BECOMING A PARENT TO AN INFANT REQUIRING NEONATAL INTENSIVE CARE

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Doctor of Philosophy

2011

Abstract

The number of babies that require care in the Neonatal Intensive Care Unit continues to rise in the UK and parents who have a baby who is born sick or prematurely find themselves adapting to this stressful and often unexpected event whilst also trying to establish their role as a new parent. With no current large British studies, this study explores the experiences of both mothers and fathers in the NICU in relation to adaptation and parental role development and how their experience changes over time.

In total 76 parents were interviewed using semi structured interviews 7-10 days following the birth to capture their early experiences of the NICU and then again beyond 28 days to explore any changes in their views and feelings over time. Interviews were tape recorded, transcribed verbatim into the written word and imported into WINMAX PRO. Data analysis revealed nine major sections. These are preparation prior to birth, labour and delivery, first sight of infant, support from the partner, family, friends and other parents, support from and communication with staff, adaptation to the NICU experience, development of the parental role, changes with time and the experiences of fathers.

Findings show differences in what mothers and fathers find stressful about their NICU experience, how they adapt to the birth of a sick or premature infant and in their development of the parental role. With the passage of time the events surrounding the birth became less significant as parents start to look to the future. Their role as a parent continued to develop with feelings that their baby needed and recognised them, but many parents felt that they were unable to influence what happened to their baby in the NICU. Recommendations are made for further research and for changes to NICU practice.

Acknowledgements

Firstly I sincerely thank my Director of Studies, Professor Sheila Glenn, for her ongoing guidance, support, patience and encouragement throughout and for which I am very grateful.

I also thank Tina Lavender, Maureen Hogan and the Steering Group for their personal support and for their ideas and suggestions.

I am grateful to Tilly Reid for giving me this opportunity, for sharing all her knowledge and experience with me and for her assistance in the project.

I am also grateful to Liz Craig, Penny Newmarch, Michael Weindling and all the incredibly professional staff at Liverpool Women's Hospital's NICU who welcomed and supported me during the time I spent there.

I am also indebted to Angela Carton and St Mary's Hospital NICU, my place of work, for their faith in me and in their ongoing commitment to allow me to undertake this study.

In the words of many of the parents in the study describing their partner support, I thank Kevin, my husband for "just being there" for me. He and our families have been a constant source of encouragement.

Lastly, I am most thankful to all the amazing parents who participated in the study and gave up their precious time. Whilst many told me that they found the interviews helpful and "therapeutic", I know that sharing their thoughts and feelings with me was also a deeply emotional experience for them.

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Chapter 1

This chapter will introduce the thesis giving a brief summary of each chapter.

Chapter Two is the introduction to the thesis giving a brief account of the history of neonatal care with particular reference to prematurely born infants. Literature is reviewed that considers survival rates of infants born from 23 weeks of gestation. A section follows reviewing the literature on the incidence of neurological and developmental disabilities in premature infants. The birth of a premature infant requiring neonatal intensive care is a stressful event for parents, and the chapter then reviews literature that has addressed the factors following the birth and how they may impact on parental adjustment to their infant. First, theories of adaptation to threatening events are discussed followed by research specifically on adaptation within a NICU setting. The next section considers parental role attainment where most of the literature has considered maternal role attainment and identity, with relatively little research with fathers and paternal role attainment. The disruption in this process due to the birth of a sick or pre-term infant is then considered. This is followed by section on the development of parental attachment to full-term and pre-term infants. The chapter concludes by highlighting the fact that there are very few British studies exploring both maternal and paternal experiences in the NICU; most studies are quantitative and the few qualitative studies have small numbers of participants.

Chapter Three presents the chosen methodology. The rationale for the chosen research design is described in relation to the study's exploratory nature and aims to explore the experiences, views, feelings and beliefs of parents in the NICU. With the purpose of generating in-depth, rich descriptions of the parental experiences, the decision to employ a semi structured interview approach with a schedule of questions based on previous research findings and theoretical frameworks is described next. The next section presents how credibility, transferability and dependability were considered in their role of ensuring the study is trustworthy. A description of the researcher as the sole interviewer conducting the interviews, the difficulties that were encountered and how they were addressed is then presented. This section also includes how the interview data was recorded.

The method section follows starting with how participants were recruited and consented and the ethical issues relating to this methodological approach are examined. The exclusion criteria are presented in this chapter before the sample participating in the study is described. Pilot interviews with six parents follows before describing the characteristics of the NICU where the study was carried out in terms of the number of babies cared for there and the population it served. The rationale for choosing the appropriate settings for the interviews is discussed before the interview schedules are presented. The questions within the interview schedules have an order which was felt to be logical and aid flow of the interview and are listed next within this chapter.

The final section of this chapter presents the process of data analysis and how the recorded interviews were handled, sorted and analysed. The very lengthy process of transcribing and checking each recorded interview into the written word is explained before the decision to use the data analysis computer software package, WINMAX PRO is justified. Finally, the process of data reduction and coding is described.

Chapter Four contains the results of the two interviews undertaken at time point one (7-10 days) and time point two (after 28 days) referred to as Interview One and Interview Two.

The results are presented in the eight major sections that emerged from the data. These are preparation prior to birth, labour and delivery, first sight of the infant, support from partner, family, friends and other parents, support from and communication with staff, adaptation, parental role and changes over time. Throughout the results chapter there are tables of parental responses and quotations from parents to support explanations and descriptions of the results. A summary of results concludes this chapter.

Chapter Five presents the discussion arising from the results. An overview of the discussion revisits the original research questions the study aimed to answer before being introduced to the two sections of the discussion. These are recommendations for supporting parental adaptation and developing parental role and the practical implications for organisation of the NICU. Firstly, parental adaptation to the NICU experience is discussed in relation to Taylor's (1983) three themes of searching for meaning in the experience, attempts to regain mastery over the specific event and life in general and an effort to restore self esteem and feel good about oneself once more despite the consequences of the personal difficulties. Differences between mothers and fathers are explained along with how adaptation changes over time.

Discussion of parental role development is organised starting with events leading up to and around the delivery, through seeing the baby for the first time and first experiences of the NICU. Next follows a discussion of the significance of holding the baby for the first time for parents, the importance of being involved in the care of the baby and of spending time alone with the baby. Parental role development in relation to the support parents receive from their partner, family, friends and other parents is discussed before that of professional support and communication with neonatal nurses and doctors. Throughout the discussion, differences between mothers and fathers are considered along with the changes over time. The next section of the discussion examines the practical implications of the study findings for the NICU with suggestions of what would make the NICU experience easier for parents.

The strengths and limitations of the study are then presented and the final section of the discussion considers recommendations for future research.

Chapter 2

This research focuses on the adaptation of parents to the birth of an infant that requires neonatal intensive care. This chapter starts with a brief introduction to the history of neonatal care, followed by a section on the increasing survival rates of infants born prematurely. The birth of a premature infant requiring neonatal intensive care is a stressful event for parents, and the chapter then reviews literature that has addressed the factors following the birth and how they may impact on parental adjustment to their infant. Theories of adaptation to threatening events are discussed followed by work specifically on adaptation within a NICU setting. Much of this research is with mothers, with a relative paucity of work with fathers. The chapter concludes with a rationale for the present study.

At the commencement of the present research there was relatively little published work, particularly on paternal adaptation. Subsequently a little more research has been published, and where relevant, this has been incorporated into the literature review.

2.1 History of the NICU

The Neonatal Intensive Care Unit (NICU) environment, the treatment, care and outcome for those infants and families requiring care within those units has changed enormously, particularly since the mid 1900's when the NICU and the care of the sick, vulnerable and premature infant made the most significant advances providing the basics we now practise as modern neonatal care.

Respiratory Support

The primary means of giving the sick neonate respiratory support was the provision of supplemental oxygen up until the mid 1960's when the first attempts were made to provide mechanical ventilation to infants with respiratory disease, known then as hyaline membrane disease caused by surfactant deficiency in preterm infants. The availability of portable xray machines allowed those infants too sick to be taken to an xray department to have an xray performed within the NICU enabling paediatricians to make accurate evaluation of the disease and to decide on the appropriate treatment and management. Mechanical ventilation was attempted with varying success only in the sickest of infants at this time and its use has seen many changes since then as ventilatory techniques continue to be refined. The studies to evaluate the value of different ventilatory techniques in the sick neonate now enable the sickest infants and those of extreme prematurity, from as young as 23 weeks gestation, to successfully receive respiratory support. In our NICU's today, this respiratory support is mostly through the use of ventilatory techniques based on the use of continuous distending pressure ventilation using volume or pressure control, high frequency oscillatory ventilation and continuous positive airway pressure.

The efforts to ventilate sick infants using negative pressure ventilation have mostly been abandoned and other techniques such as liquid ventilation have yet to prove if they have any benefit to neonates but they are further examples of how the NICU has become a highly technical environment with many different types of ventilators used even within one particular NICU depending on the needs of the individual infant. Whilst the companies making the equipment used in the NICU are making ongoing efforts and have a greater awareness about the impact these machines have on us all in terms of the noise in the NICU, the room they need and even how they look to nurses who use them and to those parents and visitors who spend many hours by their side, they remain large, imposing and, for the safety of the infants needing them, have increasingly sensitive alarms. Basic ventilator dials are being replaced by touch screen digital screens giving in depth information and options to their users, all adding to the overall image of the NICU as a sophisticated, complex area.

When a new ventilator or any new piece of equipment is introduced to the NICU, as a neonatal nurse, the researcher is experienced and comfortable with the sights and sounds of the NICU yet is also aware of how "scary" it can feel to see, hear and be around that piece of equipment when it is unfamiliar. For most parents, the NICU environment is one that they have little or no previous experience so every sight and sound is a new one for them.

In addition to the way we can now successfully give respiratory support with mechanical ventilation to infants in the NICU, the use of antenatal steroids given to mothers by obstetricians before preterm delivery and the advent of surfactant therapy have made a huge impact on the severity of the respiratory disease and the ability to support infants with respiratory disease. The widespread use of antenatal steroids and surfactant therapy since the early 1990s has had an enormous impact on neonatal survival (Philip, 2005).

Thermoregulation

The newborn infant has, in comparison to the adult, a large surface area for a small body mass and therefore loses heat rapidly. As seen with very premature infants, the smaller the infant, the greater the heat loss is and the inability to regulate their own temperature in these vulnerable infants contributed to the high neonatal mortality rates seen at the end of the 19th century. In 1933, Blackfan and Yaglou were able to show that keeping infants warmer, significantly reduced mortality and Silverman and Blanc (1957) confirmed the benefits of regulating temperature. Effective temperature control using incubators resulted in improvements in survival but was not achieved in the NICU's until the 1960s. Even then, infants often needed to be covered in the incubator and disturbing them for parents to see or touch them or for procedures to be carried out would result in temperature falls sometimes taking hours to return to normal.

The incubators used today are far more efficient, achieve higher temperatures and have the benefit of producing high levels of humidity. They allow infants to be clearly and closely seen and monitored whilst efficiently maintaining a temperature within normal limits at all times. For parents, whilst the incubator is a physical barrier between them and their infant, they too can now see their infant clearly and are able to have contact with him/her without the fear of causing detrimental effect to their temperature.

Nutrition

Prior to the availability of nasogastric tubes and intravenous feeding, efforts to provide sufficient nutritional support for the sick, weak or premature infant were limited. Breast milk was allowed to drip into the mouth of the infant or breast milk was fed from a spoon into the mouth of the infant (Henderson, 2001) before nasogastric tube feeding was first introduced in 1887.

Formula milk feeds were first introduced in the 1920s (Philip, 2005) but breast milk, particularly the composition of that produced by mothers who have delivered their infants prematurely, remains the favoured milk of choice to give to those infants with an immature gastrointestinal tract. Where this is not possible formula milk produced specifically for preterm infants with a higher calorie and protein content than other infant formula is now available following its introduction in the 1980s.

The introduction of intravenous nutrition dates to as recently as the early 1970s but techniques to cannulate peripheral and central blood vessels now enables us to deliver minute volumes of intravenous fluids and drugs to the sick infant unable to tolerate enteral feeding.

Parental Involvement

The advances made in neonatology over time thankfully include the progress of parental involvement in the care of their infant and the role of parents in decision making processes about that care and treatment.

Historically, parents had no place in the infant nursery where they were very much excluded from any participation in the care of a sick infant up until as recently as the 1970s.

Pierre Budin in "The Nursling" in 1907 recognised the importance of encouraging mothers to participate in the care of their sick baby. Budin encouraged mothers to visit and breast feed their babies making the observation that mothers separated from their young soon lost all interest in those they were unable to nurse or cherish. Yet by the mid 1950s, whilst open and unrestricted visiting policies in children's wards became accepted practice, neonatal units lagged behind, concerned by the huge susceptibility to infection of the sick and preterm infant, and these infants remained in isolation with exclusion of any visitors including their parents in the attempt to reduce cross infection.

Following the new-found theories relating to parent-child attachment and bonding such as Bowlby's Attachment Theory (1958), and emerging evidence that infants who had been separated from their parents for a prolonged period following birth were more likely to return to hospital failing to thrive or victims of non-accidental injury, parental involvement was beginning to be encouraged and accepted.

The unrestricted visiting seen in children's wards was finally embraced by neonatal units in the mid 1970s following the work of Brazelton (1963) and that of Klaus and Kennell (1982) who promoted awareness of parent-infant interaction and the process of attachment.

On the whole, NICU's today employ open visiting policies for parents; they recognise the benefits of encouraging and involving parents in the care of sick infants. Whilst some NICU's employ a totally open and unrestricted visiting policy, others still impose certain restrictions on visiting, most often visiting by children, particularly those who are not siblings, because of the infection risks.

As a neonatal nurse, the researcher believes that nursing and medical staff do feel committed to supporting and involving parents and their families, educating and informing them about their infants' illness and empowering them to make the transition from hospital to home with confidence and ease.

Where possible, parents who know that admission to the NICU is a likely prospect for their infant, are offered opportunities to visit the NICU to help prepare them; they are encouraged to experience early parent infant contact even with the sickest of infants and both parents should be given the opportunity to understand the benefits and experience skin to skin contact with their infant in the NICU today.

Outcomes

With constant improvements in technology, expertise and treatments in the NICU, researchers report that survival for infants born preterm and/or very sick has greatly improved since the late 1970s. In addition, the gestational age and birth weight at which infants are now able to survive following preterm birth has decreased (Robertson, Hrynchyshyn, Etches and Pain, 1992). It is recognised that those infants of lower birth weights and gestational ages spend longer in hospital before discharge home and may have an increased likelihood of neurodevelopmental morbidity. Therefore, whereas the focus of some outcome studies is on rates of mortality, others examine the long term outcomes for NICU surviving infants and their families. Outcome studies equip obstetricians, midwives, paediatricians and neonatal nurses with the information relevant for their peer discussions and for those consultations with parents about the possible or probable outcomes for individual infants given their particular circumstances. They provide the background information to facilitate decision making with families and they fuel professional and public debate on the ethical and moral arguments concerning resuscitation and life saving measures for sick and preterm infants, the possible cost and impact on the infant, on the families who care for them and on society. Ongoing follow up studies are also necessary to reflect changes in neonatal intensive care practices, mortality and morbidity, and to update data. By their very nature, outcome studies reflect practices of that particular time and not necessarily current practice.

Survival

According to Hack and Fanaroff's (1999) review of worldwide literature, survival at 23 weeks gestation ranges from 2% to 35%. At 24 weeks gestation the range is 17% to 58% and at 25 weeks gestation the range is 35%-85%. Differences in population descriptors, in the initiation and withdrawal of treatment and the duration of survival considered may account for the wide variations in the reported ranges of survival.
In contrast to survival by gestation, Tudehope, Burns, Gray, Mohay, O'Callaghan and Rogers, (1995) reported survival by birth weight and compared survival rates, impairment and handicap rates between two eras, 1977 to 1982 (era 1) and 1983 to 1988 (era 2). Four year survival rates for inborn infants 500-999 g improved from 32.6% in era 1 to 49.2% in era 2 but for outborn infants the improvement between 31.8% and 53.6% was not significant. There were also significant improvements in survival for inborn infants in birth weights 800-899 g and 900-999 g between study periods.

Cooke (1994) reported outcomes for infants of 29 weeks' gestation or less, admitted to a regional referral NICU between 1980 and 1989. During the study period 823 infants of 28 weeks' gestation or less were admitted to the NICU, and 56.5% (465) survived to discharge with a further 21 subsequent deaths following discharge home. The EPICure Study (Costeloe, Hennessy, Gibson, Marlow and Wilkinson, 2000) remains the largest outcome study undertaken in the United Kingdom to date of infants born extremely preterm. Unlike most previous studies reporting outcome for extremely preterm infants, Costeloe, Hennessy, Gibson, Marlow and Wilkinson, (2000) reported outcome according to gestational age rather than birth weight categories and included details of all births during a ten month period in 1995 of infants believed to be born between 20 and 25 completed weeks in all 276 maternity units in the United Kingdom and the Republic of Ireland. These are the infants very much on the fringes of viability and the authors reported on survival and complications up to discharge from hospital.

4004 births were recorded in total with 811 infants being admitted for neonatal intensive care. It was reported that there were no surviving infants born at 21 weeks, survival to discharge for infants born at 22 weeks was 9.1%, at 23 weeks was 19.9%, at 24 weeks was 33.6% and at 25 weeks was 52.1%.

Rijken, Stoelhorst, Martens, van Zwieten, Brand, Maarten Wit, and Veen (2003) reported mortality outcomes for infants born in three health regions in The Netherlands in the period of 1996/1997. Neonatal mortality in this study was found to be higher in infants born in peripheral hospitals and then immediately afterward transported to an NICU, compared with infants born in a hospital with an NICU.

Of the extremely premature infants, the study group divided the infants by gestational age of 23 to 25 weeks (n = 23) and of 26 weeks (n =23). In the first group, 12 infants died (52%), in the second group 4 infants (17%).

On a smaller scale but more recently, Field, Dorling, Manktelow and Draper, (2009) assessed changes in survival for infants born before 26 completed weeks of gestation between the two time periods of 1994-1999 and 2000-2005 inclusive. The setting was a geographically defined health region in the United Kingdom and survival was reported of all infants born in 16 hospitals at 22+0 to 25+6 weeks' gestation to mothers living in the region during these time points.

The proportion of infants dying in delivery rooms was similar in the two periods, but a significant improvement was seen in the number of infants surviving to discharge. Of 497 infants admitted to neonatal intensive care in 2000-2005, 236 (47%) survived to discharge compared with 174 out of 490 (36%) in 1994. These changes were attributable to substantial improvements in the survival of infants born at 24 and 25 weeks. During the 12 years of the study none of the 150 infants born at 22 weeks gestation survived. Of the infants born at 23 weeks there was no significant improvement in survival to discharge in 2000-2005 (12/65 (18%)) in 2000-2005 (15/81 (19%)) in 1994-1999).

They concluded that survival of infants born at 24 and 25 weeks of gestation has significantly increased. Care for infants born at 22 weeks remained unsuccessful.

EPICure 2 looked at survival in 2006 of the 1,300 live births born before 26 weeks gestation in England only, compared with the larger, original EPICure study which looked at survival and outcomes of live births before 26 weeks gestation in the whole of the UK. This study group found that overall survival had improved to 52% compared with 40% in 1995, with significant improvements above 24 weeks gestation. However, survival below 24 weeks had not improved, nor had the serious complications experienced by these babies born before 26 weeks gestation in the neonatal period.

Neurological and Developmental Disability

A review by Hack and Fanaroff, (1999) of the world literature and their own experience in a NICU in the USA revealed the range of infants with a severe cerebral ultrasound abnormality is 10% to 83% at 23 weeks gestation, 17% to 64% at 24 weeks gestation and 10% to 22% at 25 weeks gestation. Morbidity increases with decreasing gestational age and birthweight and varies according to demographic and clinical therapeutic practice differences but when compared to children born prior to the 1990's, the rates of neurodevelopmental disability have, in general, remained unchanged.

Factors affecting these wide ranges of disability include possible poor reliability of determining gestational age and to selected survival of lower risk infants of 23 and 24 weeks gestation, whether the age of the child is corrected for preterm birth and the duration and rates of follow-up. There is also variation in the clinical diagnosis of cerebral palsy and definition of lesser degrees of neurosensory and cognitive dysfunction. Children from lower sociodemographic backgrounds are more commonly lost to follow up, which also may influence outcomes.

Wilson-Costello, Friedman, Minich, Fanaroff and Hack (2005) examined rates of survival and neurodevelopmental impairment at 20 months of corrected age among 500g to 999g birthweight infants born in a USA NICU during two periods, which coincided with before and after the introduction of surfactant therapy in 1990.

496 infants with birth weights of 500g to 999 g were born during study period I (1982-1989) and 682 during study period II (1990-1998).

Advances in neonatal intensive care resulted in survival rates for extremely low birth weight children increasing from 49% during period I to 67% during period II but neonatal morbidity rates had also increased during study period II. The overall rate of neurodevelopmental impairment increased from 26% to 36%. Rates of sepsis (from 37% to 51%), and chronic lung disease, defined as oxygen dependence at 36 weeks of corrected age (from 32% to 43%) both increased. Among children monitored, and compared with period I, in period II there were decreased rates of death and increased rates of survival with impairment but also increased rates of survival without impairment. The improved survival rates in the 1990s occurred with an increased risk of significant neurodevelopmental impairment.

Tudehope, Burns, Gray, Mohay, O'Callaghan and Rogers, (1995) study evaluated the impact of changing practices between July 1977 to December 1982 (era 1) and January 1983 to June 1988 (era 2) in a tertiary hospital on survival rates and 4 year neurodevelopmental outcome for infants of birthweight 500g-999 g. Rates of survival, neurodevelopmental impairment and functional handicap at 4 years were compared between eras. The chance of a survivor being free of handicap remained unchanged at 78% and 76% for the two eras, respectively. Although the absolute number of intact survivors more than doubled (41 versus 83) so too did the number of severe or multiply severe handicapped survivors (7 versus 17). Tudehope, Burns, Gray, Mohay, O'Callaghan and Rogers, (1995) concluded that the advances in neonatal intensive care for extremely low birthweight infants between July 1977 and December 1982 and January 1983-June 1988 resulted in an increased number of non-disabled survivors but had no impact on incidence of severe disability.

Cooke (1994) assessed 442 surviving infants, born at 28 weeks gestation and less, for disabilities at the age of 3 years. Whilst 63% of survivors in this population were functioning normally, 19% were reported to have a major disability of which 9% were severe. A further 9% were reported to have a lesser disability and multiple disabilities were found in 9% of these children.

In addition to survival, Costeloe, Hennessy, Gibson, Marlow and Wilkinson (2000) reported complications of prematurity antecedent of later disability. Of the 39% of this study population that were discharged home, 62% had oxygen dependence at 40 weeks postmenstrual age, or had treated retinopathy of prematurity, or had significant cranial ultrasound scan findings (one or more cerebral parenchymal cyst and/or hydrocephalus).

The surviving infants from this study have been followed up since discharge from hospital to monitor their development in infancy and childhood. Wood, Marlow, Costeloe, Chir, Gibson, and Wilkinson, (2000) evaluated all the surviving children from the EPICure Study when they reached a median age of 30 months. Disability (described as mental and psychomotor development, neuromotor function or sensory and communication function) was found to be present in around half of all survivors at 30 months corrected age, with a quarter meeting the criteria for severe disability.

General Health

It has been reported that significantly more very low birth weight (less than 1.5 kg) infants experience recurrent hospitalisations and ill health in comparison to control infants born at a normal birth weight. Furthermore, those children born at extremely low birth weight (less than 1kg) were found to be more likely to be re-hospitalised than those born at very low birth weight. Re-hospitalisation rates are at the greatest during infancy, they then decrease during early childhood but remain at three to four times that of the hospitalisation rates of full-term controls for 2 to 5 year olds (McCormick, Workman-Daniels, Brooks-Gunn and Peckham, 1993).

When comparing very low birth weight children and controls in later childhood the prevalence of hospitalisations and infections has found not to be significantly different by the age of 8 years (Hack, Weissman, Breslau, Klein, Borawski-Clark and Fanaroff, 1993).

In a 12 year Canadian follow up study Speechley and Avison (1995) reported physical health outcomes for 116 children who had been admitted to the NICU (Level 3 Nursery) and 137 to the Level 1 Nursery at a tertiary care hospital. NICU boys had more chronic physical health problems and had been hospitalized more often than boys who required Level 1 care. A larger proportion of NICU boys had a physical impairment. NICU girls had lower social competence, social support, and self-esteem than the Level 1 girls, and the impact of NICU admission on these outcomes was significantly greater for girls than boys.

Physical Growth

It has been established that weight and height of children born at extremely low birth weight are still compromised in later childhood with these children being significantly lighter and shorter than controls at the age of 8 years (Saigal, Szatmari, Rosenbaum, Campbell and King 1991).

Gross and Fine Motor Function

Boyce, Smith and Casto (1999) reported motor skills and the community living skills required for a child to function effectively in the community were particularly low in a study group of low birth weight children with intraventricular haemorrhage.
Few studies have considered less severe impairments than the diagnosis of cerebral palsy or a major motor impairment in surviving infants born at an extremely low birth weight. Marlow, Roberts and Cooke (1989) however, compared the motor skills of 53 children born at 1250grams or less at the age of six years with a group of control children matched by age, sex and school. These extremely low birth weight children did not have cerebral palsy and were receiving mainstream education. However, this study found that they had significantly more motor difficulties than the control children.

Sensory Impairment

Schraeder, Heverly, O'Brien and McEvoy-Shields (1992) reported that children who were very low birth weight had significant difficulties with skills involving visual-motor integration, spatial memory, and planning that necessitates the integration of visual stimuli.
In a group of 58 NICU graduate children of low birth weight and with intraventricular haemorrhage, Boyce, Smith and Casto (1999) found that visual impairments were the most frequently reported problem (25%), 16% had communication problems and 9% of their study population had hearing problems at a mean age of 7 years (range 5 to 8.5 years).

Wilson-Costello, Friedman, Minich, Fanaroff and Hack (2005) compared infants born in a USA NICU during 1982-1989 (period I) and 1990-1998 (period II) and with a birthweight of 500g to 999g at 20 months of corrected age. They found that with the increasing survival rates for these infants the rate of deafness had also increased from 3% to 7%.

Hack, Wilson-Costello, Friedman, Taylor, Schluchter and Fanaroff (2002) examined the neurosensory and cognitive status of 333 extremely low-birth-weight (less than 1000g) children born between 1992 and 1995 at 20 months corrected age and found major neurosensory abnormality was present in 54 children (24%), including 20 (9%) with deafness, and 2 (1%) with blindness.

Social Competencies and Behavioural Problems

In the study of 6 year old children born at an extremely low birth weight (less than 1251 grams), Marlow, Roberts and Cooke (1989) found that parents' and teachers rated these children as being significantly more overactive, clumsy and easily frightened than the control children. In addition, teachers rated the extremely low birth weight children as more fidgety and the researchers subjectively found them to be more inattentive or distractible.

Unlike physical health, the impact on social outcomes of admission to a NICU at 12 year follow up was reported by Speechley and Avison (1995) to be significantly greater for girls than boys. Girls admitted to the NICU reported lower self esteem, social competence, social support and school performance when compared with girls admitted to a Level 1 neonatal nursery.

School Achievements

Studies illustrate increased rates of schooling difficulties, a lower IQ and problems necessitating additional educational support are associated with children who were preterm and of a low birth weight in comparison with their peers born at term and at a normal birth weight (Saigal, Szatmari, Rosenbaum, Campbell and King 1991).
A comparison of children born at extremely low birth weight with matched controls at six years of age found that the extremely low birth weight children performed significantly less well than their controls in verbal and performance aspects of intelligence testing (Marlow, Roberts and Cooke,1989).
Schraeder, Heverly, O'Brien and McEvoy-Shields (1992) described differences in academic achievement and information processing skills between children born at a very low birth weight (less than 1500g) and their classmate peers born at a normal birth weight (above 2500g). They reported fewer very low birth weight children were promoted to second grade and that significantly more of these children required special services. Boyce, Smith and Casto (1999) also reported that almost a third of their sample of low birth weight children with intraventricular haemorrhage were eligible for special educational services.

Thus, although medical and nursing care for premature infants is leading to very low birth weight infants' increased survival, this has also been accompanied by an increase in disabilities. Parents of such infants not only have to cope with neonatal intensive care, but also with the knowledge that there may be developmental problems in the future. The review moves on to considering previous work on the adaptation of parents to their prematurely born infant.

2.2 Adaptation

It must be said that much of the previous work on adaptation to a traumatic event such as that of the NICU experience, attachment theory and parental role theory was carried out during the 1970's and 1980's with little since to change or challenge those theories. Therefore the following literature review contains much of that work, which despite the passage of time, remains relevant today.

The birth of a newborn infant and the transition to parenthood represents a life changing event and a period of stress for parents (Newman and Newman, 1988). The birth may bring about a period of disorder where parents of the newborn are confronted with the task of making relationship adjustments as they redefine their identities, relationships and roles with their partner, possibly their career and their other children (Hackel and Ruble, 1992).

If an infant is born prematurely or sick the stress experienced by parents is felt more intensely (Thompson, Oehler, Catlett and Johndrow, 1993). The admission of an infant to the NICU has been described as a crisis or threatening event for parents (Affleck, Tennen and Rowe, 1991) and adaptation to the event may have similarities to the adaptive processes of any individual facing a personal setback. Taylor (1983) developed a theory of cognitive adaptation to threatening events that has provided a useful framework when considering the adaptation of parents of premature infants.

Taylor's cognitive adaptation to threatening events

When faced with a traumatic or stressful event in their lives, most individuals have the ability to manage and recover from such an event without the need to seek professional help to do so. The process of adaptation and adjustment experienced by individuals suffering from a personally threatening event, such as the diagnosis of cancer, has been described in a theoretical framework of cognitive adaptation by Taylor (1983). According to Taylor (1983), the process of adjustment has three themes: A search for meaning in the experience, attempts to regain mastery over the specific event and life in general and an effort to restore self esteem and feel good about oneself once more despite the consequences of the personal difficulties.

The Search for Meaning

In the search for meaning, those individuals experiencing a threatening, stressful or unexpected crisis or event in their lives have a need to comprehend both why the event happened to them and what the impact will be (Taylor, 1983).

One of the ways in which meaning is addressed is to look for the cause of an event and is described by Kelley (1967) and Heider's (1958) attribution theory where in response to a dramatic, unexpected or threatening event, individuals attempt to understand and gain control over their lives by initiating a causal search and by making attributions. This search for a cause is central to the search for meaning by individuals who employ efforts to comprehend the event, why it has happened, the significance of it and the impact it has had.

Taylor (1983) described the search for meaning in relationship to her study of cancer patients who, in their attempts to understand why they developed cancer, could offer explanations for why their illness had occurred. In addition to identifying why the event had occurred, the search for meaning also involves appraisal of the impact it had on the victim's life with individuals reporting adjusted attitudes and appreciation of life, a change in priorities and a newfound knowledge of self.

Questions raised in the search for a meaning for those experiencing a cancer diagnosis are said to include "What caused this to happen?" and "What does my life mean now?" (Taylor, 1983).

Cause

Apportioning blame to someone or something following a traumatic life event has been associated with the search for meaning as individuals search for a cause, whether that is something that they personally have done or not done or as a result of the actions or omissions of someone else.

Tennen and Affleck (1990) reviewed published studies of how people adapt to a range of threatening events in relation to self blame or blame of others. Blaming of others and adaptation has been explored across a range of threatening or stressful events. They include mothers of seriously ill infants (Tennen, Affleck, and Gershman, 1986), individuals with a cancer diagnosis (Taylor, Lichtman and Wood, 1984), women who had experienced a recent miscarriage (Madden, 1988), young adults who had recently lost a parent (Horowitz, Weiss, Kaltreider, Krupnick, Marmar, Wilner and DeWitt, 1984), accident victims (Heinemann, Bulka and Smetak, 1988) and victims of rape (Meyer and Taylor, 1986).

Of the 25 published studies reviewed by Tennen and Affleck (1990), participants had experienced a wide spectrum of stressful or threatening events, being victimised directly by an event or illness (Graham, Thompson, Estrada and Yonekura, 1987) or indirectly by the loss or an illness of a loved one (Horowitz, Weiss, Kaltreider, Krupnick, Marmar, Wilner, DeWitt, 1984). They included children (Tennen, Affleck, Allen, McGrade and Ratzan, 1984) and adults, both men (Croog and Levine, 1982) and women (Mendola, Tennen, Affleck, McCann and Fitzgerald, 1990). There were participants in these studies who had experienced acute stressful events (Brewin, 1984) and there were those who had chronic problems (Affleck, Pfeiffer, Tennen and Fifield, 1987).

Data was collected at varied time points following the traumatic event, ranging from soon after to several years after and there were a range of measurements of adaptation outcomes.

Irrespective of the diversity in the participant characteristics, the traumatic event they experienced, the timing of the study in relation to the event and the measurements of adaptation used in these studies, Tennen and Affleck's (1990) review found a strong relationship between blaming of others and poorer adaptation and there was impaired physical and emotional health in those participants blaming others for their adversity.

In contrast, self blame has been claimed to be associated with successful adaptation to threatening events because by blaming oneself, a sense of gaining personal control of the situation is achieved (Affleck, Tennen and Rowe, 1991).

However, in comparison to blaming others, the review of adaptation studies by Tennen and Affleck (1990) found the relationship between adaptation outcomes and individuals who blamed themselves for the stressful or threatening event was less consistent.

Self blame was reported to be associated with poorer adaptation in rape victims (Meyer and Taylor, 1986) and accident victims (Nielson and MacDonald, 1988). There were others who found no relationship between adaptation and self blame (Affleck, Allen, Tennen, McGrade and Ratzan, 1985). However, there was a relationship between self blame and positive adaptation reported in mothers of acutely ill infants (Affleck, McGrade, Allen, and McQueeney, 1985), cancer patients (Timko and Janoff-Bulman, 1985) and among accident victims (Bulman and Wortman, 1977). In a study of mothers with infants who had severe prenatal complications, Tennen, Affleck and Gershman (1986) found that a significant number of mothers blamed, in some part, their infant's condition on their own behaviour. The more severe they perceived their infant's condition, the more likely they were to employ behavioural self blame and its relationship with positive mood state was mediated by the belief that they could prevent a similar circumstance occurring in the future and by doing so, held some form of control.

Finding Benefits or Gains

The search for enriching or beneficial meaning in the psychological reorganisation following traumatic events is described in theories of cognitive adaptation by Taylor (1983), Taylor, Wood and Lichtman (1983) and Janoff-Bulman (1992). Through the cognitive adaptation of finding good out of bad, the experience may lose some of its severity and can re-establish reassuring views of the individuals self and their environment. Taylor (1983) maintains that individuals bring meaning to their crisis event by believing that there is some personal gain, growth or benefits arising from the event. By reappraisal of the experience in a favourable or positive way, individuals can even see themselves as better off than before the crisis event had occurred.

When victims of a threatening experience have the ability to perceive personal benefits or gains from the event, their psychological and physical wellbeing is believed to be enhanced and therefore these adaptive measures are claimed to be valuable in the process of coping with such experiences (Taylor, 1983). The relationship of benefit finding and positive adaptation outcomes is supported by Thompson's (1991) study of stroke victims, Taylor, Lichtman and Wood's (1984) research of adjustment in women with breast cancer and by Affleck, Tennen and Gershman (1985) in their study of mothers of high risk infants.

Different categories of perceived benefits have been identified from threatening events (Taylor, Lichtman and Wood, 1984, Thompson, 1991, Affleck, Tennen and Rowe, 1991 and Affleck, Tennen and Gershman, 1985). These categories include a change in the individual's personal priorities and goals in life, the strengthening of relationships, either with a partner or with family and friends and a positive change in their personality or beliefs, such as becoming stronger, appreciating others or themselves more, greater courage or the development of greater tolerance.

There remain very few critics or challengers to Taylor's model and evidence continues to conclude that optimistic beliefs, however unrealistic they may be, are protective of health (Taylor, 2005). However, Shedler, Manis and Mayman (1993) argued that individuals expressing positive illusions were actually denying or camouflaging psychological distress and Colvin and Black (1994) evaluated the studies and evidence that support the theory that positive illusions foster mental health and concluded that it remained unproven.

Vincze (2010) study also doubted and set out to challenge Taylor's positive illusion theory however their findings did support the theory that mild positive illusions protect us from the harshness of reality and help maintain self esteem in demanding situations.

Downward Comparisons

Social comparison theory (Festinger, 1954) draws on the suggestion that people evaluate their circumstances against that of similar others and with the implication that they do so against others in more favourable situations or by making upward comparisons. Festinger (1954) hypothesised that people prefer to compare themselves to others with slightly better performance or capabilities and that social comparisons using upward comparisons create the drive to improve performance. However, in the process of adaptation to a threatening event, upward comparisons are thought to be unhelpful with the potential for the individual to feel disappointed and in a detrimental position in comparison to others (Taylor, Wood and Lichtman, 1983).

Taylor's (1983) adaptation theory proposed that those faced with a serious illness such as a cancer diagnosis, appraise themselves and their situation by making downward comparisons with those they perceive as suffering more or who are in worse circumstances in order that they feel advantaged. Taylor (1983) and Wood, Taylor and Lichtman (1985) found that women with breast cancer appeared to have actively searched for direct comparisons with other women or hypothetical women in relation to both their illness and their ability to cope with it, in order to enhance their feelings of being advantaged. Taylor (1983) thus claims that the psychological advantage of making downward comparisons is to self protect against threat and to enhance self esteem and is a robust method of minimizing victimisation with the claims that there are many other individuals worse off than the self (Taylor, Wood and Lichtman, 1983).

Affleck, Tennen and Rowe (1991) also found that mothers of infants who had required neonatal intensive care made downward comparisons. The mothers of larger infants compared themselves to mothers of smaller infants and the mothers of smaller infants compared themselves to mothers of very sick infants and many of their participants expressed the view that outcomes for their infants could have been worse, they might not have survived at all. Many of these mothers made the claim that they were advantaged because they were better able to control any negative thoughts or emotions, perceived that they were better informed about their infant's treatment and care and that they were developing a closer attachment to the infant in comparison to other parents.

In summary, individuals search for meaning from the experience of a threatening or unexpected event by employing processes which include reappraisal of the situation in order that the event could become meaningful. They may search for a cause, have the ability to find a purpose in the event, believe that there are benefits or gains. Victims of a crisis event have claimed that their experience could have been worse and made comparisons with situations less attractive than their own. The processes employed in the search for meaning protect against the threat and boosts self esteem and perceived personal control.

Sense of Mastery.

Taylor (1983) proposes that the second theme of the adjustment process focuses on the individual's attempts to gain personal control over the threatening event. The threat or crisis event like that of a cancer diagnosis is believed to challenge the sense of control over the individual's own body and over their life in general. With the feeling of achieving control comes the belief that there is an ability to manage the crisis or prevent it from happening again (Taylor, 1983).

It is argued that personally constructed feelings of control are associated with positive adjustment to illness. For example, the cancer patients who believed that they had some direct control over their illness or the reoccurrence of their cancer or that the physician caring for them had control were significantly better adjusted than those who lacked any perceptions of control (Taylor, Lichtman and Wood, 1984).

Attempts to gain a sense of mastery are believed to include the search for a cause. Taylor (1983) suggests that people who perceive a cause for their illness can distance themselves from that cause, can argue that their life before the diagnosis was in some way different from what it was after, therefore creating the sense that things were different. By perceiving that the initial cause was no longer in effect, a sense of mastery can be constructed.

Assuming control included efforts to have a positive attitude, sometimes using techniques such as meditation, self-hypnosis or positive thinking. They made changes to their lives or behaviour with the belief that it gave them the control to reduce the likelihood of a reoccurrence occurring and Taylor's work was supported by Affleck, Tennen and Gershman, (1985) who also found that causal attributions and perceived control had a positive relationship with adjustment and enhanced coping in their study of mothers of medically fragile infants.

The Process of Self-Enhancement

The third theme proposed by Taylor (1983) is that of efforts to enhance the self and restore self esteem. The experience of a threatening event or crisis is believed to reduce self regard or esteem even when events are beyond any control of the individual. Taylor (1983) then claims that many individuals, having experienced a crisis event, initiate cognitive means to raise themselves from the state of low self esteem.

The process and benefits to the adaptation process of making downward comparisons has been discussed earlier in this chapter, and in the process of enhancing self regard and self esteem, making downward comparisons appear to be made rather than making upward comparisons. Taylor (1983) found that women with a breast cancer diagnosis specifically selected comparison persons who were worse off than they were or in the event of no appropriate comparison being available, they were found to create a hypothetical comparison. Some of the comparisons made involved women who were worse off than they were physically, or in terms of severity of diagnosis and treatments but were seen to be coping well with their situation.

These downward comparisons enable the person experiencing the threatening event to feel better about themselves and therefore enhance their self esteem. The comparisons made with women who were perceived to be worse off but coping well not only served to improve self esteem but also functioned as a role model, in that they could inspire, motivate and be a source of information. Taylor and Lobel (1989) found that the social comparisons made by individuals in a crisis were with others less fortunate than themselves with the function of enhancing self esteem and also with more fortunate others to enable the individual to improve their situation and to increase hope and motivation.

In addition to making downward comparisons as a means to self enhancement, Taylor (1983) found that more than half of women studied with a cancer diagnosis perceived that the event had changed their life in a positive way and believed that they were better emotionally adjusted at the time of the interviews than they were before their cancer diagnosis. Viewing the life threatening event as the trigger to make changes in their lives, to their personal goals, changing attitudes or strengthening relationships are believed to also contribute to self enhancement and emotional adjustment to the event.

Defining causal attributions and pursuing efforts to achieve personal control over the threatening event or situation complete the elements involved in regaining self esteem and regard.

In the search for meaning, mastery and the attempts to regain self esteem, the functions of individual cognitions overlap and may serve several roles simultaneously and may mean different things under different circumstances. For example, the search for a cause, something or someone to blame may provide an individual with meaning to the crisis, may provide them with perception of personal control or mastery and also serve self enhancement.

The theory of cognitive adaptation to threatening events offered by Taylor (1983) therefore explains the cognitive adaptations made by those individuals who have suffered a personal crisis, in order to facilitate their return or possibly to exceed their former psychological performance. Whilst there can be overlapping of functions of the cognitive processes, Taylor (1983) claims that efforts to find a cause for the experience and the restructuring process around the meaning of the event are the focus for the search for meaning. The theme of mastery involves attempts to gain or regain control over the individual's life generally and over the crisis events. Efforts to restore self esteem are made through social comparisons with others perceived as less fortunate and by construing benefits or personal gains from the crisis.

2.3 Parental Adaptation to Neonatal Intensive Care

The birth of a sick or premature infant that requires admission and care within the neonatal intensive care setting shatters the assumptions and expectations of a pregnancy for the parents involved. Parents may not believe that they are physically, practically or emotionally ready for the birth of their infant, particularly if the normal process of preparation for parenthood is interrupted by the premature and often unexpected delivery of their infant (Affonso, Hurst, Mayberry, Haller, Yost and Lynch, 1992, Lindberg, Axelsson and Ohrling, 2007). MacDonald (2007) also found mothers experienced surprise when their pregnancy prematurely ended and there was a sense of loss of the opportunities to plan and prepare for a term birth despite the additional prenatal care and monitoring they had received as a high risk pregnancy. For the parents concerned, the experience has long been recognised and described as a stressful or crisis event (Caplan, 1960, Benfield, Leib and Reuter 1976, Pederson, Bento, Chance, Evans and Fox, 1987). Mothers can experience feelings of failure when they deliver a very low birth weight infant and experience anticipatory grief fearing the possible loss of their premature infant (Silcock, 1984) and grieving the loss of the hoped-for perfect infant (McHaffie, 1990).

Kaplan and Mason (1977) explored maternal reaction to premature birth using interviews and described the birth of a premature infant as an acute emotional crisis or disorder for the mother. Affleck, Tennen and Rowe (1991) explored how parents coped with newborn intensive care and also describe the experience as a crisis event for parents that is a psychological threat and challenge to parental well being.

The experiences and reactions of parents to the birth of premature or a critically ill infant that subsequently requires neonatal intensive care has been shown to evoke considerable psychological distress in mothers (Padden and Glenn, 1997, Davis, Edwards, Mohay, and Wollin, 2003).

It has been reported that mothers of premature infants have heightened levels of anxiety, (Kaplan and Mason, 1977, Jeffcoate, Humphrey and Lloyd, 1979, Gennaro, 1988, Gennaro, York and Brooten, 1990, Doering, Dracup and Moser, 1999, Padden and Glenn, 1987, Eiser, Eiser, Mayhew and Gibson, 2005). Carter, Mulder, Bartram and Darlow (2005) reported that anxiety as a maternal response to the NICU experience was increased in those mothers with less education in comparison to mothers with higher levels of education.

Whilst some report that mothers of preterm infants are not more depressed than mothers with full term babies (Madu and Roos, 2006), others have reported mothers with infants in the NICU have increased levels of depression (Gennaro, York and Brooten, 1990, O'Brien, Asay and McCluskey-Fawcett, 1999) and Davis, Edwards, Mohay, and Wollin (2003) found an association between education and depression in mothers with infants in the NICU. Those with higher levels of education and those who perceived that they received more support from nursing staff had fewer symptoms of depression. Using standardised questionnaires in a comparison of mothers and fathers psychosocial adjustment to the birth of an infant requiring neonatal intensive care, Doering, Dracup and Moser (1999) found that mothers were more anxious, hostile and depressed than fathers. Mothers were also reported to demonstrate poorer psychosocial adjustment than fathers to their infant's illness.

A longitudinal study in Germany by Kersting, Dorsch, Wesselmann Ludorff, Witthaut, Ohrmann, Hornig-Franz, Klockenbusch, Harms and Arolt (2004) again used standardised questionnaires, and reported higher values for anxiety, depressive symptoms and for traumatic experience for 50 mothers of premature infants in comparison to 30 mothers of healthy infants. This was the case at 4 time periods: 1-3 days after the birth, after 14 days, after 6 months and after 14 months.

At all four measuring time points (except 6 months), the mothers of the premature infants recorded significantly higher values for traumatic experience and depressive symptoms and anxiety compared with the controls. In contrast to the mothers in the control group, the mothers of the premature infants displayed no significant reduction in posttraumatic symptoms, even 14 months after birth. These authors concluded that the situation of a mother who has given birth to a very low birth weight infant is a complex, with long-term traumatic event necessitating ongoing emotional support extending beyond the period immediately after the birth.

The responses of mothers of infants in the NICU have been compared to those individuals experiencing other threatening or unexpected personal setbacks, such as the diagnosis of a serious illness (Taylor, Lichtman and Wood, 1984), the loss or illness of a loved one (Horowitz, Weiss, Kaltreider, Krupnick, Marmar, Wilner, DeWitt, 1984), that of accident victims (Heinemann, Bulka and Smetak, 1988) and mothers of seriously ill infants (Tennen, Affleck, and Gershman, 1986).

For the parents involved and experiencing the crisis of neonatal intensive care the process of adjustment to the experience can be explored using Taylor's (1983) theoretical framework of cognitive adaptation to a personally threatening event as described earlier.

The Search for Meaning

In the search for meaning, parents may ask themselves why they have had a sick or premature infant, they may make downward comparisons with others deemed less fortunate than themselves and explore how they, as parents or their infant may have benefited or gained from the experience

As discussed earlier the search for a cause or apportioning of blame particularly to oneself has been associated with successful adaptation to the stressful event, in that blaming oneself may enable a sense of personal control over the crisis situation. Indeed, Tennen, Affleck and Gershman's (1986) study of mothers with infants with acute problems requiring care in the NICU, found that self blame in these mothers was associated with the severity of the illness in their infants and also their belief that they could prevent a like circumstance from occurring in the future. Lee, Norr and Oh (2005) interviewed 50 Korean mothers of premature infants in the NICU and after discharge home. When these mothers were interviewed shortly after admission the authors found self blame to be a predominant theme with mothers trying to identify where her failure lay but these feelings of guilt and self blame declined over time. Very few studies exploring paternal adaptation exist however, in a small study of 12 parents, Taylor (2008) reported that many fathers expressed feelings of self blame believing that they were personally responsible in some way for the birth of their preterm baby.

In a Canadian study (MacDonald, 2007), 8 mothers with infants in the NICU were observed caring for their pre-term infants to provide a deep understanding of the personal experiences and interviewed using a semi-structured interview framework. A purposeful sampling technique was used to select potential participants 4 to 11 weeks after the birth of their premature infant and the infants were likely to be staying in the NICU for up to six additional weeks. These participants were selected when most of the neonates were assessed as being relatively stable. This clinical stability marked a time when less medical intervention was necessary so further contact was expected to occur between the parents and the neonate.

The interviews were followed up by weekly visits to observe, photograph and document the mothers' nurturing interactions with their infant.

MacDonald (2007) reported that the mothers' understanding of their own role in the NICU was unclear. During the initial interview, many of the mothers had confusion about their image and role. Mothers expressed a feeling of not having an image as a mother, described challenges to mothering, for example, trying to be strong, feeling guilt, feeling daunted and overwhelmed. Role negotiation was observed when routines were first being taught to parents. In observations, mothers were negotiating their role both with their infants and with the NICU staff as the infants were gaining strength and independence from medical equipment and as the nurses were encouraging and supporting parents in feeding and care giving routines. During the emergence of this role, frustration was noted on the part of mothers, particularly during medical setbacks, examinations or changes to nursing personnel or procedures.

MacDonald (2007) concluded that role negotiation, transition to the maternal role and developing the role as an advocate for their infant were all crucial factors that should be recognised, understood, supported and encouraged by family members and by hospital personnel in promoting maternal adjustment to premature birth.

Sense of Mastery

In the process of restoring mastery, the victim of the threatening event will make attempts to regain the perception of personal control over the situation (Taylor, 1983) and for parents of infants in the NICU; this has been described as they take over aspects of care giving responsibilities thus reducing their feelings of helplessness and increasing their perceptions of power and control (Affleck, Tennen and Rowe, 1991). The process of mastery was described as primary control by Affleck, Tennen and Gershman (1985) whereby the cognitive adaptations of some mothers of infants recently discharged from the NICU resulted in their belief and perception that they had personal control over their infant's future recovery and development. In addition, whilst several mothers felt they had no control over the recurrence of a similar crisis event in any future pregnancy, others were confident that life style changes and seeking specialised obstetric care would control their risk. Affleck and Tennen (1991) supported the view of Taylor (1983), reporting that mothers experiencing a greater sense of control before discharge of their infant from the NICU, continued to experience a greater sense of control two years later.

Some have argued that to perceive personal control over outcomes for their infant and to hold the belief that future development of their infant is dependent on their own actions may be maladaptive and cause greater distress, particularly if the developmental outcome expected or hoped for is not achieved (Thompson, 1981). However, Affleck and Tennen (1991) reported that the sense of control experienced by mothers was not altered by the infant's developmental outcome.

Mastery has been associated with power, enablement and parent's ability to personally care for their infants (Epps and Nowak, 1988).

The Process of Self-Enhancement.

In accordance with Taylor (1983) this process of self enhancement can be fulfilled by making downward comparisons with those less fortunate or by believing that one has gained control over the event or crisis situation.

For parents of infants in the NICU, the interruption in the attachment process and altered parental role impact on their self esteem as parents struggle with lack of control, ability to undertake care giving activities and their inability to make decisions for their infant. Sydnor-Greenberg and Dokken, (2000) suggest the process of restoring self esteem for parents with an infant in the NICU may be associated with parental involvement in the care of their infant. Their interpretation of the experiences told by three parents of infants in the NCU was indicative of a link between feelings of personal control over the progress of the infant and their ability to care for him/her. Restoring self esteem by defining the crisis event as beneficial (Taylor, 1983) has been identified by Affleck, Tennen and Gershman (1985) and described as a form of secondary control by mothers of infants recently discharged from a NICU. The majority of mothers in their study expressed their belief and appraised their crisis event as beneficial or purposeful with benefits described as spiritual, emotional and family relationship growth, a better perspective on life and with a greater appreciation of the infant. Lindberg, Axelsson and Ohrling (2008) interviewed eight Swedish fathers of premature infants and they also found that fathers identified benefits to their experience. The fathers in this study believed their relationship with their partner had strengthened and they felt a changed person with different values. These Swedish fathers also felt fortunate because the time that they had needed to spend in the NICU had given them the chance to get to know and bond with their baby in a way they wouldn't had the baby been born at term and felt better educated by the NICU staff helping them to care for their baby.

Other researchers have approached parental coping and adaptation to the NICU experience using alternative theories, such as that of Lazarus and Folkman (1984) where coping mechanisms are associated with dealing with a stressful event.

Using semi structured interviews and questionnaires, Hughes, McCollum, Sheftel and Sanchez (1994) explored the coping of mothers and fathers in the NICU. During the interview, parents were asked to describe the one most significant stressor in accordance to what they perceived as the most stressful in their individual experience to date. They were then asked to describe what they did to cope and completed ways of coping and appraisal of control questionnaires. Both emotion-focused and problem-solving means of coping were identified in this study and were related to communication with others and the seeking of social and spiritual support. Whilst the authors acknowledge they did not elaborate on gender differences, they recount mothers more often reported talking to their spouses for emotional or psychological support. In contrast, fathers more often described their interactions with medical staff to provide them with information.

Lau and Morse (2001) believe that using coping strategies that are emotion-focused are most appropriate and useful in the early stages of the stressful situation when parents may feel fear, anger, anxiety and powerlessness. Subsequently, problem-solving coping is more apparent where parents gain increasing control through seeking knowledge and information. It is argued that an individual's coping process as a parent in the NICU, whilst dependent on how the event is constantly being appraised, is also dependent on their personal characteristics, their psychological status, their gender and the availability of social support (Lau and Morse, 2001, Pinelli, 2000).

In reviewing cognitive appraisal and parents' coping in the NICU, Lau and Morse (2001) support the views that fathers and mothers cope differently when faced with the experience of having an infant that requires neonatal intensive care (Affleck, Tennen and Rowe, 1991, Hughes, McCollum, Sheftel and Sanchez, 1994).

Lau and Morse (2001) state that gender is a critically important factor that may influence the coping effort of an individual. In Western societies, girls and boys are socialized differently in respect of acceptable behaviours from an early age. Girls are taught to express their emotions, while boys are taught to hide them and therefore boys and girls cope differently when they encounter stressful situations.

Pinelli (2000) stated that mothers reported higher levels of anxiety than fathers in the acute phase of the NICU experience and acquiring social support, seeking spiritual support and mobilizing family to acquire and accept help were all coping strategies that mothers reported more often than did fathers.

Over the years there has been little evidence to contest Taylor's adaptation theory and those that have, have been unable to substantiate their challenges in their research findings.

