Reflexive Note. My experience of this was the same as the other mothers, and I know that the final straw that broke the camel's back for me in my stay in the maternity ward was the constant questioning of the ward staff as to where my baby was. There are three roster changes over the course of 24 hours within a ward. For the whole three days I was there, each shift change started out with the nurse asking me where my baby was. On day three I finally snapped and (given the nature of the meals we were being supplied with) I answered this inquiry with "I ate him". This was met with a cold eyed glare from my inquisitor; nary a smile nor a flicker of amusement crossed her face. When Stephen came in I told him he was not leaving without me and we exited the hospital together.

This period of being on a maternity ward surrounded by other mothers with babies was made much more difficult and distressing by the length of time that mothers had to wait to see their babies, or even receive a photograph of them, following delivery. Though a photograph was often promised to them when they were in the delivery suite there were two mothers who didn't actually get this picture until many hours later. When mothers did get to see their babies, it was usually through their own efforts and those of their partner, rather than because the hospital staff arranged it. This experience of not getting

assistance is reflected in the account told by Caitlin Tree. I asked her when her son was born and she told me that, "*He was born at midday on the [delivery date]... And I didn't get to see him until... on the [next day], at seven o'clock in the evening. And that is because my husband got me in a wheelchair and wheeled me up there. There was no midwives available at all to, to do that for me.*"

Mary McFoley demonstrated a robust approach to being a healthcare consumer throughout her experience. Her brand of proactive behaviour was also evident in how she dealt with getting to see her baby after it had been transferred to NICU. About eleven hours post delivery she decided she had waited long enough and asked to be taken to NICU to see her baby. The nurse who was in charge of her care informed her that she needed some analgesia first and asked whether she hadn't got a photograph of the baby. Mary's response was: "*I said to her what, I said, a photograph, you are joking, and I said I don't need any analgesia, I said can someone just push me to the special care unit. So a very nice care assistant came in... and off we went to the special care unit in a chair. Which I walked back from.*" Both Caitlin Tree and Rita Street also requested to see their babies but were told there was not the staff available, or in Rita's case a chair available, for them to be taken up to NICU. Rita Street's reaction was much the same as Mary's: "*Um, I just demanded that I see him I think. I kind of got a bit stroppy. I seem to remember getting a bit stroppy*". Eventually the staff caved in and brought him down to the ward very briefly then took him back to NICU. Caitlin, on the other hand, didn't get to see her baby until more than a day post delivery. Terri Summer was not in a position to be concerned about seeing her baby in the first 24 hours because

she was very ill following delivery. In fact it was at her husband's insistence that she was taken to NICU to see Rex.

Reflexive Note. What really stuns me about Mary McFoley is that she states she walked back from the NICU having had a caesarean not more than eleven hours previously and without the benefit of any analgesia. I personally took my first trip to NICU in a chair and came back in one. I made sure I walked after that because it was the only way of getting up there; as the other mothers found there were never sufficient chairs or staff to take you. Also when it came to analgesia, the after effects of the caesarean were not pleasant and without analgesia I certainly wouldn't have been able to move. In my defence I demanded to see my baby and was taken to NICU at three o'clock in the morning after delivery at 11.55pm that night. But this not having analgesia should give you an idea of this woman's strength of character.

Helplessness

Another major theme that was obvious from the majority of the interviews was that of helplessness: a feeling of not being able to influence or control outcomes. Again this was an area where fathers consistently expressed these feelings to a greater extent than mothers did. All the fathers talked about moments when they realised they were unable to change events, the feeling of being helpless and not knowing what they could do, and in many cases this overlapped with their feelings of missing out. Some fathers talked about their frustration, whether this was with the environment of NICU or their sense of helplessness in relation to aspects of their child's treatment or health status.

Reflexive note. From my partner's perspective he says that of all the emotions that he felt through the whole process of Fenn's stay in hospital, a lot of them have faded. For example, it was not until I reminded him of it that he remembered the seemingly constant alarms from the monitors attached to Fennec, about which we both initially felt a lot of anxiety. The one thing that sticks in his mind with undiminished clarity, however, is the time immediately after Fenn was born, with lots of sound and fury and activity going on, me lying on the table semi zonked but still in lots of pain from the caesarean with somebody sticking needles in me to sew me up again, and him feeling utterly and completely helpless, with two things that were desperately important to him, me and our new baby, over which he had no influence for the better. He wasn't thinking specifics at the time, but my health and recovery, and Fenn's health and recovery, were things that he was helpless to influence for the better, and this was a situation that he found extremely disturbing.

Andrew Mulholland talked about not knowing: *"it was going in there not knowing what I could do but didn't want to leave her"*. He talked about feeling: *"totally drained, totally shocked, not sure what was going to happen, didn't want to leave..."*. When their baby was very poorly he talked about his involvement with his job at that point because as he pointed out: *"I think it was something I understood, it was something that actually... it was something that when I, when I get down to it, because when I coach rugby I tend to analyse what's going on, I tend to look at it, and it was something I could analyse, it was something I could put right... whereas Amber being prem there was nothing I could do, I could listen to what the doctors had to say, I could talk to them about it... and, um... you know... there was nothing I could do, I couldn't put anything right."*

In Andrew's case, it was clear that the areas where he felt he was missing out overlapped with his feelings of helplessness. He made many references to the fact that he *"feels like a spare part"; "I don't feel there is anything I can do"; "I didn't feel I, I was actually doing anything helpful with baby"*. And again: *"I'd sit there, but there's nothing I could do because she was in the incubator"*. By the third week Andrew Mulholland found it hard to keep going unto NICU. He stated that it wasn't because he didn't want to visit baby, but because *"I just felt like a spare part, I didn't think there was anything I could do."* And he went on to say: " *I... I get a touch of her, I get hold of her, and then, then I, let them get on with it, and in some ways that might sound callous but it was just I didn't feel I... I was actually doing anything helpful for Amber at that time."*

An example of Ted Summer's sense of helplessness was when he witnessed his baby having a nasogastric tube inserted: *"Well then it was having the tube put down his throat and him crying and, and being really distressed. I felt that..."* and he added: *"It was... I suppose you just felt so helpless really."* He thought the environment of NICU had an impact on a parent's sense of control, saying: *"Yeah, they are out of your control. Even special care unit didn't... you don't... you feel there is a distance."*

Cary Tree talked about the contrast between how he usually copes with everyday and work situations, and his feelings around his baby's stay in NICU, in a similar manner to that in which Andrew Mulholland had contrasted being able to *"put right"* his rugby coaching against his helplessness over the situation in NICU: "*I certainly, I felt helpless. I am a pretty confident self-reliant individual in my own sphere of engineering and stuff,*

and this was a completely new environment for me, um... I, I feel I am okay in dealing with most situations but this was one that I knew I needed people to help me."

He also touched on his feelings of helplessness when he felt his baby might never come home from the hospital, although he referred to this in an oblique manner, as he tended to do with many areas of significant emotional content: *"you concentrate on where you are going to be in a little while when you get Christopher home. And of course there, there were periods certainly for me when I saw Christopher certainly in the early days, that I, I, I doubted that that would ever happen..."*

Richard Street didn't appear to have the same feelings of helplessness as the other fathers mentioned, which again may be related to Rex's relatively uncomplicated stay in hospital. Rita Street, however, talked about her feelings of helplessness and distress during the thrice daily heel pricking of Rex's feet to gain enough blood to analyse his bilirubin levels: *"Just that they were causing him pain. And there was nothing I could do about it, and it was really... wasn't it. That was horrible."*

Caitlin Tree also talks about feeling helpless regarding caring for her new son. She says: "*I was... more emotionally upset because... because I wasn't able to do anything for him. Because I was helpless.*" She also refers to helplessness again when she talks about how she was supposed to be taking care of him: "*Definitely, definitely a sense of helplessness. I wasn't able to care for my child, he was supposed to come into this world, I was supposed to deal with this.*" This feeling of helplessness is also mentioned when she talks about sitting by his incubator in NICU during the three days they weren't

allowed to pick him up. She says: "*Well, you know, I just felt totally helpless. Just that, that, and that is where I spent my time was just sitting there looking at him.*"

After Cary Tree had told me: "Y*eah, I certainly, I felt helpless*", I asked him what about the situation led him to feel helpless. His answer was: "*Well I realised that I, I had to rely heavily on professionals, because I realised that this was something that I couldn't deal with my... on my own.*" So this being reliant on others added to a sense of helplessness. His way of dealing with this was to seek information: "*I didn't think it was out of my control because I felt I could, um, I could start asking questions, and I could take it on board, I can, I can rationalise even though I mean it, it is a stressful situation, I knew it was important for me to be alert, to be... you know, to concentrate, to think, and to be aware of what is going on, and, and to make sure, you know, for my part that I was doing the best for Christopher.*" Cary's thoughts on his feelings of helplessness and how he managed these is closely bound up with the next important theme, that of control.

Control

Control as a theme arose largely from the multitude of comments parents made when talking about the difficulties of trying to take a full and active part in caring for their babies in NICU. It is not surprising that control is an issue. On the one hand, the prem baby will require extensive medical intervention from hospital staff, and it is the staff who will ultimately be responsible for the decisions surrounding the majority of health care issues. On the other hand, the parents have a natural desire to take care of their

child as they would any other new baby. Control is a very difficult balance to get right in this challenging context. The theme of control was widespread in the interviews, and overlapped with issues surrounding the environment of NICU and communication, as well as being related to parents' feelings of helplessness, and also to fathers' feelings of missing out.

In the course of a normal term birth where there are no significant medical problems, issues of control will rarely arise beyond the delivery itself. During delivery, parents may defer in decision making to medical staff, but beyond that the parents are in control of the situation, and are fully responsible for the care of their newborn, particularly after leaving hospital, which is more likely to be shortly after the baby's birth. Issues of control arise in the case of a premature baby in NICU, however, where medical decisions and interventions may be required for a period of weeks, or even months after the birth, and this inevitably reduces the amount of control the parents have over the situation.

Although lack of control is partially related to the theme of helplessness, there were distinct qualitative differences between the comments parents made regarding their sense of helplessness, and their issues around control. Unlike helplessness, which is where parents recognised that a situation was beyond their ability to deal with, or even that potential outcomes were beyond anyone's influence, control issues arose where there was a question about who was responsible for making decisions. Parents found themselves feeling that they had to ask for permission to take care of their baby, for example, or felt that they were simply not allowed to do an aspect of their baby's care.

All the parents acknowledged this to a greater or lesser extent. Particularly early on, immediately following delivery, when the parents were trying to come to terms with the premature birth, and trying to get used to the environment of the hospital and NICU, several of the interviewees made a reference about feeling that they or their partner or baby was in the right place; that is, they recognised that the hospital was the right place or the safest place for them to be. This implies that the person talking feels that they are going to get the best treatment or their survival or well being is bound up in the hospital. In these situations, parents often expressed the fact that they were happy that the hospital staff were in control of the situation. A comment from Richard Street: "*Yeah, I was worried, but, you know, you were in the hospital so you are in the right place*". Ted Summer: "*because he was being looked after well in hospital.*" And again: "*So um... but I, I think he was well cared of... cared... cared with at the hospital, so that was fine.*"

Michael McFoley mentioned: "*just relying on the professionals to sort of make the call.*" And Richard Street: "*I... I... you know, was in the hands of the doctors and they were saying that, you know, it was, it was fine, he was in a bit of difficulty but... he would be coming out in time so... no problem.*"

Cary Tree: "*I felt we were in the hands of complete professionals who I have confidence in.*" He went on to add: "*...so I, I, I felt that, um, I felt we had the right people there. That is what I felt initially at the time.*" Cary talked about having to rely on the professionals because what was happening to his baby was outside his sphere of knowledge: "*this was a completely new environment for me, um... I, I feel I am okay in dealing with most situations but this was one that I knew I needed people to help me.*"

All of these comments seem to back up the belief that families will automatically give health professionals their fullest trust. Also at some level that trust gives the health professional the ultimate right in making decisions. Caitlin Tree: *"When they first initially took him away, in the ward, I wasn't at all concerned. It didn't seem, seem to concern me at all. And I wasn't really worried about his welfare, because I felt he, he was in safe hands, I, I did feel comfort from the fact that he had gone off to, to where he would be, he would be handled better than, than with me."*

In some cases this trust may have gone too far. Richard Street commented on having hospital staff talk to him about treatment for Rex in NICU: *"Well you don't know what the options are So you say... Yep".*

The point at which problems arose with issues of control was where there was no immediate medical emergency such as that surrounding the initial birth, and it was then that parents started to run up against the boundary between the hospital staff's control and what they perceived to be areas where they could take responsibility themselves.

Caitlin Tree referred to being allowed to touch her son, *"I think it was the third, I think it was the third day that I was actually allowed to touch his skin with my skin. Before that I don't think I, I wasn't allowed to..."*. In this instance, Caitlin in fact specifically referred to the control exercised by the NICU staff, in terms that indicated that she did not resent this: *"it was a completely controlled environment, which was, which means it was, it was very controlled and it is not, you know, it is not how you want it to be but it is as good as it can be, they were watching. And just checking. And I, you know, I can*

understand that because the, the babies are there to be monitored for... and they are under their care".

However, many questions around control were less clear cut than this, and seemed to be more a result of parents' reluctance to do something wrong than NICU staff's active desire to reduce or remove parental decision making. A parent may feel unsure about the safety of their actions, and may as a result defer decision making to NICU staff.

The Mulhollands referred to this sense of control in the unit, and feeling the need to seek permission to interact with their baby. Anita said: *"I do think as well initially we always used to wait until we were told we could do something".* And again: *"I remember one time we were sitting there, and they said well, are you going to take her out. And I go Oh; she said don't wait till, don't, you know, don't wait to be told just, you know, when you come in you can take her out. And we were going Oh, right, okay. And, and we were waiting for permission..."* Andrew stated: *"you are always looking back towards the um, whichever one was in the room or the woman who was on the desk, are they watching me, am I doing this right".* I asked Andrew if he felt they were in control of what was happening on the ward: *"No. Never, never did actually".*

Ted Summer felt that the lack of control added to the distance he felt from his newborn, and was related to his feelings of missing out on contact with his baby: *"Yeah, they are out of your control. Even special care unit didn't... you don't... you feel there is a distance. You know, you have the incubator between you anyway, but you can bring them out but it is a controlled environment, it is not an environment where you can*

really bond." And again: *"it is not really until you get home that you can actually bond."*

Mary McFoley talked about the staff in NICU attempting to restrict the number of times she held her baby, when as she saw it this restriction was no longer appropriate. As she pointed out, her baby had progressed to the point where a number of leads and monitors had been removed: *"What they want is, at the beginning they want you to be quite hands-off, and then they want you to take over in TC [Transitional Care], whereas what we were doing was I was going in, I used to containment holding, I would, I would, once the stuff began to come off her, which it did remarkably quickly, like IVs and stuff, I would then start taking her up and doing kangaroo care her, for hours, not moving her, not stimulating her, just do... I mean I am fully aware of how to behave, you know, it wouldn't be right to... I wasn't doing the kind of, I am going to play with her".*

The Trees expressed a number of issues around control, not all of which related to their baby's medical care in NICU. These issues included the choice of a caesarean delivery, for example, as Caitlin stated: *"they just thought it would be better for me to, to go for an elective caesarean. Rather than go through the, the worry and pain of a, of, of a natural birth. It wasn't even really discussed, a natural birth".* Cary was even more definite about this incident: *"I think there is a choice but I don't think it is relayed to you as a choice, I think ...the preference from the professionals within the organisation is that you should go for an elective caesarean afterwards and I think you have to be a fairly tough character to go against that recommendation".*

Caitlin also talked about the controls around visiting: *"they were quite strict about the, the number of visitors that you were allowed per baby. And if they weren't, um, direct family they were quite strict about the um, the amount of people that were allowed round the, around each cot at any one time".* This is definitely a control issue because the power of making a decision over who and how many can visit is in the unit's hands. Again this is an example of where the staff's desire to control the environment runs up against parents' desire to have free access to their baby for themselves, family and friends.

The McFoleys gave another example of the ways in which parents felt constrained and controlled, when they talked about breastfeeding. Michael said: *"they have got a breast-feeding counsellor up there who is obviously advocating breast-feeding but, you know, reading between the lines, it is not that encouraged. I mean it, it is not encouraged as such, I would say."* Mary then explained the process to me. In order to breast feed she had to book in advance for a specific time. Once booked in she then had to make sure that she was in the unit at the precise time. On one occasion she was less than 10 minutes late getting into the unit to find that they had already bottle fed her baby. Michael believed that the NICU staff preferred to bottle feed because: *"Well I mean it is easy, easier to, to, you know, go through the mechanics of tube feeding rather than putting Marissa on the breast and it is quicker".*

In the same way that Mary McFoley and Rita Street had been most insistent about getting to see their newborns as soon as possible, these two mothers seemed to have the most confrontational interactions with hospital staff over control issues. Rita's run ins

with staff were limited by Rex's relatively unproblematic stay in NICU, but she gave another example when she was faced with a nurse who wanted to use a Venteuse during Rex's delivery, and: *"I started to get a bit stroppy"*. She added that the nurse stood there with the Venteuse, and: *"I'm like, you're not doing... you're not having... do you know what I mean? I am not having this."*

Mary McFoley commented that the NICU staff were very keen to control their environment, and that this caused friction: *"We freaked them out because we went in there and we spent hours there are from the get go, which isn't what they expect or even want"*. She also talked about how the staff attempted to redirect her away from the unit: *"they would say to you Oh, are you getting... you know, you are not taking any time off to get everything ready at home,... you know, it was more relaxing for me to sit there doing kangaroo care with the baby and almost falling asleep. That is much more relaxing than rushing off home and, and trying to tidy up the house. Ridiculous."*

Another of Michael McFoley's comments referred to a staff member that the McFoleys did not get on with, and in relation to whom they had mentioned issues of control elsewhere in their interview: *"the most senior woman on that maternity unit was not particularly pleasant or flexible, I mean I don't know whether she had, um... something to do with the slowness with checking Mary out on the Friday afternoon, it took about four hours, and documents seemed to be missing"*. This is an interesting comment not just because of the difficulties they had with one particular staff member over control issues, but because of Michael's readiness to interpret their slowness in checking out to deliberate malice on the part of the senior nurse.

Guilt

When mothers talked about what it was like for them having a premature baby, in contrast to fathers, they were more likely to use the word 'guilt' than the phrase 'missing out'. Feelings of guilt were expressed almost exclusively by mothers rather than fathers. In particular, the mothers who already had children at the time of the premature birth talked about guilt in relation to their parenting of their older children. Anita Mulholland said she had thoughts about being a terrible mother: "*My problem was that Alexis was at school, Anna was only two and a nightmare, I couldn't go for long, so I did find I was palming her out to... to others, the whole time. And of course I was thinking, here I am, terrible mother, having to palm them out, they have got, they have got babysitters, because I was there, I only missed... one... day of visiting*". The words Anita used to describe herself as a mother are *"bad"* and *"hopeless"*. She says she felt "*so hopeless, you know, I can't even look after my own children.*"

For Anita, the reason for feeling guilty in the evening arose from the belief that, "*because you know, going out in the evening you... I suppose in theory was, you know, that treat, so having... anyway you usually go out in the evening to enjoy yourself.*" She also talks about the frequency of having the children cared for having an impact on the way she felt about it. "*I mean, you know, normally, you know, the odd babysitter was sort of, um, something but when they were having somebody, yeah, somebody every night.*"

Caitlin Tree expressed a level of guilt that was beyond that seen in the other mums. This was over a number of subjects, but in particular how she felt about the decision over selecting a date for her caesarean delivery. Despite the fact that she tried to tell the maternity team that she believed they had incorrectly estimated her baby's gestational age, she did not place the responsibility for the decision on the hospital, but rather felt she was the one to blame: "*he had come out, as I say, I think, in my view too early, and we had got it wrong, and I was almost kicking myself for it.*" "*Yeah, I think... I certainly feel guilty about the whole, the whole thing.*"

Reflexive note. This made me really think about what it is like for mothers who don't feel confident about their ability to make decisions for themselves especially in the face of strong professional opposition. Even though her maternity team failed to listen to her, Caitlin still said they did fine by her, which is not a conclusion that I reached as an external observer.

Caitlin stated: *"I am always at the hands... at the mercy of the medics,"* and: *"they have always come out trumps with me"*. In practice, Caitlin had taken responsibility for the decisions taken against her judgment by medical staff, and felt guilty about the outcome as a result. During her interview there were several times when she said she felt it was her fault about the decision to bring her baby into the world early: *"I do feel as if it was a little bit my fault that he... that I hadn't stood up and, and made, made myself a little bit more..."* and: *"I was being selfish, I do feel like I was being extremely selfish in so far as that I, I felt... I was being selfish that I wanted him to come out on [the day], I had had enough, quite honestly"*. Even though part of the reason for wanting a controlled

birth was because it lessened the impact on her family, even this caused her to feel guilty: *"I felt I was being selfish again by going for elective caesarean so it was all... you know, all sorted out for me, I could sort out childcare for her, I could sort out... I could, I could sort out clothes, I could sort out his bedroom, I could sort... so everything was ready for the [delivery date], everything was kind of geared for that day and it was all perfect for me and the family."* Because as she argues: *"it wasn't so perfect for him, and I do feel as if it is, it is partly my fault, because he, he, he needn't have come out that day. He could have come out later, and he may, may not have had to go through what he did go through."*

There is also a feeling of guilt about leaving the baby behind in the hospital. Again this seemed to be a more prominent feeling experienced by mothers who had more than one child. Anita Mulholland talked about it being difficult to leave her baby in NICU. But as she explained, the practicalities of having small children at home meant that she had to be there: "*I did torture myself about the fact that, you know, I wasn't giving them enough time. And how am I really going to affect them, and how will they come out of this*".

Caitlin Tree also described how she felt about leaving her baby in NICU because she had another child at home who also needed care and attention: "*The day I came home I think I cried for three hours. It was just horrible. Coming home without a baby. It, it was the most horrible experience, but she needed me, as much as he... she probably needed me more than he did because he was being cared for.*"

Caitlin also experienced guilt about her decision to bottle feed rather than breast feeding "*But there was a little bit of pressure applied in those initial few days, and a little bit of guilt when, when they did ask you, how are you feeding, breast milk or formula, and, you know, when it was formula it was oh, okay and just going off and doing the thing, but once, you know, that was established it wasn't an issue then.*"

Communication and Relationships

With the normal experience of birth being thrown into upheaval by a premature delivery, and the consequent problems in having to adapt to a strange and often frightening situation, it is not surprising that communication, and how it was managed, was a common theme in parents' interviews. Communication, both positive and negative, and its role in how parents found the experience of having a premature baby, appeared in many contexts in the participants' comments, in particular in the area of communication between parents and hospital staff, and it was clear that the quality of communication could have a huge effect on how parents viewed their experiences.

Andrew Mulholland gave an example of a very negative incident of staff communication. Their baby had just had a brain scan and the Mulhollands were informed quite bluntly, and without any explanation or preparation that *"she could be brain damaged"*. Andrew was adamant that: "*the Doctor shouldn't have told us what he told us.*" He added: "*when they did the brain scan and we found the, the, the two bleeds... um... the shock of that, and when you are told by the doctor, oh, she could be brain-damaged, and you were thinking Oh, she could have hydrocephalus, or she could*

have this, this, or this, and going into total shock again." In contrast, a second Doctor later spoke to the Mulhollands: "*I remember him saying to us...the neonatal brain, it will find other pathways to work, she could be, as I've seen other children, they walk in, they talk, they do everything and they walk out and they go off and play sport, there could be absolutely nothing wrong with her" "So, it was kind of, oh right, that's tot... that was totally reassuring."* The contrast between the way Andrew felt following the two different incidents of communication shows how the way in which information is given can affect a parent's emotional state.

Reflexive note. I didn't have to think very hard to recall what this experience felt like for me. I vividly recall my visit to a geneticist at Auckland Hospital 23 years ago with my then partner, where a doctor was busy giving us a talk on the possible outcomes of the genetic disorder that we had just been told my partner had inherited. I remember that he mentioned it was an Autosomal Dominant gene, but whether he gave us any more useful information than that I can not recall. Because what I do remember with great clarity was his parting request: "Oh, before you die could we please have your consent to remove your brain for autopsy, as it would be beneficial for ongoing research purposes". There probably was more useful information that was given to us during that appointment. However this is the one thing that I clearly recall even 23 years later. It is when parents are in situations where their emotions are already in a heightened state that staff should be aware that parents can develop selective hearing.