Vincze (2010) review found that despite robust data and influential arguments supporting positive illusion theory, some critics proposed that self enhancement reflects denial in the traumatised individual and camouflages psychological distress. However, Vincze (2010) own study with 102 undergraduate students was unable to support the assumption that self enhancement is also associated with denial.

Ratelle, Vallerand, Chantal and Provencher's (2004) challenged Taylor (1983) by proposing that it is the process of self-determined motivation that contributes in a beneficial way to an individual's mental health. Whilst their results could not dispute Taylor's (1983) theory of cognitive adaptation their findings claim to have important implications. Their (2004) results suggested that cognitive adaptation is achieved through the psychological process of self-determined motivation. Specifically, optimism, positive self perceptions and perceived control were associated with self-determined motivation (Ratelle, Vallerand, Chantal and Provencher's, 2004).

There is very little on longitudinal changes in adaptation following a premature birth, next to nothing on fathers, and much of the work is quantitative, and the qualitative work is on small samples. Therefore, I did a more extensive qualitative study focusing on maternal and paternal adaptation to the birth of an infant requiring care in a NICU 7-10 days following the birth and again after 28 days.

Adaptation to the prematurely born infant is also important for how mothers develop and attain the maternal role. The next section reviews work on maternal role attainment for term babies and premature or sick babies, as well as the little research on fathers.

Maternal Role Attainment and Identity

Rubin (1977, 1984) describes the cognitive process through which mothers make the transition during their pregnancy and the first month following birth to constructing a maternal identity. Her concept was drawn from her clinical observations of mothers and from those observations others have built upon and developed further the theories of adaptation to the parental role. In 1967, Rubin termed maternal identity as the goal or conclusion in the process of maternal role attainment, when mothers achieved comfort and confidence in their role as a mother.

Thornton and Nardi (1975) theorised that there were four stages in the process of maternal role attainment, anticipatory, formal, informal and personal or identity stages. Mothering behaviours are learned and reflect social norms of what mothers should or should not do in their role as a mother. The anticipatory phase during the pregnancy finds the mother seeking out role models (Rubin 1967) and begins social and psychological adjustment to the role by learning about the expectations of mothering. The formal stage, according to Thornton and Nardi (1975), begins at the time of the birth and the mothers' behaviours are influenced in the main by the consensual expectations of others. In the informal stage the mother begins to develop her own unique way of mothering and dealing with certain situations as she learns from her infant's cues and constructs the maternal role to fit herself according to her preceding experiences and her future goals. Then, during the final personal role/identity stage, as others accept the woman in her role as a mother, she herself feels a sense of security in her identity as a mother; she experiences a sense of harmony, satisfaction, a competence in the role and is emotionally committed to the infant.

Mercer (2004) makes an argument for replacing the term "maternal role attainment" with "becoming a mother". Becoming a mother is claimed to encompass the transformation and evolution of a mother's persona through four stages: (a) commitment, attachment, and preparation (pregnancy); (b) acquaintance, learning and physical restoration (first 2 to 6 weeks following birth); (c) moving towards a new normal (2 weeks to 4 months); and (d) achievement of the maternal identity (around 4 months).

Maternal role attainment occurs in progressive stages over a period of 12 to 15 months throughout the pregnancy and six months after the birth. According to Rubin

(1977) the process of maternal role attainment develops concurrently with the mother's binding in or attachment to her infant and each process affects and is affected by the other.

Mercer developed Rubin's ideas defining maternal role attainment as

"a process in which the mother achieves competence in the role and integrates the mothering behaviours into her established role set, so that she is comfortable with her identity as a mother" (1985 pg 198).

The maternal role was shown by Mercer (1985) to have been internalised over the first year following the birth of a child. Competence in the maternal role and feeling comfortable in her identity as a mother was found not to differ by age group (Mercer 1985).

When an infant is born, parents and family members experience a period of adjustment and reorganisation, a process known as the transition to parenthood (Hobbs 1965). The transition begins around the time of conception and continues throughout the pregnancy, birth and into the period following the birth. Goldenberg and Michaels (1988) estimated that the transition period ends somewhere between three months and over one year. The end brings about the end of the parents sense of crisis or change and there is a reorganisation of the family roles.

The ease of transition to the role, the nature of adjustment and the length of the transition period may be affected by many factors. Their impact on the transition to parenthood may also be affected by the interactions between those individual factors. Those factors include social support, the quality of marital relationship, parental efficacy, experiences with the infant and parental perceptions of the infant's temperament. Other changes that may affect parental adjustment during transition include restrictions of independence and freedom, disruption of old routines, sharing of affection with spouse and other children and re-examination of the commitment to the marriage (Goldberg and Michaels 1988).

Mercer (1981) concluded that research at that time found that the ages of 20 to 29 were considered to be the ideal psychological age for making the transition to motherhood. In comparison, teenage mothers are less able to recognise her infants' cues, to respond consistently to their infant (Mercer 1980) and were more insecure in their role than older mothers. The first time mother in her thirties by comparison, although has the potential for greater maturity, also has greater expectations of herself and the infant which affects ease of transition to the maternal role.

Maternal Role Attainment in Sick/Preterm Mothers

The experience of a high risk pregnancy has been suggested to affect a woman's feelings of personal control (Mercer 1990) and that the increased medical interventions contribute to a diminished belief of maternal competence in her role of protecting her unborn infant, a loss of autonomy and she may question her capabilities as a mother (Kemp and Page, 1987 and Mercer, 1990).

The birth of an infant born prematurely results in the process of maternal role transition being interrupted, often without any preparation and with uncertainties about the infant's health and survival (Mercer 1995). The formal stage of maternal role transition requires the mother to contend with the events around the time of the infant's birth, cope with any possible reasons for the premature birth, cope with the appearance of her infant, to grieve for the loss of the pregnancy and expectations. Blanch D'Souza, Karkada, Lewis, Mayya and Guddattu (2009) surveyed parents of preterm infants in six Indian NICU's and they reported high levels of stress in areas of parental role alteration, appearance of the baby and sights and sounds of the NICU. Many parents report feelings of shock, worry and fear when seeing their sick or premature baby for the first time and Gavey (2007) who interviewed 16 mothers of preterm infants in the NICU found they were overwhelmed by the sights and sounds of the NICU.

According to Rubin (1967 and 1984) the maternal role and maternal identity is acquired and modified within the situations of continual nurturing, care giving and feeding interactions with a full term infant for which the mother has complete responsibility. The infant, in addition to the mother, is very much an active partner in these interactions with mothering behaviours being in response to the infants own actions and behaviour.

In contrast to the mother of a term infant, the experience of the mother of an infant born prematurely or who is sick, differs in that she can make little contribution into decision making and care giving with regard to her newborn infant and mothers of infants needing NICU care have reported those feelings of lack of control and power (Wereszczak, Shandor-Miles, Holditch- Davis (1997).

Parents have limited sensory interaction with their infant because of the restrictions of the equipment used and because of the regimes of the NICU environment. The sick and fragile neonate has difficulty responding to external stimuli in an organised manner and can become overwhelmed by the instinctive parental attempts to hold, comfort and talk to their infant. The behavioural signs of these infants can be both unpredictable and difficult for a mother to interpret and react to. Infants' ability to respond and interact appropriately in their increased disorganised state may be unexpected by parents and can then lead to feelings of rejection and a powerlessness to comfort and connect with their infant.

With little evidence of their infants reciprocating parental interactions, getting to know their infant is described as a stressful and tentative experience. Mothers describe feelings of not knowing their infant and expressed concerns that the nurses in the NICU not only knew their infants better but could read and understand their cues better than they could and therefore responded better to the nurses caring for them (Padden and Glenn 1997; Scharer and Brooks 1994; Wereszczak, Shandor-Miles, Holditch- Davis (1997)). Adding to those concerns, mothers felt that it was the nurses that were first to recognise signs of improvement in their infant and had fears that their infant may become attached to someone else other than themselves and admitted to feelings of jealousy (Padden and Glenn 1997; Scharer and Brooks 1994).

Mothers have described the feelings that their infant did not belong to them, that the nurses held the power and had the control to make decisions and that they had to seek the permission of NICU staff to do anything with their infant. Mothers believed that the NICU staff were more capable in care giving activities and therefore disliked being watched by them fearing criticism (Scharer and Brooks 1994).

Mothers recognise vulnerability in their preterm infant; feel an increased need to protect their infant and therefore want to be with and at the side of their sick newborn infant (Padden and Glenn 1997). The need to protect their infant extended in some mothers because they held doubts about the capabilities of the NICU nurses to care adequately for their infant, particularly in their absence (Stainton 1992; Wereszczak, Shandor-Miles, Holditch- Davis (1997). Mothers believed that their presence encouraged and supported their infant and was ultimately central to their infants' recovery and survival (Lasby, Newton, Sherrow, Stainton and McNeil 1994) yet they have episodic and time limited contact with their infant.

Silcock (1984) and McHaffie (1990) found that mothers of preterm infants experienced an anticipatory grief at the likely death of their infant. When mothers were afraid their infant may not survive, some reported a fear of becoming too attached and even of distancing themselves either physically or emotionally from their infant in order to protect themselves from the pain of losing their infant if they did die (McHaffie, 1990; Wereszczak, Shandor-Miles, Holditch- Davis (1997).

Following the premature birth of an infant, parents have been found to experience a sense of personal failure, a consequent deterioration in self esteem and self confidence (Silcock 1984) and Mercer and Ferketich (1994) found that self esteem and/or mastery were consistent predictors of maternal competence. An increase in anxiety and depression in the mothers of preterm infants compared with that of mothers of term infants was reported by Gennaro (1988).

Jeffcoate, Humphrey and Lloyd (1979) carried out a retrospective study to investigate possible early bonding difficulties experienced by parents of preterm infants, compared with parents of full term infants. They also investigated parental attitudes towards the child 12 to 15 months later. Whilst the study involved small numbers, they found evidence of delayed maternal attachment in the group of families with preterm infants and a high incidence of negative maternal rating of own baby in comparison with expectations of an average baby. In addition, 2 out of the 17 preterm infants had been abused or neglected in comparison to none of the term infants in this study.

Zabielski (1994) conducted an exploratory and descriptive study with 42 first time mothers, 21 preterm mothers and 21 full term mothers to investigate the process of maternal role attainment in preterm mothers.

Mothers were interviewed once at approximately one year post-birth and completed questionnaires. There were no statistically significant relationships between length of gestation and any of the maternal role attainment variables and no difference was found between preterm and full term mothers in the mean timing of the recognition of maternal identity. However, a 10 week difference in the median timing of maternal identity recognition was found. 62% of the full term mothers recognized a maternal identity by two weeks after delivery, whereas only 24% of the preterm mothers experienced maternal identity recognition within this time frame. A statistically significant relationship was found between the timing of maternal identity recognition and maternal affective perception of the infant. The more positive the maternal affective perception of the infant, the earlier was the timing of maternal identity recognition. The study concluded that preterm mothers experienced a maternal role attainment process similar to full term mothers except that identity recognition was relatively delayed. The themes described by the preterm mothers tended to be qualitatively different and focused on denied maternal role experiences, especially denied contact with the infants and denied rights in relation to the infants.

Mercer (1990) claims that in the event of a high risk pregnancy, a woman's feeling of personal control is affected so that she questions her competence in her role of protecting her foetus and doubts her capability as a mother and Mercer and Ferketich, (1990) reported that unlike fathers, these mothers appear to be more attached to their foetus and subsequently their infant. Maternal desire to protect and ensure the welfare of their infant has been found to contribute to the development of the maternal attachment process (Condon 1985) so where a pregnancy is identified as high risk, the woman is more aware of the presence of their unborn infant and will be more inclined to make lifestyle changes to ensure the well being of the infant. Others however, report that the parental adaptation process of parents of full term healthy infants was not globally affected by an obstetrical risk when the infant is born full term and healthy (Wright and Belanger, 2000).

Paternal Role Attainment

Much less is known about paternal role attainment with most studies concentrating on the experiences of mothers. Much of the research concentrates on the role of fathers within the family unit, focusing on the traditional father role who is employed full time, is the breadwinner and has little care giving responsibilities, or the father who is becoming more involved and is taking on a greater care giving role. In Western societies, research findings highlight that more fathers are attending antenatal classes, the births of their children and have an expectation to be more involved than previous generations of fathers (Russell and Radojevic 1992).

There is little known about the experiences, perceptions and feelings of fathers of prematurely born infants. The development of their paternal role and identity for fathers of sick and preterm infants in the NICU faces different challenges than that of mothers of their infant.

Parents are separated from their sick or premature infant in the NICU but unlike mothers, fathers find there is little or no provision for them to stay within the hospital setting. Neonatal intensive care services are most often found within a hospital maternity unit and with exception of dire circumstances there is no provision for fathers to stay with his partner or with his infant. Unlike the provision of accommodation for parents of sick children on a paediatric intensive care unit, such services unfortunately remain limited in neonatal intensive care units. Adding to separation from their newborn infant, fathers may also experience time limited visitation resulting from responsibilities for caring for other children, the home and difficulties with travel and work commitments.

Levy-Shiff, Hoffman, Mogilner, Levinger and Mogilner (1990) found that fathers who visited more often were more likely to be involved in care giving activities, display positive affection and to hold their infant. The frequency of paternal visiting was a significant predictor of the father's relationship with the infant and the quality of the infant's development. Sullivan (1999) found that the earlier fathers held their preterm infant, the sooner they reported feelings of warmth and love for them and that holding their infant for the first time was reported as a significant event for fathers in the development of attachment.

Fegran, Helseth and Solveig Fagermoen (2008) found that fathers reported reluctance in holding their baby skin-to-skin in the beginning but that first experience transformed their relationship from impersonal to a relationship of belonging and protection. Fathers who were involved in an infant's care from an early stage felt their contribution to care was valued, they had an increased desire to be close to their infant, and they became more confident interacting with their infant.

A Portuguese study by Figueiredo, Costa, Pacheco and Pais (2007) examined whether there were differences between mother-to-infant and father-to-infant emotional involvement within the first few days after birth. Most mothers and fathers exhibited similar initial emotional involvement toward their infant and most showed positive emotions. There were very few negative emotions and these authors found that fathers showed less fear and mothers expressed more sadness. However only a small number of infants in their study were admitted to the NICU (14%).

The attachment between infant and parents has been emphasised as a key factor in promoting children's development; relevant research will now be described.

2.4 Attachment

Maternal Attachment

The term attachment was first employed by Bowlby (1969) to describe the characteristics of an infant's tie or bond to his mother and was defined as a unique relationship between two people that lasts through time by Klaus and Kennell (1976). The attachment process and the emotional links a parent has to their child are thought to progress and change over a sustained period of time, beginning with the planning of the pregnancy and the initial decision to have a baby. The attachment process continues to develop throughout the antenatal period as the pregnancy is confirmed and accepted by the mother although only a minority of women claim to have intense feelings of affection for their baby during the first trimester of their pregnancy (Belsky, 1999). The experience of feeling the movements of the fetus contribute to acknowledging the fetus as an individual and for the majority or expectant mothers, attachment begins when she starts to experience fetal movements for the first time and it develops gradually throughout the remainder of the pregnancy (Belsky, 1999). Siddiqui and Hagglof (2000) found that women who engaged in thinking and daydreaming about and interaction and affection with the unborn baby predicted greater attachment at 12 weeks post partum.

Klaus and Kennell (1976) identified several principles thought to be crucial in the attachment process and that govern a mother's attachment to her infant. They include the belief that there is a sensitive period in the minutes and hours following birth where close contact with the mother and father is necessary for later relationship development to be optimal. This sensitive period is believed to be a special, time limited period on which the long lasting relationship between the infant and parent is based and dependent upon. The period of time shortly after the birth has therefore been claimed to be a significant but not necessarily a critical period in the process of developing long term parent-infant relationships and attachments and was given the term, "bonding" by Klaus and Kennell (1976).

The term bonding describes the process by which a mother forms an affectionate attachment to her infant after the birth with the direction being mother to infant (Myers, 1984). The maternal-infant bond is facilitated by early skin to skin contact with their infant, mutual eye contact and suckling (Klaus and Kennell, 1976) However, Bowlby (1969) claimed that it was not the first hours after the birth that were crucial in establishing an effective relationship and bond between the mother and infant but the first six months of life after birth. Reviews of the literature (Goldberg, (1983), Myers (1984), Sluckin, Herbert and Sluckin, (1983)) also do not support the existence of a sensitive period following birth essential for parent-infant bonding. They claim there is no evidence to suggest that the parent-infant bonding process is irreversibly damaged if a mother fails to experience early contact with her infant and there is no reason for her not to develop attachment to her infant for that reason alone. The example of successful adoption for both infants and older children is used to demonstrate that attachment between the parent and child can occur without contact immediately following birth.

Regardless of these differences in actual timings, it is agreed that close contact between the parent and infant is important from the start of life in the development of their attachment to each other and for most parents seeing their infant intensifies and deepens their feelings of affection and attachment. This understanding has lead practices in the delivery room to immediate or very early and prolonged contact with the mother, skin to skin where possible and early initiation of mother-infant feeding practices. Factors such as eye contact or movements, positively received responses to the mother made by the infant, seeing, hearing, touching and holding the infant and finally undertaking the caretaking roles of the infant were all essential steps of attachment identified by Klaus and Fanaroff (1979). Moehn and Rosetti (1996) went on to produce the following steps:

Planning the pregnancy; Confirming the pregnancy; Accepting the pregnancy; Fetal movement; Accepting the fetus as an individual; Birth; Hearing and seeing the baby; Touching and holding the baby; Caretaking.

Goulet, Bell, Tribble, Paul and Lang (1998) identified three central characteristics, proximity, reciprocity and commitment, believed to be crucial to the attachment process as developed between parent and child in a natural setting. The first characteristic of proximity refers to the contact that parents utilise to interact with their infant through means of touch and visual contact. Reciprocity sees the child as an active partner in the course of parent-child interaction and communication and the development of attachment between the two depends on parents being able to understand their child's communication. Commitment refers to the continuing and lasting nature of the relationship the parent develops to the child.

Sluckin, Herbert and Sluckin, (1983) reviewed the factors that can influence the way in which a mothers reacts and behaves with her infant and report them to include, her experiences during the pregnancy and birth, her personality, her previous experience with babies, her own experience of being parented, the sex and temperament of the infant and her social and cultural background.

Positive attitudes during the pregnancy are associated with maternal responsiveness to their infants crying whereas mothers who are highly anxious during the pregnancy were assessed as having less satisfactory interactions with infants than mothers with low anxiety. Stress has been associated with less positive maternal behaviours and attitudes towards their infants (Crnic, Greenberg, Ragozin, Robinson and Basham, 1983).

The influence of experience as a mother can shape how she acts with her newborn infant in that a first time mother is more likely to feel an initial indifference to her newborn infant, be slower to respond to their baby crying and be more likely to be influenced by others than the more efficient appearing multiparous mothers.

Mothers have been shown to tend less to their female infants than to male and the temperament of the infant has been shown to affect how a mother responds to its needs as demonstrated by how she might respond differently to her different children.

As stated earlier, the time following birth when a mother first sees, hears and holds her infant is an important time for mothers to develop a bond to her infant. Most parents (over 95%) report that they love their babies by one month of age (Zeanah, Zeanah and Stewart, 1990) and at 3 to 4 months the process of maternal attachment has been observed to increase among mothers of healthy infants (Mercer, 1985, 1986). In contrast infant attachment is much less obvious during their first two months of life, where there is little evidence of preference for a particular individual to provide comfort. However, there are some subtle attachment behaviours, such as turning to the smell of their mother that are the basis for recognising different individuals and establishing attachment to the parent.

Between two and seven months of age the ability of the infant to respond, communicate and socially interact increases as they learn to smile, begin to vocalise, be interested in their interaction with others and they cry less. Infants in their first six months of life willingly accept comfort from any individual however, some mothers report that they are better able to soothe their infant when they are upset and infants at this age will interact differently with their parents and an unfamiliar person.

Around the age of seven to nine months of age, a change to become wary of those adults they are not familiar with occurs, they develop preferred attachment to a small number of caregivers who they turn to for comfort and nurturance and protest to any period of separation from them. The attachment behaviours of proximity seeking, protest at separation and stranger anxiety are therefore not shown until the infant nears the age of 1.

Paternal Attachment

Most of the literature on attachment theory focuses on the development of the bond between mother and child and it is argued that father to infant attachment is in fact, not so different from maternal attachment (Herbert, 1996). Nevertheless, there are obvious differences for mothers and fathers in the attachment process.

It has been suggested that paternal attachment appears to be less strong than maternal attachment for reasons based upon genetics, culture and custom. The human male is typically less responsive generally towards infants than females, and indeed, when observed; most male primates are protective towards the female and their young but are less nurturing than the female (Herbert, (1996) Sluckin, Herbert and Sluckin, 1983). Historically in our culture, fathers were not usually expected to perform care giving tasks such as feeding and nappy changing and traditionally their role was seen as the family member who went out to work to provide and to protect his family. This situation has changed significantly with fathers now being recognised as important participants in the care and nurture of their infants (Russell and Radojevic, 1992). Fathers now are usually involved with all aspects of child care and mothers and fathers can have less typical or traditional roles within the family unit. There has been an increase in dual-career families whereby both parents equally share child care responsibilities, work full time, part time or whereby it is the father who takes on the role as main child carer whilst the mother may be the one who returns to work (Russell and Radojevic, 1992). Despite these changes, it would appear that in the normal setting, paternal attachments do not grow at the same rate as maternal attachments because the degree of contact between the father and his infant is still less than that of the mother (Sluckin, Herbert and Sluckin, 1983). Despite this, Herbert's (1996) review found that most studies have reported that children do not demonstrate a preference for a particular parent and either will serve as an emotional haven.

Fetal attachment has been found to be a predictor of attachment to their infant in early infancy for fathers (Ferketich and Mercer, 1995) but where the maternal attachment process is triggered and developed as they experience hormonal and bodily changes and experience fetal movements, fathers lack that degree of intimacy or personal experience during pregnancy. Furthermore, the mother can control the father's access to his unborn infant (Stainton, 1990) and fewer fathers than mothers report interacting with the fetus (Weaver and Cranley, 1983).

In comparison to mothers, fathers report less intense feelings of attachment and affection for the baby during the pregnancy (Lumley, (1982) Belsky (1999)) however, a significant minority of middle class fathers have reported feeling love for their baby by the third trimester of pregnancy (Lumley, 1982). Weaver and Cranley, (1983) reported that the quality of the marital relationship was also a factor associated with father's development of attachment during the pregnancy.

Following birth, early father-infant interaction, contact and where fathers held their infants shortly after the birth have been found to correlate with increased attachment behaviours, like that of maternal attachment (Mercer and Ferketich, 1990). Fathers who held their infant shortly following the birth were reported to display more attachment behaviours than fathers who did not hold their infant until sometime later. The development of attachment between a father and his infants is also dependent on the father's past attachment experiences, his perception of the infant, and the pleasure or pain value he places on the events surrounding the infant's birth (Bowlby, 1982). For experienced fathers a positive labour and delivery experience, perceived paternal role competency, a positive relationship as children with their own mothers and infrequent contact with their own fathers were reported by Ferketich and Mercer, (1995) as the factors associated with greater paternal attachment to their infants. Mastery or a sense of control was found to be important in the attachment of inexperienced fathers to their infants (Ferketich and Mercer, 1995). But in contrast, Leonard (1976) found that the fathers of infants delivered by caesarean section reported more positive feelings about their infants with the alternative suggestion that fathers may place greater value on the infant following the stress of a difficult delivery. Grossman, Eichler, & Winickoff, (1980) also reported that fathers of infants born with lower apgar scores (again suggesting a more stressful delivery) expressed greater warmth towards their infant.

Like that of mothers, when Ferketich and Mercer (1995) compared attachment in first time fathers to experienced fathers and found that there were no differences between father-infant attachment supporting the notion that the relationship developed with a subsequent infant was as unique as with the first.

Parental Attachment in Sick/Preterm Infants

Some studies report that the experience of a high risk pregnancy does not affect the process of parental attachment (Kemp and Page, 1987, Mercer, Ferketich, May, DeJoseph and Sollid, 1988) whilst others establish that women who have a high risk pregnancy appear to be more attached to her fetus and subsequently to her infant than her partner (Mercer and Ferketich 1990). Women will often be more aware of their unborn child and will make changes to their lifestyles to ensure their infants wellbeing particularly in a high risk pregnancy where those lifestyle changes will be made earlier or to a greater extent with more frequent hospital appointments, possibly dietary modifications or restricting physical activities. These lifestyle changes that represent a parent's commitment and desire to protect and ensure the welfare of their child have been found to contribute to the development of parental attachment to an infant (Condon 1985). Mu (2004) found that high risk pregnant women begin the process of maternal role making by actively adapting their lifestyle and behaviour in order to protect their unborn baby. However, Wright and Belanger (2000) found that although high risk mothers were more involved during their pregnancy than low risk mothers, this greater involvement did not increase the attachment process.

In the high risk pregnancy the attachment process may be complicated by the pregnancy ending earlier than expected and the development of the parent-infant relationship being prematurely interrupted. Fegran, Helseth and Solveig Fagermoen (2008) compared the attachment experiences of six mothers and six fathers in a

Norwegian NICU within the first week after premature birth. One of the two main categories the study revealed was how parents were "taken by surprise". Parents described how unexpected and unpredictable aspects of becoming a parent of a premature infant had been for them.

Preterm or sick infants have several characteristics that differ from the healthy term infant and that are recognised as factors that may affect the attachment process. The physical appearance of a preterm infant differs from that of an infant born at term and has little resemblance to the infant that parents imagine they will have. Bialoskurski, Cox and Hayes (1999) study of maternal attachment in a NICU found that when the behaviour and appearance of the infant did not conform to maternal expectation, the formation of a bond may be delayed. This study supports the view that the attachment process is a dyadic relationship and that it is dependent on a reciprocal process occurring between the mother and her infant (Goulet, Bell, Tribble, Paul and Lang, 1998). The sick infant may not be able to play his or her part in the dyadic relationship and therefore the establishment of attachment in the NICU may be delayed. Furthermore, Bialoskurski, Cox and Hayes (1999) also reported that the presence of a third person in the guise of the neonatal nurse may impact on the attachment process between a mother and her sick infant. Whilst the neonatal nurse may act as a facilitator in the attachment process by encouraging physical and psychological contact between a mother and her infant, it is also possible for the neonatal nurse to hinder the attachment process if she asks the mother of a very ill, fragile and premature infant to touch her infant as little as possible.

In addition to their small, fragile and vulnerable appearance, preterm infants may be more hyperactive or more hypotonic than term infants (Eckerman and Oehler, 1992) and can be more difficult to settle once aroused (Holditch-Davis 1990). The helpless appearance of the preterm infant was suggested by Mercer and Ferketich (1990) to explain higher maternal attachment scores in high risk mothers when compared to low risk mothers in the early postpartum period.

Niven, Wiszniewkski and AlRoomi (1993) interviewed 30 mothers of preterm infants cared for in a NICU following discharge and when their infants had been home for at least four weeks. Maternal attachment to their baby during pregnancy, at birth, during the first few postnatal days, during the remainder of the infants' stay in hospital was discussed. It was reported that most mothers experienced difficulties in attachment throughout the infants' stay in hospital, especially in the immediate postnatal period. In 27 cases, these difficulties were apparently completely resolved when the baby went home. Factors which were related to attachment difficulties included shock, fears about the infants' survival, and previous reproductive problems.

Behee-Semler (1997) observational study, where 21 mothers were videotaped holding their infants in the NICU found that maternal behaviour in the NICU fell in the category of mild to moderate concern for attachment difficulties.

Feldman, Weller, Leckman, Kuint and Eidelman (1999) compared mothers of healthy term infants who maintained close proximity to their infant, mothers of healthy but premature infants who experienced some separation from their infants and mothers of very low birth weight infants who experienced prolonged separation and the potential of loss. They reported that attachment behaviours and representations were highest amongst the mothers of the term infants with a decline of such behaviours in the mothers who experienced initial separation and attachment behaviours declined further for those mothers who experienced the threat of loss and prolonged separation. These findings are supported by a study of the effects of premature birth on attachment at 6 and 18 months after birth. Borghini, Pierrehumbert, Miljkovitch, Muller-Nix, Forcada-Guex, Ansermet (2006) hypothesized that attachment representations would be altered during the first months after the hospital discharge. Fifty families with a premature infant (25-33 gestation weeks) and a control group of 30 families with a full-term infant were interviewed when their children were 6 and 18 months old. Infant risk was assessed in the premature infant group and they were separated into high or low risk. At 6 months, only 20% of the mothers of a prematurely born infant (30% at 18 months) had secure attachment representations in comparison to 53% for the control group (57% at 18 months). This study shows that parents of low-risk premature infants were as affected as parents of high-risk infants, yet in a specific way. Whereas distorted maternal attachment representations appeared as frequently in the high-risk group, disengaged representations were more frequent in the low-risk group. Disengaged representations are characterized by emotional distance and coldness in the parent-infant relationship, whereas distorted representations are characterized by emotional involvement but with preoccupation or distraction by concerns, being anxiously overwhelmed by the infant, and insensitivity to the infant's individual needs (Zeanah and Benoit, (1995).

Even less is known about the attachment process for fathers of preterm or sick infants requiring neonatal intensive care.

As with that of mothers, the development of the attachment process during the pregnancy may be cut unexpectedly short for the fathers in the event of a premature birth and in a study comparing normal pregnancies to high risk pregnancies where mothers required hospitalisation; fathers reported significantly lower attachment to the unborn child than mothers did (Mercer, Ferketich, May, DeJoseph and Sollid, 1988). The degree of control that father's perceive they have over the birth process may also affect the paternal attachment process when failure to achieve a set goal of having a healthy term infant at term following a normal labour and delivery signify loss of control (Casteel 1990).

Like mothers, early interaction between fathers and their infants has been found to correlate with increased attachment behaviours (Levy-Shiff, Sharir and Mogilner 1989) and Sullivan (1999) found that the earlier fathers held their preterm infant, the sooner they reported feelings of warmth and love for them and that holding their infant for the first time was reported as a significant event for fathers in the development of attachment.

In their study of twelve mothers and twelve fathers in a Norwegian NICU, Fegran, Helsethh and Fagermoen (2008) found that fathers' relationship with their child was experienced as more positive than the mothers' relationship. They found that although fathers were more reluctant to hold and be close to their fragile infant, when they were encouraged to do so, the experience was much more positive than they expected and more positive than experienced by mothers. Unlike the fathers, mothers wanted to be close to their infant but they experienced some negative emotions and they were inhibited by their own physical and emotional condition.

In a small Swedish study, eight fathers of premature infants perceived that they developed a stronger bond with their infant over time compared with friends who had babies born at term because the premature birth had given them time to spend with their infant, get to know him or her and to be educated by professionals (Lindberg, Birgitta; Axelsson, Karin; Öhrling, Kerstin, 2008).

2.5 Summary and rationale for the present study

The foregoing review has shown that extremely sick and very premature infants can now survive with the aid of increasingly complex and technological medical treatments. Infants born from as early as 22 weeks gestation are now being admitted to NICU's in the UK and for those born extremely preterm or with complex problems, it would be expected that they will require weeks and possibly months of care in the NICU should they survive to discharge.

Parents, particularly mothers, have reported that factors such as the increasingly technical NICU environment, the alteration in their expectations of their role as a new parent and the infant illness result in high stress levels. It is likely that this impacts on the development of the parental role, and is an area where nursing intervention and procedures are important.

There are currently very few British studies that explore both maternal and paternal experiences in the NICU. Many of the available studies are quantitative using questionnaires; however, to capture the experiences of parents from their perspective a qualitative approach is likely to be more informative. By exploring perceived stressors and parental beliefs about their role, their relationship with their infant and the role of social support, it will be possible to identify those families in need of further support. By understanding the parental experience the results may have implications for changes to nursing practices.

The transition to the maternal role is developed over time and eventually culminates in the acquisition of maternal identity. Previous research has demonstrated that infant characteristics affect this transition, together with perceptions of the birth experience, early separation, and infant illness. The present research explores the development of the maternal role over the time spent in the NICU.

Considerably less is understood about the transition to the paternal role, particularly with the changes from the traditional roles, working patterns and involvement of fathers. For those fathers of sick or premature infants the transition to the paternal role is, for the most part unclear. It has been shown that parental competence is a major predictor of parental attachment in both high and low risk women and their partners. However, fathers may have specific problems relating to worries about their partners health or recovery following the delivery. Other paternal problems may include relationship strain, early separation, feelings of isolation and lack of participation with a greater emphasis on the needs of the mother. There is the possibility of issues relating specifically to the development of the paternal role in the NICU such as practical worries, work commitments, financial worries or concerns about caring for other children, which require further enquiry.

Given the length of time that some infants and their parents now require care in the NICU, it was felt that it was important to explore how the parental experience, adaptation and parental role attainment in the NICU environment changed over time and not just at one particular time point during or after the experience like other studies.

Thus this is a qualitative, longitudinal study of adaptation and parental role development for both mothers and fathers who have an infant requiring neonatal intensive care.

The Research Questions

Both phases of this study aimed to explore the experiences of parents of newborn infants that were requiring care within a neonatal intensive care setting at different time points. The main research question was: Do mothers and fathers have similar experiences as parents of infants on a NICU? Specifically:

a) Do mothers and fathers have similar experiences as parents of infants on a NICU?

b) What stressors do they perceive?

c) What is the process of adaptation to having a premature or sick infant in the NICU?

d) Do parental views and feelings about their experience change over time?

Chapter 3

Methodology

In this chapter methodological issues are discussed. The process of choosing an appropriate research method and design for the research questions this study aims to answer are examined and justified.

The chosen methodological approach using semi structured interviews are then presented. The setting, the structure and the process of carrying out the semi structured interviews will be presented along with rationale for those decisions.

The research design was longitudinal, descriptive and exploratory using semi structured interviews. This chapter will describe the theoretical frameworks that underpin the study design and the chosen method of using interviews. The chapter will also examine the process of participant interviews as a research method, issues relating to the method and the rationale for using a semi structured interview schedule used during the interviews with parents.

The role of the researcher as the interviewer for all the semi structured interviews, the difficulties that were encountered and how they were addressed are explored.

The ethical issues relating to this methodological approach and this study are examined and how possible problems were addressed to protect potential and actual participants.

3.1 The Research Design.

The research design and the methods employed must be appropriate for the purpose of the enquiry and the questions the research proposes to answer. The research questions together with the related theoretical concepts and perspectives dictate the study design. The chosen design will then determine the methods for collecting and analyzing data in the study (Sim and Wright, 2000).

The purpose of the research questions should influence the strategies chosen. According to Robson, (2002) the purpose of an enquiry can be classified as exploratory, descriptive or explanatory. The purpose of the study however, may change as it progresses or it may encompass more than just one purpose.

Where the purpose of the study is explanatory, the questions asked are inclined to be specific, the search is for the answer to a particular query, so consequently, research questions commonly search for causal relationships to explain the phenomena or situation and may seek to test a hypothesis or theory. Explanatory research questions are therefore argued by Sim and Wright (2000) typically to employ quantitative data, but may also be qualitative (Robson, 2002).

The purpose of descriptive research, as the name suggests, is to offer a description of a situation or phenomenon. There may be existing knowledge about the phenomenon or situation from which further questions arise or a deeper understanding is sought. With pre-existing body of knowledge already established, the purpose of descriptive research is to further develop the existing body of knowledge; therefore the design and methods may be specific. Descriptive research may then develop a theory, expose or generate further questions which then may pave the way to develop a hypothesis or to base further experimental research. Descriptive research may be qualitative or quantitative.

Exploratory research questions seek to build theory in an area that lacks understanding, where the topic has only partially or never been explored (Sim and Wright, 2000) and where the purpose of the research questions are to find out what is happening, seek new insights, ask questions and assess phenomena (Robson, 2002). Where the research questions are exploratory and there is insufficient knowledge or understanding of the topic area, quantification may be inappropriate and the approach is usually qualitative.

This approach aims to discover and then explore the meanings of what there is in a unique field. Since the nature of the enquiry is to explore, the researcher has limited influence over variables and consequently it is necessary to employ an adaptable and flexible attitude. This open approach will allow the study to progress by following, exploring and probing any new areas (Cormack, 2000), and was the approach adopted in the present research.

Qualitative research methods have not traditionally been applied by those carrying out research in health care and the health care services. Researchers and health care professionals working in a clinical area with a medical or scientific background have been more familiar with the experimental quantitative research methods and designs (Pope and Mays, 2006). With the drive and a need to deliver evidence based health care, there have been arguments and beliefs that qualitative research methods are less valuable or scientific than quantitative methods and traditionally there has been a reluctance to employ such methods (Grypdonck, 2006).

The focus of health care is people and health care professionals are mostly involved with people during a period of ill health or illness. Research in health care has become increasingly interested in providing understanding of the person as a whole and not just knowledge of a particular illness. Qualitative research can be a valuable means of understanding the experiences, actions, emotions and perceptions of people, how they behave in a given situation or how they interact with the health care professionals they need (Holloway, 2005). The application of qualitative research methods have therefore seen increasing acceptance and interest in health care research and the methods used are recognised as more appropriate for some of the research questions posed by researchers (Pope and Mays, 2006).

This study aims are to explore the experiences, views, feelings and beliefs of parents in the NICU and exploratory research questions such as these, are therefore most often and best answered by qualitative data rather than quantitative (Robson 2002).

As with any research, the quality of qualitative research is central to its success and its worth. Good qualitative research is demanding and time-consuming, often more so than good quantitative research. The guidelines proposed by Elliot, Fischer and Rennie (1999) aim to reassure traditional quantitative researchers that qualitative research is methodologically rigorous. Their guidelines for qualitative research serve four functions: to contribute to the process of legitimizing qualitative research; to ensure more appropriate and valid scientific reviews of qualitative manuscripts, theses, and dissertations; to encourage better quality control in qualitative research through better self-and other-monitoring; and to encourage further developments in approach and method. In the attempt to produce quality qualitative research their seven guidelines described below have provided guidance for the research design of this study.

1. Owning one's perspective. Researchers should specify their theoretical orientations and personal anticipations. This disclosure of values and assumptions helps readers to

interpret the researchers' data and understanding of them, and to consider possible alternatives.

2. Situating the sample. Researchers should describe the research participants and their life circumstances to aid the reader in judging the range of persons and situations to which the findings might be relevant.

3. Grounding in examples. Researchers should provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them.

4. Providing credibility checks. Researchers may use any of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants (b) using multiple qualitative analysts to review or an additional analytical `auditor' to review the data for discrepancies, overstatements, or errors; (c) comparing two or more varied qualitative perspectives; or (d) where appropriate, `triangulation' with external factors or quantitative data.

5. Coherence. The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data.

6. Accomplishing general versus specific research tasks. Where a general understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified.

7. Resonating with readers. The manuscript stimulates resonance in readers, meaning that the material is presented in such a way that readers, taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.

The purpose of this type of qualitative approach is to generate in-depth, rich descriptions so the researcher can understand and explain parents' processes of adaptation and the meanings that parents draw from their situation.

In qualitative research, the common ways of collecting data are through observations, focus groups or group interviews and most commonly, individual interviews with research participants (Silverman, 2000). The process of interviewing research participants is characterised by the one to one interaction as a method to collect personal perspectives on the event and experience (Roberts, Priest and Bromage, 2001). Interviews are recognised as flexible and adaptable, giving the interviewer the opportunities to seek clarification and probe further and deeper to explore the participants' experiences, views and beliefs thus enabling a greater understanding of that experience. Whilst one to one individual interviews are the most common type of interview (Holloway and Wheeler, 2002), there are occasions when more than one participant is interviewed together. This type of interview was rejected as the study aimed to capture the experiences of individual parents and any differences between the mothers' and fathers' experiences of the NICU.

Interview types are commonly described according to the measure of how prescribed or set the interview questions are (Robson, 2002, Pope and Mays, 2006) and consideration was given to which interview type would be appropriate to answer the research questions. They may range from the fully or tightly structured interview through the semi structured interview type to the completely unstructured or informal interview type (Robson, 2002). In addition, the skills required of the interviewer were considered as they differ depending on the interview type. The less structured the interview, the more demanding the process is, requiring greater interviewer skill and expertise (Robson, 2002).

In the structured interview, a set of predetermined questions are asked and responses noted in a standardised manner (Robson, 2002) frequently using a structured questionnaire (Pope and Mays, 2006). This type was dismissed as a method for collecting data because although every participant is asked the same questions and the researcher will get the answers for set questions from each respondent in a structured interview, they do not allow for any elaboration. The structured interview has been described as a spoken questionnaire (Burnard, 2005) and similarities can be drawn between the structured interview and the self completed questionnaire (Robson, 2002). Therefore, the opportunities to explore and probe deeper for rich and meaningful data, to clarify responses or to allow participants to talk freely about their experiences would have been lost had a structured interview been chosen to collect data in this study.

The unstructured interview is one in which, only one or two issues may be covered but in great depth and the questions are generated from what the participant says following an opening broad question (Pope and Mays, 2006). Sometimes known as the in depth, non-directive or narrative interview, the unstructured interviewer will facilitate a detailed and often lengthy discussion or conversation between the interviewer and participant.

As there were existing research questions and theoretical frameworks underpinning them, the unstructured interview method was also rejected. Whilst wanting participants to talk openly and freely about their experience, the research questions were more likely to be answered and responses more relevant by using a semi structured interview approach with a schedule of questions based on previous research findings and theoretical frameworks.

Thus, the type of interview chosen was semi structured. Semi structured interviews are probably the most common of the three types of interviews (Burnard, 2005). According to Burnard (2005) the semi structured interview is one in which the interviewer either refers to a sheet which includes key areas to be covered during the interview or uses a set of preset questions but will add and include other questions in order to elaborate on responses.

In semi structured interviews the interviewer asks some specific questions to gain the information they require, opening the discussion with a question, listening and prompting the participant to answer the research question (Rubin and Rubin, 1995). Specific questions can be asked whilst also allowing for flexibility, spontaneity and freedom in how and when questions are asked, the time allowed to explore a question or response (Robson, 2002) as well as being open to new information.

As with any study, qualitative researchers must demonstrate methodological rigour and whilst the terms validity, reliability and generalisability are still common, terms more often used in qualitative research in establishing rigour or trustworthiness are credibility, transferability and dependability (Lincoln and Guba, 1985; Polit and Hungler, 1999).

A study must be evaluated in relation to the procedures used to generate the research findings to establish that they are trustworthy (Graneheim and Lundman, 2004). In this research the methodological procedures were scrutinised by a steering group of experienced researchers and their advice informed the methods from the outset. Credibility, transferability and dependability are terms used to describe the aspects of trustworthiness.

Credibility addresses the consistency between respondents' views and the researcher's representation of them, the issue that emergent themes and patterns can be substantiated in the data and the means by which the researcher ensures that the data has been analysed correctly (Polit and Hungler, 1999, Rolfe, 2006), Credibility of research findings can be achieved by member checking (returning to the participants following data analysis) or peer checking (using a panel of experts or an experienced colleague to re-analyse some of the data) Rolfe (2006). In this research, participants were re-questioned during the interview process and the researcher repeated responses back to them to ensure that the researcher fully and completely understood their responses. However, they were not asked to confirm findings after the data analysis process because of the further time demands this would impose on them and because most had either gone home or been transferred back to their local unit.

There is an argument that the researcher's in depth familiarity with the data and the subjects' world will affect the subsequent interpretation, that an independent researcher can never have that same involvement with the data as the principal researcher and that it is unlikely that two people will interpret the data in the same way (Cutliffe and McKenna, 1999). However, it is also argued that sharing data interpretation with colleagues provides an invaluable opportunity to challenge the robustness of the emerging themes (Appleton, 1995). Holloway and Wheeler (2002) refer to this process of 'peer debriefing'. They claim that peer debriefing may detect bias or inappropriate subjectivity and establish alternative explanations to the researcher's propositions and guard against the attempt to fit interpretations that cannot be substantiated by the data.

The process of coding during the data analysis was revisited by both the researcher for all of the interviews and a random sample of six interviews by three independent experienced researchers to confirm previously coded data to check both the stability and credibility of the data analysis.

The term transferability refers to the extent to which the findings of a study can be applied to a similar group or setting (Polit and Hungler, 1999). The comprehensive description of the characteristics of the setting, the similarities it has with other regional neonatal intensive care facilities in the UK, the participants, data collection, analysis and presentation of the findings in this research will enhance transferability of the NICU experience of parents in other NICU's in the UK.

Because of the large numbers of interviews undertaken over time in this study, dependability of data collected was ascertained by the use of an interview schedule. Whilst parents were encouraged to talk freely during the interview and some areas of interest were pursued when they arose during some interviews, the interviewer always ensured that all questions to all participants were covered at the end of the interview. Dependability of the findings has been addressed by the researcher revisiting all the transcribed and coded interviews to check for inconsistencies and for stability of analysis decisions and judgements made during the analysis of data.

3.2 Role of the Researcher and Ethical Issues.

I am a trained experienced neonatal nurse with extensive experience of interacting with parents of sick infants, and therefore have an understanding of the NICU environment; the illnesses or disease processes experienced by infants requiring neonatal intensive care and the vocabulary used. However, during the study, I did not give any direct nursing care to infants or families in the NICU or wear a uniform, and the research took place in a NICU not previously known to me. It was important that parents did not view me as part of the clinical team in order to support declarations made to them that any responses they made would remain confidential and not be discussed with those caring for them and their infant/s. It was also essential that participants perceived the interviewer as a researcher and not a nurse. Participants may be less likely to say what they really feel and think to a nurse caring for their infant, and more likely to give responses they thought the nurse wanted to hear in order to please them (Pope and Mays, 2006).

Personal characteristics such as class, race or sex can affect how the interviewer is perceived by the participant (Pope and Mays, 2006) and the general appearance of the interviewer is also thought to be of importance. (Cormack, 2000) advises that interviewers should preferably be close in age to that of the subjects and extremes of dress style, views or personal characteristics should be avoided to eliminate any risk of influencing responses from participants. Attention to appearance and care to dress in a neutral and neat style for the interviews was attempted to encourage participants to feel relaxed and comfortable with the interviewer and to reiterate to participants that the interviewer, although a neonatal nurse, was not connected in any way or part of the clinical team caring for their infant.

Participants in this study were themselves vulnerable in that they were parents of an infant that required neonatal intensive care services, sometimes unexpectedly, often with an infant that was critically ill or extremely premature or small. They were also going to be asked some potentially sensitive and emotive questions during the interviews and it was therefore agreed and appropriate that the ethical principles of beneficence, non-maleficence, respect and justice were adopted to protect participants.

Beneficence is the principle "to do good", non-maleficence is the principle "to do no harm". Beneficence establishes a person's right to benefits and to receive protection from harm (nonmaleficence). In research, guaranteeing this principle involves first giving a fair assessment of known risks and benefits and then monitoring the person's response during the study.

Respect for autonomy is the principle establishing a person's right to make a free and informed choice about whether to participate, not participate, or withdraw from a research study. Autonomy is based on the fundamental principle of respect for persons. There is no requirement that individuals be prevented from participating in a research study that involves risk. They must, however, be told about any potential risks and be allowed to decide whether or not to enter the study.

Justice is involved in research subject recruitment. Research subjects should be recruited from a broad population that reflects the diversity of our society, including gender, ethnicity, socioeconomic status and age. (Silva, 1995).

When parents were given information about participating in this study, they were assured that there was no obligation to be involved. They and/or their baby would not be viewed or cared for any differently (either positively or negatively) than any other parent and infant in the NICU should they choose to be involved in the study or should they choose not to participate. Indeed, it was probable that those caring for their baby would not be aware whether parents were participating or not and even if they were, confidentiality and anonymity was guaranteed. Parents were also informed that if they initially decided to be involved in this study, it was there right to withdraw from the study at any time and without consequence.

Before any interview, the researcher therefore discussed with participants the types of questions they would be asked and they were aware they were being asked to share an emotive experience and they were warned that they may find sharing and talking about their experience distressing. Indeed, for many, it was common for them to cry during the interview. They were always given the option to stop the interview process whenever they became upset or if they gave the researcher any reason to believe they felt uncomfortable in any way. All of the participants chose to continue with the interview after any episode of crying or any period of time that they needed to compose themselves and they never left the interview setting still showing distress. Participants were given the opportunity to discuss any other issues at the end of the interview. Before this, the last three questions of the interview, whilst based on parental role theory, were also purposely presented to participants at the end of the interview because they were more light hearted than others and helped serve to end the interview on a positive note.

Clarke (2006) warns that a researcher-participant relationship that becomes a friendship or personal should be avoided to ensure that the research relationship is non-manipulative and to eliminate the risk of participants divulging information, thoughts or feelings to the researcher that they may later regret. The researcher endeavoured to accomplish the balance between achieving the trust of participants and creating a comfortable connection so they were able to express their feelings and experiences whilst averting the potential for participants to agree to something or disclose information they later wish they had not. This practice of developing a non-hierarchical relationship between the participant and the researcher is sometimes employed in participatory research (Northway, 2000) to develop that participant-researcher rapport. Whilst developing and building a rapport with participants is believed to be central to the interview process (Clarke, 2006), the researcher avoided divulging private information about her own self, private life or family or developing a more personal relationship or friendship with participants,

With a neonatal nursing background, the researcher was aware to take care and be cautious about the motives of some parents to participate in this study. With or without being aware of it, some participants agree to take part in research because they think that they may benefit in some way. They may feel lonely, they may want to talk to a sympathetic listener or they participate because they want to express concerns, ask for help or ask for answers to their questions (Clarke 2006). However, the interview process should not be the arena to teach or counsel participants.

Pope and Mays (2006) state that interviewees are likely to ask questions and that by answering them, the interviewer may enforce their own views on the interview or by not answering them, lessen the participants willingness to answer subsequent questions. Where questions were asked during the interview process, the researcher usually asked if they could be revisited after the interview was completed. Some queries were simple and did not raise any ethical difficulties. Others, often those relating to specific care concerns, were sensitively dealt with, in agreement with the participant, without disclosure of information to others and without giving a personal opinion. For example, with issues or questions about infant care, the researcher would encourage participants to make an appointment to discuss those with a Consultant Paediatrician or Lead Nurse and in some cases made that appointment for them.

Recording interviews has the advantage of allowing the interviewer to concentrate fully on the interview process. The practice of writing notes during the interview may interfere with the interview process (Pope and Mays, 2006). The interviewee may interpret periods when the researcher is note taking as a sign that they are talking about something relevant or said something significant and when they are not, as a sign that the researcher is not interested in what they are saying at that point thus influencing a participants responses (Blaxter, Hughes and Tight, 2000). In addition, it is difficult for a researcher to ask questions, listen to responses and make notes simultaneously therefore some details may be lost when making handwritten notes during or after an interview has ended.

In contrast, the tape recorded interview is preserved in its entirety allowing complete, verbatim recording of both the interviewer's questions and the participant's responses which include hesitations, pauses, intonations and inflections (Sim and Wright, 2000) and although arguably time consuming and more complex to analyse, audiotapes can be transcribed verbatim.

Whilst some claim tape recording equipment may result in interviewees feeling anxious, finding it disturbing or intrusive (Blaxter, Hughes and Tight, 2000) and that it may take participants a little time to talk freely (Pope and Mays, 2006), others argue that they are not obtrusive once interviewees are accustomed to the equipment (Sim and Wright, 2000) and most people will agree to being recorded.

The two means by which interview data can be recorded were given careful deliberation. The steering group agreed that the advantages of using audiotapes in these interviews were greater than those of using handwritten notes. Audiotapes allow the interviewer to concentrate fully on the interview process, and unlike the note taking method, they are able to focus their attention on the interviewee and engage in appropriate eye contact and non verbal communication where appropriate without leading the interviewees (Blaxter, Hughes and Tight, 2000).

3.3 Method

Recruitment, Consent and Ethical Issues.

Ethical approval was sought and approved by the Ethics committees of the University department and the Local Research Ethics Committee (LREC).

Where possible, I approached parents away from the clinical area, typically on the maternity ward for privacy and to support the assurances described below. A written information sheet (Appendix 1) was given to parents along with a verbal explanation of the study to ensure that they were fully informed of the purpose, design and the dissemination of the research. Parents were then given at least 24 hours to consider whether they would like to participate before being approached again. Parents were encouraged to ask any questions and only if they were then happy to do so, an informed, written and verbal consent was obtained (Appendix 2). A telephone number was supplied with the written information so that any parents who were approached could contact the researcher with any queries.

Assurances were given to those parents who decided they did not wish to take part in the study that neither they, nor their infant would be treated negatively as a result of that decision. Participants were assured that the researcher was not part of the clinical team caring for their infant, any responses they gave would remain confidential and that their participation in the study did not involve any additional treatments or investigations for their infant.

Confidentiality and anonymity was assured and parents were able to withdraw from the study at any time with the guarantee that neither they, nor their infant would be treated any differently as a result of that decision.

Participants were informed of how their personal details and the recorded interview data would be stored, handled and finally destroyed to maintain their privacy and security. They were allocated a research number for anonymity, any names from the taped interviews were disguised when transcribed and records of parent and infant demographic information were subject to the safeguards of the Data Protection Act (1998).

Exclusion Criteria

The study aimed to explore the experiences of all parents who had an infant requiring neonatal intensive care and therefore purposefully excluded as few parents as possible.

It was however, decided by the Steering Group to be inappropriate for those parents where child protection issues were either a concern, or where child protection orders were already in place, to participate, as such of issues would potentially impact on their parental role and ability to make decisions for their infant.

It was also agreed by the Steering Group that it was inappropriate and insensitive for parents of known terminally ill infants to participate, so therefore, they were also excluded from the study. There were a total of 8 interviews that were carried out with 5 families where the infant did die on the NICU but at the time of the interviews, whilst some were extremely sick, a terminal diagnosis had not been made and full intensive care measures were being given.

Sample.

The NICU admits approximately 800 infants per year. Around 400 infants remain on the NICU at 10 days of age. From this number an allowance had to be made for refusals, some absence of fathers and some parents having two or more infants on the NICU. To produce the range of responses to describe the parental experiences it was estimated that around 50 parents would be needed to participate in the first interview. A proportion of parents would decide not to participate in the second interview, other infants would be discharged, transferred back to the parents' local hospital or would die. With around 140 infants per year still in the NICU beyond 28 days it was estimated that 25 parents would be available to participate in the second interview. As far as possible, these were targeted for the first interview, in order that adaptation over time might be explored. As no new themes were emerging from interviews of mothers of moderately well infants, a purposive sampling strategy was adopted to interview parents of infants at risk for future health or developmental problems. Interviews were continued until saturation was achieved and no new themes seemed to be emerging. An equal number of mothers and fathers of infants on the NICU were invited to participate. The interviews were tape-recorded with the participant's consent and parents were interviewed individually. Participants that were invited to be interviewed had been recruited to be involved as part of a larger study in which they had already completed a questionnaire. Although parents could obviously choose not to be interviewed, even if they had completed a questionnaire, no parent then refused to participate in the interview process.