Similarly, Caitlin Tree gave an example of the difficulties of effective communication under stressful circumstances, when she was looking at her baby in NICU for the first time: *"he is attached to all this equipment, they are making beeping sounds and, and*

the, the nurses did explain what, what each wire was, what it was doing, but I can't say that I can remember what she said to me, it was all a bit of a, bit of a blur quite honestly." Caitlin in particular mentioned the difficulty of effectively communicating with staff when she did not feel that she had the knowledge to ask the questions she needed to: *"I have not really been, um, educated enough in that... in that field, to be able to question it further. So yes I would question it further if I felt I had got more information about it".* This added to Caitlin's difficulties in striking the right balance of control with NICU staff.

Andrew Mulholland gave another example of the positive effect of good staff communication, in talking about coming to terms with his baby's apnoea attacks. Here the staff had explained: "*she is not on a ventilator... she actually breathes on her own".* This communication led to Andrew having a sense of relief: *"that felt quite good after that, I feel relieved."*

From Cary Tree's perspective the unit could improve by giving some thought to how and where they give information to parents, "*I think by, by allowing you to sit down and, and for it to be more, more of a, an interactive environment, rather then, you know, excuse me I am a very busy professional, I am trying to make time for you but I want to get on. I thought if you are sitting in a different, if you are in a different environment away from what is going on around you, you could be more focused, concentrated, you can pay more attention than... and as a result get, get more from, from the experience.*"

The McFoleys found good communication so important that it even affected their choice of healthcare professionals. Michael McFoley talked about why they stayed with their obstetrician rather than seeing the problem pregnancy specialist: "*we sort of developed a rapport with her, in the short space of time, I think we only met her the once, I don't know, maybe for an hour or so ... despite her not being the problem pregnancy specialist, in fact she actually tried to dissuade us from going with her... but we said no, we... we just found that the rapport was good, that she actually listened to what we both said, particularly Mary, and not only did she listen but she responded and that was, yeah, very important*". Mary McFoley said the reason she didn't want to see the problem pregnancy specialist was because: "*I think she was doing her best, but she didn't have the same skills, people wise, as [name] has got, although clinically I am well able to believe that she is very good.*"

The McFoleys also had issues with male obstetric staff who were seemingly not able to communicate with women. Michael McFoley said: *"I would advise every woman to actually have a female consultant obstetrician, because clearly I got more feedback out of the male consultant scanner than Mary did..." "And he seemed to pay more attention to my questions."*

Moving from the area of communication, positive and negative, to the broader topic of the relationships that parents had with the healthcare staff with whom they came into contact, a number of highly consistent comments again emerged. As the studies by Affleck et al. (1991) and Redshaw et al. (1996) previously found, parents came into contact with a large number of healthcare staff, not all of whom were familiar with the

parents' or their baby's history. This is certainly something that I experienced following Fenn's birth, with every nurse on the maternity ward asking me where my baby was at the start of each shift. Given that you feel remarkably tearful and flat with a baby in intensive care, having to explain where he was every eight hours did little to reassure me that these people knew what they were doing.

This was certainly more of an issue outside NICU, in the maternity ward itself and with midwives, but mothers in particular described the lack of continuity of care from staff as being an area of their experience that they felt was difficult. In respect to the maternity ward there were few if any mothers who felt enriched or supported by their time there.

Caitlin Tree talked about the lack of continuity with maternity unit staff: *"I don't really remember anybody, seeing, seeing anybody for more than five minutes at a time, there wasn't really any intimacy there at all."*

Cary Tree identified other areas where he felt the lack of relationships was apparent. He talked about the maternity unit, and how continuity may be a problem for the staff there in the same way it is for the parents: "*even the, the nurses have no relationship with each other, they may not even know each other, so I feel very much for them, so a lot of them are working in a strange place with, with, with colleagues that they don't know.*"

The Streets' comments on the relationships in NICU were generally positive, however like the other parents they felt the continuity of care with rotating midwives was not necessarily the best way of dealing with things. Rita felt that she had a good relationship with her Doctor, and said that one reason she felt satisfied with him is that she saw him

consistently every second visit. When she went into labour, on the other hand, she saw a midwife whom she had never met before who stayed with her throughout her delivery, past the end of this woman's shift. Rita describes her as lovely, however she ends by saying: "*but there... no real continuity.*" She goes on to talk about the fact that she had three or four different midwives who came to do home visits, and again she said: "*I had no continuity there either because I was seeing midwives from different districts.*"

Michael McFoley talked about the impact of many different staff all giving their opinion about particular facets of care, specifically regarding breast feeding, "*the problems we have had with getting Marissa to breast-feed after coming home and sort of, you know, inevitably you, you end up with, if you have four or five different nurses on a day, potentially you have four or five different feeding techniques with a bottle, you know, and to sort of overcome that is very frustrating, particularly, you know, mainly for Mary.*"

In contrast, Andrew Mulholland specifically mentioned the continuity of care in NICU as a positive compared with the other areas of the hospital. He found being there when shift changes occurred meant he saw the same people at the beginning and ends of their shift; he witnessed the exchange of information and felt reassured by this ongoing stream of communication.

Words that were used by parents to describe the staff with whom they had good relationships included: *"competent"*; *"able to give good advice"*; *"confident"*; *"friendly"*; *"helpful"*; *"willing to talk"*; *"reliable"*; *"supportive"*; *"able to step outside*

the NHS procedure"; and, from Mary McFoley, *"not averse to bitching a bit about people we weren't happy with"*. Only the first two or three of these terms can be directly related to how good the parents perceived the staff to be at their jobs. All the rest are directly related to how much of a personal relationship the parents were able to form with them. It would be a mistake to see Mary's statement about bitching in a disparaging manner, because what this staff member was doing was allowing parents to talk about their concerns over other staff. Similarly, although there were some comments about staff whose professional judgment parents did not trust, the majority of negative comments about staff members used words such as *"strict"*; *"controlling"*; *"soldierlike"*; *"intimidating"*; *"regimented"*; *"aloof"* and *"scary"*.

The likely reason why parents talked in these terms was expressed by Andrew Mulholland, who talked about the head of NICU and how she chose to run the unit: "*Although that is not the way Mica ran it because it seemed to be a family... family thing, wasn't it.*" He felt that she ran the unit this way because if it was run in a family orientated manner then the child automatically benefited. He described the unit on the whole: "*I think the thing was as well, at times, it did become like an extended family and there were people you could talk to there, and you talked about... you could talk about, you could talk about different things as well*". Andrew also described the NICU staff: *"for them, they become kind of the family, but then they have got to switch off and become kind of another family and everything else..." "... I mean it was the support, there was a really good support system there so you always felt comfortable there."*

Staff fitted into the positive category where they exhibited traits of family; that is they had the ability to talk about issues relevant to the family, they recognised outside events were pertinent to the ongoing functionality of the family, and they were open. Andrew Mulholland felt that those staff who didn't operate as members of the family in this way were there because it was a job, with a job description and an income. Anita Mulholland described the staff who did not operate in this way: "*there were some that were... purely orientated on Amber. And the well-being of Amber. I was a bit of inconvenience, I was a bit in the way. And there were others who were totally for both of you as a, as a unit. Um... and I did... there were times when I used to dread going in and think who is looking after her today. Because you would look at the name on the board and go oh... And other times you would go oh yes!*" She described the way some staff made her feel: "*I wasn't important. I wasn't relevant to them looking after Amber.*"

Medalie and Cole-Kelly (2002) identify the functional family as including those people who deal with the everyday affairs of the patient and the family. Using this definition, people who performed different functions within the family structure during the course of the premature baby's stay in NICU would include those staff who were actively involved in the day to day care of the baby. It is not surprising, therefore, that parents described staff in terms that could equally well be used to describe family members, rather than just talking about their levels of professional competence.

Baby's Appearance

One obvious difference between the experience of having a premature baby and that of having a full term baby is simply that of the baby's sometimes quite dramatically different appearance. As reported by Raeside (1997) and Lindsay et al. (1992) one of the greatest sources of stress for parents is the appearance of a fragile, sick infant.

Most parents when looking at their premature baby were shocked by its appearance; the following comment being from Anita Mulholland: "*I looked at her and I thought she is just like a skinned rabbit. I mean I had never seen a prem baby. I had never seen a baby one, that small and two, so prem, and she was just bright red.*" In tandem with this, the parents also had fears and concerns about picking their babies up, as Anita went on to say: "*you thought they were just going to sort of break"; "because it is something so... small, and it shouldn't be on the outside. It should be sort of on the inside still.*"

For Andrew Mulholland the thing he remembers is the size of his baby: "*just seeing the size of her, a bit concerned and I think it was looking around and seeing other boxes there that's... that's when I started to think about it and just hoping that she wouldn't end up there*".

Caitlin Tree talked about first seeing her baby via a photograph: "*Well I have got a photograph of him upstairs with all his bit of wires. Absolutely horrified. Horrified and, and frightened.*"

Michael McFoley recalled seeing his baby for the first time in the NICU: "*I immediately thought a Biafran baby. Because you know, sort of almost like skin and bone,*" He went on to say that the first time he was able to pick her up he was thinking: "*I suppose how, how fragile she was, and how sort of dependent she was on everyone, particularly the staff there but, you know, sort of thinking, you know, further ahead, well she is going to be sort of fairly dependent on both Mary and myself.*"

Ted Summer clearly remembered the size of the baby not being what he expected: *"I suppose just, just the size, it is not sort of what you expect when, when you have a baby, you expect a big blob, don't you..."* He described what his baby looked like: *"they sort of have like baggy skin, on their arms, like just, it is just bones but it is sort of just baggy. Um, and... yeah, um... sort of a bit of, a bit of hair on their body as well. Um, and very pink, but just I suppose... just the lungs they are sort of, they are... sort of inward, inward a bit, yeah."* Even now five or six years later this dad said when he sees the video of his first born: *"well, you know, like it still, still makes you cry when you see it on video."*

Rita Street talked about her first view of her baby: *"I just took one look at him and thought: God, he is really squashed."* ... *"So I kind of just looked at him and thought: oh. And just... kind of... you know, I don't, I don't know, I was just... it was a shock thing I think really.*" Her memory of him is that he didn't look like a baby: *"it was not like he was a tiny little... you know, thing. He looked like a little man actually. He did just look like a little old man".*

For Richard Street, at least, the relatively large size of their baby was a positive comfort: *"in that room there were, um, some twins that had been born prematurely and they were, you know, really really small. And there was a couple of children that were really small so... it... you kind of felt that things weren't too bad because, you know, our child was... of a reasonable size, he was a good size, you know, he was six pounds and um... just didn't seem as traumatic as... the other parents were going through, so it seemed... you took some comfort from that, you know".*

Trying to gauge the health and condition of their own baby by comparing its appearance with the others in NICU was a common comment, particularly among fathers. Cary Tree said: "*I can remember the babies in the other incubators and yeah, you do, you notice them all, I did. You sit there and you look at... I don't know if there is some morbid feeling of how is my baby doing with, you know, compared to the others, maybe that is what is going on, you know, how, you know, how sick is Christopher, can I do a, a visual comparison and get comfort from that.*" He talked about the obvious down side of this, "*that is okay if you are going in the right direction, if you are going in the right direction that is fine, but if you, if you see something and you... and it doesn't look right you could, you could make all kinds of assumptions, and you could be wrong.*"

Ted Summer was in the position of his baby being the smallest in the unit, and he talked about taking consolation from the condition of the other infants in comparison to Tim: "*the other babies were in worse condition really, like there were, there were various different problems that they had, they weren't necessarily premature babies, they were*

just babies born with defects... we were very lucky that Tim was premature, but there was nothing wrong with him..."

Mary McFoley talked about the shock she felt when she saw Marissa in NICU: "*I thought she is very small. That is what, that was the first thought I had really. I thought good God, she is really very small. And I mean the talk had been oh, she is... it is great, she is not, she is a pretty good weight etc etc, but actually when I saw her I thought mmm, I have never seen anything this small before.*"

There did seem to be a qualitative difference between the way fathers talked about the physical appearance of their babies and the way that mothers did. Fathers made more comments about the fragility and size of their babies, whereas mothers made more comments about their baby's general appearance. Mothers were more likely to describe their newborn using words like *"skinned rabbit"*; *"horrifying"*; *"squashed"*; *"little old man"*; *"pig like"* and also were more likely to mention the technology that the infant was attached to. Fathers were more likely to talk about their newborn in relation to fragility, size, and dependence.

The reason for this could be that Mothers may carry a more detailed picture of what their newborn is going to be like; therefore when they are confronted with the actuality of their newborn they have more descriptive terms for the difference between the reality and their expectations. As Rita Street said: *"when you have a new baby and it is your first new baby, you really... have this, you know, this sort of idealised version in your...*

of what, what it is going to be like. But um... yeah, it was just... yeah, not really... what you expect."

NICU: Physical environment

As well as the human environment of the NICU, parents also had to deal with the physical environment. In this area, the comments made by parents generally supported the findings of the studies by Brunssen and Miles (1996); Miles (1989); and Raeside (1997), in that despite NICU being unfamiliar and quite daunting, and this taking some time for parents to adjust to, parents did not seem to find the highly technological physical environment itself to be a major cause of stress.

There was certainly an initial adjustment period while parents got used to NICU, but this did not figure highly in parents' comments. The first time Anita Mulholland got to see her baby in NICU, Amber was in an incubator and on a resuscitair: "*I just remember the noise. All these alarms going off left right and centre.*" She found this initially detracted from the experience of spending time with Amber: "*Oh, I tell you, you, you start looking at the monitor all the time, and you think I shouldn't be looking at the monitor, you know, I should be able to just look at her and see... and you do come to rely on the monitors from the point of view of Oh, is she breathing, instead of actually looking at... what you have got in your arms or whatever*". Andrew had the same feelings: *"it was watching the saturation on the monitor. And watching it go up, go down, and watching for when that apnoea alarm would go off."* He also described this initial period of unfamiliarity with what was happening in the NICU environment as *"a*

frightening time." On the whole, however, the technological aspects of NICU did not seem to be overly problematic for parents, as they quickly became accustomed to the environment.

The main area where the physical environment was seen as being difficult was where parents commented about the space constraints within NICU. For example, Caitlin Tree's comment that: "*this is a, a small space that you are allowed to look after your child, and having all these other adults in the room, some... some mums were breast-feeding as well and, you know, the... people coming and going, standing, you know, a foot apart from each other whilst you are trying to care for your child*". Caitlin went on to describe the feelings of intimidation that could be caused by the close proximity to other people: "*you literally got your cot, your incubator or whatever area that your baby was in, and a chair next to it, that is what you got... So if, if you wanted to feed your child, you had that chair to feed your child, your, your baby. If the nurse had to do it then you had to remove yourself from the chair and stand in, you know, an, an open space area and, and that was the same, you were literally side-by-side, next to that, your cot, would be another chair and another incubator, so literally was, you know, side-by-side between... beside each mum. The nurses were literally there, standing right in front of you, which could be a little bit intimidating.*"

The other aspect of the space constraints within NICU that had an adverse impact on parents' experiences was where the lack of space made it more difficult to bring other children to the hospital during visits. As above, the two mothers who already had children at the time of their premature baby's arrival tended to feel guilty about the

amount of time they spent away from their other children, and a partial cause of this, at least, was the fact that it was impractical to bring their other children to NICU.

Caitlin Tree commented that it would have been beneficial for the hospital to have a crèche facility for NICU parents to place siblings in. She felt that there was very little time available for her and her husband to have any quality time with Christopher. When Catherine was present in NICU she felt that it impacted in a detrimental way on Cary's time with his new son. Caitlin talks about how they had no time for them as new parents to devote themselves to Christopher: "*we could be just as parents, just for an hour, or half an hour or something for her to go to a crèche, so we, we get quality time with our newborn son. That is what I think.*" Cary had a somewhat different opinion of what he would have liked to do, but in his case too the lack of space was the problem in achieving this: "*I didn't want to put Catherine in a crèche, I wanted to be there as a family together, be able to spend time together because I felt that was really... and it was just difficult. And, and I think, yes, you were invited to do that, but it was just not, not, not conducive to that environment. I think they had to go another step to provide that environment.*" As Cary also commented, the lack of space, little privacy when talking to staff and the feeling that they were time pressured affected his experience in an adverse manner: "*it is all done there in, in that, that environment, and perhaps they would like to say more to you, maybe they can't because they have got, they have got to get back to pressing, pressing needs, and I, I, I think yes, they could spend, you know, if they could have a bit more quality time and quality environment for the parents it would, it would help.*"

Anita Mulholland commented on what she saw as the negative impact of the number of visits she and Andrew made to NICU without being able to take her other children with them, and Andrew expressed the same feelings. If the environment and set up of NICU had facilitated the support of families visiting then it is likely the Mulhollands would have felt less guilt and concern about the amount of time spent there.

Another aspect of the physical environment that was consistently commented on related to one particular hospital where three of the mothers gave birth (it was the same hospital where Fennec was born). This was the fact that the maternity ward, where the mothers were put following delivery, was two floors removed from the NICU.

The Streets' experience of this, for example, was that it made for very difficult breastfeeding, particularly as the availability of staff made it impossible for mothers who were physically incapacitated to get from the first floor to the third. Rita even resorted to expressing milk rather than breast feeding because of the difficulty of physically getting to NICU from the maternity ward: "*I tried to express. Because obviously... yeah because he was upstairs and I was downstairs and, and so I did express a little bit. Yeah, not great, especially when you can't walk.*" The physical separation also made it much more difficult to spend the time with Rex that she wanted to: "*I would wake up and think Oh my God I have got to go and see him. You know you feel this... you need to go... So off I would shuffle, and it took me quite a long time to get there.*"

This setup also meant that fathers in this hospital were in a more difficult position when it came to having to choose where they were going to go immediately after delivery; being separated by two floors either from their partner, or else from their newborn.

Coping as a couple

Parents made widely different comments about how they had been affected as a couple by their experience of premature birth.

Richard Street said: *"I think it made us closer as a couple"*, and Rita added: *"Yeah, yeah, not... not the pregnancy so much, I am not sure that that, that... changed our relationship, I don't... I think it is actually when you have the baby that things change."* Richard talked about working as a team: *"We kind of just... worked together quite well as a team, I felt. Not that it sounds as if I did much work, it was...[laughs] I was at work all the time."*

The Streets had quite a positive picture of themselves. The qualities that they attributed to themselves included being sensible, and not focusing on worries. Richard said he quite enjoys situations like that and Rita added *"We are a bit funny, like that"*. The following extracts demonstrate the qualities that they felt they used to get through their experience. Rita: "*we are just quite practical and quite pragmatic I think"* and Richard: "*We ensure that we get the things done..."* Rita: "*deal with the situation in the, in the best way, without... getting our knickers in a twist too much about it."* Richard rounded up by saying: "*it needs doing, so there is no point worrying about it."* I enquired

whether they thought their sense of humour had contributed to the positive manner in which they dealt with their situation. They both laughed and Rita asked *"do you think we have a sense of humour?"*. But Richard said: *"I think it was more... that we are both practical people, practical and logical and... common sense prevailed."* Rita added: *"Humour helps, I suppose."* But the real belief is reiterated by Richard: *"Yeah, and the fact that we don't get... overly... worked up about... overly bogged down with things."*

The Trees also felt that the experience of a premature birth had pulled them closer together. Cary identified them as a strong family unit before the birth of Chris, and described how they got through the experience as: *"a system"*; *"getting the troops together"*; *"pulling together as a unit"*.

For Caitlin Tree the dynamics of their relationship meant that she trusted Cary to deal with whatever life threw at them. She said: "*Because I know that, you know, I can fall back on his shoulders because he will deal with it. Whatever it... life throws at us, he will deal with it.*" However there had been some changes in the way they organised their lives since the advent of Chris. They had both taken some time out from parenting to ensure that there was some time for them as individuals as well. Both Caitlin and Cary talked about rearranging their schedule to ensure they got time alone. For Caitlin this meant she was able to go out for a run every other night. Cary was now attending football every other weekend. He also talked about other changes since the birth of Chris, such as no longer going out on a Thursday night for a drink with his workmates: "*Thursday night going out with the boys for a drink, and that stuff, we have all been there, and now I don't do that, and I actually no longer miss that, I mean I did initially*

and, but no, I don't miss that now and I would rather spend time with my family and if I do get any spare time then, um, I will go for a run."

At the opposite end of the scale, Andrew Mulholland said: *"Um... I think it was a very very difficult time. Very stressful. I don't think it brought us closer together as a couple."* He went on to add: *"...I suppose it, it didn't bring us... closer as a couple, I don't think it did. No. It may have sort of pushed us away a bit more from each other and, and more down the line that we wanted to do our own things."* This couple ended up leading very different lives for a while after the advent of baby Amber. When Anita Mulholland talked about the impact on them as a couple she told me the experience very nearly ended their marriage. There was a point in their relationship where Andrew had said to her, after Amber came home from the hospital that he would be leaving. She described their experience in these terms: *"I think it was... it was the strain of trying to be everywhere, and everything. And probably not succeed... feeling we weren't succeeding at anything. And I think that is, that is, that is it really, because yes, I could howl my eyes out but, I mean, men aren't supposed to do that, they are supposed to just sort of be there and say the right things, do the right things..."*. She talked about feeling that she was going to be the one who was left at home to cope, while her partner had the option of going out the door to work. For her the lowest moment was after a Doctor had told her that there was a possibility that Amber was going to be handicapped. At this point it looks like Anita had very few resources left to cope with this news, and talking to Andrew was not apparently an option.

The contrast between the Streets and Summers on one hand, and the Mulhollands on the other, suggests that the effect on parents' relationship with each other may not be directly related to any specific aspect of having a premature birth, but be more to do with how they cope as a couple with significant life stresses. For the Streets, the stressful situation brought them closer together; for the Mulhollands it pushed them apart.

Ted Summer talked about the effect on him and Terri as a couple in slightly different terms. He felt that the advent of baby had relegated him to third position within the family: "*having kids that, that it is the biggest life changing event that you will ever go through and um, and suddenly... being in a relationship... of two, suddenly is three, and... what you want is... basically is number... is third on the... is third on the list. It is third on the pecking list. So um, so the dynamics of the relationship do change, um...*"; "*there is two other people and you have just got to really support as much as possible because... yeah, your wants don't... they sort of fade into comparison to these two others.*" For Ted there had been a dramatic effect on his relationship with his partner, which was still being felt five years later. Again, however, this seemed to be less to do with the affects of having experienced a premature birth and more to do with the changing dynamics of their relationship in the face of parenthood itself.

Help and Support

Help and support for the parents in the study took various forms. It may have been as simple as someone giving them a gift or enquiring how they were getting on. Andrew Mulholland talked about one of the people he worked with: "*they were the first of my*

colleagues to give us a present, but he was always the one, whenever I went in, to ask me how I was getting on, how things were going." Or it could be more substantial: "*the head of the senior school... turned to me and he said look, take as much time as you need, and I remember taking the next week off... I never went anywhere near the school.*"

These examples from Andrew demonstrate the two ways in which parents perceived that they got help and support from others: emotional support such as people who were available for talking, who showed an interest or sympathy with what was happening, etc.; and physical help, such as looking after other children, or taking the mother to and from hospital, for example. Some people, of course, helped in both these ways. Andrew Mulholland gave another example: "*the head of French...she was in charge of ...staff liaison ...I remember we came back from hospital... I walked in... and she had brought a bag of shopping for us... she just wanted to know how we were doing, how things were... she would always make sure that... anyone who was ill, there was always food for them in the house, Oh, is there anything I can do for you, here's my telephone number, just ring me and all that kind of thing... there was sort of support lines at school...* "

Emotional support came from a number of different sources. Anita Mulholland talked about discussing the news that her baby might be cognitively impaired with the antenatal group from her eldest child that she still met up with: "*they knew, obviously knew what everything had happened,*" and went on to say: "*I was just blubbing there, and they were just plying me with tea and coffee and biscuits and, and just being there*". This was a very important source of support for Anita.