Although equal numbers of mothers and fathers were invited and agreed to participate, for practical reasons, such as work or caring for older sibling responsibilities, fewer fathers were able to participate.

Parental and infant characteristics (see Table A below) included mode of delivery, previous preterm birth or poor pregnancy outcome, high/low risk pregnancy, gestation, birth weight, any congenital abnormality, were obtained from the medical notes and/or from discussions with the participants where such information was not available or when it was necessary to confirm or clarify details.

Mode of delivery was also available in the medical notes and was classed as a normal vaginal delivery, an elective caesarean section as a planned event or an emergency caesarean section where delivery by caesarean section was unplanned for that time or at all.

Transfer data was obtained to determine whether infants were inborn, antenatal transfers or post natal transfers.

Neonatal intensive care services were available for those mothers who had booked and received their routine antenatal care at the hospital because they lived locally and for those women who were drawing upon specialised obstetric services at the hospital due to their own medical problems or due to their pregnancy risk status. For these parents their transfer data was categorised as "inborn". "Antenatal transfer" refers to those women who did not book at the research hospital but were transferred there for specialist services following the development of problems during the pregnancy, prior to or during the early stages of labour when there was an anticipated risk to the infant calculated to require the tertiary regional neonatal intensive care services available at the research hospital. The "antenatal transfer" was available to mothers who lived within the wider Merseyside region and for whom the research hospital was the local centre for tertiary neonatal intensive care and for those women who lived outside the region and for whom the research hospital was the nearest hospital with available neonatal intensive care beds.

"Postnatal transfers" refers to those mothers who delivered their infant in another hospital, whether that was within or outside the region and whose infants were subsequently transferred to access the neonatal intensive care services the research hospital had to offer.

The high number of antenatal transfers within the sample reflects the nature of the specialist services offered by the research hospital and other regional neonatal intensive care units.

As part of the parental demographic details collected, previous pregnancy outcomes were recorded. It was noted if there had been any history of recurrent miscarriages (3 or more), previous poor outcome or preterm births for the participants. Previous poor outcome was defined as any previous fetal, neonatal, infant or child death or a severe disability or chronic illness following a congenital, prenatal or neonatal illness.

It was also noted if the pregnancy was categorised as high risk pregnancy. The definition for high pregnancy risk was determined by the steering group and it was defined as 'any clinical condition or previous history of clinical conditions in the mother, fetus or newborn which warrant current pregnancy surveillance above routine levels'. This information was usually available in the medical notes but confirmed with the participants verbally.

It was noted if the infant was born with a congenital abnormality, which may or may not have been diagnosed prior to delivery. The diagnosis of a congenital abnormality was not a reason to exclude parents from the study unless there was also a terminal prognosis with that congenital abnormality.

Table A. Characteristics of participating infants and parents.

	Number of Interviews with mothers	Number of interviews with fathers
Interview One	34	16
Interview Two	17	9
Male Infant	29	19
Female Infant	22	6
Infant with congenital abnormality	5	3
Gestational age (weeks) Mean, SD, Range	M = 29.49 SD = 4.4 Range 24-41	M = 29.70 SD = 4.7 Range 24-41
Birthweight (grams) Mean, SD, Range	M = 1442 SD = 903 Range 560-4760	M = 1500 SD = 945 Range 560-3182
Normal Delivery	23	17
Caesarian section	26	10
Previous NICU experience	6	2
Previous poor outcome	6	2
High risk pregnancy	16	7
Single, unsupported mother	4	
Local, inborn infants (n)	28	16
Antenatal Transfer (n)	19	11
Postnatal Transfer (n)	2	0

Pilot Work.

With the previous mentioned neonatal nursing experience but with no previous experience as an interviewer using semi structured interviews, the researcher spent time preparing and training prior to carrying out any interviews with parents. The recording equipment used was chosen specifically because of its size with a small inconspicuous microphone along with 90 minute audiotapes to minimise the number of tape changes. Technical difficulties or failures would be disruptive to the interview process and endanger the quality or even failure of the interview recording. Preparing and planning for the practicalities of the interviews involved checking of equipment and having all the equipment in place. All participants gave their verbal consent for their interviews to be tape recorded prior to commencing with the interview.

Where the interviewer felt necessary, additional notes were made to explain pauses, interruptions or any non verbal communication that would not be clear by the audiotape alone. Participants were sharing an experience with the interviewer that often evoked an emotional response. All participants chose to continue with the interview after any episode of crying or any period of time that they needed to compose themselves but it was sometimes necessary for the interviewer to make a note to explain these events.

Exploring the possible environments available for conducting interviews was necessary to ensure maximum privacy and the minimum potential for interruptions and the processes required to ensure that others were aware of the need for the researcher and participant not to be disturbed during the interview.

Preparation also involved becoming very familiar with the interview schedule. Robson (2002) equates the researcher's interview schedule to an actor's script and as such, the interviewer should know it thoroughly. The interviewer can change the context of the question by simply changing the emphasis on it or on one specific word in the question so it was crucial to learn to pose the same questions in the same way to each participant (Cormack, 2000). As the interviewer, the researcher was trained to refrain from introducing new questions but encouraged to ask additional questions to elaborate on or explore responses made by the participant in a non-leading way. The interviews undertaken in the pilot stages and a sample of later interviews were listened to by Steering Group members enabling experienced researchers to give their feedback, comments and advice on interviewer technique.

The researcher conducted all of the interviews to rule out the possibility that any differences in individual responses were not a reflection of different interviewers' techniques or approaches.

Pilot interviews were carried out with six parents (four mothers and two fathers) in order to determine whether any modifications were necessary to the interview process or content.

The experience with the pilot interviews indicated that the best approach was to allow parents to tell their own story (which most were enthusiastic to do) and if necessary, then return to any unanswered questions from the Interview Schedule. Minor amendments were made to the wording of some questions so that they were in no way leading and to the order in which the questions were asked to improve the way in which the interview schedule flowed.

Interviews.

The setting

The study took place in a hospital in the UK where there are around 8,000 births per year. The Neonatal Unit is a large regional neonatal intensive care unit, which provided intensive care services for the local community and also acted as the regional referral centre for infants requiring specialist or routine neonatal intensive care services not provided or available at the time in their local unit. The NICU has 52 cots, 16 of which are designated for intensive care of the newborn, 18 for high dependency, 14 low dependency care and 4 transitional care making it one of largest units of its kind in Britain. The Unit offers care for up to 1000 babies and their families per year.

Most parental studies have focused on very low birth weight infants or those critically ill and have generally recruited from the population in tertiary units. The majority of these studies have taken place in North America where they do not typically include the range of dependency levels seen in a UK regional unit. In North America, infants born locally who require lower levels of care are generally cared for in separate facilities, level 1 or level 2 nurseries. Thus, by recruiting from a UK regional centre, the full range of infants requiring all different levels of care were included in the study, and the findings are therefore more representative of the issues seen in many units across the country.

According to Dearnley (2005), the venue for the semi structured interview is of importance. It needs to offer privacy, have an informal atmosphere with attention given to décor and seating arrangements. Ideally, the venue should be uncluttered and the researcher should offer participants refreshments. In all, interviewees need to feel relaxed and comfortable in the chosen setting in order for them to tell the researcher of their experience.

The setting for each individual interview was dependent upon the individual circumstances of the participants involved and their choice of where they would feel most comfortable, feel free to express their experiences to the researcher and least likely to be interrupted. All of the interviews were carried out within the research hospital setting but in different rooms and departments of the hospital depending on availability, likelihood of maintaining privacy without interruptions and participant choice.

Particularly for Interview One, many mothers were still inpatients themselves on a maternity ward, so for those who had a private room, interviews were carried out in that room where mothers felt comfortable, they were away from the NICU setting and interruptions or distractions were less likely.

For fathers participating in the study and for mothers who had been discharged from hospital care, the setting for their interviews was in a number of rooms within the NICU. Most commonly, the rooms chosen were vacant parent bedrooms which were away from the clinical area, participants and the researcher could not be overheard, they were quiet, comfortable and efforts were made to ensure that others were aware the room was in use so disturbances kept to a minimum.

Participants had access to refreshments during their interview and the NICU parent bedrooms and private maternity rooms had toilet facilities should they be required. Despite those efforts to maintain privacy and avoid interruptions, there were occasions where the interview process was disturbed. These were when interviews were carried out in the private maternity ward rooms and the interruptions were, for example, from staff coming to empty bins, offer refreshments or looking for equipment. These rooms, unlike the parent bedrooms on the NICU, did not have a sign available outside to indicate privacy was required.

Any interruptions were brief; the tape was paused and then recommenced after reminding the participant, if necessary, of the area being discussed; they appeared to have little impact on the overall interview.

Parents were invited to participate in two semi-structured interviews, the first being at 7-10 days following the birth and the second at beyond 28 days. The interviews followed a semi-structured framework based partly on responses to stressors in the NICU environment and partly on theories of cognitive adaptation and attainment of the parental role for this infant. Both interview schedules were developed to examine experiences and feelings about the pregnancy and birth, stressors in the NICU environment, as well as adaptation issues such as the search for meaning, mastery and self esteem, communication and support from partners, other social support, interaction with the infant and maternal identity and role issues.

The interview schedule (Appendix 3) for the first interview followed a logical sequence of firstly questions about the pregnancy and birth, feelings about seeing the baby for the first time before progressing to their experiences as a parent of an infant in the NICU.

The rationale for the timing of the first interview was to capture parental views in the early postpartum period when the infant was still likely to require high levels of care, yet allowing for initial stabilisation of the infant and some maternal recovery from the birth. The memories and perceptions of the events leading up to the delivery were explored along with the first experiences of being a parent of an infant in the NICU.

The timing and rationale for a second interview was to enable exploration of how perceived stressors, the cognitive adaptation processes and parental role issues change over time in the group of parents whose infants still require care in a NICU at beyond 28 days. At this time parents have often gained confidence and knowledge in their own abilities to care for their infant but may be facing concerns about the infant's future and may have practical difficulties in regaining some kind of normality in their lives.

The schedule for the second interview (Appendix 4) deliberately included most of the same questions that were presented in the first interview to explore how, over time; the experience had changed participants' responses along with some additional questions. With the infants being beyond 28 days of age at the time of the second interview, these questions, (for example, parental ability to influence what happened to their baby) were based on parental role theory and how that develops over time. Participants were informed that the questions they were going to be asked related to their experiences prior to the birth including labour, experiences relating to the NICU, communication with staff, support and their feelings about their infant. I explained to participants that the interview schedule functioned as a guide only and they were encouraged to speak freely about their experiences, discuss any aspect they felt relevant either in response to a question or otherwise. Whilst some participants answered the questions put to them in order set out in the interview schedule, others covered questions without the need for them to be asked by the researcher. The interview schedule had groups of questions which can be related to each other. For example, a group of questions about preparation for the experience, questions about support and who participants talked to, questions about practical issues, questions about their role etc and whilst a participant sometimes only answered the individual question put to them, on other occasions, asking one particular question would naturally encourage the participant to move on to talk freely about other aspects of that experience and thus covered many other questions without the need for the researcher to ask. The researcher made time at the end of the interview to ensure that all questions within the schedule had been covered.

Participants were not interrupted by the researcher other than to rephrase a question they had misunderstood (without leading them), to clarify a response or to explore a particular response in further detail. It is imperative that the interviewer verifies that they have correctly understood participants' responses and not assume they have (Pope and Mays, 2006).

Careful consideration of the time commitment being asked of parents was given. In the first interviews, mothers were still inpatients and fathers had not returned to any work commitments, however they were being asked to sacrifice time they would otherwise be spending with their infant, or talking to those caring for him/her. Most mothers needed time to express and store milk and parents had family, friends and visitors to consider as well as time to rest and recover from the recent birth and any related medical problems they had. In the second interview, most mothers had been discharged home and most working fathers had returned to at least some of their work commitments. The time they therefore spent in the hospital was time they intended to be spent with their infant.

Dearnley (2005) warns that for both participants and researchers, time is a key element and semi structured interviews of more than an hour long may become an imposition for those being interviewed. Interviews were therefore carried out at a time that was most convenient for the individual participant, after any other commitments were fulfilled and were subject to last minute postponements if interview appointments became inconvenient. These interviews varied in length between 30 minutes and 120 minutes with the majority being around 60 minutes in length and 10,000 -12,000 words when transcribed.

A total of 39 families participated in 76 interviews over a period of 15 months. 50 interviews were completed at time point one (7-10 days after admission) and 26 interviews at time point two (after 28 days.) A total of 7 interviews were carried out at the second time point but without a first interview.

These 7 interviews were carried out during the pilot period or the timing of these was due to practical reasons of arranging an interview to suit individual parents. On these occasions parents had agreed and were enthusiastic about being involved in the study, appointments for interviews had been made but cancelled for reasons such as their baby being unstable, unexpected visitors, they felt unwell, or they were required at short notice by health care professionals for discussions about their infant, breastfeeding or discharge planning advice. Whilst this resulted in these interviews not falling into time point one, it was felt that it was not appropriate to prohibit these parents to participate when they had chosen to.

Of the 51 mothers interviewed, 34 were interviewed at time point one, 17 were interviewed at time point two with 6 mothers being interviewed at time point two only.

Of the 27 fathers interviewed, 16 were interviewed at time point one, 9 were re-interviewed at time point two and 1 father was interviewed at time point two only.

Analysis.

This section of the chapter will describe the process by which the recorded interviews with participants were handled, sorted and analysed.

Qualitative research has a tendency to involve fewer participant numbers or subjects, however, it does not follow that the data generated is also smaller scale. In reality, qualitative research can produce substantial, even vast amounts of data (Pope and Mays, 2006). Additionally, data analysis is claimed to be the most crucial, (Basit, 2003) challenging and difficult aspect of conducting qualitative research (Priest, Roberts, and Woods, (2002) Basit, (2003) and frequently overwhelming, particularly for the novice qualitative researcher (Beck, 2003).

Because it is difficult not to start thinking about what is said or seen during an interview, it is inevitable that the process of qualitative data analysis begins as early as during the data collection stage (Pope and Mays, 2006, Endacott, 2008). This early analysis of the data enabled the researcher to hone and perfect certain questions, to probe further areas of emerging interest and therefore guiding the ongoing data collection with the investigation developing from the data already gathered (Pope and Mays, 2006).

Transcribing recorded interviews into a written form is one of the first steps in the process of qualitative data analysis (Bailey, 2008) and may raise difficulties as transcribing can be very time consuming. It is estimated that it can take six to seven hours to transcribe every hour of tape recorded conversation (Pope and Mays, 2006) and possibly longer for inexperienced typists (Bailey, 2008). The first ten interviews were transcribed by the researcher to ensure a personal understanding of the experience and to appreciate the importance of the process but without secretarial experience the process was indeed, very lengthy. Therefore, after those ten earliest transcriptions, like most qualitative researchers, secretarial support was used for transcription of the remaining interviews.

The style and format which was used to transcribe the first ten interviews was shared with the secretary responsible for the remaining transcriptions and as requested, replicated by her. All verbal and non verbal exchanges such as long pauses, laughing, movements, interruptions, sighs, crying, and changes in tone were included in the written transcriptions. These all have meaning and may possibly influence the interpretation of the data (Holloway, 2005, Pope and Mays, 2006).

Unlike the researcher, the person undertaking the transcribing had not got firsthand knowledge of each individual interview or an understanding of some of the terminology or medical expressions, there were some gaps and mistakes that required correction. Each recorded interview and its transcription was therefore checked from start to finish amending any transcription mistakes.

Being the first and an important stage of the analysis process, there are claims that delegation of the transcribing process to someone else can be a mistake (Bailey, 2008). Checking and making the necessary revisions to the transcriptions was time consuming but less so than transcribing the entire interview and the practice of meticulous and repeated listening to the interviews when checking each transcription facilitated the start of the data analysis process.

Unlike quantitative data analysis the process of analysing qualitative data is not a mechanical exercise; it has no formula and is usually carried out by the researcher rather than an analyst. The purpose of qualitative data analysis is to make sense of the data. The process of qualitative data analysis initially involves reading each interview transcript several times to enhance and improve the understanding of and closeness to the material (Broom, 2005). Although, the memory of each interview did in fact remain very clear, the process of repeated listening to and correcting each transcript assisted the researcher in further developing a greater knowledge of each interview and themes began to emerge and be identified.

The analysis of qualitative data requires the researcher to attach codes to recurring, interesting, unusual, remarkable views or beliefs, words, phrases and sentences (Pope and Mays, 2006) to enable the researcher to categorise or classify them (Robson, 2002) and allocate it to one or more category. (Holloway, 2005).

As each transcript was completed and checked it was loaded onto the chosen data analysis computer software package, WINMAX PRO. Researchers analysing qualitative data face the options of which, if any, computer software package is appropriate to use.

Whilst some oppose the use of data analysis software, concerned with the possibility they may cause distance between the researcher and the data, resulting in lack of meaning and context (St John and Johnson, 2000) or that as a result, researchers may encourage a focus on quantity rather than meaning (Beck, 2003), there are many advantages of using data analysis software.

The main advantage of using a software package to assist in the analysis of qualitative data is to save time when dealing with the mechanical aspects of handling and managing the data and thus freeing the researcher to spend more time on the interpretive aspects of the analytical process (Froggatt, 2001). However, some debate that, particularly for novice researchers unfamiliar with the software and where small data sets are involved the manual approach is less time consuming. With the larger numbers involved in this study and with the support of an experienced and knowledgeable user it was felt that there were probable time saving advantages to learning and using the chosen computer software package.

Furthermore, using data analysis software enables the researcher to organise and handle the qualitative data, particularly when dealing with large amounts such as with this study and allows more rigorous data analysis by enabling flexible handling of the data (Beck, 2003).

The first stage of the data analysis necessitated becoming familiar with the transcripts by reading them several times and it was also helpful to return to the audiotapes and any notes made during the interviews to understand the paralinguistic characteristics of each interview.

The main approach used was qualitative content analysis which may be criticised as time consuming and with a risk of simply consisting of word counts; however, it is also recognised as offering several advantages to researchers. For example content analysis looks directly at communication and hence gets to the central aspect of the interaction with participants, provides insight into human thought and language use, and is considered as a reality "exact" research method when done well. It also lends itself particularly to exploratory studies and to qualitative computerised analysis. Content analysis is a systematic method of reduction and analysis whereby core or master codes may be formulated from the question areas in the interview schedule (Priest, Roberts and Woods 2002).

Once each checked interview was imported in the WINMAX PRO the process of coding the data began. Content analysis determines the presence of certain themes, concepts, phrases or characters, therefore data was then coded in response to specific questions asked based on the existing theoretical frameworks but with new codes being established for phenomena that spontaneously emerged from the data that did not readily fit into existing analytical categories. The process of coding in content analysis is one of selective reduction whereby the data is broken down into meaningful and pertinent units of information. The data was then explored further and data reduction progressed to second level coding and further.

For example, in response to the question about parental ability to talk to the neonatal nurses, interview responses were coded into positive and/or negative comments. The data was expanded further and coded at a second level. For example, the negative comments were coded into the following areas. Comments re: individuals, communication/language, fear of hearing bad news, lack of continuity/knowledge, not kept informed, pestering or bothering staff, particular incident, too busy, too many staff to get to know, unapproachable and would like more time to talk. Some areas could then be broken down further to a third level. For example, where a parents responded that they felt that they were pestering or bothering nursing staff, some responses were coded as too busy with other babies or parents own problem, i.e. not because the nurse said or did anything to make them feel that way.

Re-examining each transcript and repeatedly checking and questioning the coding were important parts of the analysis and the reliability of coded data can therefore be confirmed. Three independent analysts checked a total of six transcripts (two each) along with the coding of the written transcripts. Any coding advice was discussed and some minor amendments made where necessary. The number of participants for whom an issue is pertinent was counted giving some indication of the importance of the issue and comparisons were made between mothers and fathers.

Admittedly coding the data on WINMAX PRO was extremely time consuming and it also took some time and practice to perfect the process of selecting, importing and exporting relevant data to view and compare results. However, once those difficulties had been overcome the benefits and advantages of using WINMAX PRO were realised.

When the interviews were coded on WINMAX PRO it was then possible to select, view and concentrate on the specific responses of specific participants, responses to a particular question or group of questions and view the language used by participants in the coded sections extracted from the interviews by the program.

For example, it was possible to activate and view the responses of mothers or fathers only, choose only those participating in Interview One or Two and view the responses to a particular question, e.g the question relating to their experience of seeing their baby on the NICU for the first time. From repeating these exercises for individual questions and areas of interest the results were collated, compared and presented in relation to mother/father responses and Interview One/Two responses. Coded sections of dialogue could be exported from WINMAX PRO and used to give examples of the responses made by parents in the results.

Chapter 4

Results

Introduction

This chapter contains the results of the two interviews undertaken at time point one (7-10 days) and time point two (after 28 days). They will be referred to as Interview One and Interview Two.

There were six mothers and one father that were interviewed early in the data collection phase using the Interview One Schedule but were parents to infants that were older than 28 days at the time of the interview. Their responses to questions only asked in Interview One, for example the questions about preparation for their experience, events leading up to the birth and the labour and delivery experience, have been included in the results for Interview One. However, their responses to other questions asked at both time points, such as their feelings at the time of the interview, support questions and parental role questions, have been included in the results for Interview Two.

Whilst the Interview Schedules were followed for each interview to ensure that parents were all asked the same questions, if a parent chose not to answer a question, they were not pressed further for an answer. This accounts for why the number of responses to certain questions will not always add up to the total number of participants. The total numbers of interviews are shown in the table below.

Table 1. Total number of interviews

Interview One Mothers	Interview One Fathers	Interview Two Mothers	Interview Two Fathers
34	16	17	9

The results are presented in 9 major sections. These are:

4.1 Preparation prior to birth

4.2 Labour and Delivery

4.3 First sight of infant

4.4 Support from partner, family, friends, other parents

4.5 Support from and communication with staff

4.6 Adaptation:

Self blame

Care received

Benefits – feeling lucky/unlucky

4.7 Parental Role

Practical – what can we do

Emotional – recognition by infant; personality, distress, anger

Help from staff

4.8 Change with time (Interview One to Two)

4.9 Summary of Results

The results sections are supported by examples of parental responses. Each quotation is identified by the Interview Number e.g I 41 is Interview 41 and Appendix 5 illustrates to the reader the characteristics of that participant and their infant.

4.1 Preparation prior to birth.

Where possible, medical, midwifery and nursing staff aim to prepare parents for the experience of having an infant in the NICU. Some parents have difficulties during the pregnancy. There may be a maternal condition or illness diagnosed or there may be an antenatal diagnosis made of the foetus, any of which may give those caring for the pregnant woman some warning that the infant might need care following birth within a NICU environment.

Preparation for these families is thought to ideally include a visit to the NICU to familiarise parents with the NICU location and with the sights and sounds of what may be a very unfamiliar environment. Parents should have the opportunity to acquaint themselves with the appearances of sick and premature infants, the equipment and technology used to support them and to meet the staff caring for them. In addition to a visit to the NICU prior to the birth, good preparation for parents includes the chance to meet with staff from the NICU and be given information and explanations about what they can reasonably expect at the time of delivery and beyond.

It is impossible to know exactly chances of survival, the type of problems and difficulties an individual infant may have at birth, subsequently encounter or know the level of support and care from the NICU they will need. However, a paediatrician will try to give some guidance as to what would be commonly experienced by an infant born at a given gestation and taking any other known factors into consideration. Such a meeting also enables parents to ask any questions they have and to give staff from the NICU any information they might want them to understand about their own views and feelings.

Staff can also give parents information booklets giving written information and pictures or photographs to support what they are told verbally about the appearances of premature or sick infants, individual conditions, who the staff are and about the equipment used and seen in the NICU environment to support sick infants.

For some parents there may be little or no warning that their infant will be born prematurely or that their infant will encounter other difficulties and need care in a NICU. Those opportunities to help prepare parents for what to expect are therefore lost completely or limited to information giving in whatever time is available prior to the birth, often when a mother is in established labour or immediately prior to caesarean section. For some parents their first experiences and understanding of the NICU environment is following the birth and admission of their infant.

Preparation for the NICU experience was explored in more detail during Interview One with parents being asked specifically about opportunities to speak to a paediatrician and visit the NICU prior to the birth. However, during Interview Two parents were asked to reflect on their earlier interview responses and describe any changes to their feelings and responses.

Feeling Unprepared

Some parents spoke of feeling unprepared for their experience as a parent of an infant in the NICU. Whilst some had little or no warning that their infant would be delivered prematurely or be admitted unexpectedly, others had experienced problems during the pregnancy, had a period of time needing hospital care, had concerns about maternal or fetal health, had an antenatal diagnosis of a particular condition or had some other warning that the infant may need care in the NICU after the birth.

Table 2. Parents who did not feel prepared for the admission of their baby to the NICU.

	Interview One Mothers	Interview One Fathers	Interview Two Mothers	Interview Two Fathers
No reason given	10	5	5	3
Despite warnings	4	3	1	2
No previous warnings	4	2	0	0
Unexpected	2	1	0	0
In denial	0	0	0	1

Ten mothers and five fathers from Interview One compared with five mothers and three fathers from Interview Two told the interviewer of feeling unprepared for their experience but gave no further explanation of why they felt unprepared.

Four mothers from Interview One but only one mother from Interview Two said that despite warnings (such as early labour) and/or being told that delivery of their infant would likely be early and that admission to the NICU following delivery was probable, still felt unprepared for the experience and shocked when it happened to them.

One mother (I 69) said,

"I think that no matter how much you prepare yourself for it, it is still a shock to be told he is going to be delivered there and then" and another (I 15) said,

"...so it was like, just completely shocked, because I knew they said I would have him early, when I got admitted on the Thursday they said I will be having him early but not like two days... two days later, I didn't expect that."

One mother who had investigations following problems during the pregnancy was given an antenatal diagnosis of Downs Syndrome but she told the interviewer that despite what she was told, she still felt unprepared being unable to accept what she was told before the birth about her infant.

One mother (I 69) who had a history of premature delivery with her previous children and who was in hospital because she and the Obstetric team knew her infant was going to be born prematurely said

"I thought, well, I know he was going to come and it will be a big rush and it will be an emergency section....until they actually said to me "he is coming now, we have to do it now" and I was like Oh!...that was a bit of a shock."

In contrast, three fathers from Interview One and two fathers from Interview Two communicated to the interviewer feelings of being unprepared despite warnings and difficulties during the pregnancy and/or being told that the infant would be born prematurely. All of the partners to these fathers had been in hospital with problems prior to the delivery and were undergoing obstetric care for identified difficulties such as preterm labour. One father (I 28) whose wife had been in hospital for 10 days prior to the delivery with early labour signs said:

"...it was a shock when it happened...the doctors was saying to be prepared for it but we wasn't expecting it."

One father in this group (I 65) described his denial of the forthcoming preterm birth saying:

"...psychologically speaking I was still in denial that this baby was going to be born because I was so desperate for it not to be."

In contrast to those parents who had some warning that their baby may be born with the need for neonatal intensive care services there were other parents who had no prior warning. For these parents, the pregnancy had progressed without problems until the mother either went into spontaneous preterm labour, an emergency obstetric event requiring immediate delivery of the baby or there were some babies born at term that unexpectedly had an illness or condition that required admission to the NICU after birth.

Four mothers and two fathers from Interview One described no previous warnings or problems to indicate to them that they were going to either deliver their baby early or at term with problems that would necessitate admission to neonatal intensive care. One mother (I 38) said,

"I felt very, you know, unprepared and the suddenly, you know the operation and the baby being there was, you know, has been really, a massive shock... "

Both of the fathers who described no prior warning to their baby's' NICU admission, portrayed an unproblematic pregnancy where their partners had been feeling well and were enjoying pregnancy so delivery of their infant at that time was an unexpected event for them. These fathers expressed their shock and a lack of preparation for the experience due to how quickly the delivery of their preterm infant occurred. In these circumstances the delivery was very quick following an unremarkable pregnancy with one father not being present or even within easy reach of the hospital when the infant was delivered. One father (I 58) said,

"I was just completely unprepared for it. I mean, we were completely, as a couple we were completely unprepared for it...we were just thrown into it. All of a sudden, one minute we were sitting there and everything seemed alright and the next minute this child is coming and dear god, what on earth... "

But he (I 58) also believed that not being prepared for the experience and not knowing what to expect was in his experience, beneficial saying:

"...had I known what was meant by a ventilator...I might well have been a hell of a lot more alarmed than I was. "

Feeling prepared for the NICU experience.

In comparison to those parents who described feeling unprepared for their NICU experience there were others who described how they did feel that they knew what to expect and were prepared for their baby's admission to the NICU.

Table 3. Parents who did feel prepared for the admission of their baby to the NICU.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Problems in pregnancy	4	1	1	0
Previous NICU experience	2	1	1	0
Previous ICU experience	0	2	0	0
Television	4	1	0	0
Reading literature	0	3	0	0
Friends/relatives experience	0	2	0	0

Four mothers and one father from Interview One and one mother from Interview Two described feeling prepared for the NICU experience because of the problems they had experienced during the pregnancy. These parents had knowledge of what to expect after the delivery and the potential problems that their baby may encounter. This father (I 51) explained,

"We knew she was going to be small. Well actually she is bigger than we expected to be honest. We were perfectly relaxed. What we saw we were expecting."

One of these mothers (I 49) demonstrated her knowledge of the type of problems her baby was likely to experience by saying,

"they could see that the baby was getting stressed so I was very prepared every time that I came that I could have an emergency caesarean but I was pretty prepared... I

was aware of problems that she might have with being premature. I was worried about her lungs... they give you steroid injections. That gave me a bit of peace of mind during the pregnancy."

Two mothers and one father participating in Interview One and one mother from Interview Two described how they were already familiar with the NICU environment because of a previous experience of having an infant in the NICU. One mother (I 69) who had the familiarity and understanding of being a mother of an infant in the same NICU previously said,

"A lot of it was past experience...I think this time round I was far more prepared to what he would be like."

A further two fathers participating in Interview One felt that a previous experience of paediatric intensive care environments with another family member had facilitated their preparation for the NICU because of some similarities they could draw between the two environments. One father (I 39) explained,

"My younger brother had a very traumatic birth. He was born with a major heart defect and had open heart surgery three times in the first six months and was born without a heart beat and we were all there at the hospital. So I had seen this scenario before and had that scenario in my mind's eye."

With an increasing number of television programmes about hospitals and the departments within them, including the NICU environment, there is an increasing awareness and understanding of how sick and premature infants are cared for even for those who have never had a personal experience of such an environment.

The care of newborn sick infants is emotive, can evoke strong opinions and there is an increasing awareness of public debates surrounding the decisions to resuscitate and provide care for extremely sick and preterm infants, the cost of that care financially, and the possible long term outcomes and problems that these infants and families may face if they survive.

Television programmes were described as helpful in preparing four mothers and one father participating in Interview One compared with no parents from Interview Two for their NICU experience. The programmes showing premature infants being cared for in a NICU enabled them to know what to expect about how a premature infant looked and the equipment and environment that was necessary to support them. For example one mother (I 18) said:

"I think you see that many things on telly now a days, you are aware of that, and the tubes"

Two fathers and one mother, all from Interview One described how they had read about preterm infants in books or magazines during the pregnancy and this information had helped prepare them for their own experience. One father (I 31) whose partner had no prior warning of going into premature labour said:

"I was actually reading...one of those NHS book things about pregnancies... I was reading about premature babies in there...I knew a little bit about it before it actually happened."

One mother and one father, again from Interview One, believed that they felt in some way prepared for their own experience because they had either a friend or a relative who had had a premature infant that was cared for on a NICU.

Visiting the NICU

The chance to visit the NICU prior to the birth is viewed as an opportunity for parents to familiarise themselves with where and what the NICU is, to meet the staff who will be involved in caring for their infant and to gain some insight into the equipment, medical devices, sights and sounds common to the NICU. Parents were asked if they had been able to visit the NICU prior to the admission of their baby there. For those parents who did visit the NICU prior to the birth some described how the visit was helpful, others found the visit unhelpful and there were others who chose not to describe the visit as either.

Table 4. Parents who found their visit to the NICU prior to the birth helpful

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Visit helped	6	4	1	1
Baby size/appearance	4	1	2	1
Atmosphere	2	2	1	0
Equipment	1	2	2	0
Talking to other parents there	1	1	0	0

As seen in the table above, there were six mothers and four fathers from Interview One and one mother and one father from Interview Two who described the pre-delivery visit to the NICU as a helpful experience but chose not to explain why and were not repeatedly asked to.

Four mothers compared with one father from Interview One and two mothers and one father from Interview Two described how although the sight of the infants in the NICU on their visit could be quite shocking, the opportunity of seeing the size and/or appearance of sick and particularly extremely small infants helped prepare them for their own experience. For example one mother (I 20) explained:

"I didn't know what size to expect and so getting that into perspective did really help" and another mother (I 46) said:

"...seeing how small they are...was going to be a shock and I'm glad we had that shock and that upset with somebody else's baby."

One mother (I 4) described how she felt that the infants looked comfortable and not as ill looking as she had expected.

"The babies look really happy and well cared for as well and they didn't look as sick as what I imagined them to be. Cause when you say intensive care you imagine all these deaths door babies."

The NICU typically relies on various medical devices and monitoring systems to support sick newborn infants and with most babies who are admitted to the NICU being at the least, nursed within an incubator and having some basic monitoring, the equipment around and attached to a baby can be unfamiliar and concerning. For smaller and sicker infants there may be a need for additional support from ventilators, intravenous fluids and drugs and more complex monitoring methods which adds to the impact of technology, noise and activity around the infant.

One mothers and two fathers from Interview One and two mothers from Interview Two described how seeing all the equipment and hearing the alarms was valuable in preparing them for their own experience. For example one mother (I 17) said:

"...so at least it is not a big surprise when you go in and see all the monitors and the drips...it was useful."

In addition to the specific comments made about becoming familiar with some of the equipment used in the NICU, there were descriptions made about being prepared for the atmosphere within the NICU environment. These parents described the visit as helping them to become familiar with the environment and the atmosphere of the NICU.

Two mothers and one father from Interview One compared with one mother from Interview Two described how they were reassured by the atmosphere and environment of the NICU. They had the expectation that it would be a tense or crisis like atmosphere but the reality was that they found parents, staff and the babies to be relaxed and happy. One mother (I 4) said she expected everyone to be,

"...depressed and upset, but it was really nice. The babies looked happy and the nurses were friendly"

And another (I 47) said,

"I think I'd expected it to be more of a tense atmosphere, sort of a more of a crisis orientated atmosphere...I felt reassured." Similarly a father (I 48) explained,

"the ... calmness here... you sort of realise erm... that... all the babies here aren't in crisis and that... nobody is panicking about them, there are just staff doing their job every day... looking after premature babies, this is what they are coming to work each day and doing and they don't expect them to be... like dying."

Only one mother and one father from Interview One described how, during their visit, they had benefitted from the opportunity to talk to some other parents who already had an infant in the NICU.

Next is a table to illustrate the parental responses of those who were given the opportunity to visit the NICU prior to the delivery of their baby but did not view the experience as helpful.

Table 5. Parents who found their visit to the NICU prior to the birth unhelpful.

	Interview One Mothers	Interview One Fathers	Interview Two Mothers	Interview Two Fathers
Did not help	3	0	0	1
Scared by sights	3	0	0	0
Not their baby	2	0	0	1
Reminder of past experience	1	0	0	0

There were three mothers from Interview One and one father from Interview Two who felt the visit to the NICU preceding the birth of their baby was not a useful experience for them but chose not to explain why they felt that way.

For those parents who gave an explanation of why the experience was unhelpful three mothers from Interview One only but no fathers from either interview described the event as a frightening or one that served only to scare them.

The following are comments from these mothers (I 46 and I 5).

"...we came down the day before I had the section and then that's when I think we probably did start getting worried because we saw the babies, and I got really upset about the size of them..."

"...it scared me actually. It was on my mind for quite a couple of days afterwards...no, it never prepared me at all."

Two mothers from Interview One compared with one father from Interview Two explained that they did not find the visit helpful because seeing someone else's baby in the NICU failed to prepare them to see their own infant in the same situation.

The father (I 72) participating in Interview Two said,

"...it didn't help to prepare me to see my own son lay there"

and a mother (I 74) explained,

"...because I was looking at the other babies, and though you feel sorry for them, but it's not your own is it, so it is a lot worse when it is your own, I don't think it helped me much..."

One mother participating in Interview One who had the experience of having a previous baby in a NICU surprisingly felt that the visit she had to the NICU prior to this birth unhelpful because it reminded her of her earlier experiences.

In contrast, there were parents who were unable to visit the NICU prior to the birth and the reasons, where given are detailed in the table below.

Table 6. Parents who did not visit the NICU prior to the birth.

	Interview One Mothers	Interview One Fathers	Interview Two Mothers	Interview Two Fathers
No reason for no NICU visit	7	5	1	0
No time	7	4	0	0
No problems anticipated	4	3	0	0
Did not want to	4	1	0	0
Not well enough	2	0	0	0
Despite time to	0	1	0	0

There were seven mothers and five fathers from Interview One and one mother from Interview Two who chose not to explain why they did not visit the NICU prior to the birth.

However, the most commonly reported reason for not visiting the NICU prior to delivery was a lack of time. Seven mothers and four fathers from Interview One explained that the labour was too fast, advanced or that immediate delivery of the baby by an emergency caesarean section was necessary. For example one father (I 9) said, *"because she was going through a bad labour at the time they didn't move her. So we didn't get to see it"*. And a mother (I 70) said,

"I don't think there was any time...it just happened so quick".

Another mother (I 38) who had no time to speak to a paediatrician, visit the NICU or even see or speak to her husband revealed that following an uneventful pregnancy, she began to bleed at 29 weeks gestation, went to the hospital and *"...15 minutes after coming in here...I was in the theatre."*

Not all admissions to the NICU can be predictable. There are those newborn infants who are born at term but who subsequently develop an illness soon after birth, suffer a birth trauma or are born with a previously undiagnosed condition which requires admission to the NICU for treatment or management. Four mothers and three fathers who delivered their infants at term had no prior expectation that their infant would require admission to the NICU and therefore none of these mothers or fathers had the preparation of a NICU visit.

Four mothers and one father from Interview One declined the opportunity to visit the NICU prior to the delivery of their baby. These parents all had previous experiences of having an infant in the NICU and therefore felt a visit was unnecessary as they knew what to expect already. One mother (I 69) explained,

"no I didn't this time, I did get offered... but I didn't because I knew, ... I knew what we were looking to and I knew the size he would be and ... to me it was pointless really... I didn't feel the need to go and have a look around."

From these parental experiences, it is clear that visiting the NICU prior to delivery is not always a possibility, particularly for those experiencing a rapid preterm labour and/or delivery or indeed for those whose infant has an unexpected neonatal illness following delivery. For those who did have a visit, the majority felt that it had been a positive experience but there were some parents who found the visit unhelpful or a negative experience in attempting to prepare them for the expected NICU experience.

Talking to a Paediatrician

When there is a possibility that a woman is going to deliver a baby that may need to be transferred to the NICU for care, it is acknowledged that good preparation for the family involved includes a discussion between those parents and staff (a paediatrician and neonatal nurse) from the NICU. That meeting enables the NICU staff to explain to the parents what to expect at the time of delivery, where they will be in the room and what they will be doing with their baby in addition to preparing the parents of what to expect in the longer term.

The meeting gives parents the option to present questions that they want answered at this time and to give their own views to the NICU staff. Whilst those discussions always aim to prepare parents of what to expect in the delivery room immediately after the birth, many of those discussions also include information about the possible problems the NICU staff might expect with each individual infant and that infants chances of survival.

Each meeting and what is discussed within in it depends greatly on the information that the NICU staff have about the infant's gestation, predicted size and any antenatal diagnoses, the need for information from the parents, in that, some parents want to know every potential course of events and possible problems their baby may encounter whilst others would prefer and request not to know.

Furthermore, whilst some deliveries are expected with staff from the NICU having the time to plan and carry out such discussions without haste, other parents have little or no warning that delivery is imminent. In these cases, the neonatal staff may not be able to prepare these parents for what to expect at all or only give a very brief explanation in far from ideal circumstances.

Parents were asked if they had the opportunity to speak with a paediatrician before the birth and the responses are divided into two tables below. The first shows those parents who had been spoken to by a paediatrician prior to the birth and expressed the experience as helpful or a positive event. The second table shows those parents who viewed the experience as unhelpful or a negative event for them. In addition to the parents illustrated below there were two further mothers participating in Interview One who had been spoken to by a paediatrician prior to the birth but who did not comment on if or how this had helped to prepare them for their experiences.

Table 7. Parents who viewed speaking to a paediatrician prior to the birth positively.

	Interview One Mothers	Interview One Fathers	Interview Two Mothers	Interview Two Fathers
Felt prepared	5	2	0	1
Reassured	1	1	0	0
Were helped by seeing pictures	1	0	0	0

As can be seen from the table above, the most commonly reported advantage of speaking to a paediatrician prior to the birth was in helping prepare both mothers and fathers for what they should realistically expect, the problems that their baby may encounter, their size if they were being delivered prematurely and the likely sequence of events in the hours and days after the birth. One of these mothers (I 46) said, *"we saw a paediatrician the night before I had the section... in fact we saw two... they sort of asked us if we had any questions...they did explain, you know, the unit to us and what to expect and what they would be checking for and again that was really* *helpful."* Another mother (I 71) recalled the conversation that gave her the truthful, but not necessarily reassuring expectations of the problems her baby may encounter, saying,

"She told me he stood a good chance but not to get my hopes or expectations too high, that he'd probably be ventilated from the start, which he was, and she warned me that he may have bleeds on the brain."

A father (I 6) from Interview Two explained,

"The doctors told us.... quite in depth that there were going to be problems anyway, because of the circumstances of the pregnancy, so we were expecting that there was going to be certain amount of problems."

One mother and one father from Interview One found the opportunity to speak with a paediatrician reassuring, giving them confidence in the staff that would be responsible for caring for their baby following the birth. This mother (I 20) volunteered,

"it was reassuring because you know, he knew what he was doing and you sort of like... "Well go on then do your business you know, do what you've got to do"."

One additional mother participating in Interview One described the pictures that the paediatrician showed her during their conversation as a positive measure in aiding her preparation for her experience.

In contrast, the parents illustrated in the table below described the discussions they had with the paediatrician prior to the birth negatively.

Table 8. Parents who viewed speaking to a paediatrician prior to the birth negatively.

	Interview One Mother	Interview One Father
Unable to remember what was said	7	0
Not reassured by what was said	4	1
Did not absorb what was said	3	0
Only remembers what they want to	1	0
Felt excluded from conversation	0	1

Unfortunately, and individual to the participating mothers who were already in established labour , who were being prepared for the imminent delivery of the baby or who were themselves unwell, their situation and/or the pain relieving drugs they were receiving rendered them unable to digest and remember what was said to them at that time. These seven mothers could recollect that someone had come to talk to them prior to the birth but were unable to remember little, if anything of the content of that conversation. This questions the benefit, certainly for mothers, of talking to parents once they are in the situation where delivery is imminent or labour is already established. As one mother (I 10) explained,

"...I'd been on gas and air by then for about an hour or something so I can remember him being there but I can't remember a word he said to me..."

There were four mothers and one father from Interview One who felt that the preparation from speaking to the paediatrician prior to the birth was not a reassuring experience.

These parents were given realistic information about the problems and difficulties their baby may encounter along with their chances of survival at that gestational age. Therefore it is understandable that the information they were given may not be reassuring, particularly for those parents of babies born extremely preterm as they then had to prepare themselves for an uncertain future and the possibility that their baby may not survive once s/he was born.

As this father (I 22) explained,

"...didn't really make... me feel any better though because then...it came home then what the problems...what problems there can be with a premature baby." And a mother (I 74) said,

"even the day she was born they said, they did put it to me that she might not live..."

In addition to the mothers who had little or no recollection of the conversation they had with the paediatrician before the birth there were a further three mothers but again no fathers from Interview One who could remember what they were told but explained that they were unable to absorb and make sense of what was said. One example of a mother's response (I 68) was,

"I know they were sort of preparing us for everything you know and lots of different people coming to see us and everything but I couldn't take it in at all."

One mother (I 20) from Interview One revealed that from the information she was given, she extracted the details that she wanted to hear and remember and dispensed with the facts she didn't want to hear. She said,

"well, you remember bits. You just sort of like pick out the bits that you want to hear and then you discard the rest don't you."

One father (I 72) from Interview One complained how he felt excluded from the discussion, in that, the focus was on the mother and the giving of information was directed at her. His impression from that was that the staff from the NICU felt that it was the mother that needed the reassurance and not him as the father. He said, *"mainly the doctor spoke to (partner) rather talking to me as well...I don't know whether it was the fact that they were just ignorant or they were just... trying to reassure (partner) and didn't think I was that bad."*

Preparation by Obstetric and/or Midwifery staff

In addition to the preparation given by staff from the NICU, there were individual parents who described the support from the Obstetric team of either midwives or doctors. These were parents who had little or no time prior to the delivery to meet or speak to the NICU staff and the information that the obstetric or midwifery staff gave them was valued in helping to prepare them for their experience of having an infant on the NICU.

Two mothers and two fathers spoke of how the obstetric or midwifery staff helped to prepare them for being a parent of an infant in the NICU by talking to them about what to expect, about chances for survival and about the kind of problems infants born at a given gestation may encounter.

One mother (I 17) pregnant with twins was given information about the NICU early in her pregnancy and was advised to take advantage of a visit to the NICU saying,

"...they gave you, gave us a handout at the very beginning where erm, because you are having twins, the chances of your babies going into the special care unit are obviously higher than most..."

Opportunities to talk with partner prior to the birth.

As expectant parents of an infant likely to require support and care in a NICU, the opportunity to spend time with each other as and to discuss with one another their feelings and thoughts about the pregnancy, any diagnosis and the possibility of being a parent of an infant in the NICU was explored in the interview.

Table 9. Parents who had the opportunity to talk with their partner prior to delivery.

	Interview One Mother	Interview One Father
Talked with Partner	5	2
Able to make plans	2	3
Reassured each other	3	1
Prepared themselves	1	1
Time to discuss views	1	0
Support each other	1	0

As explained with earlier questions relating to the time leading up to the birth, parents participating in Interview Two were not specifically asked if they had the opportunity to talk with their partner prior to the birth. This explains why no parents from the Interview Two time point gave responses in this section. The responses described below are therefore those from participants from Interview One only.

Five mothers and two fathers described how they had been able to spend time with their partner to talk before the delivery of their infant. These parents did not elaborate and describe what they discussed or how they benefitted from being able to do so.

Two mothers and three fathers explained how they were able to make plans and make decisions regarding where their priorities lay when they were considering the mother and baby's health, about any delivery options or what they would do if the baby did not survive. One father (I 72) said,

"in general we decided what's best for the baby is the best way to go" and one of the two mothers (I 71) who talked about their plans should their baby not survive said, *"we talked about it quite a lot, it sounds really morbid but we'd actually planned where he would have been buried.*

4.2 Labour and delivery

Participating parents were asked about their feelings during the labour and delivery during Interview One. Again, those parents who also took part in Interview Two were not specifically asked this particular question again but asked to reflect on that time and if anything had changed how they felt generally about that period. This accounts for why the responses below are mostly from parents participating in Interview One. The responses parents gave are presented below with some parents viewing the experience as a positive one whilst others expressed the worries and fears they had during that time. There were other comments which will also be presented below. The comments made by parents who viewed the experience positively are divided into those feelings about the baby and then other feelings about the labour and delivery.

Positive feelings about the labour and delivery.

Table 10. Parents who had positive feelings about the baby during the labour and delivery.

	Interview One Mother	Interview One Father
Not worried about the baby	1	1
Reassured by staff	1	5
No problems expected	2	0
Baby monitored and coping well	1	0
Trust in God	0	1

As can be seen from the table above the total numbers of both mothers and fathers who described positive or optimistic feelings about the baby during the labour and delivery was small, for varied reasons and there were differences between mothers and fathers. Very small numbers of mothers reported positive feelings about the labour and delivery experience. The most frequently reported reason (two mothers) being from mothers of term infants who did not anticipate that their baby would need admission to the NICU at that time.

The numbers of fathers who expressed positive feelings about the baby during the labour and delivery experience were again small with the exception however of the five fathers who described feeling reassured by the staff around them at that time. One father (I 21) described how he felt reassured by the manner in which the resuscitation of his premature baby immediately following the delivery was conducted by the paediatrician and team. He said,

"They were good like, (name of Paediatrician), he was the one that done it all when she come out...done it quite good, calm and quiet and I thought they'd all be rushing round, they were good".

Table 11. Parents with other positive feelings during the labour and delivery.

	Interview One Mother	Interview One Father
A positive experience	6	3
Supported by Obstetric team	4	3
No problems expected	2	0
Not worried about partner	0	1

Positive feelings about the labour and delivery that were not related specifically to the baby were more frequently reported by parents. Six mothers compared with three fathers described the labour and delivery as a positive experience without elaborating specifically on why. One father (I 48) of a premature baby said,

"I didn't feel particularly stressed, felt perhaps excited more than anything else..."

And a mother (I 57) said,

"I thought that the labour went well in that sense and I wasn't scared. Although it was painful, the things I didn't want to do was to rip... and I didn't want a caesarean and I wanted to have him naturally so in that sense of it I did that and that went really well."

More specifically four mothers and three fathers described the support they felt by the team of doctors, midwives and nurses caring for them during this time. One mother (I 49) said,

"When I got in there everybody was absolutely great. The Delivery room seemed full and I just thought all these people are here for me and my baby and it was great. The fact that everyone was so friendly and smiling." And one of these fathers (I 48) said, *"there was a chap who I don't know what his real job was but he came across to me like his job at that point was to look after me... one of the technicians I think... but he just took a specific interest and he also took photo's for us whilst they were sorting*

(baby) out which erm... presumably that is normal procedure but that is really... maybe it isn't... but that was really, really good."

One other father described how he was reassured by how the labour progressed, it gave him confidence and he thèrefore was not worried about his partner unlike other fathers.

Two mothers had no concerns about the baby during the labour and delivery experience as the NICU admission was an unexpected event for them.

Worries and fears during the labour and delivery

In comparison, parents described more negative feelings than positive ones when asked about the labour and delivery experiences. The worries that parents described were grouped and presented below into those worries about the baby, about their partner and about themselves with noticeable differences between maternal and paternal responses.

Table 12. Parents with worries about the baby during the labour and delivery.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Worries about the baby	13	7	1	0
Worries about the baby's health	9	2	0	1
Worries about the baby's survival	9	1	0	0

Many mothers and fathers described generally about the worries about their baby at that time. A typical response from a father (I 51) was,

"Just nervous knowing that so much could go wrong." And from one mother (I 49),

"My concern really was for (baby) and no matter what, it didn't really matter what they did to me as long as she is OK."

A further nine mothers in comparison to only two fathers described the health worries that they feared for their baby during this time. One mother (I 69) described her worries about passing the infection she had onto her unborn premature baby and how that compromise his health even further. She said,

"there was obviously an infection in me because I wasn't that well [yes] I knew I had obviously passed it on to him and it was how far the infection had took hold of him and ... you know if they are already born with an infection it reduces their chances an awful lot of getting over things and I knew there was a huge possibility of him being quite ill... and that, that did bother me a lot."

There were also nine mothers in comparison to only one father who described how they feared that their baby may not survive at that time. Whilst in labour one mother's thoughts (I 19) were,

"the loss of her really... thinking she's not going to live..." and another mother (I 10) described how she had felt saying,

"I think it was almost like oh my god I'm not going to go through all this and not have anything to show, kind of thing."

Table 13. Parents with worries for self during the labour and delivery.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Worries for self	12	3	1	0
Worries re: labour/delivery	12	0	1	0
Worries re: own health/survival	5	0	0	0
Lack/loss of control	3	0	0	0
Feeling helpless	0	4	0	0
Blame or guilt	1	0	0	0
Not listened to	1	0	0	0
Denied normal delivery	2	0	0	0
Hoping it would not happen	0	1	0	0

Twelve mothers compared with only three fathers described general worries about themselves during the labour and delivery experience. One mother (I 43) said, *"It was just coping with the whole experience really [yes] that I felt as though my time had come."* A mother (I 46) who had a caesarean section described her feelings as she went to the theatre for the delivery saying,

"I was absolutely terrified when I walked down... when you're walking into there cold [yes] and everybody is liked gowned up and you can see everything then and it's like put your hand out, like they are going to put...and that was like... you know 'what am I doing, what am I doing' and then like lean forward and I think because you're so aware... [yes] that was really frightening".

The worries and fears that these mothers had were mostly related to the labour and the pain they experienced or to the concerns they had about having a caesarean section as a necessity and that is reflected in the number of mothers who described the worries they had for themselves and the labour and delivery.

Three mothers (but no fathers) described feelings about lack or loss of control during this time. These mothers typically described how their plans, preparation and hopes for how labour and delivery would progress had been stolen from them by the premature birth of their baby. One mother (I 68) said,

"from being someone that thought I was going to have a normal pregnancy, birth pools and you know all these idealistic views you have (smiling) of being, you know being pregnant and holding your baby as soon as its born and everything, I'm forced to have an emergency caesarean section and there is no other option."

In contrast to the mothers' descriptions of loss of control, four fathers (but no mothers) described feelings of being unable to help, useless and feeling powerless during the labour and delivery experience. One father (I 58) said,

"it is hellish to be powerless and as a man to be utterly powerless in the entire situation. There is nothing I could do to stop that child you know, you know stay put for another eight weeks or whatever you know. I couldn't do that... I just sort of tore my hair out."

Other worries expressed by fewer mothers were being denied the normal labour and delivery they had desired and made plans for, feelings of self blame or guilt and concerns that they were not being listened to.

There were quite obvious differences between mothers and fathers with fathers expressing very few worries about themselves during this time with the exception of feelings of being powerless and unable to help their partner in their situation. In contrast, mothers expressed more worries about themselves, mostly relating to their own health, the pain they were experiencing in labour or relating to the need for a caesarean section delivery. Mothers also described their feelings of lack/loss of control over the labour and delivery experience.

Table 14. Parents with worries about their partner during the labour and delivery.

	Interview One Mother	Interview One Father
Worries about partner	3	7
Worries re: partners health	1	4
Labour and pain	0	7
Feeling helpless	3	0
Supporting partner	0	2

Fathers were more likely to express worries about their partner than themselves during the labour and delivery experience. Seven fathers compared to three mothers spoke generally of their concerns and worries for their partner at that time. These mothers described how distressing the experience was for their partners. One mother (I 17) explained,

"I don't think it was very nice for my husband... with it being a caesarean the fact that I was out completely, he wasn't allowed to be in the room that you would normally be with a caesarean,...I think that was quite distressing for him, because obviously he was worried about me and obviously the babies as well."

Other fathers (seven) talked about their worries of seeing their partner experiencing labour, pain and the discomfort that they were in. Typical of a fathers feelings expressed was this quote from a father (I 31) of a baby born prematurely,

"I was basically worried about (partner)... she was making quite a bit of noise and she looked obviously distressed and in pain...just looking at her, she was you know crying and that, so yes, that was a bit stressful... I mean, and I knew the baby was

coming, nothing that I could of done about it but... I mean she was obviously distressed so, my main concern really was (partner) at that point."

Four further fathers expressed their concerns about their partners' health with concerns if they had a pre-existing condition or a pregnancy related illness that had the potential to threaten the health of their partner.

Other feelings about the labour and delivery experience.

Table 15. Other feelings about the labour and delivery experience.

	Interview One Mother	Interview One Father
Not as bad as expected	6	0
Didn't know what to expect	2	3
Not thinking of self	5	1
Emergency caesarean section	6	0
No time to think	1	0
Missed the birth	0	2
Concern for other children	1	0
Not thinking of baby	0	3
Didn't think it was labour	1	1

The table above shows other feelings that mothers and fathers expressed about the labour and delivery experience with differences between them. Mothers more frequently described the experience as not as bad as they expected, described not thinking of themselves or the talked of their experience of an emergency caesarean section. Whereas small numbers of fathers were thinking only of their partner and not of the baby during the labour and delivery experience and two fathers missed the birth of their baby.

4.3 First sight of the infant

There were around a third of mothers who did not see their infant at delivery because of emergency caesarean section and therefore they first saw their infant after s/he was admitted to the NICU. There were also small numbers of fathers who did not see their baby until after s/he was admitted to the NICU because they had missed the birth again because of the need for immediate delivery of the baby.

First sight of their baby

Table 16. Positive feelings experienced by parents' first sight of their baby.

	Interview One Mother	Interview One Father
Positive emotions	10	7
Happiness	5	5
Feelings of responsibility	2	3
Better than expected	3	2
Forgot worries about baby	1	1
Made everything worthwhile	3	0
Love	1	0
Reassured by staff response	0	1

Despite any antenatal diagnosis or the knowledge that the baby had been born prematurely there were more positive feelings associated with seeing their baby for the first time by both mothers and fathers. Both mothers and fathers described their happiness at seeing their baby. Despite the extreme prematurity of his baby born at 26 weeks gestation and 945grams, one father (I 31) said,

"it was brilliant, I was overwhelmed, it was absolutely wicked"

Small numbers of mothers and fathers felt that their infant looked better than they expected. Small numbers of mothers felt that this experience made them feel that all their worries and the experience of labour and delivery all worthwhile. More fathers described how the first sight of their baby made them feel responsible and protective of their baby.

Table 17. Negative feelings experienced by parents' first sight of their baby.

	Interview One Mother	Interview One Father
Shocked by size	6	2
Shock	3	0
Worry/fear	3	3
Not an immediate bond	4	1
Unable to remember much	2	0

There were more mothers than fathers describing negative emotions at seeing their baby for the first time. These parents described feelings of shock, worry and fear, particularly because of the size of their baby. All fathers describing negative emotions were worried and were fearful because of how their infant looked and because of how small s/he was.

Mothers more frequently reported that the baby did not feel like theirs. Others felt deprived of those first moments with their infant and they did not feel an immediate bond. One mother (I 5) explained,

"shock I think, more than anything because there is this tiny little thing in front of me and she's all mine but it didn't feel like she was mine".

A small number of mothers were sadly unable to remember much of the experience so soon after the delivery.

First sight of the infant on the NICU.

Parents were asked how they felt when they first saw their baby in the NICU. Whilst there were some positive feelings expressed, there were a wide range and many negative feelings about this experience described by both mothers and fathers.

The most frequently described negative feeling related to parental worries about the technology in the NICU. Many of the comments made by both mothers and fathers referred to the NICU environment, stating that they were worried by the sight of the equipment, monitors and alarms around their infant. Typically, this mother (I 30) said,

"I hated all the tubes on her".

Many mothers but only one father reported that the baby did not feel like theirs and that they did not have an immediate bond with their infant on that first visit to the NICU. One mother (I 10) said that she had thought,

"how do I know this one is my son and not that one over there".

Mothers also differed from fathers in feeling personally guilty, inhibited or restricted by their own health and had worries about their infant's health and size.

In contrast, a number of fathers (but no mothers) expressed concerns for their partner with worries about how they would cope with seeing their infant. Typically one father (I 7) said,

"my first thought was for (wife's name)...I felt a bit for (wife's name) because I knew she was worried and scared and I was trying to look strong".

Table 18. Negative feelings expressed by parents on first sight of their baby in the NICU.

	Interview One Mother	Interview One Father
Negative emotions	9	4
Worries about equipment	19	8
Not mine/no immediate bond	11	1
Worries about health/survival	7	3
Worries about size	7	1
Feelings of guilt	3	0
Worries about partner	0	4
Feeling helpless	1	1
Inhibited by own health	2	0
Inhibited by environment	2	0
Inhibited by other visitors	1	0
Seeing procedures performed	1	1
Fear of attachment	1	0
Appearance of baby	1	0
Sight of other babies	0	1

Around a third of mothers and fathers were also able to some express positive feelings. Mothers, particularly those with a previous NICU experience reported not being concerned by the equipment in the NICU. Mothers described being able to focus on the baby and were not distracted by the equipment surrounding their baby. Mothers also described their pleasure at seeing their baby. One mother (I 25) of a baby born at 25 weeks reported,

"obviously I was made up and you know proud and things like that."

Only one mother (and no fathers) reported feeling an immediate bond with their infant when seeing her baby for the first time in the NICU.

In contrast, fathers described the experience as better than they expected, feeling relieved and feeling reassured by staff or the environment. One father (I 58) said,

"oddly enough, that unit gave me cause for hope. First to see the level, the attention and the technology."

Table 19. Positive feelings of parents on first sight of their baby in the NICU.

	Interview One Mother	Interview One Father
Positive emotions	10	5
Reassured by staff	7	6
1a. Not worried by equipment	9	1
1b. From previous experience	3	0
1c. Understood reasons for equip	0	3
Better than expected	4	7
Pleased to see baby	6	2
Reassured by environment	3	3
Focus on baby not environment	4	0
Comparisons to others	2	1
Bond	1	0
Relief	1	3

What the baby looked like when first seen in the NICU as perceived by parents.

Parents were asked to describe what their baby looked like when they first saw their baby in the NICU. Both mothers and fathers made negative comments about how small, vulnerable or fragile their baby appeared. Others were concerned about the translucent appearance and red skin colour typical of babies born prematurely.

Table 20. Negative comments about what the baby looked like when first seen in the NICU.

	Interview One Mother	Interview One Father
Size, fragility or vulnerability	10	3
Equipment and/or monitors	8	3
Skin colour	7	4
Comments about appearance	4	3
Uncomfortable	0	1

Very similar numbers of mothers and fathers described how their baby first looked in the NICU as positive with fathers being more likely to describe their baby as looking not as bad as they had expected.

Table 21. Positive comments about what the baby looked like when first seen in the NICU.

	Interview One Mother	Interview One Father
Positive comments	9	4
Not as bad as expected	1	5

Parental ability to express feelings to anyone.

In this next section, the interview explored who, if anyone, parents expressed their feelings to and their sources of support in relation to their NICU experience. They were firstly asked if they were able to express their feelings to anyone.

There were small numbers of both mothers and fathers who felt unable to express their feelings to anyone but for the most, these parents explained that this was typical for them either because they felt no need to express their feelings or that was the type of person they were.

Smaller numbers of parents described a lack of understanding from others or that they hadn't the opportunity to do so.

Table 22. Parents who felt unable to express their feelings to anyone

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
No, unable to express feelings	4	1	3	4
Type of person	4	5	4	0
No need to express feelings	1	1	2	1
People do not understand	1	2	1	0
No, but would like to	1	0	2	1
Away from home	1	0	0	0
In denial of diagnosis	1	0	0	0

Most participating parents felt able to express their feelings to someone and many described more than one individual. The table below shows who parents described expressing their feelings to, but they were later asked specifically if they were able to talk to their partner, family, friends, staff and other parents so these will be discussed again later.

Table 23. Parents who felt able to express their feelings.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Yes, able to express feelings	6	4	4	0
To their partner	18	11	8	6
1.To family/friends	10	4	2	2
1a. To friends	5	1	5	0
1b. To their Mother	3	2	6	0
1c. To their Father	3	0	2	0
1d. To other family member	6	0	0	0
Nursing/Midwifery Staff	5	1	3	0
Researcher	2	1	3	2
Medical Staff	1	0	1	1
Social Worker	1	0	0	1
Chaplain	0	1	0	0
Counsellor	1	0	0	0
Health Visitor	0	0	0	1

4.4. Support from partner, family, friends and other parents.

Partner support

Parents were asked if they felt able to help their partner in the situation they were in and then if their partner was able to help them.

In response to these questions, there were some parents who described feeling unable to express their feelings to their partner. These were, in the main, fathers admitting to hiding their feelings from the mother of their baby to protect her, sometimes from facts about the baby's condition or their worries about the baby in attempt not to worry her further or in fear of upsetting her. One father (I 63) said,

"I tried not to tell her about my real worries. I try to let her know that you know I'm worried but not as deeply as she might be. When I have been. So yeah I try to protect her really."

Table 24. Parents who felt unable to express their feelings to their partner.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
1.Hiding feelings from partner	0	4	1	0
1a. To protect partner	3	5	2	1
1b. Do not want to worry partner	1	3	1	1
1c. Afraid of upsetting partner	0	2	2	0
No time to express feelings	1	0	0	0
Partner does not listen	0	1	0	0
Partner does not understand	1	0	0	0

The table below shows that whilst both mothers and fathers felt able to support their partner, more fathers than mothers reported feeling supportive particularly at Interview Two. Fathers described the different aspects of emotional support they were able to give. This father (I 7) whose baby unexpectedly needed admitting to the NICU said. *"even if I'm just here to...so she can let off steam.... Like yesterday when she sort of, well we both panicked but she started crying... so I said, "come on, you've had enough" and we just had a walk around the outside and just talked her through it."* Fathers, unlike mothers, also spoke of the practical support they were able to provide for their partner. At Interview One fathers described some of the practical care giving duties they were undertaking especially when mothers were less able as they were recovering from the delivery. At both interviews, fathers talked about ensuring mothers did not have to worry about the home, other children or pets. One father (I 51) explained,

"I try and do more things that she would do. So she doesn't have to worry about the house and the dog so I try and do as much as that on the practical side.

Table 25. Parents who felt able to support their partner in the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Able to support partner	10	8	5	7
Emotional Support	9	3	4	5
By talking	6	2	3	3
By "being there"	4	5	0	4
By listening	2	2	6	2
Giving reassurance	2	3	0	1
By sharing	3	0	0	0
Giving explanations	1	0	3	0
Protecting him/her from truth	1	0	1	1
Pushing/encouraging, involving	0	0	2	0
By being positive	1	0	0	0
Physically	0	0	1	0
1.Practical Support	2	5	0	5
1a. Caring for other children	0	1	1	2
1b. Housework	0	3	0	0

There were very few fathers who felt that their partner was unable to help them in the situation they were in. Of those fathers who did express this view, the reasons given were that they were hiding their feelings from their partner or that they did not need help. One father (I 9) participating in Interview One explained,

"I don't know if I really need help to be honest."

Mothers were more likely to describe their partner as unable to help them in their situation. The reasons given by mothers were more varied and differed from those of fathers. Mothers felt that fathers did not understand how she was feeling; they responded inappropriately, fathers' views and feelings were different or the fathers' work commitments were all contributing factors to why mothers felt their partner was unable to help them. One mother (I 36) said,

"whether he really knows what I've been through or not, I don't know. There has been things that he has said along the way that I've thought, erm, you're way off the mark but never mind, it's not important, you know, when I was very tearful in the beginning, it was sort of, you know, "you're going to be very tearful after a baby but it was a bit beyond just hormonal tears. Things like that, I felt, but yes, no, I mean I think, yes, he is very supportive and he certainly tries but I don't think to be honest he's as supportive as my friends. But I reckon that's because women know what women..."

Table 26. Parents who felt that their partner was unable to help them in the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Partner was unable to help	7	1	7	2
Does not understand	2	1	2	1
Responds inappropriately	2	0	2	0
Hiding feelings from partner	1	1	4	2
Irritate each other	2	0	1	0
Do not need help	0	4	0	0
Different feelings or views	1	0	2	0
Difficulties due to partners work	0	0	2	0
Because mother still in hospital	1	1	0	0
Lack of time for each other	0	0	1	0
Feel "left out"	1	0	0	0

Both mothers and fathers felt that their partner was able to help them in the situation they were in, mostly describing the emotional support they received. Mothers particularly described helpful partner support as fathers who were positive in their attitude and outlook for the baby, who were reassuring and those who they felt were sharing the experience with them. One mother (I 10) explained,

"He's always got positive answers for everything I'm feeling negative about. He's very loving and he's always thinking on the positive side with (Baby's name) as well. You know, if I say his gases are this and that, he'll say yes but he's tired, he's only a little chappie. So he always comes back to me with a positive."

Mothers differed from fathers by describing their partners as practically helpful by looking after other children, the home and in giving her lifts to and from the hospital.

Small numbers of mothers also relied on their partners to communicate with others, appreciated their tolerance and their explanations when they struggled to understand. Fathers differed from mothers by admitting that although their partner would be able to help them, they were not allowing them to. One father (I 58) said,

"I am incredibly positive about our relationship so I think you know she certainly could. I think it's a matter of me not wanting her to have to."

Table 27. Parents who felt that their partner was able to help them in the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Partner was able to help them	16	6	10	5
Emotionally	11	6	5	3
By "being there"	5	2	3	2
By talking	5	1	7	1
By being positive	9	1	0	1
By listening	5	2	2	2
By sharing the experience	7	0	2	1
By giving reassurance	4	0	0	1
By explaining	1	0	1	0
By communicating with others	2	0	0	0
By being tolerant	2	0	0	0
Practically	3	0	2	0
By looking after other children	1	0	2	0
By looking after the baby	0	0	0	1
By cooking/cleaning	0	0	1	0
By giving lifts to the hospital	0	0	1	0
But not allowing partner to help them	0	1	0	2

There were in fact, few mothers and only one father at both interviews who felt unable to help and support their partner in their NICU experience. The most commonly reported reason was by mothers who felt that because they were still in hospital at the time of the interview it was difficult for them to help their partner. Others reported that he did not need help or did not have a partner.

Table 28. Parents who felt that they were unable to help their partner in the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Unable to help partner	2	0	3	1
Does not need help	2	0	0	0
Because it is a different experience	1	1	1	0
Still in hospital, unable to help	6	0	1	0
No partner	1	0	1	0
Unable to understand	1	0	0	0

There were some parents who were unsure of their ability to help their partner at this time. Again, there were fewer fathers than mothers expressing these thoughts. Mothers complained that their partner did not express or share their feelings with them. Most felt that was how men typically were or that they were trying to protect the mother from their feelings in order not to upset or concern them. One mother (I 10) explained,

"he won't tell me because he's got to be the man that's looking after the woman."

Table 29. Parents who felt unsure of their ability to help their partner in the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Unsure of ability to help	6	4	2	2
1.Partner does not show feelings	9	1	4	0
1a. To protect their partner	7	0	2	0
1b. To protect self	0	0	1	0
Lack of time for each other	1	0	1	1
Denial of situation	1	0	0	0
Of ability to be supportive	0	1	0	0
Relationship with baby	0	0	1	0

Family support

Parents were asked if they felt supported by their families.

The three tables below show the parents who described the support they were receiving from families, those who felt unsupported and those who felt that they did not need support from their families.

Both mothers and fathers described their families as emotionally and/or practically supportive. Mothers rather than fathers were more likely to value and describe the emotional support they received. Whereas, both mothers and fathers (but more fathers) described how they valued the practical support family gave during this time.

Table 30. Parents who felt supported by their family.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Felt supported by parents	13	9	12	4
1.For emotional support	19	5	10	3
1a. Protecting them from others	0	0	1	0
1b. Making decisions for them	0	0	1	0
2.For practical support	12	10	7	6
2a. Caring for other children	5	2	3	1
2b. Housework inc. washing/ironing	3	3	1	1
2c. Caring for pets	0	0	1	2

There were smaller numbers of mothers and fathers who expressed their difficulties with families as a source of support. Mothers particularly believed that family did not understand their situation so found it emotionally draining to try and give explanations. Mothers also did not want to worry or burden family with their worries, often because of individual family members own health problems or difficulties in their own personal lives. Only mothers described themselves as supporting other family members and again found other family members getting distressed and upset about their situation an added burden. These mothers admitted to sometimes choosing to omit telling family certain details about the baby in order to protect themselves from the responses of family members.

Small numbers of mothers and fathers had no expectation of support from family, described their responses inappropriate or found discussions with or questions from families demanding.

Table 31. Parents who felt that they were not supported by their family.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Do not feel supported by family	2	4	3	1
They do not understand	5	0	2	1
Do not expect/want their support	2	2	1	0
Find them demanding	1	1	1	2
They respond inappropriately	1	0	1	1
They are not local	1	0	3	0
Do not want to worry/burden them	2	0	3	1
Have to support or reassure them	3	0	0	0
Envy of their time spent with baby	0	0	0	1

Only small numbers of parents felt that the experience of having a baby in the NICU did not necessitate support from family.

Table 32. Parents who expressed the view that they did not need support from family.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
1.Do not need family support	1	2	2	0
1a. Would be supportive if asked	2	1	0	1
1b. Don't have that kind of relationship	1	0	0	1
1c. Don't need their emotional support	1	1	0	2
1d. Compared to others worse off	1	0	0	0
1e. In the way	1	0	0	0

Friends.

Parents were also asked about support from friends as they were questioned if they thought friends understood the situation they were in. The tables below show the parents who believed their friends did understand their situation, those who did not and there were parents who had not spoken to friends yet.

Only small numbers of both mothers and fathers did feel that friends understood their situation and those who did, had friends who themselves had experience of being a parent of a baby in a NICU.

Table 33. Parents who felt that friends did understand the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Friends did understand	2	4	3	2
Because they had had the experience	2	2	1	0
Because they were parents	2	0	1	0
Because of their occupation	1	0	0	0

There were more parents, particularly mothers who felt that their friends did not understand their situation. Nevertheless, some still described friends as trying to be supportive.

Mothers felt that friends were unable to understand because they had never experienced being a parent in the NICU themselves, they said or acted in an inappropriate way or they could sense that friends felt awkward and unsure of what to say. One mother (I 4) participating in Interview Two explained,

"I think that she was a bit shocked when she came in here and saw him and I think that people are a...bit worried to come in and see him and buy things for him and enquire about him. And he's not, it's just that he needs a bit of help but people assume

that he's on death's door and they are a little bit embarrassed and worried about asking."

A small number of mothers and fathers described friends as over anxious and believed that friends felt the baby's condition was worse than it really was. One mother (I 38) said,

"actually sometimes receiving the cards and hearing about the phone call sets me off crying because it makes me think, god everyone out there is... you know... thinks this is a real catastrophe."

Table 34. Parents who felt that friends did not understand the situation they were in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Friends do not understand	11	2	4	2
But are supportive	9	3	2	3
Because they've never experienced it	8	1	8	1
Say/do the wrong things	6	1	1	0
Think it is worse than it is	3	2	1	1
Unsure of how to act/say	3	1	1	1
Not that kind of relationship	0	0	0	1

There were some parents and mothers, more so than fathers that had not yet spoken with their friends. For fathers, the main reason was described as a lack of time but mothers, described intentionally avoiding talking with their friends at that time because they anticipated it as too emotionally tiring or difficult for them. Some mothers were still avoiding friends at Interview Two. This mother (I 52) said,

"I think it will get really tiring, you know, having to...kind of, relay the same thing over and over again."

Table 35. Parents who had not told or spoken to their friends yet.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Not involving friends yet	6	1	1	1
1.Avoiding friends	4	1	2	1
1a. Feel judged	1	0	0	0
1b. Too difficult/tiring	6	0	2	0
None local	1	0	1	0
Not had time	2	2	1	1

Other Parents

Parents were asked if other parents in the NICU with similar experiences and anxieties were a source of support for them and if they had opportunities to talk with them in the NICU.

Many parents had experiences of talking with other parents in the NICU however some only on a superficial level. Other parents had not had the opportunity with some concerns about it being insensitive, it not being appropriate to do so or a simply a lack of opportunity.

Table 36. Parental ability to talk to other parents in the NICU.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Parents able to talk to other parents	12	4	12	3
On a superficial level only	6	6	4	3
Parents unable to talk to other parents	6	5	1	1
Because it may not be appropriate	4	5	2	1
1.But would like to	5	2	1	1
1a. To help other parents	0	2	0	0
1b. Need a place to go to talk	0	0	1	0
Chosen not to talk to other parents	2	1	0	0
No opportunities to yet	3	0	2	0
Because focusing on own child	2	0	0	1
Partner does	0	0	0	1

Many parents found that talking to other parents was a helpful experience with many mothers explaining that they had something in common with other mothers sharing like or similar experiences who, unlike friends were able to understand their situation. At both Interview One and Interview Two, mothers and fathers found that by talking to parents who had a baby less fortunate than their own, they were able to make downward comparisons and were reassured that there were other babies and parents worse off than they were.

In contrast, there were also a small number of mothers and fathers but only at Interview One who found it helpful to talk with parents with baby's who were more fortunate than they were. This father (I 21) of a baby born at 24 weeks made both downward and upward comparisons saying, *"(Other parent) told us about a baby the same age as (Baby's name) on the wing, she only lasted two days, so... and it is better the longer - she gets stronger every day..."*

and

"her baby is about 8 oz heavier... she said "oh look, they will be all right, just there will be your ups and downs"."

Mother and fathers described talking with other parents as a welcome opportunity for them to help and support others.

Table 37. Parents who found it helpful to talk to other parents in the NICU.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Was helpful to talk to other parents	8	4	9	1
Sharing/something in common	16	2	10	5
Comparisons with more unfortunate	6	1	5	2
To help them	2	3	5	4
Comparison with more fortunate	4	2	0	0
For explanations from others	2	0	0	0
Company/reassurance for partner	0	1	0	1
Company for self	0	0	1	0

Only mothers described talking to other parents as unhelpful. At Interview One and even more so at Interview Two, mothers described the comparisons they made with others more unfortunate in a negative way. Mothers described feeling guilty if their baby was progressing well in comparison with others. They were unsure of what to say to those parents and felt uncomfortable with the sense of competitiveness about how babies were progressing or how much milk they were managing to express for their babies.

Three mothers and only at Interview One felt that by talking to other parents it was unhelpful because they made comparisons with others more fortunate. They were saddened that their baby was not progressing like others were and then felt guilty for having those feelings.

Mothers (and one father participating in Interview Two) felt that no other parent was experiencing what they were and therefore it was not helpful to talk to other parents and make comparisons. These parents felt that every baby was very different and what their parents were feeling at any one time was individual to only them.

Table 38. Parents who found it unhelpful to talk to other parents in the NICU.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Not helpful to talk with other parents	2	0	4	0
1. Comparisons with more unfortunate	4	0	5	0
1a. Sense of competition	1	0	0	0
Comparisons with more fortunate	3	0	0	0
Their experience is different	5	0	1	1
Focus only on their own child	1	0	1	0

4.5. Support from and communication with Staff

Parental feelings about their ability to talk to the nurses in the NICU.

Earlier in both interview schedules, parents were asked about who they talked to, who they turned to for support with particular questions about support from their partner, family and friends. Parents were also asked about how they viewed their ability to speak to neonatal nurses to explore if parents turned to nurses for emotional support, how they viewed the role of the neonatal nurse and their perception of the communication they shared with neonatal nurses.

Their responses have been organised into negative and positive responses in the tables below. Parents who made negative comments about their ability to talk to nursing staff may also have made positive comments.

Table 39. Negative feelings about parental ability to talk to the nurses in the NICU.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Negative comments	2	0	1	3
1.Pestering or bothering staff	2	2	2	2
1a. Busy with others	8	5	4	0
Aware of sharing their time	6	2	3	0
Lack of continuity and/or knowledge	2	1	2	1
Communication and/or language	3	1	1	0
Too busy	0	0	5	0
Comments re individuals	2	1	1	2
Fear of hearing bad news	2	1	1	0
Would like more time to talk	3	1	1	1
Too many staff to get to know	2	0	1	1
Unapproachable	2	0	0	0
Not kept informed	1	0	1	0
2.Not for emotional support	1	1	2	0
2a. Not that kind of person	1	0	0	0
2b. No need from nurses	1	0	0	0

The numbers of negative comments about parental ability to talk to nurses were small. The most commonly reported negative view of communication with the neonatal nursing staff was related to the perception that nursing staff were busy, often with other babies, their awareness that they were sharing the nurse's time with other parents and/or the feelings that they were pestering or bothering busy staff. Most mothers and fathers talked about choosing the right moment to talk to nursing staff and of asking their questions when the nurse was attending to their own baby. One father (I 6) from Interview Two said,

"they have got to attend other babies... so... yes I do feel a burden sometimes..."

Another response from a mother (I 43) participating in Interview One was,

"a lot of the time I do feel as though like I am mithering them and I am being a nuisance and I am stopping them from doing their job and... I felt that... it would be easier or... more comfortable for them if I stayed away."

As obvious from the table above the numbers of parents making other same or similar negative comments were small with typically only one or two mothers or fathers expressing other like views.

Only small numbers of mothers and fathers at both time points made negative comments about an individual member of staff, about nurses being unapproachable, there being too many nurses to get to know or that they would like to spend more time talking with the nurses.

There were also a small number of mothers and fathers as can be seen in the table who interpreted the question as their ability to talk to the nurses for emotional support. Only one mother from Interview One was critical of the lack of emotional support from nurses, whilst the others admitted that they did not look to the nurses as a source of emotional support.

Table 40. Positive feelings about parental ability to talk to the nurses in the NICU.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Positive comments	22	11	10	8
Answer questions/ informative	23	11	7	5
Approachable/ giving time	14	4	8	1
Encouraging/ involving parents	11	5	2	2
Supportive	9	2	3	1
Comments re individuals	5	4	3	2
Friendly	4	1	2	2
Being honest	3	2	0	0

There were many more positive views reported about talking with neonatal nurses. Whilst some parents just made generally positive comments such as *"They are marvellous"* (I 27 Father), others explained in more depth and their responses are categorised in the table above.

The most frequently reported positive comments were that the nurses were exceptional at the giving of information and in answering their questions, however trivial parents thought their questions may be. Nurses were also described as excellent at explaining what was happening with their baby, their treatments, the equipment used and reasons. One father (I 27) explained,

"the moment you walk in they come, they update you straight away, tell you how (Baby's Name) was doing erm...and if she needs anything what, what they're gonna do, what'll happen, what can happen".

Other parents appreciated the personal knowledge of their baby that the nurses held about him or her. Nurses were able to report information to parents without having to consult charts or other forms of documentation which parents felt were reassuring. One father (I 39) said,

"it is amazing that the skill that they've got because they're dealing with a room full of babies. Different babies are coming in, different babies are going out. Sometimes they are dealing with different rooms but they have that information at the tip of their tongues, the tip of their finger tips whatever about how much food he had, when he had his last bowel movement and I am really impressed about how they, and it's great that that information is in their heads because if they had to keep looking at the files and going to the charts and saying you'd feel well is my baby important and you know is this information not going in as if it's just another statistic you know but no its great that that information is just off the top off the head".

At Interview One and Interview Two, the numbers of mothers and fathers with positive descriptions of communication with nurses in this category were very similar. Around two thirds of mothers and fathers at Interview One but fewer at Interview Two with around one half of both mothers and fathers made positive comments that nurses were informative and helpful in answering their questions. There may be a number of reasons for this change over time. Firstly, parents at the time of Interview One are learning a great deal about their baby's condition, often with little prior knowledge of their baby's illness or prematurity and therefore have many questions to ask. Babies are more likely to be at the peak of their illness at the time of Interview One and therefore be cared for within the intensive care areas where nurse to baby ratio is greater and as new parents, nurses are aware of their need for information. With the passage of time, parents' knowledge of their baby and of any disease process for most parents will be much greater than in early days so their questions or need for information may be less. Parents will also have a much greater awareness and understanding of written nursing documentation so they will also access that for information. In addition, care giving activities such as nappy changing and feeding become parental responsibilities as their confidence and own knowledge of their baby grows.

Alternatively, the reason for fewer parents describing nurses as informative and good at answering their questions is that parents have changed their views over time.

Also commonly reported positive comments were that the nurses were approachable and giving of their time and attention even when they appear to be doing something when parents first enter the room to visit their baby. One father (I 21) participating in Interview One said,

"they are brilliant... they have always got time for you" and a mother from Interview One (I 32) explained,

"they're fantastic, yes, they are, they're always approachable and they have always got time for you, they are really, really good, I'm really impressed with them."

Mothers describing nurses as approachable and giving of their time amounted to around half at both Interview time points however here there was a difference between mothers and fathers with only a quarter of fathers at Interview One and only one father at Interview Two describing nurses in this way.

Both mothers and fathers participating in Interview One frequently described nurses as encouraging and persuasive in involving them in caring for their baby. One father (I 39) described how the nurses were good at giving him the reassurance and encouragement he needed. Giving the example of feeling unsure about holding his baby for the first time, he said,

"they were very good at pushing us to a sort of next stage. So holding him felt like a big thing. I felt I wasn't ready to hold him and I didn't want to hold him because, you

know, I didn't want to infect him. But they said don't worry about him, just hold him, sit there. So we did it one evening when we weren't even thinking of doing it and we said look, lets hold him tomorrow and they said no, come on let's do it now and we both loved it."

Again, by Interview Two time point the numbers of both mothers and fathers describing nurses in this way were much fewer, probably due to the increasing confidence of parents gained over time and through their involvement with their baby. As shown in the table above there were smaller numbers of parents who described the nurses as supportive and fewer fathers than mothers at both interview time points. Whilst these numbers are smaller, parents have admitted not seeking emotional support from nursing staff but some of these comments showed that nurses offered their support and took time to talk to parents about how they were feeling even if parents did not want to share their feelings with nurses. One father (I 39) said,

"she said how's everything going and I said oh, (Baby's name is) doing this and (wife's name) is doing that and she said oh no, you misunderstood the question. How are you doing?.... I thought god, you are asking and I'm fine I think. And how are you getting on in the hospital and who are you talking to and what's your support and I thought, gosh for a neonatal intensive care nurse looking after my baby to be asking me questions.... and I thought that is something special. So basically the care is fantastic". And a mother (I 10) said,

"I think that in all fairness I don't think that we have come across one that I'd say isn't supportive. They are, they're all very supportive and they'll always ask how we feel, are you all right, make sure that we have a break and all that sort of stuff."

Smaller numbers of parents made positive comments about individual neonatal nurses who had looked after them and their baby, who they knew particularly well or had developed a close relationship with. For example, one mother (I 38) said,

"one of the midwives (crying) (Nurses name) who I can really... I really adore her, she has just been so brilliant over the last 2 or 3 days and...you know in terms of how she has treated (Baby's name) and how brilliant she has been with him and also...you know she really taken special care with me about...the expressing and just sort of (crying) just given me a lot of confidence".

Other positive comments were categorised as nurses being friendly and being honest with fewer parents making these descriptions.

Parental feelings about their ability to talk to the doctors in the NICU.

Following the question about their ability to talk to the neonatal nurses, parents were asked if they felt able to talk to the doctors. Their responses are again tabled below into negative and positive responses. In addition, and unlike the same question about nurses, there were some parents who responded by saying that they had not had the opportunity to speak with the doctors in a non critical way. There were some parents who went on to say that they had no real need to speak with the doctors in that they were happy with the progress of their baby, with the information that they were receiving form the nursing staff and that if they felt they did want to speak with the doctors they would feel comfortable asking. One father (I 51) said,

"I don't really feel the need to bother them because the nursing staff make such an effort to get the information for you." And a mother (I 69) said,

"it doesn't bother me because I always, even in the past if I have wanted to know something and I really wanted to speak to a doctor I would ask".

Table 41. Parents who had not spoken with the doctors.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Not spoken with the doctors	5	2	2	1
No real need to	4	3	1	3
Would ask if wanted to	1	0	6	1

The negative responses and feelings about parental ability to speak with the doctors are set out in the table below and like those about talking with the nurses, the numbers are small. Most commonly reported negative feelings about their ability to talk with the doctors were that parents would like opportunities to talk with the doctors more than they currently were. One mother (I 10) explained,

"they haven't had the contact with us as much as I would have liked. Even if it was only once a week or something but I can't even say once a week they've come and sat us down and had a chat. We've been here nearly three weeks now."

There were also some criticisms of the doctors' communication skills and that they felt that they were too busy to talk with parents. One mother (I 43) felt that

"if you don't ask you don't get told... and I was finding it really difficult knowing what to ask" and another mother participating in Interview Two (I 41) said,

"They have been great but I can honestly say I probably wouldn't approach a doctor as much, I'd go to the nurse because you know I feel like, you know, they obviously are very busy and I don't know if you can."

There were smaller numbers of criticisms about individual Doctors, the fear of asking the wrong doctor or bothering them and one mother was frustrated at Interview Two that they were unable to answer her questions.

Table 42. Negative feelings about parental ability to talk to the Doctors.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Negative comments	5	1	5	1
Would like to talk more with Drs	5	4	4	3
Critical of communication	5	0	2	2
Too busy	4	0	5	2
Don't feel informed	2	2	1	0
Don't feel involved	1	1	0	0
Comments re: an individual Dr	3	0	0	0
Fear of bothering/ asking wrong Dr	1	0	1	0
Unable to give answers	0	0	1	0

Again, like parental ability to talk to the nurses, there were more positive comments about parental ability to talk to the doctors than negative. However, the overall numbers of positive comments about talking with the doctors when compared to those about talking to the nurses were less. Unlike talking with the nurses, doctors were not described as involving and encouraging parents or as supportive.

There were frequent general positive comments by both mothers and fathers at both Interview time points such as a mother (I 41) at Interview Two said,

"They have been great" and a father (I 63) also at Interview Two said,

"the consultant would make a point of having a chat with you whether it was (names of Consultant Neonatologists) whoever, they all chatted."

The number of these general positive comments increased at Interview Two time point with almost all fathers at Interview Two expressing positive comments about their ability to talk to the doctors.

The most frequently reported positive parental views related to receiving explanations from the doctors about their baby, answering their questions and updating parents on progress. Fathers at both time points expressed these positive views more than mothers. One father (I 2) explained,

"they've always took time to tell you what's happening, what they're doing, why they're doing it and what they're hoping to achieve by doing it."

Although less frequently than nurses, and less so by mothers at both time points, doctors were often described as approachable or giving of their time. One mother (I 40) at Interview Two explained,

"I think they are available for you to speak to. I've never felt like no one's around for us. Just yesterday she had the time as she was examining him in the morning she had the time to explain to me, it wasn't through her explaining that I didn't understand, because she'd done quite a good job it's just that I was actually quite shocked at what I'd heard and I'd sort of stopped listening, if you like. So she just went through it again."

Smaller numbers of mothers at both time points made positive comments about talking to an individual doctor, actively seeking out a particular doctor to speak to or referring to a particular incident when their experience of talking to a certain doctor was a positive experience for them.

Small numbers of mothers and fathers appreciated being made aware of any plans of care made for their baby either through talking on a one to one basis with a doctor or by listening to the doctors on the daily morning ward round. One father (I 9) said,

"I wait for all the doctors and the consultants to come around so I listen to what's happening and what's the next course of action for him and all that sort of thing. So, I get a lot out of that."

Then there were also small numbers of mother and fathers mainly participating in Interview One who described talking with the doctors as reassuring, giving them confidence in the care their baby was receiving and appreciating of their honesty.

Table 43. Positive feelings about parental ability to talk to the Doctors.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Positive comments	10	6	7	6
Getting explanations	8	6	5	4
Approachable or giving time	8	2	5	2
Comments about individuals	3	0	3	1
Information re: plan of care	3	2	0	1
Giving reassurance	1	3	0	1
Being honest	3	1	0	0
Confidence in care	1	3	0	0

Confidentiality

Each morning in the intensive care rooms a consultant ward round took place whereby a consultant reviewed each infant along with the other medical and nursing staff involved in the infants' care. The ward round was seen as a tool for teaching and learning and the numbers of staff and students taking part could, on days be as many as ten. These discussions included all aspects of the infants' history, problems, treatments, care and future plans.

Parents were allowed open access on the NICU at all times. They were informed about the ward round and encouraged, if possible and if they wished to be with their infant during the times of the ward round so that they could listen to what was said and ask questions should they wish.

Due to the geography of the NICU, the numbers of staff involved and the no parental restriction policy during the ward round it was difficult to maintain absolute confidentiality at this time. Parents who were present, heard what was said about their own infant but also there were times when it is possible to hear what was said about other infants in that room.

Although questions about the ward round were not originally part of the interview schedule, thoughts and feelings were expressed by some parents about the ward round situation during the interview and it was appropriate to explore those thoughts at that time.

Four fathers and ten mothers felt that their inclusion at the time of the ward round was a positive one with ten comments about how they thought that the ward round was informative for them. They felt that the ward round was an extremely useful way in which to learn about their infants' treatment and care and they welcomed that at the end of the discussion they were given an opportunity to ask those caring for their infant the questions that they have. One mother (I 68) said,

"I get a very real picture of what is happening to A."

and one father (I 39) said,

"I definitely feel able to ask questions but I'm encouraged to ask questions. Encouraged on the first day, they said come to a ward round, so I came and I've been every day since and found them very instructive. I found it really helpful."

However, other parents felt that the ward round was not a positive opportunity to communicate with, particularly the medical staff. One father and four mothers made negative comments about the communication between themselves and the doctors at this particular time. These parents felt that explanations given to them were inadequate and that they moved on to the next infant leaving them, as parents with unanswered questions. One mother (I 8) talked at length about her concerns saying, "it is put so clinical to you and they don't, they leave you to it then and they leave the nurses then to pick up the pieces, because they just breeze out then and you're left there like "hang on a minute".

Two fathers and six mothers commented that the lack or loss of confidentiality at the time of the ward round was not a concern or issue for them. When asked about how they felt about the lack of confidentiality at this time said that they were prepared to sacrifice their confidentiality as the alternative would be to be asked to leave during that time. They felt a system whereby they were asked to leave whilst other infants were discussed was not acceptable and the loss of confidentiality was the "price to pay" for having open access to their infant.

However, three out of the six mothers who had reported that lack or loss of confidentiality was not an issue for them, went on to say that they might feel differently if their infant had many problems or was particularly sick. They felt that because their infant was progressing well they had no reservations about others hearing confidential information about their infant but wondered if they would feel the same if their infant was more poorly and the information discussed at this time was less positive.

One mother (I 57) said,

"I don't mind because he has not had a lot of problems. I might have felt differently if he had a lot of problems".

One mother (I 8) heard for the first time on a ward round about the plans to carry out tests on her infant for a certain condition. She did express concerns that it was inappropriate for her to be given that information in that way and she did not feel comfortable that other parents could have heard what the doctors said. She said,

"I don't think it should have been done the way it was done, because it could have been other parents around on the nursery and they could have been sort of nudging one another, oh they think that baby has cystic fibrosis and I just don't think it was handled very well".

Whilst some parents had no issue with other parents hearing about their infant, they felt less comfortable about hearing information about other parents infants, particularly if those other infants were seen as very ill.

One father and three mothers described difficulties understanding the meaning of what was said by staff on the ward round. One mother (I 70) explained,

"I sit there and listen but I don't understand what is going on (okay) if someone said to me in plain English what's going on because they come out with big words"

Unlike a discussion specifically between medical or nursing staff and a parent, the ward round situation differs in that staff are discussing their patients whilst parents listen, they use medical words and a language that may not be easily understood by those not familiar with it. Some felt that the information that they received from listening to the ward round discussion was confusing for them.

Two mothers felt somewhat intimidated by the ward round situation, with one mother (I 1) saying,

"I feel a bit strange when they're all there, you know and they're all cluttered round this one incubator and I'm sat there in the corner. No, that's the only thing I didn't really like, when there was loads of them coming round, it's a bit strange".

Mothers reported not having the confidence to either ask questions or ask for an explanation on an aspect they heard but did not understand.

4.6. Adaptation

As discussed in earlier chapters, when exploring how parents adapted to the birth of an infant that requires admission to the NICU, the semi structured interview schedule was constructed and based on Taylor's cognitive framework. Parents may search for a cause and apportioning of blame particularly to oneself has been associated with successful adaptation to the stressful event, in that blaming oneself may enable a sense of personal control over the crisis situation

In the search for meaning parents may ask themselves why they have had a sick or premature infant, they may make downward comparisons with others deemed less fortunate than themselves and explore how they, as parents or their infant may have benefited or gained from the experience (e.g. Padden and Glenn, 1997).

When adaptation to this experience was explored, parents were therefore asked if they felt that anything or anyone was responsible for what had happened and for the situation they were now in.

Blame

Table 44. Parents who expressed feelings of self blame.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Blames self	12	1	4	0
Looking for a reason	17	1	4	0
Comparisons to others	3	0	0	0
1a. Knows blameless really	11	0	0	0
1b. Reassurance from Drs sought	6	0	0	0

From the above table, many mothers, especially at Interview One expressed feelings of self blame, described feelings of guilt and were searching for a reason for why their baby had been born sick or prematurely. They agonised over their own actions and lifestyle prior to the birth in their attempt to find a reason in the early days following the delivery of a baby who needed admission to the NICU. These are typical of the comments that mothers made in response to the question.

"I suppose guilt has been my strongest feeling all the way through" (I 5) and

"I think you blame yourself, you always will do, you know there must have been something... I could have done, couldn't have done, to prevent it from happening" (I 69) and *"I felt guilty and angry at myself."* (I 5)

Spontaneously these mothers talked of the search they had made to find a cause or a reason for what had happened. Mothers questioned whether they had eaten something they shouldn't, what they had been drinking during the pregnancy, their activities, work commitments, stress in their lives and how well they had been caring for themselves in their search to find a cause for either a preterm birth and if their baby had been born with a congenital abnormality such as cleft palate.

One mother (I 19) said,

"I think the coil has got something to do with it, I mean it might not but... I don't know, I have been blaming myself thinking, I went on holiday just before she was born and thinking it was the aeroplane, because they say things about aeroplanes and I just thinking of everything really...because I am always rushing round, tidying up and running round after the kids... "

Another mother (I 38) questioned whether her work commitments had contributed to the birth of her premature birth saying,

"...how much was the abruption caused with work" and

" I thought this is something I had done, you know, is it that I have been working too hard, could it of been induced by you know, tiredness and stuff"

and another mother (I 4) said,

"Maybe, I got a bit stressed at work because I've got a stressful job, maybe I didn't rest enough, maybe I didn't do this, do that? Maybe I should have lost weight and got healthier before I was pregnant. You think it all and it's very much your fault"

The two mothers who had infants with congenital abnormalities, both with a cleft palate, both had self blame thoughts, looking at themselves and their activities during early pregnancy. One of these mothers (I 36) said,

"I think you always turn to yourself. You always think, I thought in my head, when does the palate form, what was I doing then?"

Two mothers also questioned whether their age was to blame. Of these, one was the mother of a baby born with Down's Syndrome and the other mother had preterm labour induced by an infection.

Of the mothers participating in Interview One who expressed the belief that they were in some way responsible for the situation they were in, many did go on in the same interview to say that despite these feelings and worries, they knew that they were not really to blame. One mother (I 69) said,

"I think you blame yourself, you always will do, you know there must have been something ... I could have done, couldn't have done, to prevent it but ... deep down I know there is nothing but it will never take that away ... " and another mother (I 47) said,

"I knew it wasn't my fault and I know ... it's not something... that could be changed but it is still, it was quite hard just the knowledge that he was struggling inside and he wasn't getting enough nourishment and I think, just its hard not to feel guilty".

Many mothers had made efforts to seek reassurance from others to confirm that they were indeed, not responsible for the situation they were in and for the birth of a baby that required admission to the NICU. The people that these mothers sought reassurance from, were the doctors and nurses from the NICU, Obstetricians or General Practitioners. For some mothers they had clearly made great efforts to ask if there was anything they did to cause or anything they could have done to prevent what had happened in their individual circumstances. One mother (I 38) said,

"I've had the people that I needed to reassure me about that, really reassured me that you know I could have been lying on my back for the last 6 months and it would still have happened, it is one of those things that come of the blue" and

"...its questions that erm, I have asked...but I think I have understood that it is something that would have happened whatever"

Interestingly, most of the mothers that were interviewed at both time point one and time point two and who expressed feelings of self blame during the first interview, no longer blamed themselves by the time of the second interview.

Only 4 mothers expressed self blame feelings at both interview time points. They all were still searching for a reason for what had happened. These mothers talked of their hope of answers from postnatal consultations with their obstetrician or from the results of investigations, for example, of their placenta at the time of the delivery.

One mother (I 74), in particular who blamed herself solely for the birth of her extremely preterm baby was a single, teenage mother who had experienced a neonatal death of an extremely preterm infant in the year previous to this birth. She said,

"I am going to see a specialist to see... there must be something wrong with me...I have lost two... I haven't lost two babies but I have had two babies prematurely, they were both 24 weeks... so I am thinking maybe there is something wrong with me..."

One mother (I 11) who was no longer in a relationship with the father of her premature baby, said that she believed that the father of her baby blamed her for having the baby early. She said

" ...he has already said, because it is my fault I had her early and everything that is wrong with her is my fault."

Despite the commonly reported feelings of blame, either feelings of self blame or blame of others, many mothers said that they felt that no one was actually to blame for the situation that they were in, typically saying,

"it's just one of those things. It's nature." (I 49)

"it is just one of those things [yes] and we both feel like that, it is no good looking for people or things to blame" (I 46)

Table 45. Parents who felt that no one was to blame.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
No one to blame	13	10	2	0
"Just one of those things"	11	12	0	0
Comparisons to other worse off	0	3	0	0

Most fathers stated that they thought that no one was to blame for the situation that they and their infant in the NICU were currently in. These comments were made by fathers and were typical responses to being asked if they thought that anything or anyone was responsible for the situation that they were now in.

"I know it's not her fault, I haven't blamed anybody. It's just the way it's happened, he's here now, so, he's just come a bit quicker" (I 9) and

"I don't think there's any...you can't blame anyone can you. I don't think there's any sort of responsibility. I think it's just, it's just nature isn't it"? (I 22)

In comparison to mothers, very few (only 2) fathers interviewed, questioned whether they personally were in some way to blame for their baby being born prematurely. One of these fathers had a sister who had had a premature baby so he therefore questioned whether there was a familial cause within his own family responsible for premature birth.

Fathers were aware that their partners felt responsible for the preterm birth of their infant and had blamed themselves for the situation they were in. One father (I 9) said,

"she's stressing herself out and she says it's my fault anyway, getting the infection. And I know it's not her fault," another (I 21) said,

"she had been thinking and she has tried to blame herself".

However, most fathers felt that no one was to blame for what had happened. They commonly described not giving much thought to a cause and certainly did not apportion blame. Comments such as the following were very common amongst these fathers.

"...nobody blames anybody and we are quite relaxed. It's just one of those things and it happened". (I 39)

"...just very philosophical about it, it was meant to be that way.... I am a great believer in fate and it was meant to be..." (I 42)

"It's just one of those things, I literally do think it's one of those things that's happened and I've got to, we've got to get on with it. He's here, he's here earlier but... I wouldn't change anything". (I 9)

Table 46. Criticisms of care received.

	Interview One Mother	Interview One Father
Criticism of care received	1	0
By an individual	2	1
By a referring hospital	2	0
Why no antenatal detection	3	0

Small numbers of mothers criticised the care that they had received prior to the delivery when they were asked if they believed that anything or anyone was responsible for the situation they were in. The mothers who questioned why there had been no antenatal detection of problems were mothers of babies born with congenital abnormalities (one born with Down's Syndrome and one born with a cleft palate). The mother of the baby born with a cleft palate (I 54) said,

"...you wonder why it wasn't detected cause it is something that develops very early... but I don't know why it wasn't picked up... so perhaps I feel a little bit as if I could have been warned for it".

A further three mothers specifically blamed an individual for their situation with mothers saying,

"She just didn't listen to me you know, I do resent her for that because I could have lost the baby through it all" (I 71) and

"...if the midwife that I saw the first time had of picked it up then ... and I could have had a caesarean section and then her head wouldn't have been so bruised and she'd have had drugs to have brought her lungs on so she might not have had some of the problems we've had while she's been her". (I 1)

two mothers were generally critical of the care they received in their own local hospital from where they were referred and transferred from, for specialist obstetric and neonatal care with one (I 70) explaining,

"...probably because I waited so long ...for a doctor ... and they just didn't take any notice ... but if I had have saw a doctor ... I might of got here quicker".

Quite differently from the mothers interviewed, only one father expressed a belief that he felt that someone else was responsible for his baby being born preterm. Criticising the care by an individual that his partner had received prior to transfer to the hospital he (I 72) said,

"...in my opinion... if... she had have... seen someone earlier... she had have been admitted earlier and ... things may have... been different, may have been able to ...stop it"

Why has this happened to me?

In exploring if parents searched for a reason, parents were asked if they had asked themselves why this event had happened to them.

Table 47. Parents who asked "Why has this happened to me?"

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Yes, why happened to us?	18	8	3	1
Comparisons to more fortunate	11	1	0	0
Looking for a reason	9	3	0	0
Comparisons to more unfortunate	6	1	1	0
Blames self	7	0	0	0
Finding positives	2	0	0	0

Most mothers participating in Interview One deliberated why they, as an individual or as a couple, were in this situation. Many made comparisons to other parents who were more fortunate than they were, and were searching for a reason for why their baby was born sick or premature. These quotes from mothers are representative of many that were said during Interview One.

"...at times it got me down because I kept thinking to myself, 'Why, you know, why has this happened?" (I 3) and, *"...why us, what have we done to deserve this, and I am not particularly religious or anything but you do ask the question when we discuss it between ourselves you know why does it have to happen to us."* (I 49)

Some mothers had asked themselves why this has happened to them but then made comparisons to those less fortunate to them.

In comparison, slightly fewer fathers interviewed at Interview One asked why this event had happened to them with similar comments from them. For example, one father (I 9) said,

you just sort of step back and think, what's going on? Why me? It's just a split second thought really." And another (I 2) said,

"I actually said it to (partner), why us?"

By the time both mothers and fathers participated in Interview Two, very few asked themselves why this was happening to them.

Personal gain, growth or benefits

When parents were asked if they believed that there were any benefits to what they were experiencing, there were both emotional benefits described such as enhanced relationships with their newborn baby, their partner or other family members and a changed outlook on life with an increased appreciation of what they had. Additionally, there were some practical benefits expressed.

Table 48. Perceived benefits

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Benefits	6	8	6	3
Appreciation of what s/he had	8	5	3	4
Changed outlook	3	1	3	1
1.Health benefits	2	1	1	0
1a. Baby in the best place	5	4	1	0
1b. Recovery for mother	3	1	1	0
Learning baby care/routines	2	2	5	3
Stronger relationship	4	2	0	1
Have baby now	1	0	3	3
Meeting people	0	0	3	1

Around two thirds of mothers from Interview One compared with most mothers from Interview Two were able to describe benefits in what they were experiencing. This compared to most fathers from Interview One and 7 out of 8 fathers from Interview Two who found benefits to what had happened and the situation that they and their baby were currently in. The only father from Interview 2 who failed to identify any benefits arising from the experience was the father of a term baby born without an antenatal and therefore unexpected diagnosis of a congenital abnormality.

When describing benefits from their experience fathers from both interviews felt that the event had changed their outlook on life with a new found appreciation of what they had and a desire to make the most of it. One father from Interview One (I 2) said, *"I think it just makes you appreciate certain things and it's given me a totally...I think it gives you a different outlook on life, definitely. A totally different outlook on life..."*.

Fathers in both interviews also spoke of how, as a result of their experience they had an enhanced appreciation of their baby and they took him or her less for granted than they felt they would have done had the baby not required neonatal intensive care. One father from Interview one (I 58) said,

"at this minute I can certainly say that I will be much more part of his active childhood than I would ever been had he been born full term and walked out of this hospital in three or four days" and a father from Interview 2 (I 50) said,

"I think that the whole thing has probably positively affected my relationship and in that we are just more grateful to have him and I think it will probably continue to affect it positively in that we will have a concern to make sure that he gets what he needs in terms of sort of human contact and emotional closeness. Because one becomes conscious of the difficulties of that, when he is separated from us. So I think there is a sort of focus in our minds towards that with him which will continue to be a positive thing".

Smaller but similar numbers of mothers and fathers participating in Interview One believed that the experience had resulted in the development of stronger relationships telling of improved and more time spent communicating with their partner. A father (I 2) said,

"I definitely think that it makes you talk more... I mean we haven't even been married 12 months yet, I mean it may develop better communication obviously the longer you're with somebody. Umm, I think it's definitely sort of speeded that process up between us and we've spoke a lot more and I think it has... it has brought us closer together definitely."

Only one parent, a father from Interview Two spoke of stronger relationships as a result of the experience. However, unlike in Interview One, where both mothers and fathers spoke only of the improved relationship with their partner, this father (I 45) revealed that the experience had brought him closer to their parents.

"on the positive side it has definitely brought us together much more as a family. There is plenty of things I have seen about my mum and dad that I haven't seen before. I have definitely got closer to (partner's) parents ... the experience has brought us closer".

Some parents described practical benefits for themselves or their baby to having their baby cared for on the NICU.

Around a third of fathers and slightly fewer mothers from Interview One expressed their opinion that there were health benefits for their baby, with a belief and a confidence that their baby was in the best place to meet their needs as a sick or premature infant. Only one parent, a mother from Interview Two, when asked if she could describe any benefits to what had happened described her baby as being in the best place to meet his health needs.

In addition to the health benefits for the baby, small numbers of mothers and fathers from Interview One and but only one mother from Interview Two felt that having a baby in the NICU facilitated maternal recovery from the pregnancy, labour and delivery experience. Mothers had benefitted from having time to recuperate from both a normal delivery and from caesarean section deliveries without having the responsibility to totally care for the baby without support at home soon after the birth. One mother (I 38) who had an emergency caesarean section said,

"...it has also just freed me to kind of...leave him and go back to the ward and get some rest... it has basically meant that I have been able to get stronger quite quickly"

Some mothers and fathers participating in Interview One described how they believed that the experience had benefits in establishing routines for them and their baby and they were able to learn different aspects of baby care, establishing feeding and ask many questions that arose during the time that their baby was in the NICU and before they went home. One father (I 39) said,

"...if (baby) had been born full term and we had suddenly had to take him home she would have found it much more of a shock because she has actually been able to ask many more other questions about feeding, about changing, about his health and we have got a much slower transition in from birth to home than we would normally have" and a mother (I 68) said,

"I think... you will be an expert mother before you actually get out there because you will be bathing, practising, everything... when you go home it must be horrendous you know because like your just thrown into it"

Parents participating in Interview Two, both mothers and fathers were more likely to express these benefits than those participating in Interview One.