Anita Mulholland was the only mother in the study who reported that she had suffered from post-natal depression. She felt surprised by the fact that she felt more depressed after she got home with her baby than when she had the worries and stresses to contend with of going into NICU every day: "*I remember when I... the health visitor gave me the postnatal depression form to fill in, and I said why on earth are you giving this to me, because I said, I have just brought her home, we have come home this week. I jokingly said, you know, ask me in a month's time. [Laughs] Ooooh. Well actually it was, it was actually come the August, there were... it was the summer holidays and I just felt as if I was tearing my hair out. Tearing my hair out, couldn't do anything, couldn't see light at end, end of any tunnels*". Anita was very grateful that help and support were rapidly put in place after she started to feel down, but the most important aspect of this seemed to be not so much the antidepressant treatment itself, but the emotional support she felt from the health professionals involved: "*the health visitor was then on the phone the next day... because the GP had straightaway rung the health visitor, she was on the phone, they then came round, she came round every week for the next six or seven weeks, she saw me on my own, she saw me with Andrew she came and chatted to us all, and she just kept coming back and gradually then we just... you know, spaced out, she started coming every two weeks and... and tapered it off again*"

Mary McFoley gave the example of the pathologist who dealt with their first child, and came to NICU to see their new baby: "*she was oh, she is beautiful, small, but she is beautiful, beautiful. So that was really, you know, encouraging also.*"

Caitlin Tree, like Anita Mulholland, enjoyed her health visitor calling around: "*Yeah, yeah I did very much, you, you do get a sense of, um, of worth from the... from a visit from, from the health visitor. She is not necessarily able to deal with... deal with midwife queries, but at least you get a person coming round just to see if you are okay.*" However, she did find the lack of support following their discharge from hospital to be difficult: "*once I came out of the hospital, I had no visit from anybody, no midwives at all to come and visit me.*" She describes the experience: "*Um... I would say pretty horrible... if, particularly if you were a first-time mother. Because I am a second time mother I took it all with a pinch of salt.*"

Rita Street had the same experience: *"Yeah, they never, the only people who ever came here were the, um... midwives and the health visitors. And even after... and even the health visitors didn't come here much"*

Emotional support could come from the unlikeliest places or from where the person least expected it. Andrew was surprised about the support he received from his Rugby club where he was coaching: "*the rugby club were actually very supportive, which was interesting.*" I asked him why he found this interesting and he replied: "*because ...I was dealing at that time with 17 and 18-year-old boys... some of the lads who I'd coach... were always asking after Amber, or just making comments to me, how was things going and things like this, so there always seemed to be support at the rugby club."*

Parents, then, had sources of emotional support from a wide range of sources. In some ways it was surprising that parents' family members were not mentioned as direct sources of emotional support more often, but there were some examples of this.

Mary McFoley talked about her sister being helpful: "*Tullah was the main help... Tullah came and saw Marissa three or four times on the unit, on her own... and was really outstanding.*" Mary was not talking about material help here, rather about the types of things her sister was saying to her: "*Yeah, it is, and I mean it is great to have someone who is as keen and enthusiastic as Tullah is and says oh, the baby is lovely, and all that stuff, you know, which is really good.*" The positive aspect of her sister's enthusiasm for the new baby was particularly important to her because in contrast she talked about the difficulties she found discussing things with her mother: "*you know, and my mother has lost babies and everything, but you know, is curiously unhelpful really,*"

Ted Summer specifically talked about his limited sources of emotional support. His parents live on the other side of the world: "*I spoke to mum and dad on the telephone*" and: "*I remember getting quite emotional when I was talking to them about it.*" But he felt it was a good because in effect it was support, and as he points out support doesn't actually have to be a physical presence: "*Um, but yeah, they are always on the end of the telephone anyway so, you have always got that support, even though it is not necessarily... you know, right with you at the time*" In comparison he felt that Terri was lucky: "*she was lucky she had parents close by, so she had a lot of family support, so that was, that was useful.*"

More than emotional support, however, parents talked about the physical support they got from people who helped them, particularly with childcare and transport. It would be difficult for someone who had not been through the experience of having a premature baby to imagine the scope of the logistic challenges that new parents face while their newborn is in NICU.

Reflexive Note. Stephen's parents, who had been promised a front row seat at the birth of our next baby, were doomed to disappointment yet again. However they were very good natured about it, and despite their disappointment they ensured that there was child care coverage and a driver to and from the maternity unit. Fortunately, they arrived in the country soon after Fenn's birth. Because, despite the fact that Stephen's employers were very good, there comes a point where you realise that you can't live in the NICU, and as discussed below, the pressure to return to work is constant from a number of sources. However, when you have had a caesarean, you are not allowed to drive for 6 weeks, which came as a bit of a shock to me. Without Stephen's dad the trips to and from the NICU would have been a nightmare. Certainly by the time I had discharged myself, there was a certain level of emphasis placed on the importance of breastfeeding. This meant expressing off milk at night and being in the hospital for a minimum of four feeds a day. Combine this with the needs of a two and a half year old, plus a seven year old requiring assistance in getting to and from school, and it would be easy to spot the mother under stress. The hospital was a 20 to 30 minute drive from our home, but the hospital bus would make that trip an hour long as it followed its convoluted path through the suburbs surrounding the hospital. My father in law undertook the task of driving me to and from the hospital several times a day and my mother in law looked after my other children, thus freeing up my time to visit. Without them it would have been a nightmare. When I heard

from my interviewees how grandparents in particular made it possible for new parents to visit NICU it certainly brought back memories of what nice people my in laws are.

There were a couple of cases such as Andrew Mulholland's colleague buying groceries, or Michael McFoley talking about the support his partner received from her sisters: "*her sister Tullah came over... on the Friday, and coincidentally, Tess, who lives in Dublin, was over for a week anyway and she found out by phoning back to Ireland that Mary was in the hospital and so she, both she and Tullah came to visit that Friday. And then Tullah came up quite a few times, most, most times with one or both of her children, and sometimes with her husband,*"

However, in line with our experiences, in the vast majority of cases mothers and fathers received support from their parents. Richard Street said: *"as soon as Rita was out of hospital my Mum stayed for a week."* Rita Street: *"then I think she went and then you took probably, maybe a... a long weekend, or something"*. And there was help from Rita Street's mother as well: "*my mum came to stay as well, afterwards, for a bit as well, so I had my mum there as well.*"

Rita alternated help from parents with that from her partner over the first three or four weeks when she came home with her premature baby: "*So I was fine. But no, um yeah, Richard then um, then my mum was around for a while as well. And it was okay. Yeah, yeah it was okay. We had some... we had our moments.*"

Mary McFoley, who had found her mother incapable of giving her emotional support, did find her mother a help to her when she was discharged home: *"[she] was very*

helpful when the baby came home, so I mean I said to her, come over when the baby comes home, because I knew she would be helpful then, you know."

Even Ted Summer, whose parents were on the other side of the world, received support from them: "*Dad, dad ended up coming over, um... he was over here a week or two after Tim came out of hospital in the end.*"

Other couples talked about the support their parents gave them that enabled them to keep functioning as a family unit. This help seems invaluable because it enabled parents to get into the hospital and also ensured that there was support for family members who were at home. Anita Mulholland's parents would stay till late on Thursday night which meant she and her partner were able to stay in NICU till after nine that night; her parents would drive back down to Dorset after this: "*what used to happen is that they used to drive up on a Tuesday night, so they would arrive here at about half-past nine on a Tuesday night after we got back from visiting. They would then stay until we got back on a Thursday night from visiting, and then they would drive back to Dorset. And they did that every week, for the whole time she was there.*" Anita found this extremely supportive: "*I mean that was wonderful, because they looked after... I mean, for a couple of days a week I knew the children were being well fed.*" This meant these grandparents commuted regularly for 56 days.

Support could just be the knowledge that if people needed anything someone would be there, again particularly parents. Andrew Mulholland talked about his dad: "*I mean with my parents it's, if I rang my father up and said I needed you tomorrow he would come*

up tomorrow so they, they, there's always been that closeness." This is also something Cary Tree mentioned: "*we could always call on my mother-in-law and father-in-law if we needed to.*" He added: "*Yeah, I felt we were able to do that.*"

With the decline of the extended family and the advent of working grandparents and in particular working grandmothers there is a reduction in the availability of assistance to mums when they are discharged home with a small premature infant. Michael McFoley talked about the lack of support for his partner when she came out of hospital: "*Because she doesn't really have any family locally, there are not a lot of people, well, that she can call on for help, sort of practical help or, or even moral sort of support,*" he added: "*she has got a limited social network of potential support, you know, we don't have any family really close to hand, no one can come round and you know, sort of like just watch her for like fifteen minutes, two hours or whatever.*" Even so, Mary's mother came over from Ireland for the first fortnight when baby came home: "*the first two weeks ...Mary's mother was over and she was a, sort of, great help in doing sort of chores around the place and taking the baby from time to time and giving us some advice and being a third person in an argument which sometimes actually reduces the arguments".*

One of the problems with relying on parents for support was tied to the fact that prematurity occurs more frequently in parents who are older. Therefore correspondingly the grandparents are also going to be older. This seemed to be an issue with several of the couples, who mentioned their own parents' advancing years as reasons why using them as help and support had some drawbacks. However there were positive and negative aspects of having grandparents who were significantly older.

A positive aspect was mentioned by Michael McFoley, saying that his parents were: "*eighty seven, eighty nine, so they are fairly sort of pragmatic, they can get emotional but I feel like they are, they are more relaxed than a lot of people, shall we say.*" This dad saw his parent's age as an advantage when discussing NICU with them.

The negative aspects of having older grandparents were seen when parents became dependent on them for access to the hospital or for looking after young grandchildren. This was a part of Terri Summer's concerns. She talked in her interview about exhausting her father with the number of trips he was making to the hospital with her, because she was not allowed to drive following her caesarean. Following Terri being discharged from hospital, her father became responsible for getting her to and from the hospital while her partner was at work. Ted commented on this: "*during the day her dad was taking her into the hospital. Um, and in the evenings I would take her in the hospital once I got home from work.*" He added: "*we were lucky that her father is retired, and yeah, doesn't live far away so...*" At this point I asked Ted how old Terri's dad was. He said he was sixty but with further questioning he said he was an older sixty rather than a young sixty. The reason I asked this was because when I was interviewing Terri Summer she had talked about how difficult it was for her father to take her to and from the hospital. She had felt particularly guilty because she said her father was an older man and the trips were draining for him.

The Trees were slightly different to the other couples in that both Cary and Caitlin talked about wanting to be self-sufficient in terms of support. Though for Caitlin both her brother and sister lived locally she didn't feel it was appropriate to ask them for help: "*I*

don't, didn't really felt that we should ask, ask them to look after, because, you know, they were working," she went on to add what her concerns were: "*it was expecting them to give up a day's holiday, to sacrifice that, to look after my child, which I think was a little bit unfair to ask... I would have done, if it was really... and my, my sister would happily, done that, she offered on a number of occasions but I didn't ask them to do that.*"

Although Cary Tree said: "*we could always call on my mother-in-law and father-in-law if we needed to*", he added that they made an active choice not to make use of this source of potential support: "*it was just something that I felt as a family we should... we, we were sticking together and I didn't really want to do that and, and left that as a, you know, as a last resort really.*"

Caitlin Tree also summed up her belief about external support in an interesting manner, she talked about how kind people were: "*people were very kind to ask, very very kind, and lots of gifts and presents and cards, lovely words, and, and what have you*" but she went on to say: "*when it actually came down to it, the only people we could really rely on for the whole situation was ourselves really.*" There are two quite interesting comments that she added, one being that as a family they didn't really want to rely on others: "*We didn't really want to ask anybody else, we didn't want to involve anybody else.*" And the other was that if things had gone badly then she would have considered asking her family for help: "*possibly I would have asked my, my family, if it had really got really horrible, you know...*"

However, again, Caitlin Tree also had worries regarding asking her parents for help, that were centred around her parents being older: "*my parents are old age pensioners really, my dad is going to be eighty this year, my mum is going to be seventy six. It is just not fair to ask them to look after three-year-old child, so I didn't ask them.*"

The Workplace.

All of the parents interviewed except one mother were in some form of work prior to the birth of their baby, whether that was working for their own limited company or being employed by others.

None of the mothers reported any significant problems with maternity leave (other than having to bring dates forward, or having less time than they had anticipated to get the house ready for the arrival of the new baby, of course). All of the issues around work were experienced by fathers.

The level of support from fathers' work places was variable. The types of comments fathers made about the workplace covered issues such as the ability to talk to others, others talked about the pressure put on them at work. Some fathers found that though their workplace was telling them to take as much time as they need this did not reflect the reality of the situation for them.