Also on a practical level, smaller numbers of both mothers and fathers from Interview One but more mothers and fathers from Interview Two spoke of the benefit of having the baby earlier than they should have and therefore being able to see and be with their baby sooner, have them as a small baby for longer and not having to wait for the full term of a normal pregnancy. The mother from Interview One (I 55) said,

"I've got me baby now instead of another four months." And a father from Interview Two (I 45) explained,

"It's just nice to be part of that...as he grows... It's a real privilege to watch him... do things that he would have done in the womb that he is now doing in the open air."

Parents were asked in both interviews if the felt lucky or unlucky to be in the situation they were currently in and it was in response to this question that parents made downward and sometimes upward comparisons to others.

Table 49. Parents who felt that they were lucky to be in the situation they were currently in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Lucky	11	8	6	3
To have a baby	17	5	5	3
Comparison with less fortunate	9	4	6	2
To be in this hospital	7	7	3	1
Baby doing well	7	3	7	1
To have good support	1	0	2	1

From Interview One, most mothers and fathers responded that they felt lucky to be in the position that they and their infant were currently in. However, whilst many parents still felt lucky, the numbers of both mothers and fathers who believed they were lucky had fallen by Interview Two.

Parents explained how they were lucky by making downward comparisons to others they considered less fortunate than themselves. From Interview One, around a third of mothers and fathers made comparisons to others less fortunate compared to around a half of mothers and fathers who participated in Interview Two. A mother from Interview One (I 32) said,

"You think of all these people who can't have children, or they've had the IVF and everything you know, there are people going through loads, there is, there's always someone worse off than you"

and a mother from Interview Two (I 34) said,

"I'm absolutely, I can't believe it, I think I'm so lucky, lucky that they're here. I had to go to a friend's funeral the other day, her little baby... her little baby died"

From Interview One, some mothers and more fathers believed that they were lucky to be receiving care in the research hospital. They believed that they were lucky because of the care available for mothers and because of the reputation its neonatal unit had and the regard they and others held for it. Parents compared it to other hospitals, for example their own local one when they had been referred for specialist care and services and parents also compared the hospital services and reputation to those in other countries. By Interview Two those feeling this way had fallen for both mothers and fathers

One mother from Interview One (I 59) said,

"Lucky because... this is a very big and specialised regional unit ... so it's not just one of the small district general hospital special care baby units where they are only used to dealing with a few babies at a time... they have got more... expertise"

One father from Interview One (I 39) whose wife was visiting the area with her work when their baby suddenly needed to be delivered prematurely said,

"Lucky with the quality of care, lucky that she was so well looked after and had everything done so quickly and that the neonatal side is an absolute God send. You know, yeah I mean I can't stress how lucky we both feel you know. .... Her (the mother) cousin is a gynaecologist and she said of all the places this is the top neonatal unit and can't speak of it highly enough so you now we both knew that in some ways anyway just from the experience we had but it's definitely re-enforced every day you know we are so lucky".

A mother (I 47) who had experience of living outside the UK said,

"I think our perspective is also from living in Central Asia we just know that a baby like him would have no chance... And he would not live" and a mother (I 49) of a

premature baby whom had initially been referred to the hospital for specialist Obstetric care said,

"I feel like the luckiest person alive to have my daughter... being looked after here".

Parents described how they believed that they were lucky to have a baby at all. Half of the mothers and around a third of fathers from Interview One described how they felt lucky that their baby was alive and that they were parents at all.

One mother from Interview One (I 19) said,

"I think we are really lucky that she is 9 days old today... I mean some babies don't make it" and whilst most of these mothers spoke of feeling lucky that their baby was alive and had survived so far, there were some additional comments about appreciating the opportunity to have a baby and to become a parent. For example, one mother (I 49) said,

"At this moment I feel very lucky and very privileged to have a daughter".

Similarly a father participating in Interview One (I 2) said,

"we're lucky that he's here in the first place and we're lucky that we've still got a son" and another father (I 7) said,

"I'm just lucky to have the chance to bring up a baby".

The parents participating in Interview Two were similar with around a third of both mothers and fathers expressing these feelings of being lucky to be in the position that they were in at the time of the interview. One mother from Interview Two (I 13) said,

"it just sort of made me realise how lucky I am that he's here you know at 25 weeks you know, because the chance of a 25 week baby actually surviving is quite low" and a father from Interview Two (I 63) said,

"at the moment I feel lucky because even only a couple of months ago we were still looking at you know there's a strong possibility we might not be coming home with a baby. So I feel lucky at the moment".

In addition to those parents who felt lucky to have their baby and to be a parent at the time of the interviews, others responded that they believed that they were lucky because their baby was felt to be healthy and was progressing well. Similar numbers of mother and fathers participating in Interview One compared with more mothers but fewer fathers from Interview Two spoke of their appreciation of how their baby was making progress and their perception of how well their baby was. One mother from Interview One (I 69) said,

"I have never had a big problem where they have had to come and say to us "look, you know he is really ill and all this has happened, or that's happened"... so we have been quite fortunate" and a father from Interview One (I 22) said,

"he seems quite healthy, OK he's small like but, he seems quite healthy"

From Interview Two a mother (I 64) said,

"I'm lucky that he has not had a lot of problems. You know for how early he came."

And the father from Interview Two (I 16) said,

"you can see how healthy he is, I know tomorrow, touch wood, but tomorrow he, he might not be like that, but no, very lucky".

Small numbers of parents described how they felt that they were lucky because of the degree of support that they had at this time either from staff, their partner or from family. An example is a mother from Interview One (I 38) who said,

"..that I am getting... the emotional support and the way....that the nurses will talk to me about his personality and... that he is strong, the fact that he is able to move his own head and you know, as well as being able say you know that he has put on 15

grams, they are also able to say you know about what a lively baby he is, or that he is smiling at me or, you know, there able to kind of pick up all the different things about him just makes me feel like he is being taken care of in the best possible way."

In contrast to those parents who believed that they were lucky to be in the situation that they were in at the time of the interviews, others described themselves as being unlucky.

Table 50. Parents who felt that they were unlucky to be in the situation they were currently in.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Unlucky	11	6	11	5
Comparison to more fortunate	2	0	3	1
Despite efforts to stay healthy	1	0	2	0

Around one third of both mothers and fathers from Interview One compared with around two thirds of both mothers and fathers participating in Interview Two described themselves as being unlucky. An example of a typical comment from Interview One was from a father (I 72), who stated,

"unlucky in that he... yes, he was born so early..." and from Interview Two a mother (I 76) explained,

"In some ways I'd say we were unlucky because he was so premature he seems to have been in hospital...he's ended up being in hospital a long time".

Of these parents, it was only mothers at both interviews who described themselves as unlucky compared to others. A mother of a term baby who unexpectedly needed to be admitted to the NICU after birth said during an Interview One (I 8) said, *"a bit unlucky that we have ended up here, because everybody else seems to walk out the door with the baby... and it is bye, bye to the hospital until the next time they have a baby, so a little bit unlucky that we have ended up here"*

And a mother from Interview Two (I 13) also made comparisons to others more fortunate than herself saying,

"unlucky you know, why have I had a premature baby, especially when you see all the smokers, that's what annoys me more than anything and it still annoys me now."

Small numbers of mothers from Interview Two were the only parents interviewed who described themselves as unlucky despite the conscious efforts that they had made to be healthy for the sake of their unborn baby during pregnancy. One mother (I 4) explained,

"Definitely unlucky, because we just tried everything that we could to make sure that the pregnancy went... to make sure it was healthy and I was well throughout the pregnancy and you know it just didn't happen like that at all. But, definitely unlucky and I think it's just down to luck isn't it? I mean some people smoke forty a day and drink and all that and you could say that might have contributed to the placenta not working properly but I think if you do everything you can to make sure and it happens anyway... unlucky, definitely".

Of the parents who described themselves as lucky to be in the situation that they were in at the time of the interview, there were some parents who also described themselves as unlucky.

Of the thirteen fathers participating in Interview One who believed that they were lucky, around two thirds said that they were lucky only. More than a third of the remaining fathers said that they were both lucky and unlucky. There was only one father who described himself as only unlucky. He was the father of a term infant whose baby was born by an emergency caesarean section following a massive bleed at home. His baby was critically ill and the prognosis was very poor with the likelihood of extensive brain damage as a result of oxygen deprivation.

In comparison, of the mothers participating in Interview One who expressed the belief that they were lucky to be in the situation that they were in, again around two thirds said that they felt lucky only. Similar to fathers more than one third of the remaining mothers said that they felt both lucky and unlucky. There were only 2 mothers who described themselves as unlucky only. One was the mother of a baby with Down's Syndrome who found out about the possibility of the diagnosis immediately prior to delivery. The other mother became very ill with a pregnancy related illness which necessitated the preterm delivery of her baby. This particular mother described herself as unlucky but not lucky in both Interview One and Interview Two.

Of the mothers participating in Interview Two who described themselves as lucky, around a quarter expressed the view that they were lucky but not unlucky. The remaining three quarters believed that they were both lucky and unlucky. Three mothers described themselves as unlucky only. Two out of these three mothers had life threatening illnesses themselves necessitating preterm delivery of their baby. The third was a mother of a baby who was nearing eight weeks of age at the time of the interview; the baby was still requiring full intensive care support, had had an unstable course and did die some time after this interview.

Most fathers participating in Interview Two who described themselves as lucky, two thirds of these also described themselves as unlucky. Of the 5 fathers in this interview group who described themselves as unlucky, only one did not feel that he was also lucky. He was the father of a preterm baby, who was six weeks old at the time of this interview but was still requiring full intensive care support and continued to have an unstable course.

There were a small group of parents who did not want to describe themselves as lucky or unlucky but preferred to consider themselves as "unfortunate". A mother from Interview One (I 5) said

"I wouldn't class myself as unlucky in the sense of it was unfortunate, I wouldn't say unlucky, it was unfortunate that I developed pre-eclampsia.... just unfortunate".

Another small group of parents described themselves as neither lucky nor unlucky to be in the situation that they were in at the time of the interview. Examples of parental responses are a father (I 42) saying,

"Neither... none ... it is, what's meant to be" and another (I 53) said,

"that's life isn't it... you know it is not lucky or unlucky... "

4.7. Parental Role

Parental feelings when they first held their baby.

In exploring parental role development in the parents who have baby's cared for in the NICU, parents were asked about their experience and feelings of holding their baby for the first time and after the first time.

There were a small number of parents, mostly fathers who had not had the opportunity to hold their baby at the time of the first interview. Whilst a small number of babies were still too sick to be held, some fathers felt that it was more important for the mother of the baby to hold the baby at this time.

Table 51. Parents who had not yet held their baby.

	Interview One Mother	Interview One Father
1a. Not held baby yet	4	5
1b.More important to let partner	0	2
1c. Too afraid	0	1

Many parents considered the first time they held their baby as a positive event with many mothers and fathers saying the experience was lovely, amazing or great. There were others who described their happiness at the opportunity to hold their baby for the first time.

There were a number of mothers but only one father who described feeling that the baby was their own, describing a bond or love at that time. One mother (I 10) said, *"I think that was the first time I thought actually, he's my child. Because at that stage all I'd ever done was hold his hand in the incubator. That was the first time I'd held him and he actually looked up at me. That was nice. I think that was the first time that I thought that there was a bond there, you know, this is my son."*

Table 52. Positive parental feelings when they held their baby for the first time.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Positive emotions	20	8	2	1
Happiness	6	2	0	0
Baby is mine/a bond felt	6	1	1	0
Emotional	3	1	1	0
Love	1	0	1	0
Welcome contact	1	1	0	0
Protective and/or responsible	1	2	0	0
Proud	0	1	0	0

There were however, many and varied negative feelings associated with holding their baby for the first time.

Mothers were more likely to express their worries and fears about the experience with around a third finding the experience frightening. Mothers and smaller numbers of fathers described their worries about the baby's size and the equipment attached to the baby. One father (I 53) said,

"I remember the first time I held him he was still on the ventilator and... you know he was hooked up to everything so... no, it's a little bit... you feel a little bit... apprehensive like because... only for the fact that you might disturb him or something you know... cause him some pain or... discomfort..."

Other small numbers of mothers and fathers had concerns that they may infect their vulnerable baby at this time and a small number of mothers felt that the experience was purely for their own benefit and was not necessarily in the baby's best interest. One mother (I 36) said, *"I wasn't confident in holding her, that feeling of, the baby was not happy being held, which she wasn't. I found that quite, you know, hard."*

There were very few parents at Interview Two who reflected back on holding their baby for the first time.

Table 53. Negative parental feelings when they held their baby for the first time.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Negative emotions	3	3	1	1
1a. Fear and/or anxiety	11	3	0	0
1b. Of attachment	0	1	0	0
Worries about baby's size	6	2	2	0
Worries about equipment	8	1	0	1
Worries about infecting baby	2	2	0	1
Lack of confidence	3	0	0	0
Not in baby's best interest	2	0	0	1
Comparisons to a previous experience	1	0	0	0
Feeling baby is not mine	2	0	0	1
Unable to recall experience	1	0	0	0

Holding their baby after the first time

Parents were then asked about holding their baby after that first experience and if their feelings were different.

There were only small numbers of parents who expressed negative feelings as illustrated in the table below. More parents participating in Interview Two described negative feelings and these mostly related to how the experience was limited and hampered by the baby's condition with some feelings that holding the baby was not in his or her best interest. One father (I 28) said,

"we are sort of resisting that a bit, because like he has got enough to contend with like without being mauled about with us."

Table 54. Negative parental feelings when holding their baby after the first time.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Negative feelings	0	0	2	0
Not held baby since first time	4	0	0	0
Worries about the equipment	2	0	0	1
Restricted by baby's illness	1	0	2	1
Not in baby's best interest	0	0	1	1
Feelings of baby not mine	0	0	2	0
Want to hold baby more	1	2	0	0
Feeling clumsy	0	2	0	0
Restricted by own illness	0	1	0	0
Restricted by environment	0	1	0	0
Asking permission	0	0	1	0

There were more positive feelings about holding the baby after the first time with both mothers and fathers describing their growing confidence with each opportunity to hold and cuddle their baby. Also, with the passage of time and as the baby recovers the ventilator, infusions, and monitoring may gradually be removed making it physically easier for parents to hold their baby and enabling confidence to grow.

Mothers but very few fathers described their growing feelings of love or a bond, feelings that their baby was their own and feelings of responsibility and protectiveness for the baby when they held him/her after the first time.

Table 55. Positive parental feelings when holding their baby after the first time.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Positive feelings	6	1	5	5
Gaining confidence	11	4	2	3
Feelings of love and/or bond	7	1	3	0
Baby feeling like mine	6	1	0	0
Happiness	4	1	0	0
Not worried by equipment	2	1	0	0
Feeling protective and/or responsible	2	0	0	0

Parental feelings at the time of the interview.

Parents described their feelings at the time of the interview to the interviewer. The tables below show the very wide range of responses. Parents reported mixed feelings and felt that how the baby was progressing mirrored exactly how they were feeling themselves. Parents described how they were feeling physically as well as their other positive and negative feelings.

Table 56. Parental feelings at the time of the interview.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Mixed feelings	9	1	3	1
Feelings mirror how baby is	7	0	3	1

Small numbers of mothers and fathers at both Interview One and Two described feeling physically tired by the experience with parents feeling drained and exhausted.

Table 57. Physical parental feelings at the time of the interview.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Physically exhausted	1	3	3	1
Travelling difficulties	1	1	0	0
Work commitments	0	1	0	0

The positive feelings that parents reported mostly related to their feelings about the baby's progress since admission and their optimism about the baby's future course through the NICU. These parents were happy with the improvements the baby had made, made comparisons with how the baby was when s/he was first admitted to the NICU and were relieved that the baby was stable. One father (I 39) said,

"I think it is just an accumulation of everything all going well so you know yes coming off the ventilator then starting to take his food, his brain scan going well."

Small numbers of mothers described their feelings of love and attachment to the baby with one mother and father at Interview One reporting their feelings of protectiveness and responsibility for the baby.

Table 58. Positive parental feelings at the time of the interview.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Positive feelings	5	3	4	2
Happiness and/or relief	11	4	8	5
1a. Optimistic	7	4	3	0
1b. Trust in staff	1	2	0	0
With progress so far	7	3	2	1
Protective and/or responsible	1	1	0	0
2a. Love/attachment	0	0	0	1
2b. To the baby	1	0	2	0
2c. To the NICU	1	0	0	0
Comparisons to others	0	2	0	0
Own health improvements	1	0	0	0
Better than expected	1	0	0	0
Changed perspective on life	1	0	0	0
Complete	1	0	0	0
Not stressful experience	0	1	0	0
Faith in God	0	1	0	0
Proud of partner	1	0	0	0
Increasing confidence	0	0	1	0

Despite parents feeling happy with the progress their baby was making, there were many different negative feeling reported with sometimes only small numbers of parents describing these feelings. These many varied negative feelings have been set out in the tables below.

Impact on the Family.

Mothers particularly described their worries about the impact of having a baby in the NICU on their family unit. Mostly, it was mothers at Interview One who described their worries about leaving the hospital and going home when they no longer needed to be a patient there. Mothers at both interview time points did not want to go home and leave their baby in the hospital. It felt unnatural to leave the hospital without the baby and being able to go and see the baby whenever they wanted was important to these mothers. One mother (I 57) said,

"I don't want to be that far away from him yet. And I do worry when I am not there. But when I am there and he is fine I want to leave him alone you know. But it's just nice to be able to walk down the hall."

For mothers who had delivered their baby prematurely and therefore before they had started their maternity leave, there were concerns about unfinished work commitments and the financial implications of starting maternity leave before planned.

For a small number of mothers relying on public transport or not living locally, they had concerns about travelling to and from the hospital to visit the baby once they had been discharged home.

There were also worries for participating mothers at both interview time points about the care of their other children. Mothers reported feeling torn between spending time with their baby in the NICU and their older children. They also expressed concerns about how their absence from the home and as care giver was affecting or distressing their older children.

Mothers also described their ongoing health issues that had not yet resolved from the pregnancy or the delivery. Mothers described their discomfort, pain or shock at unexpected events leading up to the delivery.

Both mothers and fathers expressed their worries about their partner at the time of the interview, how they were coping with their experience and their concerns about their partner being alone either in the home after visiting or in the hospital.

Table 59. Negative parental feelings at the time of the interview. Impact on the family.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Impact on the family	1	0	0	0
1. Worries about going home	3	0	0	0
1a. Leaving the baby	3	1	2	0
1b. Financial/work worries	5	1	0	1
1c. Travelling difficulties	2	0	0	0
1d. Lack of support network	2	0	0	0
1e. Speaking to people	1	0	0	0
1f. Leaving partner	0	1	0	0
Worries about other children	4	0	2	0
Worries about own health	4	0	0	0
Worries about partner	5	2	0	0

Parents described their various worries and anxieties when asked how to describe how they were feeling at the time of the interview. Whilst some mothers and fathers talked in general terms about feeling worried or apprehensive, others were more specific. Mothers had concerns about their baby's immediate health, whilst others had long term worries about disabilities or future problems that were a possibility. One father (I

53) explained his concerns that the impact of his baby's illness may not be obvious for many years to come saying,

"not going to know for a long time are you ... it could take years..."

There were small numbers of mothers and fathers at both interview time points who felt worried that their baby may not survive. A father (I 6) of a baby born at 28 weeks at Interview Two said,

"I am scared, scared I am going to lose him, I mean after having him this long the last thing I want is to lose him..."

By Interview Two, two mothers had worries about taking their baby home, both of babies with likely long term health problems.

Table 60. Feelings of worry and/or apprehension.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Feeling apprehensive/worry	9	2	3	1
About baby's health	3	0	4	0
Long term health worries for baby	2	2	1	0
About baby's survival	1	1	1	1
Going home with the baby	0	0	2	0
About being a parent	1	0	0	0
Lack of understanding	1	0	0	0
Not ready to celebrate yet	1	0	0	0
Producing breast milk	1	0	0	0

In the table below are the other negative feelings parents expressed at this time. The numbers are small but there were mothers and fathers who reported feeling stressed at both interview time points.

Mothers expressed feelings of guilt about the lack of time they had to spend with their baby and being torn between other commitments. One mother, having delivered her third premature baby expressed guilty feelings about being unable to spend time with this baby, her others and having had a third premature baby. She (I 40) said,

"I think it's made it worse for the fact that we knew he was gonna be early so it was our decision to carry on and have him and so it's ultimately my fault that he's been born early and that he's here."

Mothers and fathers participating in Interview Two only described their feelings of frustration, then very keen to take the baby home even though the baby was not yet ready and occasionally with the NICU staff.

Table 61. Other negative parental feelings at the time of the interview.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Feeling stressed	2	2	1	1
1. Lack of control/power	3	1	1	0
1a. Inhibited by the environment	1	0	1	0
2. Guilty	0	0	2	0
2a. Lack of time to spend with baby	3	0	0	0
Angry	3	0	0	1
Frustrated	0	0	4	2
Sad	3	0	0	0
Shock	1	2	1	0
Lonely	2	0	0	0
Tearful	1	0	1	0
Emotionally exhausted	0	1	0	1
Not bonded with the baby	1	0	0	0
Depressed	1	0	0	0
Dependent on staff	1	0	0	0
Comparison made to others more fortunate	1	0	0	0
Comparison made to others less fortunate	1	0	0	0
Comparison made to a previous experience	1	0	0	0

Being alone with their baby

Parents of newborn infants would normally spend periods of time alone with their baby immediately following birth even within the hospital setting and then more so once they are discharged home within the first few hours or days of life. Even following a caesarean birth, infants will not usually be separated from their mothers and will be discharged home within three to five days of the birth.

In being alone with their baby, parents take on the duties and tasks associated with all aspects of their baby's care and welfare. Being alone with their newborn infant and the decision making responsibilities that accompany that experience are essential factors essential in the process of parental role acquisition.

Parents of babies cared for in the NICU have, by comparison, relatively few opportunities to spend time alone with their newborn infant. Those infants who are extremely premature, particularly sick or unstable are in need of constant medical and nursing attention and interventions. For those infants who require less support, space, privacy and time alone can still be difficult to achieve. Infants share a room with others and their families. Even during the times when nursing staff are not giving direct nursing care to any one individual infant, they are always present in the room along with other various other members of the multidisciplinary team.

The development of the parental role was explored through a number of questions including asking parents if they would like to spend time alone with their baby. More fathers than mothers from Interview One said that they would not like to be alone with their baby at that time. This compares to around half of fathers and a third of mothers who said during Interview Two that they would not like to be alone with their baby.

Not all parents gave a reason for not wanting to be alone or thinking about being alone with their baby. For those parents who explained further why they would not like to be alone with their baby, the reasons were varied and as described below.

Table 62. Number of parents not wanting to spend time alone with baby

Reasons	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Happy to wait	3	4	0	0
Need staff around	3	4	1	0
Not felt to be issue	2	2	0	4
Uninhibited	4	2	1	2
Comparisons	0	1	0	0
No reason given	2	4	1	1

Two mothers from Interview One and two mothers from Interview Two but no fathers from either interview time points felt that their baby was too small or ill for them to be alone with them at that time. A mother from Interview One (I 66) said,

"Not really... he is so small [right] can't because I am scared .... he is still small... I might do damage to him"

Three mothers and three fathers from Interview One replied that at that time point they were happy to wait for that experience. One mother (I 69) responded by saying,

"I don't see the point in sitting and thinking 'oh if only'.... I just accept, just accept the situation as they are and they will change as we go on and we will have, we will have our whole life ahead of us with him so it is only a couple of months isn't it?"

And a father (I 27) said,

"I'm gonna have loads of times, with her on me own when I get home so no."

Interestingly, by the Interview Two time point no mothers or fathers expressed that they were happy to wait for the opportunity to be alone with their baby.

Three mothers and four fathers from Interview One responded that they would not like to be alone with their baby because they were dependent on, or it was necessary for neonatal nursing and medical staff to be with them and their baby. One father (I 51) explained,

"No, to be honest quite the opposite really. It's reassuring being in a bigger room, the nursing staff in the background. But to be in the room, us two, (the baby) and the monitors would be nerve racking. I need the reassurance of being able to see nursing staff, medical staff by just looking up, you know even if they are doing something else then I can call over to someone if I think something is wrong".

Interestingly only one mother participating at the second interview time point (I 79) expressed this as a reason not to be alone with her baby. She said,

"I don't know I'd probably be frightened just in case something went wrong".

Two mothers and two fathers from Interview One did not feel that being alone with their baby and privacy was an issue for them. One father (I 51) explained,

"No, not really... we make a point of not invading anyone else's privacy, you know. The temptation is to actually want to look at the other babies and see how they are doing and you want to ask sometimes but you don't because that would be wrong. Our impressions of other parents respect our privacy as much as we try to respect theirs".

At Interview Two, four fathers but no mothers expressed that being alone and privacy was not an issue for them.

Four mothers and two fathers from Interview One explained that they did not feel inhibited by not being alone with their baby in the NICU. One mother (I 32) said, *"it doesn't bother me having the people around because I talk to him as if there is no one there anyway so it doesn't bother me actually".* Similarly a father (I 2) said, *"...when I'm there, anything else around unless somebody's talking to me or unless somebody's sort of directly behind me I'm oblivious to everyone. So it doesn't bother me anyway. You know, I can only see him and sort of everything else is sort of, doesn't matter."*

At Interview Two, only one mother and two father spoke of being uninhibited by others around them. All three of these particular parents were those of babies that had progressed well and were being nursed in the least intensive room in the NICU. This room was larger, with more space, fewer neonatal staff present and a greater emphasis on parental involvement prior to infants being discharged home. From this nursery there was also the opportunity for parents to spend time alone with their baby in a discrete parent bedroom in the NICU to build confidence prior to and in preparation for going home. The parents who did not feel inhibited by being with others at Interview Two had engaged in this experience with their baby at the time of the interview. This mother (I 41) revealed,

"I like being in the nursery with her it doesn't bother me because the nurses get on with what they want so I sing to her... and talk to her just as much if I was in my own room. I don't get embarrassed I just talk away to her....I mean if you wanted to be on your own with her they would take you into a room 8 which is lovely but I feel the opportunity is there whenever you want anyway." One father (I 50) said, *"No big deal to me whether there are other people around or not. I don't feel inhibited by other people being around. So I think I have been alone with him a few times but it's not a big deal."*

One other father (I 58) participating in Interview One interpreted the question as being alone with his baby in his own single room without any other babies. He believed that sharing a room with other babies gave him the opportunity to make comparisons between other babies and his own. He felt he wouldn't like to be alone with his baby in this way because he would be deprived of making those comparisons which served to reassure him that others were experiencing similar events. He said,

"Absolutely not. I love the fact that he is in a room with a number of other children. With a number of other families because it gives me a context within which to understand, to try to comprehend what's going on... if he was in a room on his own I would feel as though I was the only one with this problem in the world and it would be just catastrophic. I love to know that there are other people."

In comparison to those parents who expressed their feelings of not wishing to be alone with their baby, around two thirds of mothers and half of fathers from Interview One, said that they would like to spend time alone with their baby. This compares to very similar numbers from Interview Two. Again, for those parents who explained why they would like to be alone, the reasons were quite varied.

The most common reason given for wanting time alone with their baby was for privacy. Mothers and fathers from Interview One explained that being alone with their baby would enable them to spend private one to one time or family time with their baby away from both staff and/or other families in the room. Privacy was considered important to these parents in enabling them to act in a manner they considered a normal way to act with their newborn baby. To be able to talk, read and sing to their baby without feeling self conscious or aware of others listening or watching them was limited because of not being alone with their baby.

One mother (I 10) explained,

"I suppose that's one of the difficulties, you're never alone with him. Sometimes you can sit there and you're talking to him but you're not alone. Sometimes you feel a bit stupid cause I'm talking away to him and I think I bet people think that I'm off my rocker. And you do want to have a mother-baby talk don't you and you do it but you've got people all around you all the time." And a father from Interview One (I 56) said,

"it would be nice to perhaps have some time alone ... without the bustle going on around .... So it could be just (the baby) and myself or, or all three of us..."

Other mothers and fathers from Interview Two gave privacy as the reason for wanting to spend time alone with their baby in the NICU. These parents gave more in depth and sometimes lengthy explanations than those given at Interview One about their lack of private time with their baby. One mother (I 4) explained,

"You just want to have a bit of time alone with your own baby, just to get to know them really and that's just got to be conducted in public and it's just not natural cause you wouldn't conduct your everyday life in public. I mean, there is times when you are in public with your child but there is lots of times also that's private and I just haven't had one private moment with him yet since I've been in here and it is a bit unnatural."

Another mother participating in Interview Two (I 64) told the Interviewer,

"last night I was reading this story and someone came up and interrupted and wanted to know what the story was about and so I had to chat and I couldn't finish the story with him." A father from Interview Two (I 45) responded,

"I've talked about this a lot with (his wife), most definitely, I feel self conscious. I feel it's not that I want to do anything special with (the baby) but I would love to be able to sing to him or tell him nursery rhymes and yeah be much more babyish with him and definitely I feel you know that I am being listened to, I am being watched."

Mothers and Fathers from Interview One said that although they would like to spend time alone with their baby, they were, at the time of the interview, happy to wait until that time became possible when their baby was stronger or their health would not be endangered by such an experience. A mother of twins participating in Interview One (I 18) said,

"I suppose I would... but I know they have got to have the care and for the moment the care is more important, because hopefully I will have that chance to be alone with them, I wouldn't like to jeopardise their health in anyway just for me to have... that single moment alone with them... I would rather wait... because I know that moment will come, whereas if there was a chance that something might happen."

A father from Interview One (I 22) said,

"At the moment I just look at what's best for him and obviously being in there's best for him."

In contrast, only one mother and one father from Interview Two felt happy to wait until they could be alone with their baby. Both were parents of infants still receiving full intensive care support at the time of the interview remaining dependent on constant medical and nursing attention. This mother (I 15) said,

"Yes, but I prefer to know that he was all right, you know that he was well enough first, you know I wouldn't want to say can I have him alone now, because I would rather, because I know he does still need monitoring with his oxygen so, but... I do look forward to the time that I can be alone with him..."

Mothers at both interviews expressed their thoughts of being alone with their baby in relation to and in comparison with being at home with him/her. There were no similar responses from fathers from either interview time point. One mother (I 8) explained, *"I want to... put him on his changing mat at home and... have a little look at him properly, because at the moment although he gets a bath and stuff its, it's all in the hospital environment, I can't just... put him on the floor on a changing mat at home... you can't sort of prod him about and have a little nose at him, you just want to do little things you know, just mess about with him... we were like giggling the other day because (husband) was messing his hair up and putting it in a centre part (laughter) and I was going "stop it, I don't want anyone laughing at him" but if he did it at home it would probably be hilarious but... it is like you don't... you can't... in the hospital, I don't think you can."*

Who knows the baby the best?

Parents were asked who they felt knew their baby the best. This question was also associated with the development of the parental role in the acquisition of knowledge about their baby, in learning and understanding his or her needs and demands and being able to respond to them (Thornton and Nardi, 1975). The table below shows the responses at Interview time point one and two to this question.

Table 63. Parental feelings about who knew their baby the best.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
S/he does	13	1	12	0
The nurses/one particular nurse	10	2	2	0
1.His partner does	0	8	0	6
1a. Then he does	0	1	0	3
Both parents do	4	4	2	2
2.Staff knows what is best for baby	2	0	2	0
2a. Know baby in a clinical sense	6	2	1	1
No one individual	2	1	2	0
Does not know	2	2	0	0
The doctors do	1	0	0	0

Around a third of mothers felt that they knew their baby better than any other person at Interview One, however by Interview Two time point nearly all of the mothers participating expressed the view that they knew their baby best. A typical response was this from a mother from Interview One (I 68) saying,

"I think probably at the moment me... because I have spent so much time [yes] erm and I think it is a different time that I spend with her than what the staff spend with her [yes] erm it's more of an emotional experience than just sort of a clinical job experience".

With the passage of time the mothers participating in Interview Two described how they were more responsive to their baby than they had been shortly after birth and they now understood their baby's needs to a greater extent than their partner or the staff caring for him/her. From an interview at the second time point, this mother (I 76) explained,

"I think me, out of all of us, I think me. I didn't really feel that at first ... I felt it was more the midwives, but I feel as though now that when I'm here with him I think he knows I'm here. I seem to know when he is upset, I know when, I feel as though when he needs changing, I'm starting to recognise when he just wants a cuddle or he's hungry, whereas, I still find that quite difficult because with the others I knew that straight away, with (baby) I didn't, it has taken this long."

In comparison, only one father (participating in Interview One) expressed the view that he knew his baby the best. Even with the passage of time no other father felt he knew his baby better than any other person. This one father explained that he was spending more time and longer periods with his baby than his partner was able to so at that time and therefore felt he knew his son better than she did. By Interview Two, he had returned home and to work many miles away and visited at weekends only so obviously no longer felt that way he had initially.

It was more commonly reported by fathers that it was their partner who knew their baby the best. Half of the fathers participating in Interview One expressed the view that their partner knew their baby best, with one father then saying he knew his baby the next best after her. This compares to two thirds of fathers participating in Interview Two who believed their partner knew their baby the best and half of these fathers expressing the view that they knew their baby the best after the mother. One father from Interview One (I 58) talking about his wife's knowledge of their baby explained,

"I mean she knows so much more about him than I do right now. It's unbelievable, I mean she knows ten thousand times more than I know about him. You know I come

and see him a couple of times a day and she sees him a dozen times a day at least. She just cares for him much more, she holds him much more. You know I mean (wife) actually knows him a hundred fold better than I do".

Interestingly and in comparison to paternal responses, no mother from either interview time point felt that their partner knew their baby better than they did. Around a tenth of the mothers but a quarter of fathers participating in both Interview One and in Interview Two responded by saying that both parents knew their baby the best rather than one particular parent. A Father from Interview One (I 39) explained,

"his consistent care is from his mum and dad. In the sort of quality touching and stroking and cuddling is all from us two".

Whilst describing who they felt knew their baby the best in this way, some of these fathers and the father who felt that he knew his baby the best in Interview One almost apologised or portray the feeling that they feel that it shouldn't be them or that they should not say it is themselves as the father who knows their baby the best. They clearly feel that they should say it is the mother who knows the baby the best. The father from Interview One (I 9) who was the only father who expressed the view that he knew his baby the best said,

"I don't know, I'd feel nasty if I said, erm, me more than (wife) in a sense. I don't know. That's because I think that I sit with him for 3 hours in the morning as well and see his little ways and stuff and then I tend to go to bed slightly later so probably in the day, I probably get slightly more hours with him than (wife)does. Cause then she's travelling off to do her milk and everything again so she loses the time there."

Another father (I 51) who said that both parents knew the baby the best said,

"I suppose it should be (wife) but I don't automatically think that that's the case. I feel I am having a bond with her. I suppose it would be natural to expect the mother

to have the greater bond but I don't know if it is greater. I feel like I have a strong bond as well."

About a third of the mothers but fewer (about an eighth) of fathers participating in Interview One felt that it was the nurses or one particular nurse who knew their baby the best. One mother participating in Interview One (I 43) explained,

"I don't feel as if I have had a chance to observe her for long enough... and because they are professionals... because they deal with that many small babies... that they must be able to erm... you know have a good judgement... about different babies... to get to know...the different personalities or... little ways and things like that... yes... I mean I don't feel as if she is totally mine yet..."

But by the time mothers participated in Interview Two only two mothers and no fathers then felt that a/the nurses knew their baby better than anyone else. One mother (I 40) who explained how she felt said,

"Personality wise they probably know him far better than I do, I think so, but that'll change so that really doesn't bother me either. It's only going to last a couple of months."

As can be seen from the above table, some parents described the neonatal nurses or doctors as not knowing their baby the best, but knowing what was best for their baby or knowing their baby in a medical or clinical sense. The percentages of mothers and fathers from Interview One who described neonatal staff as knowing what was best for their baby or knowing him/her in a clinical sense were similar. Only one mother and one father expressed this view by the time they participated in Interview Two. The mother participating in Interview Two (I 13) explained about a particular nurse,

"I think she, I don't say she knows him, I think she understands his needs better... I think at their age it is difficult to say you know them because they are such babies, but

I suppose I would like to think that I know him better but I know she understands his needs better than me at the moment, I think that is probably the difference, she understands when you can touch him and when you can't and probably I don't know understand you know whether that would harm him or not."

A number of parents felt that no one individual, were unsure of who or felt that it was the doctors who knew their baby the best, however these were smaller than other responses.

Does the baby recognise you?

As a parental role related question, parents were asked if they felt their baby recognised them.

Table 64. Parental responses to whether they felt that their baby recognised them.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Baby definitely recognises parent	13	4	7	3
S/He thinks/hopes so	13	5	2	2
Baby responds to parent	3	2	6	6
Baby recognises their partner	2	4	1	2
Baby does not recognise parent	2	4	1	2

The two most common responses at Interview One time point were that their baby definitely recognised them or that s/he hoped or thought that their baby recognised them. Although mothers were more likely to express this view than fathers, the numbers were still less than half and even by the second interview time point, less than half of mothers and only a third of fathers felt that their baby definitely recognised them. From the age of 28 days and beyond most mothers and fathers still did not believe that their baby recognised them. Very similar numbers of mothers and fathers from Interview One could not be definite but hoped or thought that maybe their baby recognised them. However, at Interview Two even fewer mothers and fathers responded this way. This does not appear to be because they were then certain that their baby recognised them because there was no apparent increase in the numbers of either mothers or fathers who said that their baby definitely recognised them at Interview Two.

There was however, an increase between Interview One and Interview Two in the numbers of both mothers and fathers who felt that their baby responded to them rather than recognised them in a way that was individual to them. A father (I 48) participating in Interview One said,

"That is probably my imagination... what he does is he responds in a unique way to certain things that only I do". And a father from Interview Two (I 28) said with confidence,

"we can calm him down, he seems to respond to us, not, obviously not respond but you know what I mean like... say like his sats get better".

In a similar way to the responses to the question about who knew their baby the best, at both interview time points fathers were more likely than mothers were to express the view that their baby recognised their partner. A father participating in Interview Two (I 28) had noticed how his baby reacted differently when his wife touched their baby in comparison to how the baby reacted to a doctor's touch. He explained,

" when... like... the doctors or anything come that stab his feet, he will move his feet and that, but he likes that, he could sit there all day and let (wife) grab his feet... she must grab them in a different way that the doctors".

Again, fathers at both time points were more likely than mothers to feel that their baby did not recognise them. Twenty five percent of fathers compared with only around six percent of mothers felt that their baby did not recognise them. Interestingly responses that their baby did not recognise them from both mothers and fathers showed no real change with the passage of time at Interview Two.

Personality

The ease of transition to the parental role may also be affected by parental experiences with the infant and parental perceptions of the infant's temperament. Recognition and knowledge of the baby's personality and response by a mother to the individual infant cues is recognised as component of the maternal role acquisition and parents were asked at both time points what personality they thought their baby had. The table below illustrates their responses.

Table 65. Parental feelings about the personality of their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Sure of personality	27	13	16	6
Personality still developing	4	5	2	3
Nurse identified characteristics	1	0	0	0
1.Does not know personality	5	1	1	0
1a. Because baby too poorly	1	0	0	0
Questions impact of NICU environment	2	1	1	0

Very similar numbers of both mothers and fathers (around eighty percent) talked with certainty and confidence about their baby's personality at Interview One time point.

With the passage of time at Interview Two the number of mothers who were sure of their baby's personality had increased to all but one whereas the numbers of fathers decreased to two thirds of those participating at the second time point.

At Interview one, mothers were often still recovering from the birth particularly if they had delivered by caesarean section or had a pregnancy related illness leading up to delivery. These mothers were still not able to spend long periods with their baby in the NICU or interacting with their baby could be physically difficult or tiring for them at that time. By Interview Two, mothers were more likely to have recovered physically from the birth experience or any pregnancy related illness they may have had in comparison to the earlier interview and were therefore able to spend more time with and getting to know their baby. This may account for why there was an increase in the number of mothers at Interview Two who described being sure of their baby's personality as they were able to get to spend more time with their baby, get to know him/her and develop their maternal role. In comparison, at Interview One time point, fathers were not hindered physically like mothers could be, nor did they have any other demands on their time such as midwifery checks, ward meal times, need for medication or expressing milk. They were also unlikely to have returned to work at Interview One time point and so they were able to spend time in the NICU with their baby. In reverse of the maternal situation, at Interview Two fathers were more likely to be spending less time in the NICU with their baby as the need to fulfil work commitments, tend to the home and any other children became necessary. This may account for why the numbers of fathers at Interview Two who described being sure of their baby's personality appears to be less than at Interview One.

A father from Interview One (I 31) responded by saying, *"he likes his little fingers, his foot, he likes getting his foot tickled, but if you tickle it too much he will put it down and then his foot will come up again. "Here you are, you can do it again" like so, there is little things, I mean I know his... he has got a little personality"*. And an Interview One mother said,

"I think she's gentle. She's like a gentle, little one...I dunno she's sweet, she's lovely (laughs). Erm...I dunno she seems to be like a quiet, little character, she doesn't cry much...like gentle, I think that's the word I'd use for her.

An example of a father's response to the personality question at Interview Two (I 65) is,

"he's competitive and he's obstinate is not the right word really, but determined maybe. Determined I guess is the right word. Determined and competitive which are two great words as far as I am concerned to define a child that I would have....I see him in an extraordinarily positive way. I don't see him as feeble. I don't see him as weak. I don't see him as any of those things. I see him as determined and competitive you know and really you know telling you what he wants". And an Interview Two mother (I 62) said,

"She's a little fighter, a little fighter. She knows what she wants and she gets it. She was put into nursery 6 and she didn't like it so she told them and so she came back. And she's playful, she loves playing with her dad and she's very easy going. But she knows what she wants and she tries to let you know as best she can and I don't just mean by crying you know. She does her best to let you know."

From Table 65 it can be seen that some parents also felt that their baby's personality was still developing. Proportionally more fathers at both time points (around one third) expressed this view compared with participating mothers (around a tenth).

Interestingly, there was no change with time in the number of either mothers or fathers who expressed this view. An Interview One father (I 39) said,

"I think he is definitely born with a small amount of character but a lot of it is now developing and is a product of how we behave with him and how calm we are with him or how lively we are and his character and personality are a complete product of how we behave with him. The things we expose him to, how we are feeling. All those sort of feelings and I think you know I definitely don't think he is born with his complete personality and you know that's sort of unchangeable". And then at Interview two the same father (I 45) said,

"definitely we are noticing things about his, you know, what his wants are and his needs and things. But yeah I still don't know whether he was shy or aggressive or any of those sort of things and I still think it's wrong to project those more adult childish traits on to a baby. But definitely more so than last time we spoke."

Knowledge about their baby, his or her personality and feelings that they, as parents, know their baby comes about by spending time with the baby and doing things for him or her. Parents were therefore asked if they felt able to do anything for their baby as part of the process of developing their parental role.

What parents felt able to do for their baby.

Table 66. Parents who expressed that they were able to do little for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Unable to do much	11	7	4	2
Too scared	3	2	0	0
Not been allowed to	0	0	2	0
More important to let partner	0	2	0	0
Baby too ill	0	0	1	0
Depends on individual nurse	0	0	1	0

From the table above there were quite a number of both mothers and fathers who felt that they were unable to do much for their baby. Most parents did not explain why they felt unable to do much for their baby at the time that they participated in the interview saying for example,

"I don't feel I can do anything. I feel absolutely powerless". (Father (I 58) from Interview One).

However, there were both mothers and fathers participating in Interview One who explained that they felt too scared to do much for their baby but by Interview Two, that fear was no longer reported by any mothers or fathers. Possibly this was due to their increasing confidence in their ability to do things for their baby over time.

Two fathers from Interview One felt that it was more important for their partner to do things for their baby and therefore they sacrificed any opportunities to become involved in their baby's care to enable the mother to fulfil that role. One father (I 31) explained,

"she needs it more than I do" and the other (I 9) said,

"I know that if I said I'll do his cares she'll allow it but.... If it makes her feel better it makes... then it makes me feel good."

This view had changed and was not expressed by any father at Interview Two time point. Mothers differed from fathers in that no mothers at either interview time point considered that it was more important for their partner to do things for the baby and undertake any of the care giving practicalities such as nappy changes.

As seen in the table, by Interview Two the number of both mothers and fathers who felt unable to do much for their baby had fallen however, more fathers than mothers still reported being unable to do much for their baby. Mothers were possibly becoming more confident in the care giving abilities with the passage of time whereas many fathers were then spending less time in hospital with their baby due to their other commitments such as work, other children and the home.

Interestingly, all of the parents who expressed that they were unable to do much for their baby at the Interview Two time point had not done so at Interview One. With the exception of one father, these were all parents of infants that remained very sick, were unstable and were still requiring full intensive care support at the time of the second interview.

When parents were describing what they felt that they were able to do for their baby, their responses have been divided into practical and emotional aspects and set out in the tables below.

Table 67. Practical aspects of what parents felt able to do for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Ability to do practical things	9	0	3	3
Change baby's nappy	26	4	14	8
Washing baby	18	5	7	3
Tube/Feeding baby	17	7	10	5
Expressing breast milk	7	0	3	0
Dressing	5	0	3	1
Help staff care for baby	2	1	0	0
Giving medication	0	0	3	1
Preparing the home	1	0	1	0
Stop smoking	1	0	0	0

There were more practical descriptions than emotional for both mothers and fathers and at both time points.

Despite describing feelings of not being able to do much for their baby, most mothers and fathers revealed that they were involved in washing and changing their baby's nappies, even at Interview One. The notable change over time was that almost all fathers described being involved in nappy changing practices at Interview Two compared with only a quarter of responding fathers at Interview One.

A small number of mothers and one father described being able to help the neonatal staff in caring for their baby however these descriptions did not extend to Interview Two. Presumably parents felt that their role was no longer in helping staff and possibly the roles had reversed and at Interview Two it was the neonatal staff who were helping them to care for their baby.

An obvious difference between mothers and fathers is mother's descriptions at both interviews of their ability to express their milk as something that they are able to do for their baby.

Unlike at Interview One, there were small numbers of mothers and a father who described their ability to give medications to their baby in the form of vitamins added to the baby's milk. One mother (I 75) said,

"I fill in the chart and everything, not everybody, not all the mums do everything but I tend to take over and do everything while I'm here, you know, filling everything in and doing her vitamins, I don't get them to do anything like that and I like to weigh her and do all that"

With growing confidence, neonatal nurses involve parents in care giving duties other than those that are usual for a new mother and father if they want to.

Table 68. Emotional aspects of what parents felt able to do for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Ability to do emotional things	8	3	4	0
Comfort, touch and/or hold	17	6	5	5
Talk and/or sing to baby	7	2	3	1
"Just being there"	5	4	0	2
Give love	2	0	4	0
Create happy atmosphere	1	1	0	0
Be an advocate for baby	0	0	1	0

The emotional aspects of what parents perceived they were able to do for their baby are tabled above. Half of the mothers and slightly more than a third of fathers from

Interview One described being able to comfort, to touch or cuddling and holding their baby. A typical comment by a father (I 58) was,

"I like holding on to his little hand and when he grips your finger and so I can sit there for an hour probably and let him just hold my finger you know and just let him know that I am sort of there and I probably feel that that's about all I can do for him."

Mothers made similar descriptions but unlike fathers there were 3 mothers who described holding their baby skin to skin as a positive way to be with their baby. One of these mothers (I 30) said,

"give her as much skin to skin and as much love as I can."

The numbers of parents describing their ability to do anything for their baby from an emotional aspect rather surprisingly does not increase at Interview Two time point with the exception of more fathers describing holding, comforting or touching their baby.

Table 69. Other feelings expressed about parental ability to do anything for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
1. Would like to do more	5	3	1	1
1a.Seen as positive parenting step	2	0	3	0
1b.Other commitments/children	0	0	1	0
1c.Staff should be more encouraging	1	0	0	0
1d.Envious of time nurses have with baby	1	0	0	0

When asked what they were able to do for their baby there were some other comments and feelings expressed that have been tabled above. Both mothers and fathers particularly at Interview One but also at Interview Two who described wanting to do more for their baby.

There were also a small number of mothers but at both time points who recognised that being able to do things for their baby was a positive step. As one mother (I 54) said,

"I don't think you bond with them immediately ...erm so it was like when you're able to handle her and hold her ... and do things for her that's where... we are sort of just coming to now, which is helping a lot".

Only one mother but of interest, expressed her envy of nursing staff for the time they spent with her baby. She (I 71) said,

"when I see the midwives trying to settle him I feel quite jealous of them actually... they're with him more than I am and when they take him out to weigh him it's like, oh I wish I could do that myself, because they get to hold him where as I don't at the moment."

In developing the parental role, parents are able to recognise and respond to the individual needs of their baby in their own individual way. Parents were then asked if there was anything they felt that only they could do for their baby. Their responses are in the table below.

Table 70. Parents who expressed things that only they could do for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Provide parental love and/or contact	10	2	7	4
Breast feed or provide breast milk	5	0	4	0
"Be there" for the baby	4	1	0	1
Talk to their baby	2	1	0	0
Comfort and/or calm baby	1	0	1	0
Be positive	1	0	0	0
Give parental standard of care	0	0	1	0

Parents most commonly described their parental love and contact as something that only they could provide for their baby. There was a difference with around a third of the mothers but much fewer fathers expressing this view at Interview One. By Interview Two the responses had changed with both mother and father numbers then similar and increased to approximately half of all parents describing their parental contact and love as something that only they could do for their baby.

One mother from Interview One describes this well and also how the neonatal nursing staff helped her understand the difference between the contact professional carers give compared to her as the baby's mother (I 38) saying,

"I have been chatting about it with one of the... one of the midwives yesterday and they were saying about a lot of people having contact with him, physical contact with him, but actually the kind of contact that you and (Father's name) have with him, and the fact that at the moment it is just the two of us holding him and erm...well, I feel that is something special that we can bring to him that erm, that other people don't"

A father from Interview Two (I 63) responded differently from Interview One saying, *"I'm convinced that she's bonded with us then I think there is an emotional level of support that can't really be offered by anyone else. As much as anyone could care for her in the right way, I don't think they can care for her in the same emotional level as we do."*

Again, mothers differed from fathers in that there were mothers responding at both time points who described their provision of breast milk as something that only they could do. Two different fathers one at each time point did however, describe the provision of expressed breast milk as something that their partner could but they couldn't provide. The father from Interview One (I 58) said,

"she can do that natural function of getting the breast milk out, getting the antibodies for him and I just think that that is just an extraordinary thing that (Mother's name) can do. That she has such a relationship with him already because she is so contributing to his survival...contributing to his extreme good health".

Sadly, there were quite a number of parents who felt that they were unable to do, or provide anything for their baby that someone else couldn't. As seen in the table below, the numbers of mothers feeling this way was around a third in Interview One and there were no changes to these numbers by Interview Two.

Whereas more fathers (around two thirds) felt that there was nothing that only they could do for their baby at Interview One but by Interview Two this number had fallen to less than half indicating a change in father's feelings over time unlike mothers.

Table 71. Parents who felt that there was nothing that only they could do for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Nothing only they could do	12	11	5	4
But partner could provide breast milk	0	1	0	1

Parents were asked if they needed help to learn those things they were able to do for their baby. Their responses have been divided into the following two tables of those who did not need help and those who did need help.

There were some mothers and more fathers participating in Interview One who simply said they did not need help but chose not to expand their answers or say why not. As seen in the table below, the numbers of responses for the reasons given were small with similar numbers saying that their previous experiences as a parent or that care giving skills were instinctive.

Table 72. Parents who felt that they did not need help to learn those things they were able to do for their baby

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Did not need help	5	3	0	2
Instinctive	3	0	2	1
Experience as parent	2	0	3	1
Previous NICU experience	1	0	1	0
Because of occupation	1	0	0	0

In comparison, and of interest to neonatal nurses caring for these infants, there were more parents who felt that they needed help to enable them to do things for their baby mostly because of the practical skills involved. As one mother (I 71) explained, *"I did because I was used to just getting a baby on a the floor on a changing mat changing his bum it's quite an ordeal trying to change a bum with leads everywhere and just going through an incubator."*

Mothers, mostly from Interview One described needing help initially because they felt scared or needed reassurance either due to the size of their baby or for fear of their baby becoming unstable when they handled him/her.

Table 73. Parents who felt that they needed help to learn those things they were able to do for their baby.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Did need help	9	1	4	3
Practical skills to learn	7	3	3	3
Scared at first	6	1	1	0
For reassurance	4	0	0	0
Needed encouragement	1	0	0	0

Would parents like more or less help?

In exploring parental role development in the NICU, parents were asked if they would like more or less help than they were receiving from staff at the time of the interview. The most frequent response from both mothers and fathers especially at Interview Two was that they would not like more or less help than they were getting. Parents reported feeling happy with the level of help they were receiving with staff finding the correct balance between supporting and helping parents and leaving parents alone to care for their baby. One father from Interview One(I 56) explained by saying, *"the feeling is that the staff will do everything unless we want to do it and when we want to do it, we feed her, we bathe her, we change her."* And another father from Interview One(I 27) said,

"I would say they're just perfect the way they are. Cos they're always helpful, if you need them they're there, if you don't want them to come near you, you can just say, you know, a bit of time on me own you know, they respect it."

Table 74. Parents who did not feel they needed more or less help from staff.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
No. Feel supported/informed	18	9	11	6

There were however, a small number of parents who did feel they would like more help from staff mostly with practical issues such as expressing breast milk/breast feeding, nappy changing, giving prescribed vitamins, provision of accommodation for a father and discharge planning. The most common reason why parents said they would like more help was actually that they wanted more information and support in understanding their baby's care and treatments. One mother from Interview One (I 43) said,

"I feel like an observer and I would have liked to have took every single thing in and I know there is probably things that... erm... that I could find out... but I haven't been informed about because I haven't known to ask about it."

Table 75. Areas where parents would like more help from staff.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
More information or support	2	3	2	0
More help with cares	0	0	2	0
With expressing or breast feeding	1	0	0	1
Discharge preparation	1	0	0	0
Preparation of what to expect	0	1	0	0
Meeting fathers needs	1	0	0	0
Giving medications	0	0	0	1

There were also a very small number of parents who did feel that they would like less help from staff but with no pattern emerging between mothers and fathers or differences between Interview One and Two. One mother and one father felt that they should be allowed to care for their baby more and two parents (again, one mother and one father) felt they needed less support with expressing breast milk or breast feeding.

Table 76. Areas where parents would like less help from staff.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
To allow parent to care for baby	1	0	0	1
With expressing or breast feeding	0	1	1	0

Feelings of Anger or Distress.

Parents were asked if there was anything about their experience of having a baby cared for in the NICU that made them feel angry or distressed. As can be seen in the table below, the most common response from parents was that nothing had made them feel angry or distressed or specifically not angry.

Table 77. Did anything in the NICU make parents feel angry

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Neither	11	8	1	3
Not Angry	7	5	4	1

There were however, a number of different factors that caused distress for small numbers of parents as described in the table below. Most frequently reported, particularly for mothers was seeing procedures done on their baby, such as taking blood samples or putting in intravenous cannulas. One mother (I 24) said,

"last night was very distressing because he was having a line put in his foot and... they had a paper towel over him and there was blood on that and that was... soul destroying, I just thought that he wasn't there, it was horrible".

Parents, mostly at Interview One, also reported feeling distressed by seeing the NICU equipment and hearing the alarms.

After which, the numbers of parents reporting factors they found distressing were very small. They included when their baby or another baby was ill or distressed or when another baby died and seeing other parents upset. Not reported at Interview One, but by Interview Two, there were 3 fathers and 1 mother who felt distressed at a level of care that they were unhappy with or fell lower than what they believed was adequate. One father from Interview Two(I 63) explained,

"the only thing that has upset us was that weekend where we felt that A wasn't getting the right level of care. That was the only thing that distressed us and it was the only thing that made us come away from here, upset."

Table 78. What caused parents to feel distressed.

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Distress	4	0	1	0
Seeing procedures performed	8	1	2	1
Monitors/ equipment/alarms	6	2	1	0
When another baby is ill	2	1	3	0
When the baby is distressed	3	0	1	0
Level of care	0	0	1	3
Death of another baby	1	0	2	0
When the baby is ill	0	1	0	1
Being unable to care for baby	2	0	0	0
Inappropriate comments	1	0	1	0
Being told bad news	1	0	0	0
Seeing babies on maternity ward	1	0	0	0
Attitudes of other parents/visitors	0	1	0	0
Security	0	1	0	0
Seeing other parents upset	0	1	0	0
Staff may infect baby	0	1	0	0

There were small numbers of parents who did feel angered by an experience in the NICU. The reasons described were fewer than those described as distressing and the numbers were very small. They were however, more frequently reported by those parents participating in Interview Two. The most commonly reported factors that angered parents were a particular incident involving their baby's care, communication issues or an issue with a particular member of staff. One mother from Interview Two (I 11) who was angry explained,

"the sats probe, that was on too tight and it wasn't getting checked often enough and she is losing one... left little toe and she is going to lose a bit of her right little toe because of it as well and erm, because like I asked for it to be checked as often as possible and it was supposed to be getting checked every halve an hour and it is not"

Less frequently reported causes for parental anger were alarms not being attended, an apparent lack of continuity or plan, being unable to deliver care giving roles or the midwifery care they received.

Table 79. Feelings of Anger

	Interview One Mother	Interview One Father	Interview Two Mother	Interview Two Father
Angry	1	0	0	1
Incident regarding baby's care	4	1	3	1
Communication issues	2	0	3	2
Comments about individuals	0	1	3	1
Alarms not being attended	0	0	1	2
Lack of plan or continuity	0	0	1	1
Being unable to care for baby	1	0	0	0
Midwifery care	0	1	0	0

4.8. The changes in parental experiences over time.

Parents participating in Interview Two were asked if any of their feelings had changed since they had participated in Interview One. Parents described positive and negative changes for them since they had participated in Interview One. In addition, some parents, particularly the fathers described no longer thinking about the time leading up to the birth of their baby and those first few days in the NICU whilst others reflected back to that time and talked of their feelings about that time.

Parents reflection on their early NICU experience.

The table below shows the numbers of parents who described no longer reflecting back on the events around the time of the birth and their early NICU experiences at the time that they participated in Interview One. Fathers were more likely to report not really thinking about the past at the time they were interviewed for the second time. One father (I 16) explained,

"I think the birth and all that's past now, I haven't really give it much thought now, I think it is err, just thinking about the present now [right] and really, the birth, I haven't really give it much thought for a while now".

Fathers also found it difficult to remember how they had felt and that period of time was now a memory, or a story to be told to friends and family or no longer of significance to them.

Two mothers and two fathers described how their memory of earlier feelings and events had faded, even though their feelings at that time were intense with many worries. One mother (I 62) said,

"in many ways it's disappointing because you want to be able to remember everything. But as each day goes on and (Baby's name) gets better all the sort of what you might say, not bad things but things that gave you a lot of worry have faded, definitely."

Table 80. Parents who were not reflecting back on their early NICU experience.

	Interview Two Mothers	Interview Two Fathers
Don't really think about the past	3	4
Events have faded	2	2
Difficult to remember	0	3
Not significant now	0	1

In contrast to the parents who did not reflect on their earlier experiences, the parents in the table below described their feelings as they did reflect back and all of these parents expressed negative feelings as they did so. Both mothers and fathers reflected with negative feelings about the pregnancy, birth and on their earlier NICU experiences and a mother and a father made criticisms of the obstetric or midwifery care they received. One father (I 65) talked at length about the delivery experience saying,

"I didn't have the confidence because the consultant who came in had been in theatre, he was really busy..... it seemed to me that the whole thing was you know reflecting back on it. It was just kind of tricky really". "to reflect back on it I was most uncomfortable there because I wasn't a 100% confident that you know the whole thing was very, very rushed."

Only mothers described looking back and realising how ill their baby had been or how life threatening their condition could have been. One mother (I 75) explained, *"every time I think about it, I think about how life threatening it was."* And another (I 44) said, *"if I had realised how vulnerable he was which you know, and now, when I look back I think gosh it's amazing that I just you know was able to sort of bond with him in that way, you know in spite of how fragile and vulnerable he was."*

Table 81. Parents who reflected back to the time around the birth and first experiences of the NICU.

	Interview Two Mothers	Interview Two Fathers
Reflection	1	1
Negative feelings about delivery experience	2	1
Criticism of Maternity care	1	1
Realisation of severity	3	0

Changes after time.

Table 82. Positive changes in feelings.

	Interview Two Mothers	Interview Two Fathers
Positive feelings	2	3
Increasing confidence	2	1
No longer blames self	2	0
Baby progressing well, less worried	1	1
Growing bond/love	1	2
Stronger person	1	0
Appreciation of what is important	1	0
Greater understanding	1	0

There were small numbers of mothers and fathers who described positive changes in their feelings from their earlier experiences in the NICU. This father (I 63) of baby born at 27 weeks said when he was interviewed for the second time when his baby was 70 days old,

"I think as I walk through the doors into the neonatal I always get a few butterflies and I still get them but they have changed and when I was previously coming in you think, I was walking in and I was expecting bad news all the time and I'd walk through the doors and sort of thought well what's it going to be like when I go into intensive care, has something happened, has her oxygen requirement dramatically increased. So I was always apprehensive but now I walk in and it's more like butterflies because I'm not really expecting a change but I'm just sort of like looking forward to seeing her. So it's still exciting, the adrenaline still pumps but it probably pumps for a more positive reason now. There's less worry there."

Both mothers and fathers described an increase in their confidence since they had participated in Interview One.

Mothers (but not fathers) described that over time they had stopped blaming themselves for the birth of their sick or premature baby. One of these mothers (I 13) explained,

"I have got better in terms of, I was telling you how apprehensive I was, I was telling you about what had happened and whether it would happen again and nobody really told me that it wasn't my fault and all that kind of stuff and I had gone through that bit of emotion but I think I have come out of the other end now......it wasn't my fault it happened...."

One mother and one father described how they felt less worried at the time of Interview Two as their baby was progressing well through the NICU and they felt more able to cope with minor changes in their baby's progress without becoming very anxious as they had earlier. The father (I 45) said,

"before I was much more concerned you know and that he had had a dip for example or that his condition was worse and was more concerned, wanted to ask the doctors more questions, wanted to ask is this normal then that such and such has happened. Now I feel a bit more independent when I come in I feel much more sort of in that respect independent that I can come to him and you know just sort of look at him and watch him without feeling as though I need to ask what's happened in the night. I feel much less concerned."

One mother and one father talked of their growing love for and bond with their baby and how their baby was now very much part of their life as an individual and as a family unit. This father (I 50) described his changes in feelings over time as

"I would say in precisely the same way what I would take to be the sort of normal development of feelings when you have a baby so that your feelings immediately afterwards are the sort of wonder of this new person coming into the world and it all just seems so amazing. Whereas after some time then the baby becomes part of what life consists of. So then the fundamental, I can't remember exactly what I said then. I probably said something about being proud of him, feelings of love for him and so on and obviously that is still there but that now becomes part of the sort of what's normal in life same as my feelings towards (Wife and older daughter)."

One mother described herself as a stronger person because of her experience and of having a newfound appreciation of what is important in life. This mother felt that she had to be her baby's advocate on occasions and question decisions in a way she would never have done earlier in her NICU experience.

Finally, one mother described herself as having a greater understanding at Interview Two of her baby's illness and treatment and of why her baby had been born so prematurely.

Table 83. Negative changes in feelings.

	Interview Two Mothers	Interview Two Fathers
Negative feelings	3	2
Sadness at not going to term	4	0
Fear of same thing happening	3	1
Guilty feelings	3	1
Level of care	3	1
When baby is ill	2	2
1.Frustrations/lack of control	2	2
1a. Establishing breast feeding	2	1
1b. Contact with baby	1	0
1c. In decision making	0	1
1d. Needing to work	0	1
1e. Travel difficulties	0	1

In comparison to the positive feelings parents expressed at Interview Two, there were more negative feelings described about how their feelings had changed with some differences between mothers and fathers.

Mothers of babies born prematurely described their sadness at not carrying their baby to term, feelings of guilt and of a fear of the same thing happening again in any future pregnancies. This mother of a baby born at 30 weeks gestation (I 75) said, *"Still very shocked and feeling very cheated by the pregnancy I had that I didn't have really and in many ways, not something I want to be thinking about, the circumstances, it would take a lot before I could start thinking about having children again."*

In contrast, fathers described their feelings of frustration and lack of control. Whilst some mothers also described these feelings, fathers described different frustrations and areas where they felt they lacked control. Fathers expressed their issues relating to more practical problems such as work commitments, travel difficulties and decision making frustrations. One father (I 45) said,

"we definitely know the facts about how he is behaving and so yeah it would be nice to be consulted, be nice to be informed before the event and also nice to feel as though we could challenge the decision and talk it through if we felt it was something that we disagreed with...."

The mothers described their frustrations at the constraints of the NICU routine for their baby, in establishing breast feeding and being unable to cuddle their baby when s/he was too sick. One mother (I 44) described her frustrations at the routine she and her husband had to adhere to saying,

"there feels more at times more of a tension about you know what we can do and what we can't do and having to fall into a routine that's kind of imposed here and just not really feeling that we have got much control about things" and *"you're clock watching the whole time. And trying to kind of create this space where you are going to be quite calm with him and not feel rushed or you know. But it's like his next feed is at thing and I just need to try and squeeze everything in."*

There were criticisms of some aspects of care their baby was receiving made by three mothers and one father. For those parents whose baby had progressed from an intensive care room through a high dependency room and into the nursery room from where they would be discharged home, there were comparisons with the level of care their baby received. Whilst some recognised that this progress was a good reflection of their baby's improvement away from the need for the constant attention received in intensive care, others felt it was an indication of less commitment from neonatal staff working in those lower dependency areas. One mother (I 44) explained,

"some of them are really proactive and really focused but some of them you just feel it is just a 9 to 5. Whereas in intensive care the nurses didn't really talk to each other, they were just there, really focused on doing the job and so that's been the big change."

Progress since Interview One.

Parents were asked about any progress they felt had been made since they participated in Interview One. Their negative and positive responses are in the tables below.

The negative feelings about progress were mainly associated with their worries about their baby's health. Mothers expressed these worries more than fathers, particularly in respect of their concerns about their baby's future health as a diagnosis was evolving and uncertainties about the implications of that diagnosis emerged. One mother (I 34) said,

"I found out that (Baby's name) had had a head bleed which was a bit of a shock and they didn't know if he was going to get hydrocephalus and they are still monitoring him for and that was I think the worst thing I went through out of all of it."

Both mothers and fathers also reported feelings of powerless about their baby's health and concerns about slow progress. This father (I 28) of a baby born at 27 weeks gestation who was still dependant on the ventilator at Interview Two talked of his frustration of knowing when his baby needed suction but as his father, he was unable to do that for him and his frustration that his baby could not successfully get off the ventilator for any length of time.

"we know... probably more than them because we spend more time with him, even though we're not in a position to do anything for him." "when he wants suction you can't do anything...he's been off (the ventilator)six times now... it might be seven now."

Three mothers but no fathers made comparisons with others in the NICU and their frustrations about their progress compared to other babies. These mothers described how difficult they found it seeing other babies being cuddled, breast feeding and going home when their baby was not at the stage where those things were possible. One mother (I 13) said,

"it makes it hard when you see other people having contact with their children, you know you don't begrudge them it of course, but it does make it hard when you watch them picking them up..."

Two fathers but no mothers described that they were established into a routine of visiting daily but this was tiring and a strain. One father (I 63) said,

"it's hard to imagine what life was like before she was born to be honest. Every day seems to be the same really. It's very much a routine, a tiring routine."

Small numbers of mothers and fathers made other negative feelings about their progress. Movement of their baby through the rooms as their condition improved was seen as a positive step by other parents but for one mother and one father, this movement was viewed with caution and this mother found the process of getting to know new staff traumatic.

There were small numbers of mothers and fathers who expressed their frustrations at the lack of progress they were experiencing, still had worries about survival, had criticisms of care, worries about maternal health, expressed sadness at what their baby was enduring or had concerns about going home with the baby.

Table 84. Negative feelings about progress since Interview One.

	Interview Two Mothers	Interview Two Fathers
1.Worries about infants health	3	1
1a.Evolving diagnosis, future health worries	4	0
1b.Feeling powerless	1	1
1c.Lack of progress	1	1
1d.Other commitments	1	0
Comparisons with others	3	0
Movement through rooms	1	1
Frustration with lack of progress	1	1
Criticisms of care	1	1
Tiring/Strain	0	2
Sadness at what baby is enduring	1	0
Worries about maternal health	0	1
Fear of going home	1	0
Survival	0	1

There were greater numbers of positive feelings expressed by parents about progress since Interview One compared with negative feelings.

Most frequently described positive feelings were those relating to the health improvements that their baby had made over time. Mothers and fathers talked about the different milestones their baby had achieved to measure their improvements such as gaining weight, coming off a ventilator or oxygen, feeding or going from an incubator to a cot. One mother (I 62) described her baby's journey off respiratory support saying,

"she's doing really well. She spent about 6 weeks in intensive care. She was on the ventilator and she came off and she ended up going back on for a short spell. Then she went on the NCPAP and then she went into the head box..."

Mothers and Fathers also described their baby as looking stronger, being more robust and being more alert or responsive to them. One mother (I 76) said,

"he never woke up, he used to just lie there he didn't really do much, he never cried. Now when it comes to feeding time he's crying, he's ready. Screaming out where is my food. (Laughs)"

Both mothers and fathers described their developing bond, love and relationship with their baby and how that had changed a great deal for them since Interview One. One father (I 65) said,

"I think you had asked me in the first interview if I had established a relationship with him yet and I think I said no probably. But I think (Mothers name) had but I hadn't. I would say that's certainly changed a hundredfold."

Some of these parents described how their ability to do things for their baby had facilitated those feelings *"She's 6 weeks old so probably half that time, say around the 3 weeks point when I could actually do things for her and when I could actually get my hands on her and sort of camp out with her you know."* (Interview Two Mother, I 60) and many parents described the time that their baby was moved out of an incubator into a cot as a significant event. The physical barrier of a closed incubator removed, parents reported feeling closer to their baby and felt that they were able to care for the baby and pick him/her up without having to ask.

"I feel a bit closer to him now, especially since he came out of the incubator, it seems that, it's just easier to have access to him, talk to him." (Interview Two Father I 28)

Both mothers and fathers talked positively about their increasing involvement in their baby's care and how they were growing in confidence in being able to handle their baby and carry out certain tasks, such as nappy changes. The reasons given for the growing confidence parents were describing were because the baby was improving and considered less fragile but also that parents were learning the skills from the NICU staff. One father (I 45) explained,

"The access we get to him and also our own ability I suppose, you know to handle him with more confidence because we are practising more and I think that the biggest sort of bonus for us is being able to get into the incubator and just do all the practical things whereas in intensive care although we were definitely encouraged to do that, I felt much more self conscious about touching him because of the infection, because he looked so fragile and because of all the wires and the tangle and everything, but now there's less of that and we are more involved."

Both mothers and fathers described how they were looking forward and thinking about the future in contrast to Interview One where progress was still being measured by hour by hour changes in the baby's condition. These mother and fathers were optimistic about the future and were looking forward to discharge home. One mother (I 62) explained,

"now it's about moving forward and not hanging on what's happened. I know what's happened and I know what's happened is very serious but it's like you come in and

every day she seems to have changed a little bit more and its all positive instead of all the worry that I used to have."

For the mothers and fathers whose baby was not in their local NICU, the plans to transfer the baby back to a NICU closer to their home was seen as a positive step in the baby's overall progress. Parents described feeling excited about the move and viewed as a step towards going home and normal family life. One father (I 78) said,

"Very happy, different than a couple of weeks ago when I was stressed out, but now I'm feeling a bit more happy because now he's being transferred back to (local hospital) which is a big step. In fact it's basically getting back down to family life again now."

As described earlier there were a small number of parents who viewed the movement of their baby through the NICU as they progressed as a negative move. However, there were more mothers and fathers who viewed this movement as a positive step. Whilst parents described intensive care, high dependency and nursery areas as very different and unsettling when their baby was first moved from one area to the next, parents then described the moves as huge steps forward in their baby's progress. One mother (I 44) explained,

"I remember feeling quite anxious about the readjustment and this new environment and the new team and that kind of thing. And since we talked that environment has become much more familiar but I also feel it is very different from the experience in intensive care and that's partly that environment and it's partly us as well....I kind of find that the atmosphere in high dependency is quite empowering because its more laid back than intensive care."

Only fathers described how they had returned home, and for some fathers, home was a significant distance from the NICU where babies had been transferred for specialist neonatal care. These fathers described the routine they had established going home, their return to work and visiting their partner and baby in the NICU. Spending time at home was considered a positive step. This father (I 16) of a baby born at 25 weeks gestation said,

"the only thing that has really changed is the fact that I am going home, and I think sometimes that's a slight relief on me, it might sound horrible but it is like sort of I don't have to watch the monitors."

Table 85. Positive feelings about progress since Interview One.

	Interview Two Mothers	Interview Two Fathers
Improvements in baby's condition	7	5
Developing love/bond	6	4
Involvement in baby's care	4	3
Looking forward	4	3
Movement to other hospital	5	2
Movement through rooms	3	3
Gone home, returning to normal routines	0	3
Needing to share feelings less	1	1
Not a stressful experience	0	1
Sharing feelings with others	1	0
Now involving others	0	1

Parental feelings about going into the NICU to be with their baby.

Parents were asked to describe how they felt about going into the NICU in order to further explore how their feelings may have changed since Interview One and any emerging parental role or adaptation issues.

There were small numbers of parents who still felt worried about going into the NICU, these being parents of babies who continued to have a turbulent course and were still receiving intensive care or those who were concerned that their baby may take a major step back after a period of progressing well. One mother was torn between visiting the NICU and her other children's needs.

Table 86. Negative feelings about going into the NICU.

	Interview Two Mothers	Interview Two Fathers
Cautious	0	2
Worries about baby's condition	1	1
Lack of time	1	0

There were far more positive feelings reported about going into the NICU. Parents looked forward to seeing their baby. For many, their baby was no longer requiring intensive care support and they had moved on from the early worries of walking in to find the baby less well or requiring more support. These parents therefore looked forward to spending time with the baby and often described themselves as excited.

Table 87. Positive feelings about going into the NICU.

	Interview Two Mothers	Interview Two Fathers
Positive feelings	4	5
Looking forward to seeing baby	7	2
Establishing routines	2	0
Getting involved	0	1

Did parents feel needed?

Parents were asked if they felt needed at Interview Two which related to parental role development and the baby's dependence on the parent. Whilst there were some fathers who reported not feeling needed only one mother felt this way.

Table 88. Parents who did not feel needed.

	Interview Two Mothers	Interview Two Fathers
No	0	1
No, but not an issue	1	1
Not by the baby	0	1

Most mothers and many fathers felt that the baby did need them. There was a common belief that the baby had progressed since birth and was spending more time awake, recognised or responded to the parents and needed them to be in the NICU spending time with him/her. One mother (I 76) said,

"I do now I didn't at first but I do now. You know I mean sometimes when she is looking at me and I just think oh because they do need you so much don't they, just rely on you and everything and so much trust in you and oh it's lovely."

Table 89. Parents who did feel needed.

	Interview Two Mothers	Interview Two Fathers
Yes	3	2
By the baby	12	5
By his/her partner	5	3
By other members of the family	5	3

Parental views about their ability to influence what happened with their baby.

Parental role involves the parent making decisions and exercising their control over what is best for their baby and how they would like things done for the baby. They may listen to advice from those close to them but then make their own decisions about how to care for their baby. With this in mind, parents were therefore asked at Interview Two if they could influence what happened to their baby.

Their responses are tabled below. Whilst some parents felt that they could influence what happened to their baby there were others who were less confident in their ability to do so.

There were parents who described their ability to influence care for their baby but very much saw that in a negative sense with the potential for conflict between neonatal staff and themselves as a result. These parents were both mothers and fathers however there were more fathers responding in this way.

Both mothers and fathers described having to apply pressure on neonatal staff to influence the care that was delivered in a way they believed was in the baby's best interest. One father (I 28) explained,

" at the end of the day like, I don't really care what people think about me as long as he is getting what I think he should be getting [yes] and I can take him home... "

Whilst these fathers described not feeling particularly worried about how the neonatal staff regarded them as a result, fathers had worries about how their actions or any challenging behaviour they exhibited may influence how the staff may then feel or act toward their baby. They worried there may be consequences for their babies and his/her care as a result of any demands, questions or challenges they made, particularly when they were not there.

Some mothers and fathers believed that their presence in the NICU influenced the care that their baby received. These parents felt that whilst they were visiting their baby the standard of care exceeded that level of care when they went home. Parents described examples or particular incidents where the baby was stable or made progress during the day time when they were present but then deteriorated after they left to go home.

This father (I 28) of a baby born at 27 weeks who was still requiring intensive care at the time of Interview Two when that baby was six weeks old said,

"I just don't think he... is being attended to when we are not there, certainly as much as when we are there anyway....all I am asking for is standards, I don't want anyone doing anything special because it's (Baby's name) like, I just, I don't think he gets the same care when we are not here."

Table 90. Negative feelings about parental influence.

	Interview Two Mothers	Interview Two Fathers
Parental pressure	3	2
Particular incident	2	2
Concerned about effect on care	0	3
Care depends on parental presence	1	2
Care depends on individual caring for baby	0	2
Will ask	1	1

Some mothers but only one father viewed their ability to influence what happened to their baby in the NICU in a positive way. These mothers felt able to contribute to the plan of care made with neonatal staff for the baby. These mothers described how they had expressed their opinions when they felt a certain plan of care was not appropriate for their baby and how they had worked as a team with neonatal staff with the baby's best interest at heart.

Mothers also differed from fathers by describing the emotional impact and influence they had by being with their baby in the NICU.

Table 91. Positive feelings about parental influence.

	Interview Two Mothers	Interview Two Fathers
Positive comments	3	0
Emotional impact	2	0
In plan of care	4	1

The table below shows the parents who felt unable to influence what happened with their baby in the NICU and whilst some mothers and fathers felt that this was not an issue in that they had a trust and confidence in the expert and knowledgeable care of the NICU staff, most viewed their inability to influence what happened to their baby negatively.

Some parents did not feel that they were able to say anything to the NICU staff whilst others, particularly fathers complained about not being involved in decision making and of feeling powerless. One father (I 45) said,

"we definitely know the facts about how he is behaving and so yeah it would be nice to be consulted, be nice to be informed before the event and also nice to feel as though we could challenge the decision and talk it through if we felt it was something that we disagreed with."

Table 92. Parents who felt unable to influence what happened with their baby in the NICU.

	Interview Two Mothers	Interview Two Fathers
Unable to influence what happens	3	1
Confidence in staff/unit	3	2
Don't feel able to say anything	2	2
Not involved in decisions	1	2
Powerless	0	2
Criticism of an individual's care	1	0
No, but partner can	0	1

4.9 Summary of results

Below is a summary of the nine results sections

4.9.1 Preparation prior to birth

Clearly preparation will depend on whether the delivery was unexpected, and this can be seen in the different responses. By and large mothers who were expecting an early delivery because of known complications, had received good input in relation to information about prematurity and visiting the NICU so that they knew what to expect. The majority found that these initiatives were helpful. Talking to a paediatrician prior to labour was welcomed by mothers, but not by mothers when in labour. This latter group had little memory of what they had been told, and suggests that the paediatrician's input would be better following delivery.

4.9.2 Labour and Delivery

Parental experiences of the labour and delivery were dominated by worries about the baby and the baby's health. Mothers but not fathers were likely to worry about the baby's survival at this time. Fathers were more likely to express worries about their partner than themselves whereas mothers expressed worries about themselves, their pain and some had concerns about their own health and even survival at this time. For small numbers of parents, the labour and delivery experience was a positive one. Whilst for some, this was because the problems the baby experienced after birth were not anticipated. However, for others the positive experience was as a result of the support and reassurance parents received at this time despite knowing the baby would need care in the NICU.

4.9.3 First sight of infant

Despite the birth of their sick or premature baby, on the whole, many parents reported positive feelings about seeing their baby for the first time, however they also described their shock, worry and fear at this time. Some mothers also described not feeling an immediate bond. Unlike most new parents, for some of these mothers and fathers it was not possible for them to see their baby at delivery so their first sight of their baby was in the NICU.

When parents first saw their baby in the NICU, they again reported mixed emotions however; the majority of mothers and fathers reported negative feelings about the NICU environment, equipment around the baby and their worries about the health and survival of their baby. Both mothers and fathers described their baby as looking small, vulnerable or fragile. Mothers, but not fathers reported that they did not feel that the baby was hers or not an immediate bond.

4.9.4 Support from partner, family, friends and other parents

The majority of useful support and help was between partners with most mothers and fathers believing that they were able to give and receive support from their partner. That said, some mothers felt that their partner did not share his feelings or was deliberately hiding his feelings in order to protect her. Fathers were able to offer both emotional and practical support whereas mothers were less able to give any practical support.

Both mothers and fathers described their families as emotionally and/or practically supportive. Mothers rather than fathers were more likely to value and describe the emotional support they received. Whereas more fathers described how they valued the practical support family gave during this time. There were parents who found family lacked understanding or found that their responses were unsupportive.

Most parents described their friends as unable to understand the situation they were in. Furthermore, particularly mothers described intentionally avoiding talking with their friends at that time because they anticipated it as too emotionally tiring or difficult for them.

Only mothers described talking to other parents in the NICU as unhelpful. They described making comparisons with others less fortunate than themselves and more fortunate than themselves as of no benefit to them. Despite this, other parents felt that because other parents were sharing a similar experience, they had something in common with them so it was of value to talk with them. Making comparisons with others less fortunate was also useful and fathers felt that being able to help other parents was helpful for them.

4.9.5 Support from and communication with staff

Neonatal nursing staff were very highly regarded by parents who felt that they were exceptional at the giving of information and in answering their questions. They were described as approachable, encouraging and supportive. Some parents described a particular nurse who they had developed a special or close relationship with. There were, in comparison, few negative views of communication with the neonatal nursing staff and mostly related to the perception that nursing staff were busy often with other babies with awareness that they were sharing the nurse's time with other parents. Communication with doctors was also rated highly by parents although was considered different than that with nurses who were constant and always present. Communication with doctors was less frequent and sometimes parents had not spoken with a doctor and whilst some parents were happy with that level of communication, others would have liked more opportunities to talk with doctors.

4.9.6 Adaptation:

The adaptation process based on Taylor's cognitive framework associates successful adaptation to the stressful event with parents searching for a cause and apportioning of blame particularly to oneself. Blaming oneself may enable a sense of personal control over the crisis situation.

In the search for meaning parents may ask themselves why they have had a sick or premature infant, they may make downward comparisons with others deemed less fortunate than themselves and explore how they, as parents or their infant may have benefited or gained from the experience (e.g. Padden and Glenn, 1997).

Self blame

Only mothers reported feelings of self blame describing feelings of guilt and were searching for a reason for why their baby had been born sick or prematurely. They agonised over their own actions and lifestyle prior to the birth in their attempt to find a reason in the early days following the delivery of a baby who needed admission to the NICU. Self blame was less obvious by Interview Two and fathers in comparison did not employ self blame as a means of adaptation.

Care received

Blaming hospital care or that of a particular health care individual was employed by only small numbers of mothers and only in the earlier interview. Fathers in comparison did not blame the care they had received for the situation they were in.

Search for a reason

Whilst fathers did employ the same strategies as mothers in looking for a reason for why this situation had happened to them, they did not however, blame themselves or make upward comparisons with others more fortunate or downward comparisons with others less fortunate like mothers did. These strategies were no longer used by either mothers or fathers by Interview Two time point.

Benefits – feeling lucky/unlucky

Mothers but particularly fathers could describe benefits arising from their situation. A changed outlook on life, an appreciation of what was important in their lives and stronger relationships were reported. Parents also felt that there were health benefits for baby, the mother and the family. There was a confidence that the baby was in the best place, the mother had time to recover from the birth experience and the couple had support whilst they learned how to care for a newborn baby.

Despite being a parent of a baby in the NICU, parents believed they were lucky. They felt lucky to have a baby at all and made downward comparisons to those more unfortunate than themselves.

4.9.7 Parental Role

Parental role theory relies on parents adjusting to the birth of their new baby by spending time with him/her, being able to recognise and respond to their needs, make decisions and have the confidence to deliver care as they feel appropriate. Parental role appeared to be developing even at Interview One and increasing with time as parents became confident in their own knowledge of the baby, his/her recognition of them and by being sure of the baby's personality.

Practical – what can we do

Whilst some parents described feeling that they were unable to do anything for their baby, nursing staff clearly involved parents from a very early stage, even with very sick or premature babies. Almost all parents described being able to wash, change and carry out other practical care for their baby even at Interview One time point. Parents were obviously also encouraged to talk to the baby, comfort, touch and cuddle whenever possible even when parents were apprehensive about that experience. Whilst parents were often happy to wait until their baby was very stable, spending time alone with the baby was seen as important in being able to act and talk in a way that they were otherwise unable or inhibited to do. Again, nursing staff encouraged parents to spend time alone with their baby even when parents felt anxious about doing so.

Emotional – recognition by infant; personality, distress, anger

Despite in some cases of extreme prematurity or illness, many mothers appeared to believe that they knew their baby better than anyone else even at Interview One with this belief growing with time. By Interview Two fathers had begun to believe that after the baby's mother, they knew the baby best but on the whole never claimed to know the baby better than anyone else.

Mothers also had a growing belief that their baby recognised them whereas fathers preferred to describe their baby as responding to their presence and almost all parents felt sure of their baby's personality traits even as early as Interview One.

Very little caused parents to feel anger however, parents reported feeling distressed at seeing procedures done on their baby, seeing other baby's that were very ill and with time there were more anxieties about levels of care.

On a practical level, staff were seen as very supportive and encouraging.

4.9.8 Change with time (Interview One to Interview Two)

With the passage of time parents thought less about the events around the pregnancy and delivery and those first experiences in the NICU. Parents were no longer asking themselves why this had happened and mothers were no longer blaming themselves. By Interview Two most parents described benefits to their situation and many felt lucky

Despite many positive feelings about their baby's progress, there were also different negative feelings about progress from Interview One. Parents had current and potential future health worries, made comparisons with others more fortunate and had more frustrations and criticisms over time.

Parental role continued to develop with parents feeling that their baby needed and recognised them, however, many parents felt that they were still unable to influence what happened to their baby in the NICU.

4.9.9 Experiences of Fathers

The experiences of fathers and how they differ from those of mothers has been described within each of the previous 8 results sections and summaries however, they are also worthy of highlighting to the reader again in this separate section.

Prior to the birth, in contrast to many mothers, fathers had a good recollection of the information they were given and admitted to protecting their partner by not repeating what they were told when she could not remember. Unlike some mothers, very few fathers found a visit to the NICU in the antenatal period unhelpful.

During the labour and delivery fathers differed from mothers in that they expressed worries about their partner, described feeling helpless and did not express worries about their baby's survival at this time.

The experiences of seeing their baby for the first time following delivery, in the NICU and holding the baby for the first time raised more practical based concerns for fathers compared with mothers. There was a need for information about their baby's health, treatment and care. Fathers continued to have concerns for the mother of their baby and many had not had the opportunity to hold the baby at Interview One believing it was more important for the mother to do so. Unlike mothers, fathers did not express any worries about not feeling an immediate bond or feelings about the baby being "mine".

Fathers felt more able than mothers to give support to their partners especially at Interview Two and unlike mothers, fathers felt able to give their partner practical support as well as emotional support. In contrast to mothers, fathers admitted to hiding their true feelings to their partner in order to protect them. Indeed, fathers were more likely to say that they did not need any support in the situation they were in.

Fathers differed from mothers in that they were more likely to value the practical support offered by family and often protected mothers from having to talk with other friends and family when they felt unable to do so.

Fathers, in contrast to mothers, described the experience of talking to other parents in the NICU as an opportunity to help others.

In the process of adaptation, fathers differed greatly from mothers in that they did not search for a reason or blame themselves, any other person or event for the situation they were in. Fathers especially could identify benefits to what had happened, with a greater appreciation of what they had, a changed outlook on life and an appreciation of the baby care skills and knowledge they were gaining from their baby being in the NICU. Fathers generally felt lucky to be in the situation they were in.

In development of the parental role, fathers sacrificed opportunities to carry out practical care giving roles in the belief that it was more important for his partner to have contact with their baby especially in the early days of the experience where opportunities could be limited when a baby was very sick. Many fathers had not the opportunities that mothers had to hold their baby at Interview One but most had by Interview Two. Unlike mothers, at no point did fathers believe that they knew their baby better than anyone else but by Interview Two many felt that after the baby's mother, they knew their baby best. Fathers also differed by commonly describing their baby as "responding" to them in a particular way in contrast to mothers who felt that their baby "recognised" them.

The changes over time saw fathers feeling increasingly powerless and expressing frustrations about their inability to influence their baby's care. Fathers described their concerns that the standard of care their baby received was dependent on their presence in the NICU and feared that if they voiced any concerns or challenged NICU staff, staff may form opinions about the family and care may be affected in a negative way.

Chapter 4

Discussion.

4.1 Overview

The aim of this study was to investigate how parents adapt to the birth of an infant requiring Neonatal Intensive Care Unit (NICU) care and to answer the following research questions:

a) Do mothers and fathers have similar experiences as parents of infants on a NICU?

b) What stressors do they perceive?

c) What is the process of adaptation to having a premature or sick infant in the NICU?

d) Do parental views and feelings about their experience change over time?

Through the interview process with parents, the results show the processes of parental role development and adaptation to this stressful event but also the practical issues significant to parents about the structure and organisation of the NICU. These practical issues have implications for NICU practices but there were practical issues that also could influence adaptation and parental role development.

1. Recommendations for supporting parental adaptation and developing parental role.
2. Practical implications for organisation of the NICU.

4.2 Supporting parental adaptation and developing parental role.

It is important that NICU staff understand not only the processes of adaptation and adjustment that parents may employ following the birth of a sick or premature baby requiring care in the NICU, but also how their care can influence those processes. There are also differences between mothers and fathers and changes over time to be aware of.

To remind the reader, Taylor (1983) states that the process of adjustment to a traumatic event has three themes: A search for meaning in the experience, attempts to regain mastery over the specific event and life in general and an effort to restore self esteem and feel good about oneself once more despite the consequences of the personal difficulties.

In the search for meaning, those adjusting from a traumatic life event need to understand why the crisis has occurred. There is a search for a cause in order to understand why this has happened and regain personal control (Taylor, 1983). Self blame has been associated with successful adaptation to threatening events because by blaming oneself, a sense of gaining personal control of the situation is achieved (Affleck, Tennen and Rowe, 1991, Affleck, McGrade, Allen, and McQueeney, 1985). Mothers can experience feelings of failure (Silcock, 1984) and grieve the loss of the hoped-for perfect infant (McHaffie, 1990). These findings highlight that fathers differed greatly from mothers in that there was little evidence that fathers searched for a cause or employed strategies of blaming oneself or blamed anyone or anything and fathers were also aware that mothers blamed themselves for the situation they were in. Self blame was only reported by mothers in this study with far fewer believing their actions or omissions were a causal factor in why their baby had been born sick or premature by Interview Two. Mothers therefore only used self blame strategies for adaptation in the early days following the birth of a sick or premature baby in this study. Lee, Norr and Oh (2005) interviewed 50 Korean mothers of premature infants twice in the NICU and a further three times after discharge home. When these mothers were interviewed shortly after admission these authors also found self blame to be a predominant theme with mothers trying to identify where her failure lay but these feelings of guilt and self blame declined over time.

In a small study of 12 parents, Taylor (2008) reported that many fathers expressed feelings of self blame believing that they were personally responsible in some way for the birth of their preterm baby. However, at no point did the fathers in the present study adapt to this event by examining their own actions, those of the mother and rarely those of others such as health care professionals in search for a cause. Fathers frequently reported that looking for a cause or blaming an individual was not of significance to them, the birth of their sick or premature infant was "just one of those things". These findings are supported by Tennen and Affleck's (1990) review that found a strong relationship between blaming of others and poorer adaptation. These fathers appeared to adapt to their situation successfully with little attention given to causal attributions. Fathers focused on the situation they were then in, not what caused it.

In support of Taylor's (1983) theory and the findings of Padden and Glenn (1997), parents frequently asked themselves why this stressful event had happened to them. Mothers searched for a reason, blamed themselves, made downward comparisons with others less fortunate but also commonly made upward comparisons with others more fortunate than themselves. In contrast to mothers, fathers described briefly asking themselves why this had happened to them before moving on and thinking only about the present or future for their baby. Fathers in this study did not employ the adaptive mechanisms of self blame probably because it is the mother who experiences the pregnancy and birth. Few fathers made comparisons with others less or more fortunate than themselves or reported looking for a reason when they were asked if they had ever asked themselves why this had happened to them.

With the passage of time, by Interview Two this mechanism of asking why this had happened disappeared for both mothers and fathers. Asking oneself why this event had happened is therefore common in the process of parental adaptation to the birth of a premature or sick baby but only in the early days following admission to the NICU but not a continuing theme.

In direct response to being questioned if parents ever asked themselves why this had happened to them, fathers differed from mothers by rarely making either upward or downward comparisons with others. Fathers appeared to adapt remarkably well to their situation by giving little regard to the situation of others and focusing only on their own baby. They appear to exhibit this even at the first interview and continued to do so with the passage of time.

A sense of mastery sees the victim of the threatening event making attempts to regain their perception of personal control over the situation (Taylor, 1983). For parents of infants in the NICU this has been associated with their increasing perceptions of power and control as they gradually take over aspects of care giving responsibilities (Affleck, Tennen and Rowe, 1991). Mastery has been associated with power, enablement and parent's ability to personally care for their infants (Epps and Nowak, 1988).

From very early in the NICU experience, the NICU staff were seen as encouraging parents to assume the role of care giver and were supportive even when parents felt afraid, anxious or believed they were not ready. Parents were able to carry out many practical aspects of their baby's care even at Interview One, but NICU staff also fostered the importance of parents recognising the emotional impact they had through touch, comfort and giving of parental love. Staff in this NICU were excellent at empowering, giving confidence and encouraging parents despite resistance from some parents in assuming care giving roles and spending time alone with the baby when s/he was well enough. In support of the literature, parents viewed being able to care for their baby favourably and recognised that engaging in these new roles were an important step in parenting. In further support, there were parents who could identify things that only they could do as a parent for the baby despite his/her illness or prematurity and dependence on the NICU.

However, there were again, quite remarkable differences in experiences for fathers in this study. Fathers (unlike any mothers) described sacrificing their own opportunities to carry out practical care giving roles and/or holding their baby in the belief that it was more important for his partner to have contact with their baby. This was found to be particularly so at Interview One in the early days of the experience where the opportunities to have this level of contact with their baby could be limited if the baby was very sick. Despite the importance of encouraging parents to hold their baby in the NICU, many fathers had not had the opportunities that mothers had to do so at Interview One but most had by Interview Two.

Probably as a result of the fewer chances fathers had to undertake care giving roles and to hold their baby, there was evidence that fathers had not developed their parental role in the way that mothers in the NICU demonstrated. Fathers at Interview One did not hold the belief that they knew their baby better than anyone else. However, by Interview Two the paternal role was increasingly apparent with many fathers describing that after the baby's mother; they felt that they knew their baby better than any other individual.

These differences between mothers and fathers have implications for nursing practice. Nurses in the NICU must be made aware of the how paternal role development may be further delayed in the NICU when a father has fewer opportunities to carry out basic care giving roles such as washing, nappy changing and holding their baby. Fathers should be encouraged to be involved in their infants care even when they are reluctant and would prefer the mother to be given those opportunities. The perception of personal control (Taylor, 1983) is also supported by those parents who believed that they are able to influence what happens to their baby whether that was by being involved in planning of care or through pressure they exerted if they wanted something particular done or not done. There were however, some parents who felt unable to influence what happened to their baby at Interview Two. They felt powerless, not involved in decision making and felt unable to voice their wishes or opinions because of the possibility that any resulting conflict between staff and the parents might have an impact on the baby's care.

The changes over time saw fathers particularly and often in contrast to mothers feeling increasingly powerless and expressing frustrations about their inability to influence their baby's care. Fathers described their concerns that the standard of care their baby received was dependent on their presence in the NICU and feared that if they voiced any concerns or challenged NICU staff, staff may form opinions about the family and care may be affected in a negative way.

For fathers the ability to influence what happened to his baby and to be involved in decision making was seen to have greater importance than that expressed by mothers. It is therefore recommended that in support of The Department of Health's Toolkit for high quality neonatal services, (2009) and The National Institute for Health and Clinical Excellence (NICE) Specialist Neonatal Care Quality Standards (2010) that parents are encouraged to be involved in planning care and making decisions following the appropriate level of communication with medical and nursing staff in the NICU. Restoring self esteem can be fulfilled by making downward comparisons with those less fortunate, through belief of personal benefit or use of positive illusion or by believing that one has gained control over the crisis situation. (Taylor, 1983) The search for enriching or beneficial meaning in the psychological reorganisation following traumatic events is described in theories of cognitive adaptation by Taylor (1983), Taylor, Wood and Lichtman (1983) and Janoff-Bulman (1992). Taylor (1983) claim that individuals bring meaning to their crisis event by believing that there is some personal gain, growth or benefits arising from the event. The relationship of benefit finding and positive adaptational outcomes is supported by Affleck, Tennen and Gershman (1985) in their study of mothers of high risk infants.

The present study supports these views with many parents reporting that they could identify benefits to having a baby in the NICU. Fathers particularly, believed that there were benefits to their situation with an appreciation of what was important and meaningful in their life. They had a greater appreciation of being given the opportunity to be a parent at all and a changed outlook about their relationship with the baby and others around them. This study supports Taylor's process of adaptation, in that by reappraisal of the experience in a positive way, these participants could see themselves as better off than before the crisis event had occurred.

Parents and particularly fathers often recognised not only psychological and emotional gains from the NICU experience but also practical and physical benefits. These parents described the health benefits in terms of appreciating the expertise of this particular hospital's NICU, for the mother to have the time to recover in hospital and without the total responsibility of caring for her baby, of having the baby sooner and therefore longer and the benefit of spending longer in hospital learning how to care for the baby. Lindberg, Axelsson and Ohrling (2008) interviewed eight Swedish fathers of premature infants and they also found that fathers identified benefits to their experience. These fathers believed their relationship with their partner had strengthened and they felt a changed person with different values. These Swedish fathers also felt fortunate because the time that they had needed to spend in the NICU had given them the chance to get to know and bond with their baby in a way they wouldn't had the baby been born at term and like the fathers in this study, felt better educated by the NICU staff helping them to care for their baby.

The presents study adds that over time, there was an increased appreciation of having the baby in the NICU. Parents welcomed the ongoing support of the NICU staff as parents learned the practical skills of caring for a baby, as they established breast feeding and daily routines in comparison with parents who take their baby home soon after delivery.

The different categories of benefits identified from threatening events (Taylor, Lichtman and Wood, 1984, Thompson, 1991, Affleck, Tennen and Rowe, 1991 and Affleck, Tennen and Gershman, 1985) are also supported. These categories include a change in the individual's personal priorities and goals in life, the strengthening of relationships, and a positive change in their beliefs, such as becoming stronger, appreciating others or themselves more, greater courage or the development of greater tolerance. The present study also found that parents identified practical and physical benefits that parents identify with and how those are amplified with the passage of time.

From my NICU nursing experience, there are often concerns that parents appear to be over optimistic, buoyant or have not appreciated the severity of illness. However, these findings can inform NICU staff that most parents but particularly fathers are likely to have a positive attitude towards the NICU experience and that it is more common for fathers to believe they and their family are able to reap benefits from their experience and that they are advantaged in comparison to other parents despite even severe illness in their infant.

Taylor's (1983) adaptation theory claimed that those faced with a serious illness such as a cancer diagnosis, appraise themselves and their situation by making downward comparisons with those they perceive as suffering more or who are in worse circumstances in order that they feel advantaged. By making downward comparisons the individual is able to protect themselves against the threat and to enhance self esteem and is a robust method of minimizing victimisation with the claims that there are many other individuals worse off that the self (Taylor, Wood and Lichtman, 1983).

Affleck, Tennen and Rowe (1991) also found that mothers of infants who had required neonatal intensive care made downward comparisons. The mothers of larger infants compared themselves to mothers of smaller infants and the mothers of smaller infants compared themselves to mothers of very sick infants and many of their participants expressed the view that outcomes for their infants could have been worse, they might not have survived at all.

The present study supported these findings in that mothers compared themselves to others less fortunate than themselves when they participated in Interview One; however, fathers were less likely to make these downward comparisons. Both mothers and fathers described themselves as lucky. They believed they were lucky to have a baby at all and here, both mothers and fathers made downward comparisons with other parents who had a baby smaller, sicker or a baby who had died.

However, there were mothers at Interview One and even more so at Interview Two who found that talking to other parents was an unhelpful experience because of the downward comparisons they made. Mothers described feeling guilty if their own baby was progressing well in comparison with others. They were unsure of what to say to those parents and felt uncomfortable with the sense of competitiveness about how different babies were progressing.

Many mothers also made upward comparisons with others more fortunate than themselves. Mothers questioned why they had been unlucky in comparison to other mothers in the hospital, friends, relatives, work colleagues or those women who were perceived as not taking the care that they had during pregnancy in their attempts to give birth to a healthy baby. These upward comparisons are thought to be unhelpful with the potential for the individual to feel disappointed and in a detrimental position in comparison to others (Taylor, Wood and Lichtman, 1983). There were some mothers in the present study who made upward comparisons with others and found these comparisons unhelpful. Mothers described almost a sense of competitiveness which was not beneficial and they had feelings of guilt when they were disappointed that there baby was not progressing as others were. However, whilst mothers made upward comparisons in the early days of the NICU experience it was not reported later in the NICU experience when parents were interviewed for the second time.

Indeed, there were mothers and fathers who made upward comparisons which was associated with successful adaptation. Parents described how helpful it was to see that other babies overcome similar health problems to their own; they grew bigger and healthier and ultimately went home with their parents. The success stories posted on the NICU notice board, the thank you cards and pictures of babies who had once been in the NICU all served to give parents hope and confidence that their baby could also successfully survive the NICU experience.

There were also parallel comparisons made by parents with other parents and babies who were experiencing the same difficulties, problems or progress and these were seen as helpful when parents talked with other parents in the NICU. The sense of having something in common and of sharing similar experiences was helpful in that parents felt that they were not alone in their situation. Other like parents were seen as able to comprehend how they were feeling and they understood both their practical and emotional difficulties in a way friends and family could not.

Nursing practice in the NICU should appreciate that the value of talking with other parents should be assessed on an individual parent basis. These findings demonstrate to NICU nurses that whilst some parents will benefit from spending time with other parents, others may not find the experience helpful and that they have valid reasons for their reluctance to chat with other parents.

Parental role

Mercer (2004) makes an argument for replacing the term "maternal role attainment" with "becoming a mother". Becoming a mother is claimed to encompass the transformation and evolution of a mother's persona through four stages: (a) commitment, attachment, and preparation (pregnancy); (b) acquaintance, learning and physical restoration (first 2 to 6 weeks following birth); (c) moving towards a new normal (2 weeks to 4 months); and (d) achievement of the maternal identity (around 4 months).

For the parents of infants born prematurely, the process of achieving parental identity is interrupted by the often unexpected early arrival of the infant, perceptions of the birth experience, early maternal-infant separation and infant illness. In the first instance, the attachment process and preparations during pregnancy in the earliest stage of becoming a mother as defined by Mercer (2004) is arrested by premature birth. Other studies have focused on the development of prenatal attachment as a woman prepares herself for becoming a mother. Siddiqui and Hagglof (2000) found that women who engaged in thinking and daydreaming about and interaction and affection with the unborn baby predicted greater attachment at 12 weeks post partum. Mu (2004) found that high risk pregnant women begin the process of maternal role making by actively adapting their lifestyle and behaviour in order to protect their unborn baby. However, Wright and Belanger (2000) found that although high risk mothers were more involved during their pregnancy than low risk mothers, this greater involvement did not increase the attachment process.

Fegran, Helseth and Solveig Fagermoen (2008) compared the attachment experiences of six mothers and six fathers in a Norwegian NICU within the first week after premature birth. One of the two main categories the study revealed was how parents were "taken by surprise". Parents described how unexpected and unpredictable aspects of becoming a parent of a premature infant had been for them. Similarly, the present findings highlighted that many parents were taken aback because there were no warnings of premature birth or antenatal diagnosis of an infant illness or condition prior to the birth. But, even where there were prior warnings that an infant may be born prematurely or sick, parents still expressed feelings of shock and described feeling unprepared for their experience. NICU staff should be aware of the parental feelings of shock, surprise and the feelings of being unprepared for the birth of a premature or sick infant despite advice or threats during the pregnancy.

Where a Paediatrician spoke to parents when the mother was already established in labour or where delivery is imminent, there was little or no recollection by the mother of what was said. Calam, Lambrenos, Cox and Weindling (1999) similarly found that mothers often had no time to psychologically prepare herself for preterm birth because of the unexpected nature of the delivery, there was no time for professionals to give information and there was little or no recollection of information given immediately following the preterm birth. This suggests that unless there is prior warning of the birth of a sick or preterm infant, information giving should wait until after the birth when the mother is more able to absorb the information she is given. NICU staff should not assume that because a father has heard and understood explanations given to the couple immediately prior to delivery, that the mother has also retained that information. Likewise, it may be that a father will withhold information he has been given from his partner in order to protect her from what he thinks may upset her.

For those parents who did have some prior warning that their baby may require NICU care, although they sometimes found preparation for the NICU experience frightening, parents did welcome the opportunity to familiarise themselves with where and what the NICU was, the staff who worked there and be given information of what to expect. Staff from the NICU should therefore aim to prepare parents wherever possible for their NICU experience. If parents are familiar with the sights and sounds of the NICU, they are more able to focus on their baby after admission. In support of this, The Department of Health has published guidance (Toolkit for high quality neonatal services, 2009) to improve the care provided for premature and sick babies and their families. Within this document there are clear principles for NICU's to be guided in the deliverance of family centred care and promote attachment between a baby and the family. One of these principles states that wherever possible, parents should be given the opportunity to visit the NICU and meet key personnel prior to admission.

Efforts to introduce parents to the sights and sounds of the NICU environment, to NICU staff and to the likely size, appearance and probable difficulties their baby may have will only ever be possible for those parents who are given some prior warning. Whilst the events leading up to and around the delivery were a cause for great upset at Interview One, by Interview Two, the significance of these events had faded and were far less important or significant to parents with much more emphasis on the baby's progress and future with the passage of time.

A Portuguese study by Figueiredo, Costa, Pacheco and Pais (2007) examined whether there were differences between mother-to-infant and father-to-infant emotional involvement within the first few days after birth. Most mothers and fathers exhibited similar initial emotional involvement toward their infant and most showed positive emotions. There were very few negative emotions and these authors found that fathers showed less fear and mothers expressed more sadness. Although there were a small number of infants in their study admitted to the NICU (14%), most of the infants in this study were born at term and followed a normal neonatal course following delivery.

In comparison, parents in the present study also described many positive feelings about the experience of seeing their baby for the first time, despite infant prematurity or illness. This echoes the findings of Padden and Glenn (1997). MacDonald (2007) also reported that mothers' images of their babies were overwhelmingly positive. However, the eight mothers in her study were interviewed later into the NICU experience at 4-11 weeks after the birth when recall of the experience may have been changed by time.

Despite these positive feelings, most parents also described feeling shock, worry and fear when seeing their baby for the first time and like Gavey (2007) who interviewed

16 mothers of preterm infants in the NICU, they were overwhelmed by the sights and sounds of the NICU. Blanch D'Souza, Karkada, Lewis, Mayya and Guddattu (2009) surveyed parents of preterm infants in six Indian NICU's and they also found high levels of stress in areas of parental role alteration, appearance of the baby and sights and sounds.

There were feelings that there was no immediate bond or the question "how do I know this baby is mine?" that mothers expressed when they visited their baby for the first time in the NICU. These findings support literature describing how early maternal-infant separation may be detrimental to the attachment process (Brimblecombe, Richards and Roberton (1978), Minde, Whitelaw, Brown and Fitzhardinge (1983). Interestingly and again, quite notably different from the responses made by mothers to seeing their baby for the first time in the NICU, fathers did not respond in this same way. The focus for concern for fathers was not about feeling an immediate bond but more practical based concerns about the equipment in the NICU, the health of the baby and their concerns about the mother at this time.

Like Reid (2000), for mothers in particular, holding their baby for the first time was an important event in developing feelings of attachment and feelings of the baby being hers. Even when infants were very sick, there were very few mothers who had not been given the opportunity to hold their baby at Interview One. This shows how the staff in this NICU have embraced practices to promote early mother-infant contact such as skin to skin or kangaroo care whereby the parent is encouraged to hold their baby close to promote both attachment and lactation.

Sullivan (1999) found that the earlier fathers held their preterm infant, the sooner they reported feelings of warmth and love for them and that holding their infant for the first time was reported as a significant event for fathers in the development of attachment.

The present findings were that fathers were less likely than mothers to have had the opportunity to hold their baby for the first time at Interview One. The opportunities to hold their baby were sometimes limited because of the baby's illness in those earlier days so fathers would sacrifice their own needs feeling it was more important for the mother to hold the baby. Fathers in this study also differed from mothers when they held their baby for the first time by being more likely to describe feeling "protective" and "responsible" when they first saw and held their infant in contrast to mothers who chose to associate the experience with the words such as "love", "bond" and feeling that the baby was "mine".