One common complaint amongst all the male parents was about the level of paternity leave. Some fathers interviewed had had their baby before the introduction of paternity

leave. Others had not taken paternity leave but had been given compassionate leave by their employer.

Paternity leave in the United Kingdom was only introduced on 6 April 2003. To be eligible a father needs to: have or expect to have responsibility for the child's upbringing; be the biological father of the child, or the mother's husband or partner; and have worked continuously for their employer for 26 weeks ending with the 15th week before the baby is due. Fathers can choose to take either one week or two consecutive weeks' paternity leave (not odd days), and will be paid Statutory Paternity Pay at the same rate as Statutory Maternity Pay: £100 a week or 90% of average weekly earnings if this is less than £100 (DTI, 2003).

Even fathers whose babies were born after April 2003, and who therefore had the option of taking paid paternity leave didn't make use of this in all instances. They found that they were financially better off taking annual leave than accepting the £100.00 paternity pay allowed to them per week.

Richard Street's premature baby, Rex, was born before 2003: *"Um... I didn't officially get... paternity leave, as such... paternity leave didn't exist. When Rex was born..." "You didn't get anything. So I took holiday. So, you don't have paternity leave to take."* For this couple to spend time together either in NICU or as a family following discharge from NICU meant taking some of their annual leave. Richard said further on in his interview that it would have been nice to take some more time off, because Rex was particularly unsettled following his discharge home, and Rita was finding it difficult to

deal with him: "*I was, I was back at work full-time by then.*" "*I would have liked to have probably taken another couple of days, um, with hindsight I probably should have taken another couple of days.*" Richard ended up going back to work sooner than he had planned, after discussing the situation with Rita: "*Rita suggested it and she said, why don't you go to work in the mornings...*" "*like Rita said, there is no point being in hospital all day every day...*". The decision to go back to work was partly driven by the desire to spend more time together at home after Rex came out of hospital, but Richard admitted that part of the reason that Rita suggested he return to work was because: "*she knew that... I was under pressure, as well. At work.*"

Cary talked about the inadequate amount of paternity leave available to him: "*Yeah, it is rubbish in the UK and I, I work for a major corporation... and I get three days paternity leave.*" Baby Chris spent 14 days in the NICU, so to cope with the amount of time their baby was in hospital Cary took three weeks annual leave from work. Here he gives a breakdown of how this time was used: "*I took three weeks leave, and I spent the first week travelling between here... home and the hospital with Catherine, and then the second week travelling to the, the hospital... we spent the second week travelling from home, the three of us, Caitlin myself and Catherine to see Chris. And then the third week we were at home together. Trying to recover and get a system at home. And then it was back to work.*" The impact on them was quite significant from a financial point of view, because Cary was working as a contractor; he explained what this meant from a financial point of view: "*the contract that I have in my business is such that I have to... I buy my leave. It comes out of my contract, so I, I, I spent some of my contract*

remuneration on my leave." It also meant that in this particular instance he was left with no leave until the following financial year. I asked him how it had affected them from an economic point of view but he corrected me: "*it didn't affect us economically. It affected us with the amount of time we could spend together as a family, which is more important.*" As he pointed out: "*the impact is I used my leave up, um, to spend time when Christopher wasn't even with us and it is, it was time used travelling to and from hospital, and only a little bit of time with us as a, as a unit. And I would have liked to have spent more time with my family.*"

For Ted Summer finance was a big issue, he had immigration problems to deal with and had only started work shortly before Tim arrived. I asked him if the job that he held entitled him to any paternity leave, "*No. No. Well, I was... it was just sort of a fixed term contract, you know... I wouldn't have had any leave... generally speaking as a contractor you only... well you can take leave but you don't get paid for it. So it sort of works out doubly expensive you going on holiday.*" But as Ted pointed out for him, as for Cary Tree, taking leave was in many ways more important when his baby came home than when he was in NICU. "*I think probably taking leave... yeah, when he, when he came home was still probably the best option because he was being looked after well in hospital*". He added: "*but obviously if I... it would have been nice to have had a little bit more time but, you know, you can't do much about that if you are a contractor.*"

Richard Street discussed work pressure again: "*there were pressures from work, in that the business I was in was a 24 hour business, seven days a week, so... it was a business that required a lot of my time... the pressure was from my own making, in that my boss*

said, you know, take as much time as you want... but clearly [laughs] but clearly I knew that the day-to-day work needed doing, and he wasn't about to do it for me."

What fathers had to say about the work place pressure was that even though they were told to take as much time as they needed there was pressure for them to return to work. Some fathers referred to the unrealistic nature of this offer. Other fathers felt that though their overall employer had given them as much time off as they needed, this was not always the feeling of their immediate supervisor or boss. Also some of the fathers talked about the pressure that they placed on themselves in regards work.

Andrew Mulholland talks about being given time off. He was grateful that his employer continued to pay him throughout all the time he was absent. His employer gave him compassionate leave when his baby was in NICU. However the reality of work pressure from his immediate boss made it very difficult for him to actually stay away from work: "*I had support from my head, of... head of the school, head of my part of the school and, and the principal, but I didn't feel that I had the support of my head of department*". And again: "*I felt from my head of department that I was under pressure to get back to work and get on with it. Because he felt he was carrying the department without me.*" Andrew talked about his day's schedule: "*it was going... going from the hospital, straight in, get out of the car, and timing it, some days, when I'd just get out of the car straight into the lesson, no preparation, just get on with it and just go, and then work through till four o'clock, and because the way that the sport at [school] worked, there were some nights, there were, there were practices after school or there would be, um, matches after school*". Initially he was not attending the matches after school but was

soon back to doing these as well. Andrew also related his feelings of missing out on caring for Amber directly to the demands of returning to work: *"I felt I'd missed out on some things because some things had already been done but I, I was working so I knew... that was part of the reason why I had missed out. And I... I felt it, at times I found it difficult actually to combine work and, and hospital visits."*

However it would be wrong to paint this picture as all black. Andrew also talked about his return to work as being part of his coping mechanism. He also said that: *"but there was also from my point of view it was, I needed to get back... really, I needed to get back to... I needed to get back to things, to get myself on an even, an even keel"*. The contrast between Andrew and Anita demonstrated how parents could differ in their approach to dealing with their experience of NICU. As Andrew Mulholland added if he didn't get back to work he could see himself in the same position as his partner: "*because otherwise... I could see myself... the whole, doing what Anita was doing, spending the whole time going to the hospital.*"

Like other fathers, scheduling his day became important. Ted Summer talked about his routine: "*Um, be getting up at six." "I would be going straight from work to go... to go there, so I would probably get there about six thirty or so and sort of leave at about nine. Nine thirty.*" "*well work was quite busy, yeah, being contract you are generally pretty busy*". He went on to add that his work was quite sympathetic about letting him get away a bit earlier: "*they were pretty good, like I, I, I managed to finish on time or... leave a bit early most days anyway, um, to go and see her at the hospital.*" However, again despite what his employer may have been saying, he felt pressure both from work

and from within himself: "*like any new job you, you, you have got to impress and you don't want to, um... yeah.*" "*there was a lot of work to be done before the year 2000 came about. So there was a lot of stress, um, working at that place...*"

Michael McFoley talked about his way of arranging his working time around NICU: "*apart from the first four days she was in special care, I was working Monday to Friday the rest of the time so it was just up in the evenings but all the spare time and weekends, we were up there, yeah.*" Michael worked for his own limited company therefore like those other fathers on contract any time he took off was time without income coming in, and down time for his clients: "*Mary had said quite early on, I forget, at maybe three months, that she wanted me to take six weeks off. Now effectively I run my own business, if I don't work the six weeks I, I don't get paid, but potentially the business can evaporate.*" The impact on them financially had not been that worrisome but the impact on his work had given Michael pause for thought. Due to the nature of his partner's ongoing health issues it meant that when I saw them at ten weeks post discharge that he had actually been at work only intermittently from the end of the planned six weeks. The following extracts cover his concerns about this: "*you know... she can't do whatever needs to be done so then, you know, I do it which means actually I have got more to do in a day... so I split my day and often I find once I come home... I am not so productive businesswise so it is, yeah, it is extr... it is pretty frustrating, yeah.*" He went on to add: "*Actually, I feel I have been grounded for six weeks, both of us for the most part, ... I haven't been generating any income during that time, well that is not strictly true... I did*

actually do about twenty five hours work in the last couple of weekends, which is not great because I try to keep the weekends for Mary and Marisa, but..."

Childbirth is a difficult event to plan exact timescales around at the best of times, but this problem is inevitably exacerbated with a premature birth, in that in the majority of cases the birth is unexpectedly early, but also there is uncertainty around the date when the baby will be discharged from hospital. Michael also talked about his frustration around the difficulties getting some sort of general statement out of NICU regarding possible discharge dates. He wanted some sort of ball park figure so he could arrange time off work to be with his partner and baby when they came home: *"I was asking all the time, you know, when, when do they expect her to come home, so at least I could sort of plan around my, my absence for six weeks, um, and they... I suppose, you know, they didn't want us to be disappointed, they wouldn't give any real indication, which I found extremely frustrating."* He adds that it wasn't as though he wanted a date set in cement: "*at the end of the day, all I wanted was, you know, a best guess in the world, and I mean because they are the ones in, in special care, you know, I am sure they could have, if they wanted to, but their mindset is, is against it."*

When I talked about paternity and maternity leave with mothers none of the above issues really came to the fore. For mothers the only issue over paternity leave was really about *when* their partners where going to take some time off. Mothers' issues covered topics such as getting transport to the hospital, the use of their partners for childcare if there were other children already in the family, and support and time together after mother and

baby both returned home. From this point of view, they needed to figure out when was the best time for their partner to be used in a support role.

CHAPTER 6: DISCUSSION

The process of trying to make sense of the themes that arose from the parents' interviews, and trying to understand the influences that shaped their experiences, is a difficult one. NICU is characterised by a number of factors that make it a challenging environment for parents, which can interact with each other in different ways. The need for intensive medical intervention with the newborn is an obvious source of stress and anxiety for parents; healthcare staff, particularly NICU nursing staff, take a significant role in the care and management of the baby, and encroach into areas for which parents are normally responsible; and the physical environment of NICU requires people to work and interact in very confining small spaces. The particular medical requirements around neonatal care, together with the space limitations within NICU, cause hospitals to enforce a number of rules and restrictions on how interactions between parents and the newborn can take place, and how often they can occur, as well as diminishing the scope for other family members and friends to visit the baby and parents. Even the noise of constant alarms on NICU, where the babies' incubators are close together, could have a direct impact on parents (Topf, 1992).

In order to investigate how the feelings that parents expressed could have come about, and what their implications are, it is useful to consider what factors will act on parents through the course of their experience with NICU, and how these will interact.

The first and most obvious source of stress on the parents in this study was the delivery itself, which was often unexpected and could be quite physically and emotionally

traumatic in the case of emergency caesareans. The main feelings that seemed to arise from this period, unsurprisingly, were feelings of helplessness at parents' inability to influence outcomes for their newborn babies. For fathers, this was added to by being unable to influence outcomes for their partners either. Following delivery, then, parents' found themselves in NICU, an unfamiliar and highly technological environment, under conditions of extreme stress, and experiencing a loss of control.

The early period around the time of delivery is the time when medical intervention is likely to be at its most extreme, and parents have to rely on health care professionals for the level of expert medical care that their baby needs (and sometimes that the mother needs as well). During this period, parents generally expressed positive feelings about the hospital and staff. They felt that they and their baby were in the right place, and they trusted the care of their baby to the professionals.

During this period, parents were content to give control and responsibility for the health and well being of their baby to the hospital. Undeniably staff involved in specialist cares such as those associated with NICU do have a level of knowledge that parents do not possess regarding the treatment of their premature newborns. For instance, they posses a greater repository of knowledge that is related to technical cares such as oxygen saturation, treatment for physical problems involving respiratory issues that require interventions such as CPAP or ventilation and treatment of bilirubin levels. These are all parts of the core knowledge held by professionals working in NICU. Parents will in these instances be happy to have NICU staff take responsibility for these cares.

At this stage, it was not important that parents had individual relationships with the people responsible for their baby's care. The one problem that could arise in communications was on occasions where they felt that they were not informed what was happening. This was particularly true of the baby who was taken to NICU after initially having been taken to the labour ward with his mother, however. Parents whose babies went directly to NICU did not express the same concern.