Fegran, Helseth and Solveig Fagermoen (2008) also found that fathers reported reluctance in holding their baby skin-to-skin in the beginning but that first experience of close contact was a momentous one in transforming their relationship from impersonal to a relationship of belonging and protection. Fathers who were involved in an infant's care from an early stage felt their contribution to care was valuable, they had an increased desire to be close to their infant, and they became more confident interacting with their infant.

The present study found that holding their baby on subsequent occasions was strongly associated with feelings of attachment in that the baby was theirs, feelings of love and a growing bond for mothers and much fewer negative feelings for both mothers and fathers as their confidence grew. As highlighted earlier, the importance of offering fathers and not just mothers opportunities to touch and hold their baby as soon as their condition allows must be recognised by NICU nursing staff as significant experiences in the process of attachment and these opportunities must continue for both parents throughout the NICU experience. NICU nurses should be made aware that fathers often put the needs of the mother before their own and need encouragement to be as involved in care giving and comforting their infant as the mother.

Nirmala, Rekha, and Washington (2006) assessed parental perceptions of kangaroo care with mothers and all their mothers reported that holding their baby skin to skin improved bonding, made them feel good and happy to be contributing something for the baby.

The Department of Health's document (Toolkit for high quality neonatal services, 2009) advises that parents should be encouraged and supported in participating in regular skin to skin care, providing comforting touch and holding, particularly during painful procedures, feeding and day to day care such as nappy changing. Parents reported being able to do all of these (and more besides) comforting and practical care giving practices for their baby even as early as Interview One. Even the fathers at Interview One who sacrificed holding, comforting or carrying out practical care giving duties so that their partner could experience these opportunities reported being involved in care at Interview Two.

Mothers demonstrated their maternal role development in that many expressed their beliefs that they knew their baby better than anyone else even at Interview One. At Interview Two, maternal perception that they had a greater knowledge and understanding of their baby than any other individual was greater still. Mothers were more likely to believe their baby recognised them, were sure of their baby's personality and almost all described being involved in practical care giving activities even in the early days of the NICU experience.

Development of the parental role by Interview Two saw mothers and fathers recognising a change in their baby since birth, spending more time awake, recognising or responding to the parents. Parents therefore perceived their baby as needing them to be with him/her and responding to their needs.

In contrast, fathers at both time points described other individuals as knowing their baby better than themselves and fewer fathers in comparison to mothers felt that their baby recognised them at both time points. With fathers having fewer opportunities to hold their baby, being less involved in care giving duties at Interview One and being unable to identify anything that only they could do for their baby, attachment and parental role development for fathers was less obvious.

Wright and Belanger (2000) found that men begin their attachment process later than women and Sullivan (1999) found that fathers lacked physical contact with their infant in the NICU and despite the passage of time it appears that fathers still experience fewer opportunities to touch, hold, comfort and carry out the practical care giving activities which are linked with developing parental roles and attachment. However, Lindberg, Axelsson and Öhrling (2008) small study of 8 fathers in the NICU found that paternal feelings and attachment increased over time as they became more confident as a father and these fathers believed they had a stronger bond with their child compared with friends who had babies born at term.

Pohlman (2005) interviewed fathers 6 to 8 times over a 6-month period, beginning within 1 month of the birth of their infant and continuing after discharge from the NICU. Fathers revealed the primacy of work in their lives; work remained a pivotal focus even after an early birth. Fathers returned to work quickly after their infant's birth. They approached their work with a renewed sense of fervor in order to provide financially for their families. They found comfort in their work because in the work setting they felt that they were the experts, as opposed to feeling like novices in the NICU. The most stressful aspect of the experience was juggling their time between work and the outside world. In contrast to these findings, the fathers in the present study described wanting to spend more time with their baby in the NICU than their work commitments would allow. Financial responsibilities and work demands were the concerns of fathers in order to provide for his partner and family, but fathers described returning to work when they perceived they had no choice but to do so. With the passage of time at Interview Two, fathers raised their concerns about having to return to work which for some fathers involved long distances from the hospital. Work distanced fathers from their baby and they relied on information given over the telephone or from their partner which created frustrations and reiterates the importance of giving fathers complete and in depth updates particularly when they are unable to visit.

Parental views about being alone with their infant showed a parental dependence on the NICU staff but also recognition of the importance of being alone with the infant to empower parents to make decisions for their infant. Parent's comments suggested that becoming a family needs time on their own together where they can act, talk, sing and interact with the baby without feeling self conscious or being inhibited by others around them. Heermann, Wilson and Wilhelm (2005) and Jackson, Ternestedt and Scollin (2003) also found that mothers wanted privacy with their baby.

Time with their baby out of the clinical setting of the NICU in a private area is clearly only appropriate for those babies in a very stable condition nearing discharge home. However, NICU staff should recognise the importance of encouraging parents to take advantage of those facilities, of spending time alone with their baby and family and empowering parents to make their own decisions of how, when and where to respond to their baby's needs.

Support for parents

The role of support for parents in their experience of becoming a mother or father and having a sick or premature infant in the NICU was divided into a) the support parents received from their partner, family, friends and other parents and b) the professional support parents received for doctors and nurses in the NICU.

Both mothers and fathers regarded their partner as their primary source of support throughout the NICU experience and felt that they were able to help and support their partner and their partner was able to help and support them. Again, there were significant differences between mothers and fathers to be noted and for NICU staff to be aware of.

More fathers than mothers felt that they were able to support their partner, particularly at Interview Two and it was only fathers who described practical support and at both time points that they could provide in terms of looking after other children and the home. Moreover, fathers were less likely than mothers to feel that their partner was unable to help them in their NICU experience. For those few fathers who reported their partner as unable to help, the reasons given were different than those mothers gave in that fathers admitted to hiding their feelings or felt that they did not need help. Mothers however, described their partner as unable to understand, responding inappropriately, having different feelings or being unable to support her because of work commitments.

At Interview One, fathers were much more likely to hide their feelings from their partner in order to protect her and in attempt to avoid upsetting or worrying the mother by divulging his anxieties and concerns. Mothers were aware that their partner was hiding his feelings from her and therefore some mothers were unsure of their ability to support the father of their baby.

Family support was also important for parents and although some parents reported family as demanding, lacking in understanding, responding inappropriately, having no need of family support or parents did not want to burden them, on the whole parents welcomed the support they received from family members. Again, there were differences of views between mothers and fathers with mothers more likely to describe and value the emotional support they received from family members whereas fathers were much more likely to describe and value family for their practical support at both time points. This suggests that whilst the mother is in hospital immediately after the birth and then still focusing on her sick infant in hospital later in the NICU experience, fathers assume the roles of care giver for other children, in maintaining the home, caring for pets etc therefore support they receive to help them was of greater value to the father than the mother during this experience. These findings are similar to those of Sloan, Rowe and Jones (2008) who studied stress and coping in fathers of relatively well preterm infants and found that partners and families were the most frequently identified sources of emotional support, family and friends the sources of social support and families the source of practical support.

In this study, support from friends was not greatly valued particularly by mothers with a common belief that friends did not and could not understand their situation. Indeed mothers avoided telling friends that they had given birth to their baby or they actively chose not to speak to friends feeling that to do so would be too emotionally exhausting.

Parental views about support from other parents in the NICU were mixed. Both mothers and fathers described the worth in terms of sharing or having something in common with other parents as they experienced similar problems or progress. Parents also felt that talking with other parents was useful as they described making downward comparisons with others less fortunate than themselves and being able to help and support other parents as helpful and meaningful to them. Mok and Leung (2006) also reported that mothers of premature infants in a Hong Kong NICU benefited a great deal by speaking to other parents because they received validation and empathy for their thoughts and feelings from these other parents, as well as insight on how to handle the stress encountered during the hospitalization of their preterm infant.

However, fathers differed from mothers in that there were some mothers who found that talking to other parents unhelpful. Where others were less fortunate than they were, mothers felt guilty about their own baby's progress, unsure of what to say and described a sense of competitiveness that was awkward.

Tran, Medhurst and O'Connell (2009) used questionnaires in an Australian study to explore the support needs of parents with infants in the NICU. The findings of this study revealed that parents' perception of the level of nursing support was very positive. Blanch D'Souza, Karkada, Lewis, Mayya and Guddattu's (2009) study of stress, coping and nursing support in Indian NICU's also found that mothers reported high satisfaction from the support they received from the baby's primary nurse. They found that providing information may reduce parental stress and encourage parental involvement. Nurses, therefore, have a key role to play in supporting the educational and informational needs of parents. Furthermore, Cox and Bialoskurski (2001) study of factors that facilitate and hinder family and mother attachment in the NICU found that a lack of communication and information from the nurse was viewed as a hindering factor in facilitating a feeling of attachment. Mok and Leung (2006) explored the supportive behaviour of nurses as experienced by mothers of premature infants in Hong Kong. There was a significant mean difference between perceived and received nursing support demonstrating that parents desired more nursing support than they received, particularly in the area of supportive communication and the giving of information. All six mothers in this study reported that communication and information support, emotional support, affirmation and encouragement from the nurses, involvement in the care of the infant and the quality of the care given to the infant were the most important types of support they received from the nurses.

In the present study communication and its relation to encouraging the attachment process in the NICU was greatly valued by parents. The nurses in this NICU were regarded as exceptional at the giving of information and in answering their questions; however trivial parents thought their questions to be. Nurses were also described as excellent at explaining what was happening with their baby, their treatments, the equipment used and reasons. The nurses were considered approachable and giving of their time and attention even when they appeared to be doing something when parents first entered the room to visit their baby.

Parents appreciated personal knowledge of their baby that the nurses held about him or her and when nurses were able to report information to parents without having to consult charts or other forms of documentation parents felt reassured and saw nurses as having a true understanding and in depth knowledge of their baby as an individual. Furthermore, both mothers and fathers participating in Interview One frequently described nurses as encouraging and persuasive in involving them in caring for their baby showing that these nurses recognised the importance of parental involvement in infant care despite the reluctance of worried or fearful parents. By Interview Two mothers and fathers were less likely to describe nurses as encouraging and persuasive, however, this may be due to the increasing confidence of parents gained over time and through their growing involvement with their baby. Or it is possible that as parent confidence grew they could be more critical.

The parents participating in Tran, Medhurst and O'Connell (2009) study stated that they required more emotional support in the form of empathy and understanding from nurses than they received. In contrast, the present findings were that nurses were not expected to be a source of emotional support. However, there were parents who described nurses as offering emotional support and taking time to talk to parents about how they were feeling even if parents did not want to share their feelings with nurses. Mok and Leung (2006) also found that emotional support was rated less important as well as having been less often received than other forms of support.

There were a number of parents who said how helpful they had found the interviews in that they were able to think and talk about their feelings at length, in confidence and without consequence. This, along with the mixed feelings about where parents received their support from, their ability to support their partner and who they felt able to talk to supports the recommendation of a counselling service available for parents in the NICU.

Despite the overall views that nurses in the NICU were supportive and communication with them was regarded highly, parents also perceived nursing staff as busy, often with other babies. There was awareness that parents were sharing the nurse's time with others and parents described times when they felt that they were pestering or bothering busy staff. Others felt that they were in the way, particularly when the nurses were busy with the baby or procedures were being performed. Wigert, Johansson, Berg and Hellstrom (2006) found that mothers expressed a feeling of not being welcome, of intruding, feeling superfluous and having nothing to do. In comparison, the present study found that although there were a small number of parents participating in Interview Two who reported feeling unwelcome, most parents felt that they were welcomed into the NICU. This supports the findings of Reid, Bramwell, Booth and Weindling's (2007) development of a rating scale to assess the quality of communication between staff and parents in the NICU. These authors reported feeling welcomed into the NICU was positively perceived by parents. Parents in the present study also reported feeling valued, included in care giving duties and in general chatting or conversations sometimes unrelated to the baby which parents enjoyed participating in with staff.

Parents also described their ability to take control and do things for their baby dependent on which individual nurse was caring for their baby on any given day. Whilst most nurses encouraged and empowered parents to be involved, take control, make decisions and deliver care giving duties, there were some individuals who were less supportive. Higman and Shaw (2008) interviewed seven neonatal nurses and found that nurses were aware of the needs for families to be involved in all aspects of their baby's care but also highlighted a lack of formal training. Nurses in this study relied on experience to facilitate the delivery of family centred care which may go some way to explaining why the present findings highlighted differences in the practices of the neonatal nurses.

Parents often reported feeling that they should ask permission from NICU staff to touch or hold their baby or that the baby belonged to the NICU or NICU staff. However, some parents did not always view this negatively and felt that it was appropriate to check with the nurse prior to interacting with their baby, particularly when they first arrived on the NICU.

Parents at Interview Two found that as their baby progressed and was no longer dependent on the intensive care services, they were moved to high dependency rooms and then the nursery. Whilst these moves were a positive step in terms of their baby's progress, parents could find it difficult to adjust to an environment with fewer staff and less nursing and medical intervention and attention. Hall and Binchmann (2009) found that despite the intensive care rooms being filled with technological devices, equipment, monitors and alarms, the mothers they interviewed perceived this room as quiet and caring. Progress and movement to the next room brought with it more noise, busier nurses and lots of movement of babies in, out and around the room. These factors gave mothers a sense that they had no personal space and the feeling of not belonging that they did have in the intensive care room.

Similar to the findings of Reid (2000), having to meet and establish new relationships with the staff working in different areas within the NICU was also a testing time for some parents. Care was sometimes delivered by a different nurse each shift and there were criticisms that in these situations there was a lack of continuity of care, nurses were unable to have indepth knowledge of their baby, a plan of care was changed or routines were altered. Echoed by the findings of Fenwick, Barclay and Schmied (2001) for a parent who had perhaps arranged the timing of his/her visit to the NICU to fit in with their baby's routine, it was extremely frustrating to arrive and find a feed and nappy change already completed by the nurse or no longer due at that time.

Aagaard and Hall's (2008) meta-synthesis of mothers experiences of having a preterm infant in the NICU found that established relationships with constant caregivers make it less intimidating for parents to ask questions and that continuity of care affects a mothers perception of her baby's safety and her own emotional safety.

It is recognised that continuity of nursing care is difficult to achieve, particularly in a large NICU where there are very large numbers of staff and where there is movement of the babies through different areas of the NICU as they progress. However, an increased awareness of the impact of many different caregivers on parents should be recognised by staff in the NICU and an improved continuity of care, greater communication with parents about planning of care and efforts not to change routines without reason are recommended.

The support from doctors was viewed very differently by parents from that received from the NICU nursing staff. Whilst nursing staff were constant, always present and seen as a source of everyday information, guidance and support, doctors were seen less frequently, discussions were sometimes ad hoc by the bedside but often more formal by appointment or arrangement away from the clinical area. Parents sometimes described doctors knowing their baby in a clinical sense, holding information about diagnosis, tests, investigations and results. Doctors were less likely than nurses to know their baby as an individual with personality or with the same depth of knowledge as the nurses. Similarly, MacDonald (2007) found that parents perceived the role of the neonatologist as that of decision maker based on information given to them by the nursing staff.

Communication with doctors was positively regarded by many parents with more positive comments about parental ability to talk to the doctors than negative. Positive perceptions of doctors were that they were approachable and were valued for their information giving and explanations. However, unlike the nurses, doctors were not described as involving, encouraging or as supportive. There were also some criticisms about the language that some doctors used, particularly during the consultant ward round leaving parents confused about what they had been told or heard. Other parents described wanting the opportunity to be talk with the doctors more often and a regular formal update out of the clinical area was a suggestion made to discuss the baby's condition and plan of care.

Some parents reported that they had never spoken with a doctor and whilst some viewed this as a reflection of their baby progressing uneventfully and there being no need, parents should expect information and discussion with doctors involved in their baby's care throughout their NICU stay .The Department of Health's document (Toolkit for High Quality Neonatal Services, 2009) advises that parents should have the opportunity to discuss their baby's diagnoses and care with a senior clinician within 24 hours of being admitted to the NICU or a significant change in condition. There were a small number of parents who positively described being informed of the plan of care for their baby however parents did not perceive themselves as being involved or consulted in the process of planning care with NICU staff. Yet, the role of becoming a parent involves the parent making decisions and exercising their control over what they believe is best for their baby and how they would like things done for the baby. They may listen to advice from those close to them but then make their own decisions about how to care for their baby.

With the passage of time, parents at Interview Two were asked about their ability to influence what happened to their baby in the NICU. A small number of mothers but only one father viewed their ability to influence what happened to their baby in the NICU in a positive way. These were mothers of babies who were progressing very well and were nearing discharge home. The involvement in decision making that these mothers described related to fairly minor but not insignificant decisions such as feeding regimes made with the nursing staff. However, these mothers felt able to contribute to the plan of care made with neonatal staff for the baby and they described how they had expressed their opinions when they felt a certain plan of care was not appropriate for their baby and how they had worked as a team with neonatal staff with the baby's best interest at heart.

There were more parents who reported that they felt unable to say anything to the NICU staff, some with concerns about how that may affect care whilst others, particularly fathers complained about not being involved in decision making and of feeling powerless. Being able to influence what happened to their baby was often associated with concerns about inconsistencies in levels of care. Parents felt that the attention the baby received whilst they were with their baby was superior, staff were more thorough and care was of a greater standard than when the baby was alone in the NICU.

Parents should not only feel able to influence what happens to their baby and be involved in the planning of care without the above discussed concerns, it is recommended that they should actively be encouraged to do so. This is supported by The National Institute for Health and Clinical Excellence (NICE) who published Specialist Neonatal Care Quality Standards in 2010. These standards laid down the involvement and encouragement parents should expect in their baby's care in the NICU and directs NICU's to communicate regularly with parents of babies and ensure parents are encouraged and supported in being actively involved in planning, joint decision-making and providing care for their baby.

4.3 Practical implications for organisation of the NICU.

In the section above discussing parental adaptation and parental role development there have been practical implications highlighted and recommendations made for nursing and medical staff in the NICU. In addition to these, there were some practical suggestions that parents made that would enhance their experience and make their time in the NICU easier. These recommendations made by parents often related to the facilities made available to them and are relevant to this particular hospital and NICU and will obviously be different in other NICU's. However, there may be lessons to be learned for staff in other NICU's despite these suggestions being associated with one particular NICU.

The facilities for parents to use in this NICU included an open seated area at the entrance to the NICU where visitors could wait and meet parents and there was a sitting room with chairs and a television for parents and their children to use. There were two parent bedrooms with bathrooms for families to use when it was appropriate for their baby to come out of the clinical area and spend time alone with their parents and an equipped kitchen. There were also facilities for mothers to express and store their breast milk. Elsewhere in the hospital, there was a shop selling confectionary, drinks, sandwiches, newspapers etc, a separate sandwich shop and the hospital canteen which were all day time opening only.

Parents felt that there was a lack of facilities for fathers. Even following the admission of a particularly sick or premature infant, local fathers were expected to go home at night but as a NICU accepting infants requiring intensive care from out of the local area, there were some fathers who did not have that option. These fathers were given a reclining chair for use at night next to the mothers' bed on the maternity ward. In comparison to inpatient mothers, fathers felt that they had no space of their own to withdraw to, they felt that they were intruding on the maternity ward and there were restrictions such as not being able to use the toilets there which made them feel as though it was improper for them to be there.

Separate accommodation for parents was a suggestion made by fathers who were travelling considerable distances every day to see their partner and baby and also by mothers who found being in a maternity ward surrounded by well babies inappropriate or distressing. There were comparisons made to children's services where parents often have their own on-site accommodation to enable both mothers and fathers to stay close to their baby. The mothers participating in Wigert, Johannsson, Berg and Hellstrom (2006) Swedish study of maternal experiences in the NICU reported that they found meeting mothers who had their newborn baby with them on the maternity ward emotionally difficult. But nor did mothers feel comfortable in the NICU because there was no bed or place for mothers to go to if their baby was sleeping or they felt they had nothing to do.

Whilst most mothers accepted that they could not stay on the maternity ward for longer than their own obstetric needs dictated or demand for their bed allowed, there were some mothers who were reluctant to leave the hospital and their baby. Going home for mothers raised new problems of getting to and from the hospital particularly if it involved long distances or the mother was unable to drive following caesarean section. Maternity wards can be very busy with a demand for fast turnover of mothers through them and it is not always appropriate for the mother of a baby in the NICU to be staying there. However pressure to leave can add to an already stressful situation and for those planning a move or designing a new NICU, adequate parent accommodation should be given sufficient consideration to meet the needs of these parents.

Beck, Weis, Greisen, Andersen and Zoffmann (2009) evaluated changing the physical layout of a Danish NICU to provide smaller rooms with a parent bed next to the infant. Parents reported an increased feeling of being a mother and father and of feeling closer to their baby but staff expressed concerns that parents were unable to relax and were constantly disturbed by activity in the room. Clearly, the ideal place for mothers and fathers to stay and go to when they need to relax is dependent on many factors and parental needs and what may suit one parent may not suit another. Later in the experience, wherever possible both parents tended to have gone home, and these parents described a general lack of facilities for parents in the NICU. Parents suggested an area for them to get away from the clinical rooms to be alone for a period of time or be with their other children. Parents also suggested that they would appreciate somewhere in the NICU where they could make a hot drink or buy food, snacks and hot or cold drinks from a vending machine without having to leave the NICU. Parents should expect to be introduced to facilities, routines, staff and equipment on admission to the NICU (Department of Health, 2009) but parents in the present study were not always informed of the facilities in the NICU that would have made their experience easier. Whilst this NICU did not have any vending machines for parents or visitors, there was a kitchen with tea/coffee making facilities, a microwave to heat meals and a room for parents to sit and relax in. In order for parents to utilise the facilities available to them, NICU staff need to ensure that parents are aware of them.

There were parents who were aware of the parent sitting room but still felt that the NICU failed to provide them with somewhere to relax. There were criticisms that the furniture in the room were not conducive to relaxing, it could be busy and noisy with other people and one mother reported she could not go there to relax because amongst other leaflets she had seen in there were leaflets about post-mortem which she found inappropriate. There were some parents who wanted privacy, whilst others would have liked somewhere to chat with other parents, demonstrating that it is difficult to meet the needs of every individual parent. However, a room with comfortable furniture, seating and facilities to make a hot drink would be recommended as a good foundation for parent facilities. Whilst there are many parent information leaflets that are appropriate for general distribution, leaflets providing specific or sensitive information, such as post mortem, should only be given to those parents who have a need for that information and at a time when it is appropriate to do so.

Like Wigert, Johannsson, Berg and Hellstrom (2006), some parents described their need for some privacy and time alone with their baby and for some parents there was a perception of inadequate space (particularly when the NICU was very busy) between each incubator or cot space intensifying their concerns about a lack of privacy in the NICU. Hall and Binchmann (2009) also supports these findings with mothers in their study finding it increasingly difficult to establish a personal space or privacy and Beck, Weis, Greisen, Andersen and Zoffmann (2009) reported that the introduction of smaller rooms positively supported family centred care, there was space for privacy, the atmosphere felt more intimate and staff became more sensitive to the needs of parents.

In a small Danish study of 5 mothers by Hall and Binchmann (2009), the provision and use of a relative room was welcomed and reported as a place where mothers felt good, it was a place of her own where she could be herself and get to know her baby. The present findings are that many parents had not yet had the opportunity to take their baby into a parent bedroom for some time alone and they believed that to have that level of privacy would make their experience easier to bear. This opportunity is only appropriate for clinically stable babies who are nearing discharge home, so there may be a long waiting period for those parents of babies born very preterm or sick where they are unable to be completely alone. NICU staff should be aware of these parental feelings and wherever possible the perception of being alone and spending time in privacy with their baby can be respected. Minimising interruptions, careful positioning of the baby within the room away from busy areas such as sinks and providing screens around the family when the baby is out for skin to skin contact with the parents are recommended.

Finally there were small numbers of parents who described their need for access to written information or a resource centre and small numbers of mothers who were dissatisfied with the facilities or support for expressing/breast feeding mothers.

Parent accommodation for all fathers and for mothers when a bed on the maternity ward is no longer appropriate would enable both parents to stay close to their baby, have the necessary facilities for them to sleep, rest, eat and drink and to meet their hygiene needs. Provision of this level of facilities would clearly be a considerable undertaking for any NICU which does not already have these services however, this is the level of amenities that are provided for parents in children's hospitals and something that NICU's should aspire to.

Although it is not generally possible to change the geography of a NICU, there are changes or improvements that NICU staff can make to enhance the experience parents have. Relatively easy changes to promote parent comfort, relaxation, privacy and actual or perceived time alone with their baby are measures that all NICU's can assess and where necessary make changes. More importantly, NICU staff need to implement a system to check that parents have been made aware of the facilities available to them. Whilst it may not be immediately appropriate to show parents where they can make themselves a drink when parents visit their baby for the first time in the NICU, efforts should be made to ensure that on subsequent visits this information is given to parents. Written information for parents could include details of NICU facilities to reinforce any verbal information given at the bedside.

4.4 Summary

In reflecting on the qualitative method used, the use of semi structured interviews is believed to have accurately explored and described the experiences of parents in the NICU. The interviews were time consuming and sometimes difficult to arrange because of the demands on parental time, but in comparison to other means of collecting data, is still judged as the most appropriate method of exploring the experiences of individual parents in such depth.

With the emergence of such differences between the maternal and paternal experience, it may have been helpful to have interviewed a greater number of fathers at Interview Two. However, it is said with confidence that the ethical issues involved in recruiting participants into a study which involved exploring feelings and views of a traumatic or stressful event were robustly addressed. Therefore, the demands on the time of fathers as most returned to work and had limited time to be with their baby in the NICU, resulted in these fewer interviews with fathers at Interview Two time point. The transcribing of sometimes extremely lengthy interviews was very time consuming, as was the process of coding each interview on WINMAX Pro, however both processes was helpful in becoming familiar with each interview. That said, despite the large numbers of interviews in this study, it was always easy to remember each individual interview quite clearly. WINMAX Pro was also found to be enormously useful in the organising of the vast quantity of data that the interviews produced and examples of text could be exported to give the reader an insight into parental responses when presenting the results.

The research questions have been addressed and recommendations for practice made throughout the discussion but are summarised briefly for the reader below.

a) Do mothers and fathers have similar experiences as parents of infants on a NICU?

This study has shown that the experiences from prior to the birth, through the early NICU experience and with the passage of time are indeed very different for mothers and fathers. Adaptation for fathers appears to focus on feeling lucky in comparison to others less fortunate and by identifying benefits to their situation for themselves, their infant and his/her mother. With respect to apportioning blame, self blame was almost entirely only described by mothers in their attempts to regain control over the event. Development of the parental role was less obvious in fathers than mothers. Fathers were less likely to undertake care giving roles or to touch, hold and comfort their baby either because they were more reluctant to do so or because they believed it was more important for the mother to do so, particularly earlier in the experience when there were fewer opportunities. However, paternal involvement in care giving activities and holding his baby was associated with increasing feelings of attachment and protectiveness. It is therefore recommended that fathers need opportunities and encouragement to be as involved as mothers in care giving activities.

Whilst hospitalised mothers were able to focus on their sick infant, fathers had other concerns such as practical issues, maintaining the home, care of other children and work or financial worries. Particularly at Interview One, fathers were the interface between the mother and the outside world, protecting her from questions or difficult conversations with friends or family members.

b) What stressors do they perceive?

There were many aspects of the NICU experience that parents described as stressful and included the labour and delivery experience, the sights and sounds of the NICU and the appearance of their sick infant. Events in the NICU such as procedures being performed, hearing bad news and seeing other infants becoming acutely unwell or dying were also described by mothers and fathers as distressing.

Practical issues of maintaining the home, care of siblings, travelling and work stressors were mainly described initially by fathers. But with the passage of time, mothers were discharged home from hospital and the practical difficulties of visiting their infant also became a stressor for mothers.

Communication with staff was generally viewed favourably; however, these findings highlight the need for greater discussion opportunities with Doctors. Fathers particularly described their need to be given factual information about their baby's condition and treatment and expressed their frustrations in the later interview at being unable to contribute and influence decision making. It is therefore recommended that parents should be spoken to by a senior member of the neonatal team within 24 hours of admission and at regular intervals depending on individual need and changes in clinical condition of the baby. It is also recommended that parents are considered and involved in the decision making processes affecting their baby in the NICU. In the process of information, it should not be assumed that one parent will share what they have been told with the other. Fathers described trying to protect the mother of their baby from information or facts they may find worrying or distressing. It is therefore recommended that where possible parents are given information together or that it is repeated to both parents.

Support between the mother and father was mostly positive and of the greatest value to parents. Family members were often a valuable source of emotional and practical support however, mothers, particularly in the early NICU experience avoided conversations with friends as they were too exhausting and difficult for them to consider at that time.

It is recommended that NICU staff should encourage opportunities for parents to talk and support other parents. However, they should also be aware that not all parents will choose to do so.

Recommendations have been made to improve the experience for parents in providing basic provisions for somewhere to relax, store, prepare and consume meals and spend time alone with their baby and family when appropriate. These were highlighted by parents as details and ideas that what make their time in the NICU easier and less stressful.

c) What is the process of adaptation to having a premature or sick infant in the NICU?

The process of adaptation for mothers and fathers has been shown to be very different for fathers in comparison to that of mothers. Blaming oneself for a traumatic event has been associated with successful adaptation as the victim establishes a sense of control over the situation they find themselves in. Whilst the mother of an infant requiring NICU care described feelings of self blame, guilt, searching for a reason and making upward and downward comparisons with others, these were not responses replicated by fathers. Fathers did not apportion blame to themselves, any other person or event. However, fathers appear to adapt and adjust to their situation successfully with an ability to describe many benefits to having an infant cared for in the NICU. Fathers described a changed outlook in life, an newfound appreciation of what was important in their life and frequently highlighted health benefits for the mother (e.g time to recover from the birth experience), for the baby and for the couple as parents as they learned baby care giving skills in the NICU.

Like fathers, many mothers also described benefits to their NICU experience and both parents considered themselves lucky to be in their situation and made comparisons to others less fortunate than themselves.

d) Do parental views and feelings about their experience change over time?

For both mothers and fathers the events around the time of the birth of their baby became less significant by Interview Two time point and the focus of their experience was directed towards progress made and ultimately discharge home.

Those feelings of self blame and guilt expressed by mothers were no longer apparent at Interview Two and both parents continued to describe themselves as lucky to be in the situation they were in and described benefits.

Over time there were clear signs that there was a development of the parental role for both mothers and particularly fathers as they became more involved in care giving duties and had increasing opportunities to hold and comfort their baby. Unlike mothers, there were a number of fathers at Interview One who had not yet held their baby, whereas all fathers had by Interview Two. Parents described increasing feelings of being needed by their infant as love and attachment were expressed. Like mothers, fathers believed that the mother of their infant knew their baby best but both parents felt that their infant was able to recognise or respond to them and they were able to describe the personality of their baby with confidence at Interview Two.

In contrast to Interview One, at Interview Two, fathers were frustrated by their inability to influence care in a positive way. Some described feeling reluctant to voice their views and concerns, in fear of any negative impact that may have on the care of their infant. Other fathers described feeling powerless or felt that the care that their infant received was dependent on their presence or parental pressure they exerted.

Parental responses to questions relating to support from their partner, family, friends, other parents and NICU staff also showed changes over time.

The findings of the study have implications for those teaching health care professionals, particularly nurses and doctors who are involved in the care of the sick neonate and their family. These have been raised throughout the discussion and other recommendations for practice have been made.

4.5 Strengths and Limitations

Qualitative research can be criticised for depending on small numbers of participants however, a strength of this study are the large numbers of mothers and fathers who participated. Interviewing parents at two different time points is also a strength of the study in that new or changed views and feelings were revealed and explored. How adaptation to being a parent in the NICU and developing the parental role saw changes over time and these were captured by interviewing early in the NICU experience (7 to 10 days after birth) and then later in their NICU experience(from 28 days).

The interviews were conducted by one interviewer thus removing any variances possible if multiple interviewers were involved. As the sole interviewer, I am an experienced neonatal nurse, with experience of interacting with parents of sick infants, had an in depth understanding of the NICU, the illnesses or disease processes experienced by infants requiring neonatal intensive care and the vocabulary used. However, I did not give any direct nursing care to infants or families in the NICU or wear a uniform during the study, and the research took place in a NICU not previously known to me. Parents did not view me as part of the clinical team so were confident that their responses would remain confidential. That said, participating parents knowing I was a neonatal nurse may not have wanted to appear critical of nurses.

Recruitment was from a single site; therefore generalisation of the findings may be restricted although many of the findings of the present study are supported by other authors.

Fathers, who remain under represented in parental experiences in the NICU are included in the present study to compare the experiences of mothers and fathers. However, as in other studies, fathers of sick, preterm infants were more difficult to recruit than mothers. Fathers were enthusiastic about participating but arranging a time to conduct the interview was often practically difficult to organise, particularly at the second interview time point. Fathers had commitments of the home, other children and with the passage of time, most fathers had to return to work so their time with their baby in the NICU was precious and often limited to evenings by the second interview time point. Hence, there are fewer fathers than mothers participating.

The use of semi structured interviews are sometimes criticised as potentially prescriptive and leading but the advantage of using a semi structured interview approach was that although questions were predetermined, they also allowed participants and researcher to pursue areas in more detail or be directed by the participant. Parents in the present study were encouraged to talk freely and openly with a conversation about one aspect of the NICU experience often leading to another. The interview schedule was sometimes only required to start the interview and then checked at the end to ensure that all questions were covered. Furthermore results were very similar to those obtained from other research using different techniques such as grounded theory, which suggests that parental responses were not constrained by the interview structure.

4.6 Recommendations for Future Research

These findings have highlighted the many differences between the NICU experience for a mother and for that of a father. Adaptation to the NICU experience and paternal role development was found to be unlike that of maternal adaptation and role development. Furthermore, the support needs, communication needs and stressors for fathers appear to be quite different from that of mothers. It is therefore recommended that there is a need for future exploratory study of fathers in the NICU in order to explore their experiences further and then to meet their specific needs.

A longitudinal follow up of parents and infants post discharge, as well as plotting the course of becoming a parent, would also enable parents to reflect back on their NICU experiences and possibly provide a more critical evaluation.

In the present study there was relatively little concern expressed about possible future developmental problems. This was in spite of some parents having been informed by neonatologists that the infant had scans showing bleeds in the brain and that outcome could not be predicted. Parents appeared to be focused solely on taking the baby home. Follow up into later months and years when a diagnosis of disability had or had not been made would also help to inform communication with parents in the NICU.

It would also be informative to use psychological assessments of such individual characteristics as coping skills, self efficacy and self esteem in order to determine whether the small number of mothers who felt unlucky, saw no benefits, did not make downward comparisons, felt powerless in the NICU had particular characteristics that influenced their 'becoming a mother' of a premature baby. If this were found to be the case then interventions aimed at increasing coping skills for example, and following up post discharge would be indicated.

As described in the results, during the course of the study there were different parental views about being present and hearing what was said on the Consultant ward round. This led to a study to discover parental preferences about visiting during ward rounds in the NICU. Using a short structured interview, Bramwell and Weindling (2004) found that sixty three parents interviewed had visited their baby during a ward round and 13 had specifically chosen to visit at that time to be present and hear what was said. About half had overheard conversations about other babies or thought discussions about their baby had been overheard. Parents were found to have little information about the ward round and held varied views. They described concerns about communication, practicalities, and issues of ethics and principle. Whilst many parents expected some sharing of information between families on the unit confidentiality was a matter of concern for others. Bramwell and Weindling (2004) concluded that NICU's should consider the information they provide for parents about ward rounds, the possibility that consultations may be overheard and the opportunities for parents to communicate with the clinical team.

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Appendices

Appendix 1. Parent Information Sheet

PARENT INFORMATION SHEET

Parental Experiences of Neonatal Intensive Care

Investigators (names removed)

What is the study about?

We wish to investigate the experience of being a parent in NICU in order to provide more appropriate support whilst parents are in our care. Whilst we appreciate some of your needs and try to help in any way we can, we recognise that we don't understand enough about what is happening to you during this time. We wish to know more about what you are experiencing, and what you think about the support we currently provide so that future parents may benefit from your experiences.

What will taking part in the study involve?

The study consists of 2 questionnaires and 2 interviews, and we welcome the views of both fathers and mothers. Completing the questionnaire should not take more than 15 – 20 minutes. A further two brief checklists are included in the study when completing the first questionnaire only.

Some of you may initially agree to participate but feel reluctant to commit yourself to any follow up. This is entirely acceptable; completing the first questionnaire does not commit you to participating in interview or further questionnaires. The reasons for follow up by interview and further questionnaires are twofold. Firstly, many issues that are relevant to your experiences do not fit neatly into a questionnaire format. Secondly, you may find that your views or your feelings change over time.

Are there any benefits to me taking part in this study?

From previous experience of talking to parents during this stressful time, we have found that many parents benefit from talking to someone outside the general nursing and medical relationships that you will develop. This opportunity to tell us about your feelings or your experiences will hopefully benefit future parents, but may also help you to express your own difficulties.

Are there any risks to me taking part in this study?

The research team is not directly involved with the clinical care you or your baby will receive. Your responses will not be discussed with clinical staff. No risks to you or your family are anticipated.

Do you have to take part in this study?

If you agree to participate in this study you will be asked to sign a consent form when the questionnaire is given to you. This should occur between the second and fourth day following admission. Please do not feel obliged to participate. Your baby's care will not be influenced in any way by the decision to either decline or agree. You will be asked to consider having an interview about 10 days following admission. If you agree it will be conducted at an agreed time in a private room on the neonatal unit. You may withdraw from the study at any time without fear that your care or your infant's care will be influenced.

What else will be involved with this study?

This study will be followed up after your baby has been discharged home. Any further investigation will take the form of postal questionnaire concerning how you are getting on. This will take place about 1 month after discharge and again when your baby is about 10 months old.

This does not commit you in any way, you can still choose not to continue with the project at any time.

If you have any further questions about this project, please do not hesitate to contact any of the research team

Appendix 2. Consent form.
The identity and location of the ethics committee has been removed.

CONSENT FORM

Parental Experiences of Neonatal Intensive Care

I have read the information sheet concerning the above project, and I understand that further information will be provided if I request it.

The project has been explained to me by:

____

I also understand that I may withdraw at any time and that ongoing participation is entirely voluntary.

I hereby consent to participate.
Please PRINT name and relationship to infant:

____

Address:

____

____

Signature: ______________________________________

Infant's name and medical record number:

____

Signature of Investigator:

____

Date: ____________________________________

You will be contacted after discharge to invite you to participate in follow up. This will take the form of postal questionnaires at 1 month after your baby's discharge and when your baby is about 10 months old.
Please tick the box if you DO NOT wish to be contacted after your baby has gone home.

Mother ....☐ Father...........☐..

Appendix 3. Interview One Schedule

Interview 1

Pregnancy and birth

1. Did you have any worries about the baby during the pregnancy?
2. Did you expect any problems once the baby was born?
3. Were you prepared for the baby's arrival?

   Did you have a chance to talk to a paediatrician prior to the birth?

   Was NICU admission discussed in parent education?

   Did you have an opportunity to visit the NICU prior to the birth?

   Do you know anyone else who had experience of the NICU?

4. Were you able to talk about things with your partner before the birth?
5. How would you describe the labour and delivery?
6. How do you feel about the situation that you were in?

   (Do you feel anyone or anything responsible for your situation?)

7. Have you ever asked yourself "why did this happen to us?"

Feelings about the baby

1. Can you describe your feelings when you first saw your baby?
2. What about when you first saw your baby on the NICU?
3. What did your baby look like?

   (As you expected? Shocked?

How did you feel about the environment/equipment?)

4. What was it like to hold your baby for the first time?

5. And since then, are things the same?

Your feelings and experiences

1. What kind of words best describe your feelings at the moment?

2. Are you able to express them with/to anyone?

3. Can you tell me who you are able to talk to?

4. Does it help?

5. Have you been able to talk to other parents?

6. Does it help?

7. Do your friends understand your situation?

8. Do you feel supported by your family?

   In what ways?

9. Do you think that you are able to help/support your partner?

   In what ways?

10. Do you think that your partner is able to help/support you?

    In what ways?

11. Can you tell me the things that you are able to do for your baby?

12. Did you need help to learn these things?

13. Have you been able to talk to the nursing staff?

    Would you like to talk to them more/less/about right?

    Do you ever feel like you are bothering staff?

14. Does it help to talk to the nursing staff?

15. And what about the doctors?

16. Has anything that you have seen made you feel angry or distressed?

17. Are there things that you would like more or less help from staff with?

18. What would make this time in the NICU easier for you or your family?

19. Some parents see this whole experience as a complete nightmare and can see nothing good coming out of it. Others can describe benefits to what has happened. Do you see any benefits in your experience or is it a nightmare?

(Example, stronger relationships?)

20. Do you regard yourself personally, or as a family as being 'lucky' or 'unlucky' to be where you are right now?

21. Can you recall the strongest feelings you have had since your baby has been in the NICU?

22. Have you any thoughts about the future for your baby?

23. What about future pregnancies?

24. Would you like to be alone with your baby?

25. How do you think that this would make you feel?

26. Would you like to spend more or less time in the NICU?

27. What prevents this from happening?

28. Do you ever feel that you are in the way or do you feel welcome?

29. Are there things that only you and your partner can do?

30. What can you do to help your baby?

31. Who do you feel knows your baby the best?

32. Do you think that your baby recognises you?

33. What kind of personality has your baby got?

34. Are there any other issues that you feel are important that you would like to talk through?

Appendix 4. Interview 2 Schedule
Interview 2

Recall of earlier interview and any developments.

1. We talked about the events leading up to and including the delivery of your baby. Have you got any further thoughts or feelings you would like to share about the pregnancy or the birth?
2. Have your feelings changed between the first interview and now?
3. Can you tell me what has happened since we last talked?

About the baby

1. In the first interview we talked about how you felt when you first saw and held your baby. Have things changed since then?
2. What do you feel like when you come into the nursery to be with your baby?

Your feelings and experiences

1. What kind of words best describe your feelings at the moment?
2. Are you able to express them with/to anyone?
3. Can you tell me who you are able to talk to?
4. Does it help?
5. Have you been able to talk to other parents?
6. Does it help?
7. Do your friends understand your situation?
8. Do you feel supported by your family?

   In what ways?
9. Do you think that you are able to help/support your partner?

In what ways?

10. Do you think that your partner is able to help/support you?

In what ways?

11. Do you feel needed? By whom?

12. Can you tell me the things that you are able to do for your baby?

13. Did you need help to learn these things?

14. Have you been able to talk to the nursing staff?

Would you like to talk to them more/less/about right?

Do you ever feel like you are bothering staff?

15. Does it help to talk to the nursing staff?

16. And what about the doctors?

17. Has anything that you have seen made you feel angry or distressed?

18. Are there things that you would like more or perhaps less help from staff with?

19. What would make this time in the NICU easier for you or your family?

20. Some parents see this whole experience as a complete nightmare and can see nothing good coming out of it. Others can describe benefits to what has happened. Do you see any benefits in your experience or is it a nightmare?
(Example, stronger relationships?)

21. Do you regard yourself personally, or as a family as being 'lucky' or 'unlucky'to be where you are right now?

22. Can you recall the strongest feelings you have had since your baby has been in the NICU?

23. Have you any thoughts about the future for your baby?

24. What about future pregnancies?

26. Would you like to be alone with your baby?

27. How do you think that this would make you feel?

28. Would you like to spend more or less time in the NICU?

29. What prevents this from happening?

30. Do you ever feel that you are in the way or do you feel welcome?

31. What can you do to help your baby?

32. Do you believe that by being here, you are able to influence what is happening

    to your

    baby?

33. Are there things that only you and your partner can do?

34. Who do you feel knows your baby the best?

35. What kind of personality has your baby got?

36. Do you think that your baby recognises you?

37. Are there any other issues that you feel are important that you would like to talk through?

Appendix 5
Parent Interviews and their Characteristics

Parent Interview	Mother or Father (M/F)	Interview Time Point (1, 2 or TP 2)	Mother/ Father Dyad (a,b,c)	Birth Order	Boy or Girl Infant (B/G)	Infant gestation (weeks)	Birthweight (grams)	Delivery (ND, EM or ELCS)	Transfer (NO, AN or PN)	Congenital abnormality (Y/N)	Previous poor outcome (Y/N)	High risk pregnancy (Y/N)	Experience of ICU (Y/N)	Single Mother
1	M	TP 2		1	G	25	692	ND	AN	N	N	N	N	
2	F	1	a	1	B	37	2710	ND	AN	Y	N	Y	N	
3	M	1	a	1	B	37	2710	ND	AN	Y	N	Y	N	
4	M	TP 2	b	1	B	28	720	EMCS	AN	N	N	N	N	
5	M	1		1	G	33	1772	EMCS	NO	N	N	N	N	Yes
6	F	TP2	b	1	B	28	720	EMCS	AN	N	N	N	N	
7	F	1	c	1	B	41	3812	ND	NO	N	N	N	N	
8	M	TP 2	c	1	B	41	3812	ND	NO	N	N	N	N	
9	F	1	d	1	B	25	860	ND	AN	N	N	N	N	
10	M	1	d	1	B	25	860	ND	AN	N	N	N	N	
11	M	TP 2		1	G	26	780	EMCS	PN	N	N	Y	N	Yes
12	M	TP 2		1	B	26	832	ND	AN	N	N	Y	N	
13	M	2	d	1	B	25	860	ND	AN	N	N	N	N	
14	M	1		1	G+G	34	1630/1856	ND	NO	N	N	N	N	
15	M	TP 2		1	B	28	998	EMCS	NO	N	N	Y	N	
16	F	2	d	1	B	25	860	ND	AN	N	N	N	N	
17	M	1		1	G+G	34	1684/2020	ELCS	NO	N	N	N	N	
18	M	1		1	B+B	29	1000/1088	EMCS	AN	N	N	N	N	
19	M	1	e	1	G	24	560	ND	AN	N	N	N	N	
20	M	1	f	1	B	27	1105	ND	NO	N	Y	Y	N	
21	F	1	e	1	G	24	560	ND	AN	N	N	N	N	
22	F	1	f	1	B	27	1105	ND	NO	N	Y	Y	N	
23	M	1		4	B	28	1226	EMCS	AN	N	Y	Y	Y	

Parent Interview	Mother or Father (M/F)	Interview Time Point (1, 2 or TP 2)	Mother/ Father Dyad (a,b,c)	Birth Order	Boy or Girl Infant (B/G)	Infant gestation (weeks)	Birthweight (grams)	Delivery (ND, EM or ELCS)	Transfer (NO, AN or PN)	Congenital abnormality (Y/N)	Previous poor outcome (Y/N)	High risk pregnancy (Y/N)	Experience of ICU (Y/N)	Single Mother
24	M	1		1	B	24	815	EMCS	NO	N	N	N	N	
25	M	1		2	G	25	850	EMCS	PN	N	N	N	N	
26	M	TP 2	g	2	G	32	1468	ND	NO	N	N	N	N	
27	F	TP 2	g	2	G	32	2468	ND	NO	N	N	N	N	
28	F	2	f	1	B	27	1105	ND	NO	N	Y	Y	N	
30	M	1		1	G	31	1705	ND	NO	N	N	N	N	
31	F	1	h	1	B	26	945	ND	NO	N	N	N	N	
32	M	1	h	1	B	26	945	ND	NO	N	N	N	N	
33	M	2		4	B	28	1226	EMCS	AN	N	Y	Y	Y	
34	M	2		1	B+B	29	1000/1088	EMCS	AN	N	N	N	N	
35	M	2	f	1	B	27	1105	ND	NO	N	Y	Y	N	
36	M	1		1	G	38	4760	ELCS	NO	Y	N	N	N	
37	M	1		2	G	31	1885	EMCS	NO	N	N	N	N	
38	M	1	i	1	B	29	1535	EMCS	AN	N	N	N	N	
39	F	1	i	1	B	29	1535	EMCS	AN	N	N	N	Y	
40	M	2		4	B	27	970	EMCS	NO	N	Y	Y	Y	
41	M	2		1	G	31	1705	ND	NO	N	N	N	N	
42	F	1	j	1	G	32	1525	ND	NO	N	N	N	N	
43	M	1	j	2	G	32	1525	ND	NO	N	N	N	N	
44	M	2	i	1	B	29	1535	EMCS	AN	N	N	N	N	
45	F	2	i	1	B	29	1535	EMCS	AN	N	N	N	Y	
46	M	1		1	G	30	1180	ELCS	AN	N	Y	Y	N	
47	M	1	k	2	B	32	1075	ELCS	NO	N	N	Y	Y	
48	F	1	k	2	B	32	1075	ELCS	NO	N	N	Y	Y	
49	M	1	l	2	G	27	970	EMCS	NO	N	Y	Y	Y	
50	F	2	k	2	B	32	1075	ELCS	NO	N	N	Y	Y	
51	F	1	l	2	G	27	970	EMCS	NO	N	Y	Y	Y	

Parent Interview	Mother or Father (M/F)	Interview Time Point (1, 2 or TP 2)	Mother/ Father Dyad (a,b,c)	Birth Order	Boy or Girl Infant (B/G)	Infant gestation (weeks)	Birthweight (grams)	Delivery (ND, EM or ELCS)	Transfer (NO, AN or PN)	Congenital abnormality (Y/N)	Previous poor outcome (Y/N)	High risk pregnancy (Y/N)	Experience of ICU (Y/N)	Single Mother
52	M	1	m	2	B	39	3318	EMCS	NO	N	N	N	N	
53	F	1	m	2	B	39	3318	EMCS	NO	N	N	N	N	
54	M	1	n	2	G	38	3582	ND	NO	Y	N	N	N	
55	M	1		1	G	24	686	ND	NO	N	N	N	N	Yes
56	F	1	n	2	G	38	3582	ND	NO	Y	N	N	N	
57	M	1	o	1	B	31	1705	ND	NO	N	N	N	N	
58	F	1	o	1	B	31	1705	ND	NO	N	N	N	N	
59	M	1		2	G	33	1620	ND	NO	N	N	Y	N	
60	M	2	n	2	G	38	3582	ND	NO	Y	N	N	N	
61	F	2	n	2	G	*38*	3582	ND	NO	Y	N	N	N	
62	M	2	l	2	G	27	970	EMCS	NO	N	N	Y	N	
63	F	2	l	2	G	27	970	EMCS	NO	N	N	Y	N	
64	M	2	o	1	B	31	1705	ND	NO	N	N	N	N	
65	F	2	o	1	B	31	1705	ND	NO	N	N	N	N	
66	M	1		3	B	35	1610	ELCS	NO	Y	N	Y	N	
67	M	1		1	B	36	1620	EMCS	AN	N	N	N	N	
68	M	1		1	G	30	1175	EMCS	NO	N	N	N	N	
69	M	1		4	B	27	970	EMCS	NO	N	Y	Y	Y	
70	M	1	p	2	B	25	842	EMCS	AN	N	N	N	N	
71	M	1	q	3	B	27	972	ND	AN	N	N	N	N	
72	F	1	q	3	B	27	972	ND	AN	N	N	N	N	
73	F	1	p	2	B	25	842	ND	AN	N	N	N	N	
74	M	1		2	G	24	725	ND	AN	N	Y	Y	Y	Yes
75	M	2		1	G	30	1175	EMCS	NO	N	N	N	N	
76	M	2	q	3	B	27	972	ND	AN	N	N	N	N	
78	F	2	q	2	B	25	842	EMCS	AN	N	N	N	N	
79	M	2	p	2	B	25	842	EMCS	AN	N	N	N	N	

Key

Parent Interviews are referred to as I 1, I 2, I 3 and so on in the text.

Interviews. Interview 1 (7-10 days post birth), Interview 2 (beyond 28 days) and TP 2 where the first interview with a parent was at Interview 2 time point.

Mother/Father Dyad. Mother a and Father a are the parents of the same infant. Mother b and Father b are the parents of the same infant and so on.

Birth Order. 1 is first born, 2 is second born and so on.

Delivery. ND is a normal delivery, EMCS is an emergency caesarean section and ELCS is elective caesarean section.

Transfer. NO is where the baby was born in the parents local hospital, AN was where the mother's care was transferred to the research hospital antenatally and PN was where the baby was transferred to the research hospital postnatally for NICU care following birth.

Previous poor outcome refers to a parent who had previously experienced 3 or more miscarriages any previous fetal, neonatal, infant or child death or severe disability or chronic illness following a congenital, prenatal or neonatal illness. Charted as Y for yes, N for no.

High pregnancy risk was defined as any clinical condition or previous history of clinical conditions in the mother, fetus or newborn which warrant current pregnancy surveillance above routine levels. Charted as Y for yes, N for no.

Experience of ICU was any parent with previous experience of a NICU or a Paediatric Intensive Care Unit with their own infant/child or other family member. Charted as Y for yes, N for no.

Single mother was charted Yes for any mother unsupported by her baby's father.

Appendix 6. Example of an interview.

I: Did you have any worries during the pregnancy about the baby?

R: No, thankfully absolutely no worries at all. Other than, well, I mean...I'm err...just sort of normal worries you know like is the baby developing and urm my brother had sort of heart disease so we wanted to just check that out but no we were very well looked after in London and all the scans were fine so thankfully no. It was the most wonderful pregnancy until it all kind of went wrong.

I: Right.

I: So what point were you aware that the baby was going to be born?

R: Well I was down in London and A was up here running a conference and I got a call at 10 o'clock you know on the Tuesday, last Tuesday evening and A just said something doesn't feel quite right and I've noticed some bleeding and I said well just go into the hospital, just for a check up and just make sure. And at that point we didn't think there was anything urgent, nothing and she just happened to be with a friend, you know, whose wife had had their kids here and this is the hospital to come to, you know, which was fantastic. I mean, literally, I've just seen where she was, I mean she was about five minutes away by car in Hope Street and she came straight in. And I think initially you know nobody here thought anything because I think A was just very relaxed and she just said look can you just check everything is OK and as soon as they had done the you know ultrasound scan they said no they couldn't quite hear the baby's heart beat or the baby's heart beat was very slow and at that moment everything sort of came away and there was this whole abruption and they rushed her off and the next thing I heard down in London I mean, A's mobile had stopped working and everybody went out of contact so I got the number here and I said my wife must be here and you know at half past ten they said she had arrived and we will let you know. And I called again you know, 20 minutes later and they said yeah she's now in, having a Caesarean and they are taking the baby out. So from her saying to me at 10 o'clock I am just going to go in and check everything is OK, knowing that she had arrived at half past and then suddenly saying she's had a Caesarean and the baby's out and we will find out what sex it is but you know your wife is under general anaesthetic and I said OK I'll get in the car, so here I am.
I: That really is very sudden isn't it and you obviously, how were you feeling being in London?