The main problem in adjusting to the situation initially was experienced by mothers. Fathers generally got to visit their babies in NICU quite quickly after delivery, but mothers had to wait for periods of time up to nearly a day and a half to see their babies. This was something that mothers found very distressing, and was exacerbated by the fact that they were on labour wards where all the rest of the mothers had their babies with them. Mothers found this an upsetting and disorienting experience, and expressed feelings of anxiety at not seeing their babies. Fathers also experienced anxiety around this, as they all expressed the feeling that their partners needed to see the baby as soon as possible. One father even insisted that his partner see their baby when she was too sick to really care on her own account. Generally, though, it seemed that these issues were short lived, lasting only as long as mothers were unable to visit NICU.

In terms of understanding the challenges that face parents initially in coming to terms with the environment of NICU, it is useful to look at the ecological psychological model (Barker, 1968) which describes how environment-behaviour relationships are ecologically interdependent. In this model Barker states that the behaviour setting is perceived as a unit in itself, and is made up of the interactions and interplays between

standing patterns of behaviour and the actual physical enclosure where these take place. The standing patterns of behaviour are composed of the collective interactions of the group rather than ascribed to any one individual within the setting. The standing patterns of behaviour of NICU staff will be highly modified to the unique environment in which they work. For parents entering this environment, then, there is likely to be a period of challenging adjustment, during which time the NICU staff are at a relative advantage at functioning within the environment. This, along with the unfamiliar physical environment itself, will cause stress on parents additional to that which they are already experiencing at the premature delivery of their baby.

Parents indeed seemed to find it difficult to come to terms with NICU at first. The comments they made about their feelings on first seeing their baby's appearance generally focused on the small size of their infants. It seemed that mothers did make more descriptive comments, which suggests that they had a more completely formed mental picture of what their baby would be like, and so could describe how the reality differed. Fathers tended to focus on the baby's size and frailty. However, almost as many comments were about the shock at the number of wires and tubes attached to the baby when it was in an incubator, so the technological aspects of NICU certainly caused additional anxiety. At this stage, the standing patterns of behaviour of the staff, and the staff themselves, were just another aspect of this disconcerting environment. Parents did not talk directly about their interactions with staff; they had not yet had time to differentiate between staff members, and their focus would have been solely on the baby, so relationships with individual staff members were irrelevant.

For parents who already have children, their adjustment to NICU may be further complicated by the fact that they will have already developed patterns of behaviour in relation to their own previous newborn babies, and will thus have the dual challenge of trying to modify their approach to caring for their premature baby to fit with the constraints of NICU, while at the same time trying to come to terms with the NICU environment. Again, the fact that there were other people involved in the situation, the NICU staff, who were part of the environment in a way that the parents were not, was an additional departure from their previous experiences.

This may be useful in gaining an insight into why control is such an issue for parents in the situation of having a baby in NICU. This is because it is possible for an undesirable event to lead to a strain in our ability to perform information processing (Bell, Greene, Fisher, & Baum, 2001). For parents who are in NICU, the stress of having a very small and sick infant and the challenge of adapting to the environment is likely to interfere with their ability to take on board all that is going on around them. Parents referred to this directly, in talking about nurses having explained to them the purpose of all the various machines and monitors attached to their baby, but being completely unable to retain any of this information. This loss of the ability to process information then leads to a perceived loss of control over the situation. This is the first step in what is known as the behaviour constraint model of environmental stimulation, where something about the environment is limiting or interfering with things we wish to do (Proshansky, Ittleson, & Rivlin, 1970). The constraint can be an actual impairment from the environment, such as an incubator not allowing direct contact with a baby, or it can be our belief that the

environment is placing a constraint on us, such as parents who did not understand enough about the situation to know whether a particular action towards their baby was safe. Once a person cognitively interprets the situation as being beyond their control, they will then start to experience unpleasant feelings. This is certainly something that most of the parents talked about regarding their experience in NICU, both their feelings of stress and anxiety, but also in particular feeling that they were being watched, for example, or feeling that they had to ask permission from nursing staff to carry out cares for their baby. Control issues in this context do not have to be an overt statement or an order where a parent is told to do or not do something, but may simply be a feeling on the part of the parent. These feelings then have an impact on how the parent behaves within the NICU environment, and may lead to a vicious circle of more stress, and more powerful feelings of loss of control.

To some extent these issues are unavoidable. Where a baby is very fragile and unwell it may be in the neonate's best interest that staff limit access to it, because any unnecessary handling of very premature infants can actually lead to a downturn in their ability to regulate their physiological responses (Browne, 2000; White-Traut et al., 2004). This is then a positive aspect of the balance of control over the situation being in the hands of NICU staff rather than those of the parents.

It seemed invariably to be the case, however, that parents felt that NICU staff retained control over the care of their baby past the point at which they should have done, and that the parents had to constantly battle to be allowed the free access they wanted to their babies, and to take responsibility for aspects of the baby's care. And although it could

be argued that medical staff will be better judges of what contact with a baby is appropriate than parents will, there is a danger that NICU staff being responsible for making a large proportion of decisions initially, and with almost total control over the situation, may then become so used to this role that they are unaware when they step over parental boundaries, or when their level of control is no longer necessary.

One difficulty of striking the right balance of control between parents and staff is that there seem to be other positive benefits from the point of view of NICU staff in retaining control over the situation, over and above any medical benefit to the baby. They will have a natural resistance to modifying their standing patterns of behaviour in the environment of NICU in response to the particular requirements and demands of parents, for example. Also, the decision regarding the level of restriction on the amount of contact that parents could have with their babies may be biased to benefit the nursing staff. This may be unconscious on the part of the staff, but again it seems they may have good reason for acting in this way, at least from their perspective. A study by Paludetto, Faggiano-Perfetto, Asprea, de Curtis, and Margara-Paludetto (1981) found that where parents were allowed unrestricted access to their babies in NICU, paternal bonding was encouraged, for example, but the running of NICU could be disrupted.

It is important to note that problems around control and contact with the baby were more acute for fathers than for mothers. The experiences of the parents in this study definitely align with the attitude that the mother-infant bond was seen as being of paramount importance. Mothers felt that they did not get enough time with their babies, or that the

restrictions on contact were difficult, but fathers reported feelings of missing out on contact with their babies altogether, and that their presence was superfluous.

It may be in the situation of NICU, where contact with the baby has to be restricted for very good medical reasons, that fathers miss out more on the normal experience of having a new baby than mothers do. It seemed that when the amount of contact was reduced, this was done more at the expense of the fathers than the mothers. Again, this is likely to be due at least in part to the emphasis on the mother-infant bond, and fathers seemed to give up more of their already limited time with their newborns to increase the amount of contact their partners could have, without even consciously thinking about it, or realising that they were doing so.

There were of course other factors that contributed to reducing the amount of time that fathers got to spend with their newborn. The very limited amount of paternity leave available is quickly used up when measured against a stay for the baby in NICU of weeks or months, and if a father took paternity leave (or other time off work) when the baby was delivered, as all the fathers in the study did, this was at the time when they were least likely to be able to have significant contact with their newborn. Fathers confirmed that the situation for them improved markedly when their baby returned home, particularly when they then took additional time off work. The comment was made that fathers did not bond properly with their babies until this point, weeks or months after the delivery itself.

After having made some adjustment (more or less successfully) to the environment of NICU, and to the restrictions around contact with their baby, the relationships and communication that parents had with individual staff members, and their ways of working, started to become more important. And this is where the next set of problems arose for parents.

The amount of interaction and communication that hospital staff have to engage in with hospital visitors will be lessened to some extent for most patients by the fact that visitors can gain information about a patient's state from the patient themselves. For parents who are visitors to their babies in NICU, they are almost completely dependent on communication with NICU staff to gain information about the status and prognosis of their baby, and to determine what actions on their part are and are not appropriate. Again, this will tend to exacerbate the difference in control over the situation that can be exercised by parents compared with staff.

Another factor in this situation is discussed by Olsen (1978, cited in Bell et al., 2001), who talks about how hospitals communicate the message that "people are sick and dependent and should behave in an accordingly passive manner". This is fundamentally the case in NICU, where the patients are incapable of asserting their independence. It may then be the case that NICU staff are correspondingly more likely to see themselves as being in full control of the situation. The comments that parents made regarding feeling as though they were irrelevant, or even a hindrance to the NICU staff, certainly fit in with this idea.

Communication and relationships were a very important part of whether parents had positive or negative experiences as a result of their interactions with staff. In terms of the way that parents related to staff, they felt there were two types of staff within the NICU environment and classified them accordingly. Parents either saw staff as being part of "the family" of caregivers, displaying qualities such as kindness; care; support and good rapport. Or they fell into the category of "outside the family", where parents described them as controlling; regimented; cold and aloof. In the majority of cases, whether a staff member was "inside" or "outside" the family did not necessarily correlate with parents' opinions of their professional competence.

This fits with Medalie and Cole-Kelly's (2002) description of the functional family during a health crisis as including caregivers and health professionals, in that even without consciously thinking about it, parents consistently described staff in terms related to family membership. Some parents even made a conscious connection with these ideas, and described staff directly as being like a member of the family during their baby's stay in NICU. However, there may have been more at stake for parents than the question of whether staff members were part of the family or not. In descriptions of the staff members who saw parents as being a nuisance, or irrelevant, and for whom the baby was the limit of their concerns, there is an indication that in fact some staff members may have seen themselves as being the core members of the baby's functional family. For parents dealing with this belief system, the question for them is not whether staff members belong in the functional family, but whether they themselves are part of the functional family of their own baby. Again, these problems were more acute for

fathers than for mothers, with fathers feeling as if there was no purpose to them being within NICU.

There may have been a recent emphasis on "family-oriented" care in hospitals, but Petersen, Cohen and Parsons (2004) reported that although nurses generally agreed that family-oriented care was necessary, they did not consistently apply the relevant principles in their nursing practice. Interestingly, they also found that NICU nurses gave lower ratings to the importance and practice of family-oriented care than paediatric and paediatric intensive care nurses. This fits with the comments made by parents in that they felt included or excluded from the situation to different extents with different staff members. One couple commented that the head nurse of NICU deliberately fostered a family-oriented approach, but that some of the staff members on the unit did not follow these ideas, and were focused solely on their specific role as the carer for the baby, with no interest outside this scope.

In addition, one of the recommendations of the report by Petersen et al. (2004) was that in order to implement family-oriented care effectively, modifications to the physical environment may be necessary. This touched on another of the issues that parents commented on in the current study, in that the lack of space within NICU meant that parents were in close proximity not only to other babies and parents (the incubators in NICU are much closer together, of course, than ordinary beds in a hospital ward), but also to NICU staff. In situations where parents were already struggling with issues of control with staff, they felt that the close proximity exacerbated their feelings of being

watched over, so the physical environment was not only daunting in itself, but affected the way parents felt about their relationships with staff.

Parents also said that their experience would have been improved if there had been additional space away from the NICU ward itself, partly so that families could be together, but also to facilitate communication with medical staff. Parents found it difficult to gain information from staff in the stressful and busy surroundings of NICU, putting further barriers in the way of them gaining control over the situation.

The specific recommendations that were made by Petersen et al. (2004) were very similar to the changes that the parents in the current study suggested, in particular additional space that was more "friendly" than the forbidding physical milieu of NICU itself. Such space would be an environment in which family-centred patterns of behaviour could be conducted more easily, and that levelled the environmental balance of control away from medical staff and towards parents, in order to facilitate communication.

When we consider what parents' reactions might be to their seemingly inevitable feelings of loss of control, the behaviour constraint model proposes that a perceived loss of control leads to efforts to regain freedom of action. Averill (1973) identifies three types of control a person has over their environment. Behavioural control is where a person will modify their behaviour to increase their control over the situation. Cognitive control is seen where the person's control over the situation does not change but they modify their response to it, and reduce their stress levels, by finding out information

about the situation or reclassifying it as less stressful. Finally, people can exercise decisional control by making choices to maximise control and minimise stress.