R: Pretty sort of helpless because you know I mean there was nothing I could do only getting in a taxi and making sure you know you ask all the right questions but then everything went quiet because you know A didn't have a phone and I just thought well, gosh if she's not phoning then things probably aren't OK because she would always phone. But I'll tell you the hospital was fantastic I mean I was not only put through and they said gosh we can't normally put you through but I said these are the circumstances and they put me straight up onto the ward. A doctor came straight on the phone, she said yes I have seen A and she has told me you know that she is very concerned that you get to know what's happening and this is exactly what's happened and I was able to ask all the questions about you know what has happened?, what has led to this?, what state is she in? Can somebody find out about the baby? And somebody came back on the phone, I gave her my mobile number, Dr A and she was just amazingly reassuring. You know in these circumstances, this is what happens at this stage and the baby had been moved to an intensive care bed and you know and drive carefully. She said exactly was what I wanted to hear.

I: Yeah. In the time that A was on the way in until that conversation did you have concerns then?

R: Well I had huge concerns then. When I was driving up in the car.

I: Before you knew the baby had been born or before the baby was going to be delivered.

R: What do you mean in that period between sort of knowing that A had come in here.

I: Yeah, I was fairly relaxed I knew A should get checked out and I knew she was with a friend who knew Liverpool and they had gone into a taxi and because A was just very relaxed at that stage she was just saying I am just getting it checked out and it doesn't feel quite right and we've always said all the way along that we become more cautious if we need to be and because things have gone so well and you know the scans had all gone well and there was just nothing you know, to give us any warning that anything would go wrong. At that stage, I was just thinking...I remember I was just sitting at home I was just looking up in the books, what does bleeding mean and how does it happen and at what stage is the baby in at 29 weeks. But no I was really relaxed at that stage. And it was only literally, the only moment, the first moment that I thought something is wrong was when I got on the phone to the doctor. The doctor had said on the ward, she had said don't worry about travelling up I'll call you if there is any reason to travel you just sit tight and don't worry. And then she didn't call back and I thought well that must be a bad sign so I called again 20 minutes later and that's when she said she had gone in for Caesarean.

I: Right. So that initial phone call was before the baby had been born did the doctor prepare you in any way for what ?

R: Might happen?

I: Yeah!

R: No. They just said she had arrived and she is having some ultrasound tests. I suppose that's fair enough I mean at that stage they didn't know and it all happened in such a hurry but she had the baby by 11 o'clock and she had gone in by quarter to, so literally by 10 o'clock when I first knew about it A had arrived by half past, she had gone in to have the Caesarean by quarter to 11 and then the baby was born at six minutes past 11. So it was just very quick. I think...there was, there was nothing else they could, they were very, very informative. After the baby had been born they called you know and they said look it's a boy and A is here and when you come this is where you should come to. But up until then I was calling but, you know...and from sort of from quarter past 10, when I thought, A hasn't called me back till 11 o'clock when I found out the baby had been born I was sort of in limbo and then after that I was quite shocked. I remember thinking oh she's had a Caesarean, the baby's now been born and everything suddenly got telescoped and I was very concerned about how A… you know, I didn't know anything about this hospital, you know and we had all the plans made for being in London and so all the unfamiliarity and then this suddenness you know and so yeah it all came as a huge shock and then I had no idea how L was and they were being ultra cautious and it was the same Dr A it was good to have continuity of speaking to the same person, but she was saying you know well these are all the problems. You know and not saying everything is going to be fine which she could have done but was actually saying there was a problem with his breathing and he wasn't breathing when he came out. He had to be ventilated, his lungs are immature you know and she took me through the whole list of all the developmental, prematurity sort of associated problems and I felt actually more reassured. I felt that I understood the picture you know and I was able then to say well is that unusual for a baby born at 29 weeks and what are the chances and what do other babies do and so we were able to go through in much more detail over the phone while we were driving up. You know, rather than thinking while I was driving up everything is fine and he is just in very good hands and had some vague sort of you know, notion that he was being well looked after but he was a premature baby. I actually knew quite a lot of detail at that stage so I could then call my mum and dad and call other, you know, close family just to say that this is what's happened and they could, and they were all abroad so they came back.

I: So did you have any idea about premature babies before that or had you ever had…?

R: Well I had a slightly unusual… not about premature babies but my younger brother had a very traumatic birth. He was born with a major heart defect and had open heart surgery three times in the first six months and was born without a heart beat and we were all there at the hospital. So I had seen this scenario before and had that scenario in my minds eye you know when we were driving up and I've seen, well my brother was worse because when I saw him his chest was open and tubes and wires and his face was all puffed up with all the drugs.
I: How old were you then?

R: I was 18.

I: Right.

R: So it was 12 years ago. And in some ways, I maybe skipping ahead but I mean when I walked in the first thing, I mean I went to the wrong place and I came up here in the back way and the first person I saw was L and saw him with all the wires and tubes and ventilator and I wasn't as shocked as I thought I was going to be because I was imagining it to be much, much worse. And he seemed to be doing much better. I think the staff here thought that I was more shocked than I really was and they said "come on let's take you out of here, and we'll take you in to see A, you know before we do anything else" and I didn't mind at all. I was…yes, I was more sort of…I suppose I was slightly anaesthetised because I was shocked. But I felt I also had a lot of information and I was expecting something much worse.

I: In terms of how he looked physically, or the monitors or, why did he look better?

R: He looked bigger than I thought he would be, I thought... I had an image in my mind, the baby the size of my hand you know and he wasn't. He was the size of my hand to my elbow you know, he was bigger and he wasn't as puffed up and he didn't have as many wires and the staff were very calm in fact, and I thought all of that contributed to me feeling less panicked and almost immediately I had come in to the room to see A, a doctor came in and said right, you know, let's sit down and I will take you through the story because A was very sort of, blurred. Although she had come around after the anaesthetic by about 3 o'clock, well she had come around a couple of hours before. But I got here...I arrived here at about 3 o'clock, she was still a bit incoherent but the doctor came in and explained absolutely everything and again we had a conversation about what the significance of the poor lung development and what the significance of the ventilator and what are the next stages. So I got another very realistic picture and I felt probably at that stage a bit more sort of depressed and you know, because I was actually sitting with A and I had seen L and at that stage they were saying you know it will take two weeks at least. He's going to be in hospital for... you know, two months until his due date. And I thought, my goodness this is really serious. I think at that stage I thought, I've understood the significance of it, more so than I had in the car when I was just getting all the verbal information and hadn't got a mental picture of what they both looked like. So I thought that was very helpful you know, to be taken out of the room, to be put with A and think have everything sort of explained slowly so I could ask questions.

I: Yeah.

R: And the doctor came in and one of the paediatric nurses so

I: Did you have a chance at all to speak to A?

R: No, about this. No she deliberately, no we both did the questionnaire and we deliberately didn't talk to each other but then compared notes afterwards and she said I am not letting you know anything at all. She said N is very nice but I am not letting you know any more than that, we can compare notes afterwards.

I: How do you feel about the situation that you are in? Do you feel anything or anyone is responsible?

R: I see, what the whole burden and why it's happened?

I: Yeah.

R: Well it did go...it's gone through both of our minds and I know, well I think what's gone through our minds is you know, was A working very hard? You know was she working too hard, you know, did that bring anything on or did she run upstairs or did she lift something or you know we both asked each other all those questions and I think the reason, I mean they are obvious questions to ask but partly we had pressure from my Mum and Dad who definitely come from a culture of you know, when you are pregnant sit back and put your feet up and do nothing and my sister had done that and she has just given birth literally in May and she stopped work, stopped everything and put her feet up and sat at home and had a perfect pregnancy and gave birth two days late and you know and in some ways that was partly their model and I think yeah, both of asked those questions but then we sort of looked at each other and thought well let's ask people who know, you know. And so we asked the gynaecologist in London and he said no, it's nothing to do with it, it's just one of these things that happens and you know, sometimes if you are sitting in a car and the seat belts whips you in the middle of the stomach or something like that then possibly. But, just working doesn't have any connection with it at all and you know and you would feel and A didn't do any of that sort of thing. I mean yes, she worked and worked very hard which is a stressful thing but plenty of people have stressful jobs and have perfectly normal pregnancies and give birth relatively normally. So, I think yeah, I mean neither of us blames... other than in our most tired and irrational moments do we think that it was anything that A did and what we have heard from the gynaecologists and doctors is nothing to do with it, nothing at all. But you know we are concerned, that you know, to make sure it doesn't happen again and they say, the same gynaecologist says there is a 2% chance of having had this placental abruption once, that it might happen again but they can watch for it more closely and maybe next time you know, come six and half months A will take is slightly easier but that's all you know, unnecessary... being unnecessarily cautious, but nobody blames anybody and we are quite relaxed. It's just one of those things and it happened, as I say with my younger brother and we asked the same questions then, you know, was he born with this heart disease, you know, because of anything that happened. I remember when my Mum had fallen over, had a skiing accident and again they said no, it's just pure luck, there is no connection at all.

I: But quite early on then you felt the need to ring your obstetrician in London.

R: Yeah we did.

I: To sort of alleviate those kind of questions?

R: Yes, well we had, well I know you said at the beginning about sort of support networks, I mean, A's Dad happens to be a GP and that actually was very helpful in the car driving up and we were able to say well what the significance of prematurity and he was able to answer some of those questions about if it was anything that A has done and in some ways, we all knew what the answers were, but it's quite reassuring just to have that. And then yes, I called A's GP and the obstetrician and he happened to be away on holiday but spoke to the doctor and had asked some of those questions here so we were hearing all the same answers which was... and you may ask the questions over and over again, it all goes over in your mind over and over again. It's helpful to hear the reassuring answers again and again you know.

I: Confirms...

R: Yes, exactly.

I: And so early on, you thought about the significance that this may have on perhaps future pregnancies.

R: Yes, I suppose, yes it's... one of those, I suppose there are two obvious questions, is there anything we did and will it affect things in the future and I mean yeah, I mean what I say is pretty I suppose insignificant compared to how A feels because come the next time and we do want to have more kids you know, one other baby ? er I wonder. If I was A I would find it very difficult to actually completely forget about all of this and think let's just have a baby and you know not think about any of the consequences or some of the things that might have occurred so I think we won't start with a clean sheet. You know we will think back what happened. But you know what we have always done is always ask the questions and make sure we are probably monitored and look after this one thing. But also be aware that anything can happen you know and one of the things that gynaecologists tend to ask right at the start was that vast majority of all pregnancies are perfectly normal. That's what makes them normal you know. So you know you that you can buy all these books and you can worry yourself about all the problems but actually you know there are tonnes of problems but worry about them if they happen and they are more than likely not to *happen. His philosophy* was, I don't know whether I accept it but his philosophy was keep an open mind and have a nice day! *Which is great. But we have always thought* his was very good philosophy because then you will come back for more. And I think you can focus on the problems. I mean people do have problems, births and problems with pregnancies but it's something that you don't really focus on the problems is actually what you focus on is how sweet you know his fingers are and how cute he looks when he's sleeping and you know and really you can't wait to spend a fantastic time with him. And you don't actually think I mean hopefully, oh yes of course it is pretty bright in our you know recent memories you know of what he has just been through and its awful you know it looks painful and all those things. But that memory will fade and we'll actually associate you know with the sort of happy things.

I: So have you thought why has this happened to us?

R: No, other than, no just maybe fleetingly it has come through my mind but I am thinking about it there is no basis for worrying is there anything we did or.

I: The next questions are about L

I: Well you have told me what you thought when you first saw him can you describe your feelings?

R: Yes I can actually, they were a whole mixture of feelings though. I mean I thought I would be overjoyed to see him and I probably wasn't to start with. I thought OK this is a problem, I want to see A where is everybody? What's the information? And who are you? And OK I want to go and see A and I want to know the whole picture and the story and I remember the first person who said congratulations! To me and I thought that is so inappropriate and insensitive because I don't feel congratulations are due and I also think this is not a time to be happy this is a time for you know getting to grips with the whole, with all the information and this is serious, he's in a critical condition and yes that's right we are the new parents but...I thought yeah, I thought I would feel walking in, gosh how wonderful, how beautiful and everything and I took a quick look at L and I just thought right and then I will need to know all the facts and I need to make an action list of people I need to call and I need to check A is OK and all those sort of things. So I surprised myself a bit about how I felt. I was much more detached.

I: Was that following or perhaps the next time or were things different?

R: Yeah, I found the more time I spent with him the more than I went away I could close my eyes and I could see a mental picture of him.

I: Yeah.

R: And the more time I spent in the Neonatal Intensive Care Unit the more I was talking to the nurses, the more I went to the ward round, you know I went to the ward round deliberately the first few mornings. The more the vocabulary changed you know from critical and stable you know to start with for the first couple of days. It then went to progressing. It then went to brilliant and smashing and then he went to the high dependency unit and the next stage or the nursery. So the language was very, I know that's one of the things I was really conscious of over the next few days the language that the nursing staff used I thought was possibly the most significant thing because I could then take that back to A you know when she was in the maternity unit and delivery suite and then when she was back in Mat Base 1 of the maternity section. It was words like that you know because I could say things to her like this is the amount of, these are the drugs that he has been given and all that sort of goes over both of our heads. She and I found it more significant to say they used this word yesterday and they are now using this word its progressing and they don't use those words lightly because we knew from the first couple of sessions we had with the doctor on the first night that they were very realistic if not bleak about his chances and saying that this is going to be a roller coaster ride and you will dip and you must prepare yourself and all these wires and all these tubes. And actually it came as much more of pleasant surprise when he actually kept on progressing and he didn't dip. But we were expecting it.

I: Yeah.

R: You know and I thought much more helpful to have the digestible language you know 'progressing' and 'coming off his feeds' and 'he's done a big poo' and all that sort of stuff than yeah. I mean yeah we both come from medical families though it's not complete jargon but just at that stage it was much more helpful to have user friendly language. But I also found when one of the paediatric nurses was sort of changing nappies or you know in his incubator they were I don't know whether consciously but they seem to be very careful about the words they were using like you know 'you are wonderful' and very sort of reassuring, very sort of motherly language. Because they could be seeing you know 40 babies every week or whatever, you know quite blasé about saying come on move your legs but they flippant at all and I found them very, very careful. May be they are different when I am not around but when I was around. Because I was really looking to them for reassurance for the work because they are so expert you know and they see so many babies, you know you really try to latch on to the words they are using you know like well, gosh, excellent and you know poo and all this sort of stuff. Just really little things like that and I thought that was the most significant just the tone and the language and the actual words they used.

I: Interesting yeah.

I: So have you held him?

R: Yes, which was wonderful.

I: What was it like to hold him for the first time?

R: I'm trying to think because I have held him a few times now. But I remember he is so light as well and I remember thinking he is so small because he is slightly distorted when he is in the incubator and you hold him close and I was worried about holding him as well. I was worried because I have had this cold now for sort of three weeks and I thought God I am going to infect him and they keep on saying you know the most significant thing at this stage is you know the anti immune system and infection and I was really. But they were very reassuring because I said I have got this cold, shall I wear a mask and they said no as long as you don't go and sneeze all over him and he is not as fragile as you think. You know you can move his head around and look I can hold him in one hand. I was really sort of worried not so much about dropping him because the whole thing is, just because he is so fragile about the breathing on him and you know you see him in the incubator and you think gosh he's a doll and I mustn't touch him or anything but they were very good at pushing us to a sort of next stage so holding him felt like a big thing. I felt I wasn't ready to hold him and I didn't want to hold him because you know I didn't want to infect him. But they weren't worried him just hold him, sit there. So we did it one evening when we weren't even thinking of doing it and we said look lets hold him tomorrow and they said no come on let's do it now and we both loved it. So once we done it. I was apprehensive before of doing it.

I: So did you still feel that apprehension when you were holding him for the first time or once he had been in your arms did that go away?

R: I now feel much more comfortable just holding him in one position.

I: Yeah.

R: I still feel, I wouldn't feel comfortable taking him out of the incubator or putting him back. I have changed his nappy, which was fine. Yeah holding him I still feel apprehensive about moving position or when he wriggles that he is going to wriggle out or one thing and when I am passing him over to A his head is going to drop. So yeah I still haven't quite. I know there will come a time pretty quickly when he will just feel you know come on you know you are not as fragile piece of china or something. But I haven't quite got that yet.

I: So what kind of words best describe your feelings at the moment?

R: At the moment much more settled. Excited, yeah just can't wait to see him every day and looking forward to going home but not in any rush to go home. Lots of positives and very few negative sort of thoughts. Negatively since the first day, well first couple of days I mean when we were being fed a lot of realistic there were some quite negative information. You know I remember consciously sifting quite a lot of... and giving A quite a lot of positive information while she was coming around from the anaesthetic. But now actually A genuinely hasn't got any negative thoughts at all. It all seems to be positively. Because even though we are quite contained you know we are not sort of saying you know yet everything is going to be wonderful and we haven't told quite a lot of people yet because everything is still we are trying to keep under control and who knows what will happen. But certainly I feel positive.

I: Do you think that is related to anything you feel in particular like coming off the ventilator or something like that or do you think it just the time thing?

R: I think it is just an accumulation of everything all going well so you know yes coming off the ventilator then starting to take his food, his weight and the scan going well. The comments from all the... you know consultants and the doctors. I don't think of anything oh I mean there was a day when his weight dropped significantly and he was jaundiced but that's totally normal apparently and he was under his photo light. And that was probably the only day when I suppose all we were looking was his weight and you could say gosh well he has dipped but apparently that's just part of the process and they told me that was progress that his weight was dipping because he was doing something normal. I think that actually the accumulation of everything going right and I think even if things had gone wrong we were still who knows but I think I certainly felt prepared for things to go wrong. But also wasn't worried about them going wrong because I knew he was being taken care of and also there were other babies as well. I don't know whether there is a thing about confidentiality or not but you get to see all the other babies in the unit and the nurses do say 'you know well, there was a baby that had to be resuscitated yesterday and this baby here did make a big dip' and it isn't all just roses and it doesn't always progress as you like. But actually if the baby does get and infection or if the weight does dip this is what we can do we put antibiotics we give them more lipids we do this we do that and you just think well that's fine. Even though there are things that probably could or you know maybe likely to go wrong you can still be under control and nothing was you know I honestly felt nothing was sort of life threatening and you know he was getting the best possible help. I mean we had so many people saying this is the best place that you could possibly be which is all very reassuring yes.

I: So the feelings that you were having and have now are to able to express them to anyone?

R: Yes. Mostly we are focused on A and I mean most of my views have been positive. I mean I went through sort of a teary day at the beginning I was sort of telling my parents. I was sort of quite emotional sort of telling them what his name is because we named him after my grandfather who worked here but who died very young and while my dad was still at university and we thought it was just such a coincidence so his middle name is that and his first name is the name of my great grandfather and so that was very emotional you know. He'd come through and we named him and just at that moment you know you felt like a sort of a viable person. You know you felt like you were carrying on a family tradition and all those things. I mean at that moment I just felt we had invested a lot of significance in him as a human being and you know yeah so if things had gone wrong at that stage I was just sort of all that was going through my mind do you think he would make it and it feels like it was so long ago now you no, so I can express my feelings on my mum and dad or around here and we have had loads of visitors and A's family are around but that sort of chatting I do with A and I haven't been nearly as wobbly or needy or bored so yeah.

I: Just from what you have said earlier do you think that you have protected A a little bit from what you were saying before?

R: I think I did a tiny bit I mean at the beginning but I probably couldn't protect A anyway on my own because there were so many people you know coming in and going out and telling her the information and there was her parents. But certainly yes I did make a conscious effort urm I'm not sure if it was right or wrong or whether it was just a reflex. While she was coming out of the anaesthetic there were something's that really set her off and I think like the period we were going to be in here for which I think came as a bit of shock. Yeah, yeah I know A pretty well and things that she normally wouldn't get upset about you know she was getting really upset and then really laughing, really quite sort of extreme you know and I just thought at that stage you know she is going to need I suppose some time before she is settled and back to normal. I mean she is still not back to you know her good normal self and even though she looks normal she came round really quickly and she is really strong and full of beans and everything and she seems fine but there is a lot of little things you know. Like she doesn't usually sort of burst out laughing and burst out crying. She does cry a lot but much more so than normal and many things now set her off but I sort of love all that sort of very, very expressive but she I definitely made a conscious effort you know but I am not any more.

I: Yeah. Was that probably because you feel incompetent.

R: I suppose so, I think it is both. But all the news is positive actually. I think if people were still saying to us you know just because nobody is saying to us be contained because things could still go wrong everybody is saying he is doing brilliantly so I have actually got nothing to hide... about at all I can tell A. I don't even have to exaggerate I mean it's all there the facts speak for themselves.

I: Do you feel supported by your family then?

R: I do but I feel that I don't actually need that support as much I mean they're around and they are doing wonderful practical things. Things that we probably couldn't do if they weren't around like for example they are helping me wash my clothes you know and I mean we are in a very sort of I would imagine from other people who normally come we are in quite an unusual position because we are from London and you know everybody has had to fly in and drive up or whatever.

I: Your mum and dad were abroad were they?

R: Yeah, they were actually on holiday.

I: Are they actually in a hotel near here.

R: They are in a hotel. They are originally from Liverpool but they haven't lived here well my dad hasn't lived here for 30 years but they kept a house in Liverpool not in Liverpool just outside actually, just outside Chester. So they stayed in a hotel for the first week at the Holiday Inn until today and then they are now moving down to Chester tonight and they will just pop in once a day.

I: So they are there aren't they for you?

R: Exactly. Which is lovely. I mean even if they are only popping in you know for half and hour or an hour its lovely to know that they are just literally round the corner. Because for a couple of days I went over I just had a sleep in their hotel room and they were able to do some shopping for us and they brought us some dinner and all those sort of things. So those sort of things are really helpful even though I don't sort of usually have a one to one chat about how I am feeling and that with my mum and dad.

I: Have you not told from what you were saying earlier you have not really told many friends?

R: No, we have spoken almost to nobody yet and I had said to A that I really want to tell oh that was really quite a conscious thing between A and I you know just about 1. That when we told people you know we were absolutely sure that things were going to be OK because I think we had thought if it would be much harder if things went wrong to have already told people then to have to, to them you know and one of the luxuries about A being up here is that we are cocooned from all of that. And A says I just love it I just want to get settled first because we keep thinking about what this would have been like if the baby had been premature in London everybody would have been popping in. But she has already had a few, some people have got the phone number you know of the ward, you know and the midwife will come in and say look it's your aunt or your second cousin or you know I will go to the phone but if I am not there A took a call the other day and you know of my sort of slightly batty aunt and you know it was sort of really inappropriate and it was just too much and A said I have got to go and I think yes I mean I want to call all friends and tell them and they will be really shocked. But in some ways I have been doing all that. I mean lots of people have called and we have called lots of A's work colleagues I mean I have spoken to all the work colleagues and that's fine but still that's slightly different from calling your close friends who are much more shocked. Yes I mean we have called one or two of A's friends who, and that's been lovely because they are so sensitive but I think when we start to tell our broader friends then yeah it's a bit more uncontrolled and who knows that they will all call and may be some of them will travel up.

I: And so dealing with them that's going to make it difficult for you both. Is that why you are putting it off or you don't want to?

R: I would like to call but I know I would like to call everybody but definitely we are holding back because I mean I could also say I would quite like to call this friend who has got a child and they know what it is like and don't call them because they are trying for a baby and it would be really difficult for them. Don't call her because she is expecting twins and she is really dramatic and all that. I think we have got to try and filter what people's reactions would be.

I: Yeah.

R: I mean the more I think about it the more I want to just call and do it. Because once it's done then it's done and we can deal with you know how they are going to be but I can say on the phone well don't come because we are trying at the moment to get settled.

I: So what about other parents on the unit. Have you had any opportunities to talk to them?

R: Yes. They have actually been lovely. There was one other family that we got on well I got on with really well with who had sort of similar sort of things he was a solicitor.

I: Oh yes, he was in the same room.

R: Yeah. I got on well with him and his wife. I think he had other children and that was lovely. And I think from my point of view having somebody I can bump into in the corridor and saying How is your baby doing? I think that's great and actually if there was ever a petition you know about reducing the number of babies or I mean I think it's absolutely right in the intensive care because there hardly seems to be any parents coming in there may be just one other or two other groups and they are really strict about the number of parents who come in and mixing with them I mean it's quite. I mean you can go over and you talk to them there and they come over and I mean it was very fortunate for us because their baby had been born three or four days before and was doing well. I can imagine that it's not always the case but I can imagine it's all a roller coaster and something you compare and it's not very helpful but when its going well its lovely. But we definitely found in the high dependency unit that there is much less control you know fewer nurses than there are babies and also there are many more visitors and your baby feels much more insignificant you know I came in and L had been moved. I don't know whether I am coming on to but in the intensive care section he was in exactly the same position all the time and it sounds a bit insignificant but I went down with my mum and dad and he had been moved and we didn't know and I just shut the door behind me and I said "Where is he and you know?" and they said "oh right has nobody told you he had been moved" and I said "where has been moved to"? "Oh he's been moved the high dependency"! "Oh what's that you know" and I thought at that stage you know somebody I suppose would have known that there was going to be that move and I felt a bit unprepared for it and I don't know what the next stages were but also I was with my mum and dad and he had been moved. But when he was moved and when you say did I mean other parents then that's going a bit off but in the high dependency there were three or four groups of parents but with three or four of their friends and relatives. There were groups of sort of six people around and I went in and L was sort of in a corner and when I came back again he had been moved and shifted up and I thought what on earth you know where is he! You know and it is very reassuring to see your baby in exactly the same place. It sounds, I think it's not the sort of thing I usually say but it is very reassuring to see your baby in exactly the same position. Not crowded around or pushed aside because other families wanted more space to walk around and yeah it surprised me that the sort of really healthy environment of the intensive care seemed to be, well maybe that's deliberate because it is a different environment and the baby is healthier and doing better but still he's only a week old and I knew A felt that and found that quite difficult as well, so yeah.

I: Is there a lack of privacy issue there as well.

R: Well its congested and there were more people, there was more movement and all of those things make you baby feel less special.

I: Yeah.

R: But the privacy didn't matter at all because well neither of us really minds that much about talking you know when you hear about people and hearing what we say but A wanted to do a breast feed last night and we had the screen around and that was absolutely fine. And also I mean to put it in prospective I suppose you know we were more urm negative about it because it happened suddenly and without warning but you know over time and also were having to make new relationships and we had made relationships with all the sort of you know the staff in the intensive care but it's the extra time and we will get used to it and then as soon as we have got used to it he will move into the nursery and then we'll move down to London.

I: So there was an element that you weren't prepared for or that move and how that made you feel ?

R: I think that's right. Yes I didn't quite know what all the different nurseries were and what the significance of being moved was. Yes I mean basically the care is fantastic and one after the other. You know all the nurses are just brilliant I mean not only brilliant in terms of the confidence which they you know care for you and that confidence is infectious and you feel reassured by it but also they are pretty up front about asking you how you feel you know and that's the first time somebody in intensive care said, she said how's everything going and I said oh L's doing this and A is doing that and she said oh no you misunderstood the question how are you doing? You know I thought god you are asking and I'm fine I think. And how are you getting on in the hospital and who are you talking to and what's your support and I thought gosh for a neonatal intensive care nurse looking after a baby to be asking me questions and I am a dad you know and I thought that is something special. So basically the care is fantastic but just that one transition I thought it came as a bit of a shock.

I: So how do you feel about going back to London?

R: I haven't really thought about it hugely. I mean I can see there will be three or four things about going back to London. There is going to be the journey itself and we are both slightly apprehensive about how that is going to work. I mean are we going to drive L? Is he going to go in an ambulance? Is he going to fly? Or can we travel with him? So there is the journey side of it. Then there is actually being in the hospital. I mean will he be in our local hospital? Will he be in a specialist paediatric hospital? And we spoke to our gynaecologist and he is sort of trying to find things out about where he would go and we have had conversations up here. So there's a whole issue about where would he go? And where will his care all his care be like? And will it be the same quality as here, you know and I think this is going to be difficult to match you know because of that consistency and that high quality care and it's just its got such a fantastic reputation and you really feel reassured they are by today really are looking after your baby. So yeah well I am slightly worried about where he is going to fit in and building a new team around all that and how long will he be there for and will he be properly looked after. And then there is another issue about being back home as well. And I am sort of just beginning to think of I mean when I left there was a bed as far as I know that was completely unmade and all the papers were where I left them and the nursery has got the cot up against the wall and all my office and business stuff is up one side and I mean everything is still in boxes, and all of the pram. I know there will be an issue about it but I think that is the least significant of the three. But there definitely will be something about going home. I mean our baby being born but not taking him home. But that's only a matter of time but the other two. But out of all of those three I am more concerned about the care he gets when he comes to London. But you know we will see and I have every confidence that there will be enough liaison between here the more I think of it you know here and whatever L needs in London, they will make sure of that transition.

I: Can you tell me the things that you are able to do for L?

R: Like change his nappy and things like that?

I: Yeah.

R: Yeah, I've changed his nappy. We haven't taken him out. We have sat and we have held him. I haven't been able to do very much for him. I would love to be able to do more for him like he was hot the other day and I would like to take his things off and you know choose the things because he looked boiling and he had three layers and a blanket on him and yeah. I mean basically all I am able to do is hold his hand and touch him and then hold him when he is out and yes change his nappy.

I: Why did you feel that you couldn't perhaps undress him?

R: That's just me. I think it was I always feel as though I need to ask and sometimes its right to ask because I mean he was crying and he had a dummy in his thing and I said shall I put the dummy in his mouth and they said no lets sterilise it first and I was sort of glad I asked. Partly I think am I doing the right thing. Am I interfering because they put the clothes on for a reason. Sometimes I say, I know these are only tiny criticisms but sometimes I say gosh there is this wire around his neck that looks as though he will pull it and he will strangle himself and they say no its fine look you know. I mean they said no he's fine, don't worry about him but it still looked as though literally a wire around his neck and his hands are going everywhere. So partly I have got that anxiety there saying that we are looking after him so don't worry about all the technical stuff and sometimes I say for example gosh that thing is beeping you know and they said just look if we are worried then you need to be worried otherwise don't worry. Well I just think well if that's the attitude I feel reassured because I know you do know what you are doing but when it actually then comes to me doing something if you are saying to me look at the nurse for guidance when it comes to me doing something for myself I think well I need to ask the nurse and I think you know I shouldn't interfere because I might be doing something that was wrong and they have deliberately put him in that position. There is definitely a feeling that they have got the knowledge and they have additional authority and they know what they are doing that I ought to be asking so that it means that I have very little independence when it actually comes to doing stuff on my own. I don't mind that because I feel that it's only a matter of time and I don't need to disturb all that. I mean if we are talking about a couple of days you know then me being able to take him out of the incubator or me being able to take his hat off or moving his head like yesterday his ear was all sort of curled up and I wanted to move his head and just move his ear and yeah I just don't feel that I have the confidence to do it and maybe if I had been playing with him more I would have seen you know and could have easily coped with me just moving his head around. Because it's easier said than done because you know you sit here and you think gosh its easy just to move your baby around and it is actually your baby and you have seen him on the ventilator and you worry about infection and you think well I had better be a bit more cautious.

I: So the things that you do for him have you needed help learning those things.

R: Yeah, the people have been really, really helpful yes absolutely I couldn't change his nappy and I didn't know anything about from going from top to bottom and front to back. Yeah, I mean that's like A learning how to breast feed and to be able to express. I have changed nappies before but when it's your own baby and when it's in intensive care, a premature baby yeah I am very much eyes and ears wide open, mind wide open and learning from scratch and I have needed total guidance and yeah I am almost able to do it now without help. So, it's nice to have somebody watching over and making sure you are doing it right. Because it's quite a technical thing. I was surprised you know how much you know you need to you know think about what I just wouldn't have thought of instinctively and the oils and the disposal and the cleanliness. I needed all the help that I got.

I: Did you think there was anything only you or A or and A can do for L?

R: What now?

I: Yeah

R: Well now.

I: Yeah.

R: No. I mean I suppose there's the expressing which only A can do but all the things like his changing, his cleaning, his food no its nice to be doing all that but in some ways at the moment but actually at the moment its quite nice that somebody else is looking after him. So if can actually look after A and I can go and do the shopping and bring some food in and sit and talk and we can both come over together. Actually it's a bit of weight off our minds at the moment. Yes I mean it's lovely to be feeding him but its quite a technical thing I mean fill a syringe, via tube into his gut and it's a far cry from breast feeding and spoons and cow and gate and whatever but no I think beyond territorial there's absolutely been about there are things that we should be doing and I don't want other people interfering with them you know. I feel very much because the care is so good I think yes I feel differently if he was being man handled or he was being bullied or pushed about in any ways and he is not at all so I feel, well actually I am learning from what I am seeing.

I: Do you feel that you have had enough opportunity to do those things?

R: Yes. I mean I haven't needed to as much as A *in terms of you know she wanted to* learn more about the expressing and that has been quite prolonged and with lots of tips and techniques to learn. I mean every time I have popped in I have always had a question you know how is he doing and is there anything I need to be concerned about and always somebody come over immediately actually I haven't even had to ask. They just see me walk in, gone over to the bed and someone almost instantly comes up and tells me what's happened the last time you have been in and so I have found all the nurses always available without exceptions yeah.

I: So you felt you could talk to them?

R: Absolutely, no question about it. And one of the reassuring things is that they speak in the same language and say similar things and I am solicitor and I have to sort of process a lot of information and deal with cases and different facts and it is amazing that the skill that they've got because their dealing with a room full of babies. Different babies are coming in, different babies are going out. Sometimes they are dealing with different rooms but they have that information at the tip of their tongues, the tip of their finger tips whatever about how much food he had, when he had his last bowel movement and I am really impressed about how they, and it's great that that information is in their heads because if they had to keep looking at the files and going to the charts and saying you'd feel well is my important and you know is this information not going in as if it's just another statistic you know but no its great that that information is just off the top off the head. It doesn't matter if it's not, I mean I don't need to know these I mean 4.2 ml of dopamine per I mean basically I just want to know the obvious information you know his breathing his sound and his pulse rate is doing this and he is coming off and he's taking a little bit more food. And they are able to say that and I am impressed as to how much is just free flowing yeah.

I: Have you ever felt in the way or not welcome?

R: No. When the high dependency unit was crowded I thought everything was spaced for me and I wanted to bring my mum and dad in but consciously brought them in one at a time. Amazingly I could have brought them all in together if that was the policy but I thought actually there wasn't much space in here so that's they only time I felt, but no I've never felt in the way. Always felt at any time of the week coming in at silly hours like at 3 o'clock in the morning and 6 o'clock I have always felt welcome.

I: Going back to what you said a little bit earlier. Have you found that you concentrate of some of this technical aspect of perhaps the monitors and drugs and such?

R: Yes, and I was quite quickly told. Because I would sit you know just looking at the monitors and thinking my goodness his saturation has come down, his pulse rate has gone up and you know and more or less the nurses you know have noticed me just staring at the monitor and they said look there is no point in looking at the monitors at all because you can get very anxious about the alarms going off and basically they said there is two things that you need to look at. You need to look at your baby and if your baby looks well then everything is fine then you need to look at us and we are worried then there is something to worry about. And if we are not worried then you don't need to worry. And I think that is the most helpful thing really because yeah there was a time that I did and a little bit of it is a safety blanket you know looking at the screens and looking at all the chemicals you know going in and thinking gosh I need to understand all of that. Eventually it's a much more freeing to forget about all of that. Yes, to know that it's all being looked after. To know just in general what the substances are and what they do and this is a stimulant and that's a sedative but not necessarily to know that he had 9 mls in the morning and now its 10 mls because I mean yes I would ask those questions if I wanted to know more and I thought comforted enough to know that the nurses are comfortable on how he's doing, that the consultants are comfortable generally what the substances are doing you know and yes and I have a pretty full brief at the beginning and that was enough. I would have felt a bit at sea if I hadn't known and we were taken through everything that was on the screen and you know and every line and all the monitors and everything and all the drugs and what they did and yeah if I hadn't had that I wouldn't be feeling as confident as I do now. So that was useful. But it was also useful for them to say you know all that but just don't concentrate on it too much.

I: Yeah.

R: Just sort look at us and usually there isn't anything to worry about because I mean you know they say the slightest movement of his arm will just send the rubbing sky rocketing. The thing can fall off his foot and then his blood saturation goes off and don't worry about that.

I: For them saying that to you it's been a positive thing, it's not made you feel oh I can't ask about that.

R: Oh I see, no I always felt able to ask.

I: Yeah.

R: And quite do ask a question and they have always said ask the questions. Yeah everybody has said keep asking and I do like to know and it is reassuring but sometimes you can get too much of making and also sometimes you can worry too much about things changing and is that negative or is that positive and again it is much more freeing to know that its under control and you basically know what's going on. I mean of course I don't need to know the sort of information to be an intensive care nurse and there's part of you that thinks I do need to when I want to look after my baby and I want to know everything that's going right and everything if it goes wrong I want to understand it because I want to prepare but yeah its much the best and I know I have said that its absolutely the right thing.

I: So how about the doctors have you had enough opportunity to speak to them?

R: Yeah. They come around at the time that they come round at 8.30 in the morning and whenever goes on their ward round and we come up every morning and I noticed were very unusual and I think we are almost the only parents who are ever there. I am not quite sure why that is because its great I mean it's very really that you get the whole days history and the doctor then you know says what he says and gives a description for the day you know and tells you what's going to happen during the day and then he says you can ask some questions and usually I do have a few other questions I just want to ask. Ask what one of the nurses has said so I find it quite strange that nobody is there. Almost everyone. I mean we have been here for a week now and had eight days of being on a ward round and 99% I mean there was our family the Lees were there. I think there were only our family. I don't know whether people feel nervous about being around or nervous about asking questions but I think it's unusual. But I definitely feel able to ask questions but without really been encouraged to ask questions. Encouraged on the first day they said come to a ward round so I came and I have been every day since and they found them very instructive. I found them really helpful.

I: Oh good.

I: Has anything that you have seen made you feel angry or distressed?

R: You mean in general about everything?

I: Yeah.

R: Well here I don't know whether here on the Neonatal Unit or whether there are things on the maternity unit.

I: Well its more specific to the unit?

R: Well there are lots of little things on the maternity unit but on the neonatal unit nothing at all. I felt just this quality of care is five star you know and everybody approaches them with very, very high quality. Nothing at all. What did you say 'angry or distressed'. I was a tiny bit distressed yesterday evening. One of the nurses had a really streaming cold and was sneezing all over the room and occasionally washed her hands. I was sort of watching her and I was thinking am I being very harsh or very tired or something but I was thinking don't touch my baby you know and she did have a really bad cold and I think that's the only thing I thing makes me angry, I thought slightly distressed if that's the right word. Slightly apprehensive that she was going to infect him particularly because we had heard that it was so important for him not to get infected. But no not at all I mean basically very re-assured and there are people who my dad and people who know my grandfather so we have felt very at home.

I: So are there are anything that you would like more or less help from the staff or?

R: The one thing that A has needed help with is with the expressing and she has had loads of help with that and even less actually. She has probably seen now about four or five advisors and it was just this morning that the balance slightly tipped. There was another breast feeding advisor who said I just want to give you a questionnaire about breastfeeding and A just said 'Look I'm fine with breastfeeding now, I'm fine

with expressing' and I think she didn't give this person the cold shoulder but I got the impression she was thinking I think I have got it now with expressing. But she did need up until that point seeing the four or five different people to get their different views, to get the different techniques so I can say look I've been doing this for three days now am I doing it right. She absolutely was just this morning having had all those sessions which were all essential and there is no way of knowing whether you are the sixth person or you are the eighth person or the third person and you are being helpful. So I think those comments are not a criticism at all it was just that at now I think she has got to the stage in expressing just for the time being. I mean who knows she may be worn out. But I think she knows enough people now to ask and enough experts. So apart from that no everything is exactly right. Because there are enough nurses you know on and enough doctors. I'm very surprised sometimes about how many it's like being on a film set you know when the ward round comes round and there is 20 people and you think God and they all know about L and I mean its helpful you know it's all about right.
I: Is there anything then that would make this time on the unit easier for you?
R: On this unit?
I: Yeah? I mean what's happening on the maternity unit is all part of your experience.
R: Yes. The maternity unit has made it very different. I mean the neonatal side is faultless. I mean I've got the parenting room that I can use and having a waiting room that I can put I am from a big family. I can put my family in there and bring them in one by one. All those things are great. There's a phone here and a couple of waiting rooms. I mean all of that seems very well thought through. Because we have used all of that. I mean none of it is superfluous. I mean I am relying on the shower. I come in the night and use the loo in here because I'm not allow to use the loo in the maternity thing so the neonatal side is a real saviour you know for the whole stay and I don't know what other parents say but I found all of the different things, with the loo, the waiting room the parent room you know everything to be in really in proportion, worthwhile and very useful. On the maternity side things are very different. Not very different I mean there are understandable things like I'm not allowed to use the shower, not allowed to use the loo. They are very busy and so they can't you know run along and get a glass of water or whatever and we can't go to the kitchen and there are lots of rules and people come into our room a lot when we are trying to sleep and they don't knock and all those sort of things. But I know that's beyond but it does, beyond this survey. It is part of the experience.
I: So really the facilities for you as a parent compared with the neonatal unit are ?
R: Yeah, I mean we have got it lucky in some ways because you know we happen to be in a side room which is. I mean we could be on a ward I would still have to stay. Partly the reason we are in a room is because we are not from around here and yes I mean if A was on a ward I would have had to have either checked in a hotel or found a room somewhere or a bed somewhere or chair or something, or maybe I would have slept in the parenting room or something. Yes I mean that side of it hasn't been I mean you know it isn't beyond kind of odd times you know particularly I can understand it there is a 5 o'clock evening meal and A isn't ready for an evening meal at 5 o'clock and I'm not ready for it. And then I don't know whether you are the same but normally I have an evening meal at 8 o'clock and yeah I mean it slightly changes the rhythm and the people coming in. I mean it's all understandable. They don't like people phoning and the visiting hours are strange particularly if you are all staying at a hotel. I either come in the morning or later. Age old hospital problems!

I: So some parents would describe their experience of having a baby on the neonatal unit as a complete nightmare and other parents can describe some benefits to it. Can you agree with either of those or?
R: I don't agree with either of those. Well I don't agree that it has been a nightmare at all I think it has been a very positive experience. We as a family have been cared for on the neonatal unit. People have been concerned with obviously how L's doing but also concerned with how A is doing and how I'm doing as an individual, also as a family but actually it really focused in on us and seen our individual needs so its definitely as about as far away from being a nightmare as you can get. In terms of benefit, yes it has. I mean it seems again it is beneficial for your baby to be on a neonatal ward virtually given that he is premature and these are the circumstances that we are in. This neonatal unit and I can compare it with other neonatal units because of the experience I have had with my family and my brother. This neonatal unit has been extraordinarily embracing, informative you know and really helpful in terms of taking us apart from that one transition from intensive care to the high dependency unit has actually really taken us through all the stages from coming off the ventilator to going on to foods, through the brain scan and to all that sort of lung development and all that process side of it has been really helpful and one of the things I know A has said which has had an effect on me is if L had been born full term and we had suddenly had to take him home she would have found it much more of a shock because she has actually been able to ask many more other questions about feeding, about changing, about his health and we have got a much slower transition in from birth to home than we would normally have. So actually yes if you are going to credit anybody with helping us with that transition then it's the neonatal unit.
I: So personally or your family would you regard yourself as being lucky or unlucky?
R: Yes, very, very lucky. Lucky that you know A was 10 minutes was away. Lucky with the quality of care. Lucky that she was so well looked after and had everything done so quickly and that the neonatal side is an absolute God send. You know, yeah I mean I can't stress how lucky we both feel you know. I don't know whether A mentioned but one of her cousin's is a gynaecologist and she said of all the places this is the top neonatal unit and can't speak of it highly enough so you know we both knew that in some ways anyway just from the experience we had but it's definitely re-enforced every day you know we are so lucky.
I: Can you recall your strongest feelings that you have had on the neonatal unit.
R: In terms of what, when I felt most emotional or?
I: Yeah. Or maybe a feeling that over-rides any other feeling.
R: I can remember telling my mum and dad I think is probably the most emotional, twice, I mean telling them this is what is now happening you know A has gone in. She has had a Caesarean and the baby's been born and it's a boy and you know this is the situation you know its critical but stable and then telling them what we called him it was very emotional. But yeah. I imagined it was going to be difficult but the most emotional time was seeing him for the first time but I think I didn't find that as strong. I sort of have quite a strong mental image of what it was going to look like and yes it was emotional seeing A but again I sort of knew I mean I have seen A in hospital before and have cared to A when she has been ill so I didn't find that I mean she bounced back really quickly as well so I didn't find those maybe as emotional as other people find those similar experiences. But you know I found dealing with my mum and dad.
I: Was that because of their reaction or was it difficult because of the name?

R: Both actually yes, both. It was a bit difficult. I suppose they were the first people you said you know God how awful for you because up until then I had been thinking of A and thinking of L and I had been with A's mum and dad and we were really focused on A and we you know not so really sort of on anything else and they were the first people who said yeah how are you coping and we are going to come. And you know I was feeling a bit guilty that they had to cut short their holiday and they said no they would come but yeah realising that you know I was involved in this as well and probably it was focusing on me it was definitely it was probably the strongest yeah.

I: So have you finally thought about the future for L?

R: What he is going to be when he grows up or?

I: When you think about the future do you think that far ahead or do you think lets get home or what?

R: It depends on the time of day I mean sometimes you look at him and you think absolutely you know he is going to be an athlete or he is going to be a conductor or he is going to I don't know concert pianist, he's got very long fingers. But then partly you know when you are a bit more sort of grounded and down to earth you think it is just day to day and you know how are we are going to be tomorrow and but also all those things that we have just talked about I mean the transition down to London so it depends on how we are feeling. I think we definitely see the whole spectrum of how over time a few weeks or something we can all see a little boy and which is all very positive. Because I remember absolutely at the start thinking in terms of hour by hour, six hourly periods you know a day at a time and what everybody thought you know people started. I remember my mum said at one stage have you thought about putting his name down for schools. I remember sort of barking down you know and thinking that is so inappropriate because you know we don't even know whether he going to make it through till tomorrow let alone whether he is going to make through till he gets to school stage. So I remember getting quite angry at that stage but I mean it feels much more appropriate now to start thinking about looking for schools and I have just registered this morning so yeah there was definitely a time when I was thinking gosh is this important to register him I mean if he doesn't make it then you know. So yeah we have turned all the emotional corners and I feel that we are over all those major hurdles and somebody said at the beginning I think it was Dr B said you know after a very bumpy start. You know he had a pretty bad start but everything is looking very good from now on.

I: Do you have any worries about his future health?

R: Yes. Just at the moment I am worried about his brain development because that was something that the craniologist was concerned about at the start. But less concerned about what seems to be developing. I was slightly concerned about his lung development and you know his ability to play sport he must be healthy. Because you know he was suddenly thrust into the world and put onto a ventilator then on drugs and yes that's right he was on a drug stimulating surfactant whatever and he was on a caffeine stimulant and that may have some effect I just don't know. And then his gut and all of these things are sort of today's worries and hopefully in a weeks time they will be memories and all forgotten. But no I have residual doubts about his development but nothing hopefully that will still be with us this time next week.

I: Would you like to be alone with him?

R: Yeah absolutely I would.

I: Would you been surprised how you would feel?

R: Yeah, I would love it. I mean I go in always with A and we do have I mean basically when I am sitting there just really focusing on him it's almost as if I am allowed anyway and its lovely to have A there and then I wouldn't want it any other way but you know it would be lovely just to be on my own yeah.
I: Would you like to spend more or less time on the unit than you do?
R: Well again that depends I mean the more time I am the more I think I just want to get out of here. I just want to take him home and but then again when I think about it I just think he isn't ready to come home and I am not in a hurry to get him home and we will take him home when we are ready to go home. My gut is saying I would like to have less time on the unit because if I spent less time on the unit it just means its more a bit backwards he more I feel that he is healthier and more and more I want to go home but actually because you can see it the other way around I would like to spend more time on the unit because if he is here then he needs to be here and I would like to spend more time with him you know. But I don't feel restricted about spending time with him at all because I feel as though I can spend as much time as I need to and the door is always open and I can buzz to get in and sometimes nobody answers but usually they do in a few minutes. So yeah whenever I get the chance to come usually at feeding time I pop over and see him. It's a modelled answer for a very simple question. I mean yes I would like to spend more time with him when he is here but I would also like to have him at home.
I: Who do you feel knows him the best?
R: That's a good question! I don't know whether anybody really knows him that well at all I mean he's only eight days old. There were a couple of days when I thought A knew him better because she was spending more time with him and you know had changed his nappy twice during the day and all that is just really insignificant I think but we are both getting to know him pretty much in step with each other and I don't feel because I know some questions on the questionnaire about. Do you feel that the nurses know him better? And I don't feel that at all. I really feel they are doing their job and they are not telling him stories and they are not singing to him and they are not stroking him and they are changing his nappy. So they are being very functional things with him and that's totally appropriate and also the change over in staff is so quick. You know the shifts and the nurses don't come back exactly in the same place and he moves as well. So you never feel as though one nurse is sort of hogging him sort of you know dominating the attention. Yeah his consistent care is from his mum and dad. In the sort of quality touching and stroking and cuddling is all from us two.
I: Is it these things that contact that you have?
R: Well I think I think that I don't know well maybe there are some nurses that hold his hand but they couldn't take him out and cuddle him and this sort of thing that A does of putting him on her skin nobody does that. I mean yeah I'd love to be able to walk around with him and you can't do that because of the wires. But that will come and I am not inpatient about that so I think that the quality time that we spend is pretty unique and it is important for our own wellbeing as well as L's that he gets to hear our voices and smell what we smell like.
I: Do you think he recognises you?
R: Well we think so but I am sure he doesn't. I mean you see their eyes all over the place and you come really close and he goes back a bit and I have seen a picture of what a baby sees and nobody knows what a baby really sees, they think that is looks like a complete blur and maybe they recognise us. I mean they react when you talk to him and that's great but he also reacts when other people talk to him as well and he reacts to loud noise in exactly the same way. So it's only a matter of time when he

will recognise us and I mean it's very rewarding what he does do when we talk to him he does open his eyes and he seems to smile although he is not smiling. But yeah he definitely does react. He does seem to respond.

I: What kind of personality would you say he had?

R: I'm not 100% sure we were actually having this debate about what his nature and his nurture and there's no answer to that question. A seems to think that he has got his personality and he's you know pretty individual and that he likes to tell people when he is ready for things and he tells you when he doesn't like it but I think he is definitely born with a small amount of character but a lot of it is now developing and is a product of how we behave with him and how calm we are with him or how lively we are and his character and personality are a complete product of how we behave with him. The things we expose him to, how we are feeling. All those sort of feelings and I think you know I definitely don't think he is born with his complete personality and you know that's sort of unchangeable. Definitely there are things that he does that on day one I still noticed you know like his little scream or his little movements but their not if you asked somebody what somebody's character traits are like are they shy or are they outgoing or are they inquisitive. I mean he looks around but it's difficult for him for adult character traits or even child character traits on to L who is basically sleeping most of the time and reacting occasionally and occasionally crying but I am much more sort of whole educational upbringing and see how he develops in response to his environment rather than thinking is it unchangeable.

I: So you have obviously thought about that kind of side of things. Did you watch that television programme?

R: I do watch some of those things and I just think I know exactly what you are talking about and I just think he's well I am slightly biased because I have a friend who works on that show and she is a researcher and she doesn't speak very highly of him but also I could just think as subjectively as I can be that he jumps to conclusions. He did the whole thing about babies recognising sounds from their womb you know their womb music and he said that babies could distinguish you know say the womb music was Mozart and then at a year old he then played Mozart then he played Brahms or something and then he said look the baby can distinguish between the.... And I can even distinguish between I mean I am a professional musician, well I was and I just thought it was a bit silly I think. Those sort of things that he was saying are lead you to believe that they were distinguishing by the way the baby turned you know one way and then turned the other way. There needs to be more evidence and I think yeah you could jump to conclusions quite quickly I think so I would like to see more. If I was asked to say "Is he a shy person" or an "outgoing person".

I: Yeah I was going to ask you that but that was part of it whether you think he is shy or not?

R: I think that develops over time and it also develops in response to little things like you know when people become shy because they were bullied or because they had a bad experience or they said something and were made to feel small and then people who come outgoing because they were encouraged and because they were told they were good.

I: Well that's the last of my questions is there anything else that you feel or more that you would like to talk about?

R: No, well there were a few concerns about the maternity side but I think I we touched on that and they are significant to the general scheme of things. But no all the feelings about the whole neonatal side, you know I am certainly thinking in terms of things of when L is better and I can take some photos of the neonatal staff and I just want to do things I can do you know. You know when we were in London and we were at G Hospital we made a small donation and things like that I would like to be able to do that or donate a picture or some toys or yeah we have got really strong, positive feelings of the neonatal unit.

I: Do you think that from talking to other people that most dad's feel part of what's going on or do you think that maybe dad's don't always feel part of the whole process?

R: The thing that I have been really struck by is that not only am I the only person who goes on the ward round sometimes and increasingly I have been doing it with A but at the start I was the only person that I mean maybe it's because of the time that I come but I noticed that I am the only dad who sits in the expressing room and I just think maybe it's the group of people who are here at the moment but I don't get any sense of any of the other fathers apart from B who I met. Or a place that were they could talk things through but I got the impression that there are not many men around. I don't know whether that's right or not I mean occasionally at visiting time you see a few but there is none doing, seem to be doing what I am doing which is staying here or maybe that's wrong because I am, because I am waking up at different times but there certainly doesn't seem to be anybody else who is sleeping on the ward or supportive for whatever they endure. I know there are some mothers who's baby's are still on intensive care who are now better and ready for discharge and they are just staying here because its more convenient and maybe they don't need their partners or whatever I don't know what the reasons are but you know there are very few guys around.

I: Some dads are occupied at work and things. From your experience you wouldn't say that you felt left out?

R: No, no not at all I mean there is less for me to do because I don't have the daily routine of expressing and there is much more of a daily routine for a mum but I can still do the routine around sort of changing nappies, coming to visits and holding L and there is less of a biological focus for me. But I am already in some ways back at work doing what I do like at the hotel, you know in the gym and all that sort of stuff and some of my routine is now outside if anything you know going shopping and A's routine is very much is absolutely routed in the hospital which is a big difference. And in some ways it is harder for a man to be involved in the biological; I mean I can try and get involved in the expressing and in that sort of side and I do feel involved absolutely up on the ward I mean going on the ward round and people recognise me you know the doctor does and I feel very involved in all of that. But there are some things I just can't be involved in and I don't feel involved at all in them on the maternity unit because I am an accessory you know which is true. I have a chair and I sleep at my chair and I know I sleep on the floor you know but it is A's room and A is the patient you know and L is the patient here so it is inevitable but I do feel involved as much as I can be. And I sort of force myself in the ward round and do as much holding as I can, yes.

I: Thank you very much that was really good.