In this study, cognitive control was used as a strategy by both mothers and fathers: they tried to understand the situation within NICU by seeking information about consequences and outcomes within the unit, as well as gradually being able to reduce their stress levels in response to monitor alarms going off, for example. The most notable examples of attempts at cognitive control were given by fathers, who described a strategy of trying to stay alert and understand everything that was going on around them. One father even specifically stated that he was aware that there was nothing he could do to influence outcomes directly (this was at the time his son was first admitted to NICU and put in an incubator) but that by trying to take on board all the information he could, he felt he would be in a better position to help his son in some way.

A necessary part of the strategies of control, of course, is access to information, either in order to be able to make informed decisions, or in order to understand the situation better and hence reduce stress levels and increase perceived control. As noted above, parents made both positive and negative comments on the communication and relationships they had with NICU staff, framing these in terms of whether staff were inside or outside the "family", but in fact there were relatively few comments about staff who were able to communicate information about the situation effectively. For example, one set of parents talked about conversations they had with two different staff members, one of whom told them their baby could be brain damaged and the other who told them that there may well be nothing to worry about. Although the parents felt a

much better rapport with the second staff member, and undoubtedly much less stressed after the second conversation, they did not in fact gain any more accurate information from either. Both staff members effectively told these parents that their child may be brain damaged, or may not. Given the choice, any parent would choose to feel reassured rather than to feel devastated, but in terms of access to information there did not seem to be much to choose between the two. Looking back at the parents' comments on these two conversations, it is apparent that neither doctor actually gave them a clear picture of the likely prognosis, or the relative probability of different outcomes.

Similarly, other parents talked about contradictory advice (on breastfeeding and other matters), an unwillingness on the part of NICU staff to give any indication of timescales for discharge, and information that was given to them but that they failed to understand. This included the nursing staff who explained the function of a multitude of monitors and alarms when babies were first admitted to NICU, when parents were almost incapable of taking in information. The functions of these devices and the implications of alarms going off were not subsequently explained again, and the process of parents adjusting to the NICU environment through cognitive control therefore seems to have been more arduous than it needed to have been. For instance, parents tended to learn the significance of particular alarms through a process of observing the nursing staff's reactions to them over time, rather than deliberate communication from the staff.

Some of the most worrying examples of lack of communication on the part of hospital staff were seen in relation to specific medical interventions, however. These included the caesarean of one mother against the evidence of her own well-founded estimate of

her baby's gestational age, and the couple who agreed to medical intervention for their baby in NICU while admitting that they had no real idea of what the options were. This suggests that the principle of informed consent was being stretched, at the very least. Orfali (2004) looked at comparisons between decision-making over healthcare issues in France, where cultural factors mean that parents tend to be more passive in the decision making process, and America, where parents expect to be more involved. The conclusions of her work were of interest in the context of the current study, in that parents' attitudes and reactions to NICU are at least partly culturally determined (and thus that the findings of the current study cannot simply be generalised across cultural boundaries). However, another observation that is particularly relevant is that healthcare professionals will modify their communications with parents to bring about the same results, despite the cultural differences of parents being more passive or more assertive in the healthcare setting.

The use of decisional control was also demonstrated as a coping strategy, but here the decision that fathers tended to take was to reduce their visits to NICU and instead return to work, or to playing sport instead, for example. It is inevitable that the decisions made to return to work, in particular, were prompted partly by work pressures, and most fathers commented on the difficulty of resisting these pressures for long, even with the most understanding of employers. However, it seems clear that a major factor in these decisions was where work pressures combined with the father's feelings of marginalisation and exclusion from NICU and caring for their baby. By returning to work, fathers could exert decisional control which reduced the stress of pressure to

return to work, while simultaneously removing them from a situation in which they no longer felt they could exert other forms of control.

Another factor to take into account when looking at fathers' decisions to return to work is the gender differences in relation to sources of stress, and in ways of coping with stress. Matud (2004) found that financial and work-related stress were two of the most significant stressors cited by men. What is more, men tended towards rational and detachment coping strategies, which fits with their decision to remove themselves from the NICU environment.

In addition to this, Sullivan (1999) found that the earlier fathers got to hold their babies the sooner they reported feelings of warmth and love towards them. While this may not be surprising, it does mean that a period in NICU immediately following the birth of a preterm baby may make it more difficult for a father to bond. In this study fathers talked about the fact that they felt alienated from their babies, that they felt their partners had more frequent and more protracted contact with their preterm infants, and that their partners had bonded more successfully than they had. In this situation, where fathers were not feeling a strong emotional bond with their babies, the rational and detachment coping strategies would indeed have remained viable.

All the parents in the study, then, struggled with issues of control, with some being more successful in these struggles than others. Bell et al. (2001) suggest that if efforts at reassertion of control over stressful situations are unsuccessful, learned helplessness may be the result. Learned helplessness effects are interpreted in terms of attribution theory

(Abramson, Seligman, & Teasdale, 1978), where attributions are inferences about causes of events or about characteristics of people or events. This theory tells us that helplessness effects are more likely to occur if we attribute our lack of control over the environment to stable rather than unstable factors, general rather than specific factors, and internal rather than external locus of control. It seems that some parents in the study reached the point of learned helplessness, as they referred to episodes during their baby's stay in NICU when they arrived on the ward, but then passively sat and waited for staff to give them permission to interact with their baby. They seemed to have given up trying to understand the restrictions around caring for their baby to the extent that they could make these decisions for themselves, and did not even actively seek permission or information from the nursing staff on their arrival in NICU for a visit. The fact that parents reached the stage of learned helplessness, even if only occasionally, suggests that their struggles for some degree of control over the situation had failed.

If we look at parents' feelings regarding their experiences as a whole, there is a lot of consistency in that all parents struggled with control issues, with coming to terms with the environment of NICU, with their relationships with staff, and so on. However, mothers seemed to remain engaged with the process throughout, however difficult they found it, and did not express the same level of helplessness, the same feelings of marginalisation, and ultimately the dissociation from the situation that fathers did. Considering the factors that influence parents' reactions to their experience, it is hard to avoid the conclusion that if you wanted to design an environment in which it was as difficult as possible for fathers to cope with around the birth of a baby, then the

environment that these fathers found themselves in would look very much like it. The initial stress of being unable to help either their newborn or their partner predisposed them to feelings of a loss of control; this was added to by the difficulty of adapting to the NICU environment; their instinct to reassert cognitive control was made more difficult by the difficulties in communication with staff; their level of contact with their newborn was reduced more significantly than the mothers'; and finally they received the message that they were superfluous to the situation, simultaneously with a strong pressure to return to work, both of these working together with their natural responses to stress, and their coping mechanisms.

Seen in this light, it is not surprising that the fathers in the study tended to withdraw from the situation to a greater or lesser extent. If we consider what the impact of this might be, there are some unexpected possibilities for the long term consequences. A longitudinal study by Levy-Shiff, Hoffman, Mogilner, Levinger, and Mogilner (1990) found that where fathers visited their babies in NICU more frequently, this was correlated with better bonding and more positive fathering both at discharge and follow up (at 8 and 18 months post discharge), which does not seem too surprising given the above discussion. However, more frequent visits by fathers were also associated with better weight gain and outcomes for the baby. This study cannot necessarily be used to demonstrate a direct causative relationship (although the authors do propose some possible mechanisms), but it should at least be taken as supporting evidence for the importance of facilitating early contact between fathers and their premature babies.

Another possible longer term consequence of the problems that parents had in relation to their difficulties in gaining information from hospital staff is that they may leave NICU without having a clear picture of the possible long term effects of the premature birth. Previous studies, including Simons, Ritchie, and Mullett (1998), have found that parents of babies in NICU retain only a proportion of the information about medical diagnoses that they are given regarding their babies, and also that parents' understanding of the current and future implications of these diagnoses was questionable. Of the parents in the current study who had had their premature babies within the previous year, none of them mentioned any concerns about the possible future health effects of their baby's prematurity, despite the high number of chronic complications that can arise as a result of an early birth. The parents whose babies had been born more than a year before had already coped with, or were continuing to cope with the crisis that had arisen later on when it became apparent that the health effects of their baby's stay in NICU could last well beyond discharge from hospital.

In conclusion, throughout parents' experiences of their baby's premature birth, one overarching theme emerged that in retrospect was important not only in the experiences of the people I talked to, but also in terms of the questions I had decided to ask in the first place. This is that parents felt that in having a premature baby who required a stay in hospital, the normal experience of having a baby had been interfered with. The other major themes discussed above all fit to a greater or lesser extent within this theme. For people who have not experienced a premature birth, this theme does not include things that on the face of it they might expect to find in parents of a baby in intensive care, such

as fears and worries about whether the baby is going to be OK or not, or gratitude that things worked out OK. The interviews initially showed a lot of comments from parents about how the NICU staff were really good and competent and calming and so on, but then further on in the interview, parents started to talk about their unhappiness with the fact that some of the NICU staff would rather give bottle feeds than breast feeds, and that the staff did not like people staying too long in the unit, and that there was nowhere to go and just sit with your baby, and many other similar feelings. Even the Trees and the McFoleys, both of whom presented themselves as being reasonably forceful and assertive couples, seemed to struggle against being trammelled away from just being with their babies and doing normal "parent with newborn baby" things. This overall theme of parents having to struggle against the alteration of their normal parental role tallies with the findings of the earlier studies by Hughes et al. (1994); Moehn and Rossetti (1996); and Shields-Poe and Pinelli (1997), and is intimately bound up with the struggle over control issues that all the parents faced through their experiences in NICU.

However, this theme is also reflected in the questions I decided to ask up front, within the structured interview guideline. How did you find the NICU staff? Were there any problems with the rules about visiting hours? How did you feel about the fact that the labour ward was not in the same part of the hospital as NICU? Did you get to do kangaroo holds and other cares with your baby? Was there enough space to just sit and be with your baby? In terms of my own experiences informing my approach, the fact is that I am a very assertive (to the point of non-compliant) consumer of healthcare. I had already had three babies, including two home births, and I had very clear ideas about

how I wanted things to run, and found myself kicking against the system to get what I wanted rather than being helped by it, this frustration being one of the main reasons that I was drawn to the research topic in the first place.

I think it is unlikely that anyone who had not been through the experience themselves would have focused to the same extent on those topics; the questions would more likely all have been about how people coped with the fears and the worries of their baby being in NICU, rather than how they coped with the mechanics of not being able to care for their baby as they wanted to.

It could be argued that this is a measure of how good the NICU staff are: that they can allay parents' fears to the extent that they are free to worry about the mechanics rather than worrying about whether their baby is OK or not, but alongside all the frustrations of seemingly trying to fight against the system, the underlying worries of the baby's health and wellbeing are also never far away.

In considering the scope and application of the current study, the parents who took part were middle class and of similar socio-economic status, mostly tertiary educated, and with only one exception, white. There are good reasons for ensuring that future studies involve parents of different cultural backgrounds, as cultural factors can influence people's reactions and experience of NICU. Orfali's (2004) study discussed above suggests that parents who are used to operating within a different set of cultural values may find it even more challenging to strike a balance of power and control with NICU staff. Again, because of cultural differences, the findings of this study cannot

necessarily be generalised to parents' experiences of premature birth within other cultures, because hospital staff as well as parents are subject to cultural factors.

Of the five families in the study, three had their premature baby at the same hospital (also the same hospital where I had my premature baby), which will have tended to emphasize certain aspects of parents' experiences that may not be universally relevant. As noted above, the physical layout of this hospital was a particular problem, for example.

The parents in the study were also of a similar age when their premature baby was born, being older than average. This is unsurprising given that the rates of prematurity are higher for older and younger mothers, but it may be that young parents' experiences of premature birth differ from those of older parents (although it seems unlikely that younger parents would find the experience any less stressful).

Listening to other parents talk about their experience of having a premature infant has been a tour of enlightenment. There were common aspects of their experience that made me say mentally, yeah I can remember exactly what that felt like, and there are moments where I take a huge breath and think boy am I glad that wasn't what happened for me. Through writing up this research project my partner and I have revisited many aspects of what the experience was like for us, and though I would like to say that the further you get away from the event the less emotionally upsetting it becomes, I would have to say that for us this is not true. When Ted Summer talks about watching the Video of his son Tim taken in the first few weeks of his life in NICU, and that it still makes him cry

watching it, I have this to say to him: those feelings are never going to go away. Every time you get out the photo album or the video tape, it is like stepping back through those doors into NICU. The immediacy of the situation comes flooding back and those feelings of disbelief, wonder and fear will once again have you in their grip.

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